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Medicaid Institutional (ICF-MR) and Home and Community Based Services for Persons with Mental Retardation and Related Conditions

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Research and Training Center on Residential Services and Community Living
Institute on Community Integration/UAP
University of Minnesota

Medicaid Institutional (ICF-MR) and Home and Community Based Services for Persons with Mental Retardation and Related Conditions

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EXECUTIVE SUMMARY

Since its enactment in 1971, the Intermediate Care Facility for the Mentally Retarded (ICF-MR) program under Title XIX of the Social Security Act has become the primary source of federal support of services to persons with mental retardation and related conditions. On June 30, 1989 more than 147,000 persons were residents of the 4,917 ICFs-MR located in every state except Wyoming. Altogether during Fiscal Year 1989, expenditures for the residential and habilitation services received by these individuals exceeded 6.6 billion dollars, of which over 3.7 billion dollars were federal government reimbursements.

In 1981, amendment of Title XIX provided states with the option of requesting a waiver of certain Medical Assistance regulations to permit the provision of Home and Community Based Services (HCBS) as an alternative for persons who would otherwise require ICF-MR services. This "Medicaid waiver" program has grown rapidly, with 80% of all states providing Home and Community Based Services on June 30, 1989 to a total of 35,100 persons with mental retardation and related conditions. On June 30, 1990 there were 39,800 HCBS recipients with mental retardation and related conditions and the costs of services to them in Fiscal Year 1990 was nearly 850 million dollars.

In 1987 the Omnibus Budget Reconciliation Act (OBRA-87) required states to undertake screening and where appropriate improved habilitation activities or alternative placements for the approximately 40,000 persons with mental retardation living in nursing homes. These new requirements present substantial challenges to states as they seek to continue their nearly universal efforts to move greater numbers of people from institutions to com.munity settings, to avoid new institution placements, and to deal with the growing numbers of people awaiting residential services.

The purpose of this report is primarily to provide a statistical update on the utilization of Medicaid ICF-MR, HCBS and nursing home services for persons with mental retardation and related conditions and the characteristics of the service recipients. Data collection and analyses were carried out as part of the National Recurring Data Set Project on Residential Services funded by the Administration on Developmental Disabilities, with supplemental support from the Health Care Financing Administration. Among the findings of this study were the following:

- *The ICF-MR program has continued to grow, but has slowed dramatically in the past several years.*
  - The June 30, 1989 total of 147,148 persons with mental retardation and related conditions in ICFs-MR was only 1,014 more than in 1988 and only 6,400 more than the total in 1982.
  - Growth after 1982 was much slower than in the 5 previous years. Between 1977 and 1982 the number of ICF-MR residents grew by 33,000, or from 106,166 to 140,682.
  - Between June 30, 1982 and June 30, 1989 a majority of states (27) actually decreased the total number of people living in ICFs-MR.

- *Populations of large ICFs-MR have decreased in the past several years.*
  - On June 30, 1989 there were 114,877 persons in ICFs-MR of 16 or more residents. This represented a 2% decrease from 117,147 residents in 1988 and a 10% decrease from 130,767 on June 30, 1982.
  - On June 30, 1989 large ICF-MR residents included 81,605 people in state-operated facilities and 33,272 people in nonstate facilities.
  - On June 30, 1982 large ICF-MR residents included 107,081 people in state-operated facilities and 23,686 in nonstate facilities.
  - On June 30, 1977 there were 104,456 residents of large ICFs-MR including 92,498 in state facilities and 11,958 in nonstate facilities.

- *There has been a continued growth in smaller community facilities in the ICF-MR program.*

- On June 30, 1989 there were 32,271 residents of ICFs-MR with 15 or fewer residents. This represented an 11% increase from 28,987 over the previous year and a 200% increase over the previous 7 years. Small ICF-MR residents included 27,742 people in nonstate facilities and 4,529 people in state-operated facilities.
- On June 30, 1982 there were 9,985 residents of small ICFs-MR including 8,358 residents of nonstate facilities and 1,627 residents of state-operated facilities.
- On June 30, 1977 there were 1,710 residents in small ICFs-MR, including 1,354 in nonstate facilities and 356 in state-operated facilities.

- *A decreasing majority of ICF-MR residents reside in state-operated facilities.*
  - On June 30, 1989, 58.5% of residents of all ICFs-MR were in state-operated facilities. This compares with 77.2% in 1982 and 87.5% in 1977.
  - The deconcentration of ICF-MR residents in state-operated facilities is associated with the general depopulation of state institutions and the increase in community ICFs-MR, 86% of which were operated by nonstate agencies.
  - Between June 30, 1977 and 1982 large state ICF-MR populations grew by 16% despite an overall 21% decrease in state institution populations (from 154,600 to 122,600) as states continued to certify for ICF-MR participation previously uncertified units. By 1982 almost nine of ten state institution residents were in ICF-MR units and as state institution populations decreased by 24% between 1982 and 1989, the total number of residents of large state ICFs-MR also decreased by 24%.

- *Since 1977 states have steadily consolidated the ICF-MR certification of large nonstate facilities.*
  - On June 30, 1977, 23% of the 52,718 residents of all large nonstate mental retardation facilities were in ICFs-MR.
  - On June 30, 1982, 41% of the 57,396 residents of all large nonstate mental retardation facilities were in ICFs-MR.
  - On June 30, 1989, 73% of the 45,548 residents of all large nonstate mental retardation facilities were in ICFs-MR, up from 70% of 45,907 residents in 1988.

- *States have increased certification of small ICFs-MR, but have remained generally reluctant to certify large proportions of their small residential settings for ICF-MR participation.*
  - On June 30, 1989, only 21% of 134,475 persons living in small nonstate settings were in ICFs-MR. This was a proportional increase from 14% of 61,145 total small nonstate facility residents in 1982. However, the more than doubling of the total small nonstate facility residents nationwide between 1982 and 1989 was a greater factor in the increase from 8,358 to 27,742 small nonstate ICF-MR residents than were increases in the proportions of small nonstate facilities certified.
  - Small state operated facilities were relatively few (only about 4% of all small facility residents in 1989), but are much more likely to be ICF-MR certified (64.3% of small state facility residents are in ICFs-MR).

- *Small state ICFs-MR were highly concentrated in a few states.*
  - Of 501 small state ICFs-MR, 482 were in only 5 states.
  - Of 4,529 residents in all small state ICFs-MR, 66% lived in New York.
  - Only 12 states had any small state ICFs-MR.

- *Small nonstate ICFs-MR remained concentrated in relatively few states.*
  - On June 30, 1989, 73.9% of all residents of small nonstate ICFs-MR were in 9 states.
  - On June 30, 1989, the 25 states with the lowest utilization together had only 2.3% of all small nonstate ICF-MR residents.
  - On June 30, 1989, New York alone accounted for 19% of all small nonstate ICF-MR residents.
  - On June 30, 1982, Minnesota and New York had the majority (52%) of all nonstate ICF-MR residents (29% and 23%, respectively) and 5 states accounted for 68% of all small nonstate ICF-MR residents.

- *There has been continued growth in Home and Community Based Services recipients.*
  - On June 30, 1982 there were only 1,605 HCBS recipients.
  - On June 30, 1986 there were 23,053 HCBS recipients.
  - On June 30, 1989 there were 35,077 HCBS recipients.
  - On June 30, 1990 there were 39,838 HCBS recipients.

- *Growth in the total number of ICF-MR and HCBS recipients has slowed substantially.*
  - Total increase from 1977 to 1982 was 36,121, averaging 7,224 per year.
  - Total increase from 1982 to 1986 was 24,955, averaging 6,239 per year.
  - Total increase from 1986 to 1989 was 15,060 averaging 5,020 per year.

- *Average size of large state ICFs-MR continues to decline.*
  - In 1977, large state ICFs-MR had an average 406 residents.
  - In 1982, large state ICFs-MR had an average 368 residents.
  - In 1989, large state ICFs-MR had an average 297 residents.

- *The average size of large nonstate ICFs-MR has stabilized since 1982.*
  - In 1977, large nonstate ICFs-MR had an average 76 residents.
  - In 1982, large nonstate ICFs-MR had an average 66 residents.
  - In 1986, large nonstate ICFs-MR had an average 62 residents.
  - In 1989, large nonstate ICFs-MR had an average 64 residents.

- *Average size of small nonstate ICFs-MR has stabilized since 1982.*
  - Small nonstate ICFs-MR had an average 9.2 residents in 1977.
  - Small nonstate ICFs-MR had an average 8.0 residents in 1982.
  - Small nonstate ICFs-MR had an average 7.6 residents in 1986 and 7.7 in 1989.

- *Average size of small state ICFs-MR has increased slightly since 1982.*
  - In 1977, small state ICFs-MR had an average 8.7 residents.
  - In 1982, small state ICFs-MR had an average 8.6 residents.
  - In 1989, small state ICFs-MR had an average 9.0 residents.

- *Reduction in populations of large state ICFs-MR has been widespread.*
  - Between 1982 and 1989, 43 states reduced populations of large state ICFs-MR.
  - Between 1982 and 1989, only 6 states increased populations of large state ICFs-MR.

- *Recently, Home and Community Based Services have been the most rapidly growing service model.*
  - Between 1986 and 1989, residents of large ICFs-MR declined in number by 8,070.
  - Between 1986 and 1989, residents of small ICFs-MR increased by 11,106.
  - Between 1986 and 1989, recipients of HCBS increased by 12,024.

- *From 1977 to 1989, residents of ICFs-MR serving six or fewer persons grew as a proportion of residents of all small ICFs-MR (i.e., those with 15 or fewer residents).*
  - In 1977, 16.7% of all residents of small ICFs-MR lived in ICFs-MR serving six or fewer persons.
  - In 1982, 26.5% of all residents of small ICFs-MR lived in ICFs-MR serving six or fewer persons.
  - In 1989, 31.6% of all residents of small ICFs-MR lived in ICFs-MR serving six or fewer persons.

- *From 1977 to 1989, residents of state ICFs-MR serving six or fewer persons declined as a proportion of all state and nonstate ICFs-MR serving six or fewer persons.*
  - In 1977, 12.5% of all residents of state and nonstate ICFs-MR serving six or fewer persons lived in state ICFs-MR.

- In 1982, 8.1% of all residents of state and nonstate ICFs-MR serving six or fewer persons lived in state ICFs-MR.
- In 1989, 4.2% of all residents of state and nonstate ICFs-MR serving six or fewer persons lived in state ICFs-MR.

- *Large ICF-MR facilities had the highest proportion of persons with profound mental retardation.*
  - 54.5% of large ICF-MR populations were persons with profound mental retardation.
  - 17.4% of large non-ICF-MR populations were persons with profound mental retardation.
  - 13.6% of all small facilities' populations were persons with profound mental retardation.
  - 16.5% of small ICF-MR populations were persons with profound mental retardation.

- *Persons with related conditions, but not mental retardation were most likely to reside in non-ICFs-MR.*
  - Persons with related conditions were estimated to be less than 1% of the mental retardation facility population.
  - Persons with related conditions were 1.4% of the non-ICF-MR population.
  - Persons with related conditions were 0.6% of the ICF-MR population.

- *States continue to house tens of thousands of persons with mental retardation and related conditions in nursing homes.*
  - States reported 37,143 persons with mental retardation in Medicaid nursing homes in June 1989.
  - The 1987 National Medical Expenditure Survey (NMES) provided estimates of 37,005 persons with a primary diagnosis of mental retardation in Medicaid nursing homes and 45,261 in all nursing and related care homes.
  - NMES estimated about 12,600 persons with other developmental disabilities in nursing homes in 1987.
  - 1987 nursing home populations included an estimated 7,700 persons with a primary diagnosis of mental illness, but with mental retardation indicated and 24,800 persons with primary diagnosis of medical conditions but with mental retardation or related conditions indicated.

- *Persons with mental retardation and related conditions tend to be younger than the general nursing home population, but much older than the population of mental retardation facilities in general and ICFs-MR specifically.*
  - An estimated 88% of all nursing home residents in 1987 were 65 years or older as compared with 34% of those with a primary diagnosis of mental retardation or a related condition.
  - The estimated 34.3% of older (65+ years) nursing home residents with mental retardation or a related condition was much greater than the estimated 5.5% of all mental retardation facility residents and 5.8% of ICF-MR residents.

- *Despite total population increases of only 4.6% between 1982 and 1989, ICF-MR costs increased by about 80% over the same period.*
  - In 1982 total public expenditures for ICF-MR services to a total of 140,752 people (on June 30) were about 3.6 billion dollars.
  - In 1989 total public expenditures for ICF-MR services to a total of 147,148 people (on June 30) were about 6.6 billion dollars.
  - In 1977 the average daily per resident cost of ICF-MR care was $41.00. In 1982 it was $79.00. In 1989 it was $123.14.

- *HCBS costs per recipient were less than half the per resident ICF-MR expenditures.*
  - ICF-MR annual expenditures per ICF-MR resident on June 30, 1989 were $44,946.
  - HCBS annual expenditures per HCBS recipient on June 30, 1990 were $21,246.

MEDICAID INSTITUTIONAL (ICF-MR) AND HOME AND COMMUNITY BASED SERVICES FOR PERSONS WITH MENTAL RETARDATION AND RELATED CONDITIONS

Overview of Report

Introduction

This report on Intermediate Care Facilities for the Mentally Retarded (ICF-MR) and related programs under Title XIX (Medicaid) of the Social Security Act is the fifth since 1985. The annual issuance of these reports has been requested because of ongoing interest in the ICF-MR program on the part of state and federal agencies, advocates and others interested in policies affecting persons with mental retardation and related conditions. This interest is clearly evident in discussions with state officials about the ICF-MR program generally, and more specifically, on the uses and limitations they see for it in meeting the challenges states currently face and/or anticipate in the future (see Lakin, Jaskulski, Hill, Bruininks, Menke, White, & Wright, 1989). The interest of federal officials is reflected in the 1988 Department of Health and Human Services Report to the Secretary on Policies Affecting Mentally Retarded and Other Developmentally Disabled Persons (Helms, 1988) and numerous efforts to reform the ICF-MR program within the federal legislature (Mitchell, 1988).

In interviews with state officials, they have noted a number of controversial aspects of the ICF-MR program and their states' participation in it, including: 1) the difficulties of providing appropriate, personalized services when the predominant service model (ICF-MR) is based on uniform standards for "facilities," 2) the unavoidable financial influences on service decisions when federal cost sharing is more readily available for some services (e.g., congregate care) than for others (e.g., semi-independent or supported living), 3) the escalating costs of meeting minimum ICF-MR standards, 4) the difficulty of stabilizing or reducing public institution expenditures despite continued deinstitutionalization, 5) the challenge of meeting the needs for "active treatment" and/or more appropriate residential placements for people with mental retardation and related conditions now living in nursing homes; and 6) major pressures for service system expansion to respond to growing waiting lists, accompanied by a growing perception that this cannot be accomplished without greater efficiency, flexibility and equitable federal financial participation for all appropriate services. In large measure these same themes were evident in the deliberations at the federal level cited above regarding reform of Medicaid programs for persons with mental retardation and related conditions.

To the concerns noted by state officials may be added those found at the federal level about the growing costs of the ICF-MR program, from 1.1 billion dollars in FY 1977 to 6.6 billion dollars in FY 1989. There is also considerable debate about the extent to which the federal government should dictate, or at least influence substantially through different levels of financial participation, the size and nature of the service settings supported by federal funds. Such influence is often seen as contrary to the growing consensus that the best program decisions for individuals are made by those individuals and/or people who are particularly

knowledgeable about their unique characteristics, abilities, needs and life circumstances. Such issues have dominated consideration of the need for significant reform of Medicaid's programs for persons with mental retardation throughout the 1980s. Presumably they will continue in the 1990s until some resolution is attained regarding the incongruity between perceptions of the ideal service system for people with mental retardation and related conditions and the reality of the current Medicaid dominated system.

Purpose of Report

This report is not intended to respond directly to the concerns noted above nor to possible means for their resolution. It provides a description and an update of the status of the ICF-MR program, the Medicaid Home and Community Based Services (HCBS), and related programs to assist in evaluating changes and considering alternatives to current Medicaid services for persons with mental retardation and related conditions. The report contains two basic sections: 1) a brief background description of the key Medicaid programs of interest; and 2) state-by-state and national statistics on ICF-MR and related Medicaid Home and Community Based Services and nursing home utilization and the people utilizing them.

PART I: BACKGROUND OF ICF-MR AND RELATED MEDICAID PROGRAMS*

Federal Involvement Prior to ICFs-MR

Federal involvement in care for individuals with mental retardation and related conditions is fairly recent in this country. In the nineteenth century, public funding of services for persons with mental retardation was limited to state and local governments' responsibility for almshouses and other public institutions. Private charity and voluntary associations, on the other hand, were the only source of support for people with mental retardation who were living outside those public institutions. In 1935, after five years of declining revenues during the Great Depression, the U.S. Congress enacted Titles I, IV, and X of the Social Security Act to provide federal funds with which states could begin to provide direct cash assistance for certain classes of dependent individuals, notably elderly, blind, orphans, and other "children deprived of parental support." The majority of recipients under these Titles were elderly persons living in their own homes. In fact, these initial Titles of the Social Security Act carefully precluded federal assistance for persons in institutional care, which was at the time becoming a growing burden to states. For example, from 1923 to 1935 the average daily populations of state mental retardation institutions nearly doubled from 48,000 to 90,000 (Lakin, 1979). Even persons who were elderly, blind, orphans, or other children deprived of parental support were not eligible for federal program participation if they resided in a public institution or in any institution for "mental disease." When the Social Security Act was extended to include persons with disabilities

*The discussion on pages 3-5 was adapted from E. Boggs, K.C. Lakin, & S. Clauser (1985).

under the Aid to the Permanently and Totally Disabled (Titles XIV and XVI) in 1950, the same prohibition extended to persons with disabilities living in institutions.

Major developments leading to federal participation in long-term care of persons with mental retardation came in the 1960s. Among these were the attention drawn to the needs of persons with mental retardation by the President's Panel on Mental Retardation, first appointed in 1961; the Maternal and Child Health and Mental Retardation Planning Amendments and the Mental Retardation Facilities and Community Mental Health Centers Construction Act, enacted in 1963; and, beginning with Senator Robert Kennedy's well-publicized inspections of New York State institutions in 1964, the national attention drawn to the inadequacy, abuse, and overcrowding within state institutions. Another important step in the eventual federal involvement in long-term care for persons with mental retardation came indirectly with the Kerr-Mills Act in 1960, which established open-ended federal reimbursement according to a federal-state matching formula to the states for medical assistance costs, even though the Act was originally limited to aged populations.

In 1965, Medicaid was enacted as Medical Assistance, Title XIX of the Social Security Act. It contained the structural characteristics of the Kerr-Mills Act, but extended medical assistance to people in the categories of blind, disabled, and dependent children and their families as well as to elderly people. Although at least some persons with mental retardation were thus included for Medical Assistance, Title XIX also carried forward the exclusions of otherwise eligible persons in public institutions (except "medical institutions") and in any institution for mental diseases. An exception was that states could claim Federal Financial Participation (FFP) for residents 65 years and older in psychiatric institutions which met established standards. Importantly, although persons in public mental retardation institutions were still excluded from coverage, otherwise eligible adult residents of private nursing homes, including facilities serving people with mental retardation, became qualified for Medicaid participation if the homes met established standards.

Thus Title XIX brought a number of incentives that were not necessarily beneficial to persons with mental retardation in long-term care settings. First, states were stimulated to concentrate the funds they had available for improving public institutions on their mental hospitals, virtually all of which had substantial numbers of residents 65 years or older. Indeed, on June 30, 1964 public mental institutions held 144,000 residents age 65 years or older, or, in comparison, about three-quarters as many people as were in state mental retardation institutions (Lakin, 1979; National Institute on Mental Health, 1975). In return for efforts to bring their mental hospitals into compliance with Title XIX standards, states were rewarded with federal contributions of at least half the costs of caring for residents who were elderly. Second, states had an incentive to convert their public institutions into "medical institutions," that is, Skilled Nursing Facilities (SNFs). Once done the residents were then eligible for inpatient coverage under Title XIX. Eleven states actually did so between 1966 and 1969. But as a General Accounting Office (1970) audit in 1970 noted, SNF standards generally required more medical services than most residents needed or, for that matter, actually received, and did so virtually to the exclusion of developmental programming. Finally, because FFP was available for

residents with mental retardation in private facilities meeting either SNF or "intermediate care" (ICF) nursing home standards (the latter being under Title XI from 1967 until conjoined with Title XIX in 1971), it was relatively easy and financially beneficial for states to transfer people with mental retardation to private nursing homes. The effects of this policy are still felt today as nursing homes remain a major residential alternative, with nearly 40,000 residents with a primary diagnosis of mental retardation in nursing homes nationwide (Lakin, Hill, & Anderson, 1991; Parts II and III of this report). By 1970 the effects of these policies were increasingly viewed as detrimental to providing the kinds of residential care then considered most appropriate.

Establishment of the ICF-MR Program

It was only shortly after the introduction of federal reimbursement for skilled nursing care that the U.S. Senate noted rapid growth in the numbers of people who were becoming patients in Skilled Nursing Facilities. It was further documented that many of these individuals were receiving far more medical care than they actually needed, at a greater cost than was needed, largely because of the incentives of placing people in facilities for which half or more of the costs were reimbursed through the federal Title XIX program (U.S. Senate, 1967). Therefore, in 1967, a less medically oriented and less expensive "Intermediate Care Facility" (ICF) program for elderly and disabled adults was authorized under Title XI of the Social Security Act. Although ICF standards still primarily addressed medical and personal care needs, they required less intensive medical services than did the SNF standards. In 1971 the SNF and ICF programs were combined under Title XIX. Within the legislation combining the two programs was a little noticed, scarcely debated amendment that for the first time authorized FFP for "intermediate care" provided specifically in facilities for people with mental retardation. The authorization of Intermediate Care Facilities for the Mentally Retarded (ICF-MR) was the culmination of considerable lobbying on the part of the National Association for Retarded Citizens and a number of directors of state mental health or related agencies.

Three primary outcomes of the ICF-MR legislation appear to have been intended by Congress. First, the ICF-MR program was clearly intended to provide substantial federal stimulation through the availability of FFP for upgrading the physical environment and the quality of care and habilitation being provided in public mental retardation institutions. Second, it is probably fair to say that there was intent to neutralize the previously existing incentives for states to place persons with mental retardation in nonstate nursing homes or certify their state institutions as SNFs in order to gain FFP. A third and related intention was to provide FFP for care and habilitation specifically designed to meet the specialized needs of persons with mental retardation--specifically, "active treatment" and "health or rehabilitative services" rather than focusing exclusively upon medical care. A fourth desired outcome, not as readily apparent as the first three and more doubtfully achieved, was that federal funding would only support, not supplant, the existing levels of state funding for residential services to result in improved conditions. (The requirement of state maintenance of effort actually expired in 1975.) Clearly, too, an outcome desired by many proponents of the new ICF-MR program, some of whom were in Congress, was to find a way for the federal government to assist states in

affording the rapidly increasing costs of state institution care. States were experiencing average real dollar increases of 14% per year in the five years prior to the passage of the ICF-MR legislation, a real dollar growth rate even greater than that experienced since the ICF-MR legislation was enacted (Greenberg, Lakin, Hill, Bruininks, & Hauber, 1985).

The ICF-MR program was initiated in a period of rapid change in residential care for persons with mental retardation. For example, by Fiscal Year 1973 the population of state institutions had decreased to 173,775 from a high of 194,650 in Fiscal Year 1967 (Lakin, 1979). Public and professional perceptions about the appropriateness of large institutional care were clearly changing. Nevertheless, states overwhelmingly opted to participate in the ICF-MR program. Two notable outcomes were that 1) nearly every state took steps to secure federal participation in paying for state institution services, and 2) in order to maintain federal participation, most states were compelled to invest substantial amounts of state dollars in bringing institutions into conformity with ICF-MR standards. As evidence of these outcomes 40 states had at least one ICF-MR certified state institution by June 30, 1977. Nearly a billion state dollars were invested in institutional improvement efforts in Fiscal Years 1978-1980 alone, with a substantial majority of those dollars being invested in improvements directly related to meeting ICF-MR standards (Gettings & Mitchell, 1980).

In the context of growing support for community based residential services, such statistics were used by a growing number of critics to charge that the ICF-MR program 1) had created direct incentives for maintaining people with mental retardation in state institutions by providing federal payment of from 50% to 80% of the costs of care in those facilities; 2) had diverted funds that could otherwise have been spent on more integrated, community based programs into extremely costly institution renovations solely to obtain FFP; and 3) had promoted numerous inefficiencies (and often enhanced dependency) by promoting a single uniform standard for care and oversight of ICF-MR residents irrespective of the nature and degree of the residents' disabilities and/or their relative capacity for independence. These criticisms, and the growing desire to increase residential opportunities in community settings, along with the continued desire of states to avail themselves of the favorable federal cost-share for ICF-MR care, helped stimulate the development of small ICF-MR facilities and the eventual clarification by the Health Care Financing Administration (HCFA) of how the ICF-MR level of care could be delivered in relatively small (4-15 person) group homes.

Small ICF-MR Certified Facilities

The expansion of the ICF-MR program beyond use only for public institutions was a major development. Private residential facilities were not an issue at the time of original enactment, probably because: 1) most of the total capacity of private facilities was already technically covered under the 1967 amendments to the Social Security Act authorizing private ICF programs, and 2) in 1971 state facilities were by far the predominant model of residential care. Indeed, the 1969 Master Facility Inventory indicated a total population in nonstate mental retardation facilities of about 25,000, compared with a state mental retardation institution population of 190,000 (Lakin, Bruininks, Doth, Hill, & Hauber, 1982).

Significantly, although Congressional debate had focused on public institutions, the statute did not specifically limit ICF-MR coverage, standards, or reimbursement to publicly operated facilities. The definition of "institution" which serves as the basis for participation in the ICF-MR program is the one that also covers the general ICF institution. This definition includes facilities serving "four or more people in single or multiple units" (45 CFR Sec. 448.60 (6) (1)). Although it cannot be determined whether Congress, in authorizing a "four or more bed" institution, purposely intended the ICF-MR benefit to be available in small facilities, it does seem reasonable to suppose, in the absence of specific limitations, that Congress was more interested in improving the general quality of residential care than it was in targeting specific types of facilities. Regulations governing ICF-MR certification, published in January 1974, also supported the option of developing relatively small facilities. These regulations delineated two categories of ICFs-MR, those housing 16 or more and those housing 15 or fewer residents. Further, the regulations contained several specifications that allowed greater flexibility in meeting the standards for small facilities.

Despite the regulatory provisions which recognized and to some extent facilitated the development of small ICFs-MR, the numbers of such facilities actually developed varied enormously among states. Furthermore, while states in some DHHS regions (e.g., Region V) had developed hundreds of small ICF-MR certified facilities, other regions (e.g., II and X) had none. The variations among states and regions reflected what some states and national organizations considered a failure of HCFA to delineate clear and consistent policy guidelines for certifying small facilities for ICF-MR participation and/or reluctance on the part of some regional HCFA agencies to promote the option for states to do so. Such criticisms were seen as evidence of a lack of commitment within HCFA to support the expressed federal goal of deinstitutionalization.

In response to continued complaints from the states that there was a need to clarify policy regarding the certification of small ICFs-MR, in 1981 HCFA issued "Interpretive Guidelines" for certifying small facilities. These guidelines did not change the existing standards for the ICF-MR program. Their purpose was simply to clarify how the existing standards for ICF-MR certification could be applied to programs delivering the ICF-MR level of care in facilities with 4 to 15 residents. Even though the guidelines did not substantially affect the options available to states under the ICF-MR program, they were viewed as important in demonstrating the degree of flexibility available in providing the ICF-MR level of care. It is also clearly the case that publication of the guidelines was followed by substantially greater numbers of states exercising the option to develop small ICFs-MR. Ironically, these guidelines were published in the same year (1981) that Congress enacted legislation that would give even greater programmatic flexibility to states in their use of Medicaid funding, the Medicaid Home and Community Based Services waiver authority (Section 2176 of P.L. 97-35).

Intensified Federal Look-Behind

The federal Health Care Financing Administration (HCFA) provides federal oversight of state implementation of the ICF-MR program. The oversight includes development of standards for providing the

ICF-MR services authorized by Congress and monitoring of state efforts to assure that ICF-MR providers are in compliance with federal program standards. Congressional hearings in 1984 gave considerable attention to reports of poor quality and abusive conditions in some residential settings that states had certified as ICFs-MR for federal financial participation. Particular interest centered on two problems: 1) delegation to states of responsibility to monitor their own state institutions; and 2) limited effort by HCFA to ensure that state certification efforts were sufficient to assure compliance with ICF-MR standards. As a result of the 1984 hearings, Congress allocated funds for over 50 new positions at HCFA to carry out substantially intensified federal "look behinds" of state program review efforts. Not only did federal oversight efforts become more numerous but they also shifted markedly from review of administrative procedures and compliance with basic health and safety standards to direct monitoring of residential and habilitation services ("active treatment") provided to residents. The look behind surveys resulted in numerous corrective actions being required. Many corrections required higher ratios of staff to residents, especially among the professional staff whose availability is considered integral to the concept of active treatment as defined in federal regulations. Many states were required to increase staffing levels and/or reduce populations of large state facilities in order to maintain their ICF-MR certification. Some facilities, primarily older state institutions, also were cited for numerous deficiencies related to the physical plant. Although frequently described as a difficult experience, the look behind surveys have been seen by many as helpful in improving program quality, in stimulating improvements in the quality assurance process itself, and in helping to clarify the rationale for state agency preferences for community based residential services (Lakin et al., 1989). However, required corrections were described as so costly in some cases as to reduce significantly the amount of funding available for expansion of community based services. This was particularly true where substantial increase in staffing levels or major capital improvements were necessary. Perhaps most relevant to the ongoing debate about the future role of the ICF-MR program in the evolution of residential services, there has been considerable doubt expressed by government officials and advocates alike about whether the generally costly corrections required actually had a notably positive effect on the quality of life and active treatment received by residents, particularly those in large institutions (Lakin et al., 1989).

Phase Down Option

The ultimate sanction that may result from state or federal findings of non-compliance with federal regulations by an ICF-MR can be termination of the provider agreement, thereby making the ICF-MR ineligible for reimbursement of costs under Medicaid. In practice, few terminations of provider agreements have resulted from the intensified review of ICF-MR programs since 1985. Other actions have been taken to require corrections by ICFs-MR found not in compliance with federal standards. Nevertheless, threat of termination of a provider's agreement is a powerful incentive. There was concern that states might, under threat of terminations for non-compliance, expend funds to bring facilities into compliance that might be used more effectively to develop community services. As a result, the Consolidated Omnibus Reconciliation Act

of 1985 (P.L. 99-272) contained provision for an optional response to deficiencies identified in federal look behind surveys. To correct deficiencies, an ICF-MR facility could employ a planned phase down of all or part of the facility that would extend beyond the normal time periods allowed for compliance, provided that the deficiencies did not pose a "significant threat" to residents' health or safety. Final regulations for this program were published in January 1988, with the provisions of the phase down option interpreted by HCFA as being applicable only to deficiencies identified in surveys conducted after the regulations were published. Since this interpretation did not allow states to use the option for facilities found deficient in surveys conducted between 1985 and 1987, the option has been of little use to date in avoiding large scale investment in inefficient and obsolete facilities.

New ICF-MR Regulations

In June 1988, the Health Care Financing Administration (HCFA) published revised regulations to govern the ICF-MR program, effective in October 1988. These regulations included a number of significant changes in the conditions for participation in the ICF-MR program. While the changes are too numerous to outline in detail here, the increased flexibility in ways by which facilities can meet the various service requirements of the 1971 legislation is noteworthy. At the same time, considerably increased attention has been given in the new regulations to the conditions for "active treatment" and "client behavior and facility practices." In the new standards it is clear that ICFs-MR will be expected to pursue aggressive, planful and monitored programs of treatment. It is also clear that HCFA considers persons who are not in need of "active treatment" to be persons who, "by definition," are inappropriately placed in ICFs-MR. Whether this will have effects over time on the ICF-MR placement of persons with relatively mild levels of impairment which frequently is the case in small community based, ICFs-MR is not clear. However, it is clear from data presented in Part III that there are on average few differences between people living in community based ICFs-MR and those living in other community facilities.

Medicaid Home and Community Based Services (HCBS)

Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35), passed on August 13, 1981, established the option for states to provide Medicaid Home and Community Based Services (HCBS) to persons with mental retardation and related conditions. Under this section, the Secretary of Health and Human Services was granted the authority to waive certain existing Medicaid requirements and allow states to finance certain "non-institutional" services for Medicaid-eligible individuals, hence the frequent reference to this option as the Medicaid "waiver" program. The HCBS program was designed to provide home and community based services for people who are aged, blind, disabled, or mentally retarded or who have a related condition and who, in the absence of alternative services, would remain in or would be placed in a Medicaid facility (i.e., Skilled Nursing Facility, an Intermediate Care Facility, or an Intermediate Care Facility for the Mentally Retarded). The program operated under interim rules from October 1981 until March 1985, when

the final regulations were published. Since 1985 a number of new regulations have been added, although none of these changed the fundamental nature of the program.

Non-institutional services that can be provided under the waiver include case management, personal care services, adult day health services, habilitation services, respite care, or any other service that a state can show will lead to decreased costs for Medicaid funded long-term care. Although not allowed to use HCBS reimbursements to pay for room and board, virtually all states offering HCBS to persons with mental retardation do provide residential facility based services under the categories of personal care, habilitation, and homemaker services, while in most instances using cash assistance from other Social Security Act programs to fund the room and board portion of the residential program. Given both its flexibility and its potential for promoting the goal of community based care and habilitation, the HCBS program has generally been recognized as having considerable potential in assisting states in the provision of community based services as an alternative to institutional care.

The overriding fiscal principle in providing HCBS is that a state must explain in its waiver application how, if it uses the waiver to provide non-institutional, community based services, the total amount of state Medicaid expenditures will not exceed total expenditures in the absence of HCBS. States have used two main arguments in justifying these assurances: 1) that existing ICF-MR capacity can be "closed" (people would be deinstitutionalized and not replaced) as a result of services provided through the waiver; and/or 2) that new ICF-MR capacity that otherwise would have been opened will not be opened because people will be diverted from institutional care as a result of the HCBS provided. Recent publications (Lakin et al., 1989, 1990; Smith & Gettings, 1989) have documented the attractiveness of the HCBS option to states in providing noninstitutional services. These and other documents show program participation to have grown from 16 states on January 1, 1983 to 33 by January, 1985 to 43 by January 1, 1991. These documents also describe a sense of frustration on the part of states in having their utilization of the HCBS option directly linked to reduced ICF-MR utilization. Most states today seek substantive Medicaid reform that would provide the kinds of flexibility to provide services outside ICF-MR certified settings as available under HCBS, but without the specific limits on beneficiaries or amount of federal funding now experienced under Medicaid HCBS (Lakin et al., 1989). The new Medicaid Community Supported Living Arrangements program enacted in the Omnibus Budget Reconciliation Act of 1990 will offer some assistance to states in this regard. However, as enacted, participation in the program will be limited to no more than 8 states with a total financial allocation of 100 million dollars over 5 years.

Nursing Home Restrictions

Almost from the inception of Medicaid long-term care benefits concern was expressed about the reimbursement incentives created for states to place persons with mental retardation and related conditions in nursing facilities (National Association for Retarded Citizens, 1975). There was a sense among the advocacy community that many more people with mental retardation and related conditions were living in nursing

homes than could be thought to be appropriately served in them. In time supportive documentation became available. For example a 1985 study of 2,700 nursing home residents with mental retardation and related conditions (Davis, Silverstein, Uehara, & Sadden, 1987) concluded that only 10% needed services warranting nursing home placement. In 1987 Congress responded to these and other criticisms of nursing home care in the Omnibus Budget Reconciliation Act of 1987 (P.L. 100-203). Provisions of this legislation were intended to reduce and eliminate inappropriate placements of persons with mental disorders in nursing homes. They restricted criteria for admissions to Medicaid reimbursed nursing facilities, so that only those persons requiring the medical/nursing services offered could be admitted. Current residents not in need of nursing services were required to be moved to "more appropriate" residential facilities, with the exception of individuals living in a specific nursing home for more than 30 months should they choose to stay. In either case nursing facilities are required to assure that each person's needs for active treatment are met. This legislation is expected to have a substantial effect on both the numbers and experiences of people with mental retardation and related conditions living in nursing homes.

Data Presented

The statistics presented in this paper focus on topics of utilization, change, and beneficiary characteristics in the ICF-MR program and in a more limited way certain related programs. Many of these findings are directly relevant to the ongoing evaluation of present Medicaid policy at the federal level. They show where the ICF-MR and Medicaid waiver programs currently stand in terms of utilization, where they have been, and with cautious extrapolation where they appear to be heading. In the discussion of findings Medicaid programs are often treated as though they are a single federal program. To the extent that they derive from a common federal entitlement program they are. But Medicaid programs are ultimately shaped by the policies of individual states and states vary dramatically in their Medicaid funded residential programs. Therefore, the data in Part II on program utilization are presented for individual states as well as the nation as a whole. These data also show longitudinal national trends in Title XIX services for persons with mental retardation and related conditions, when compared with data obtained from earlier studies by the Center for Residential and Community Services. Part II also uses secondary analysis of different sources of data to describe in more detail the nature of the programs being discussed and the characteristics of their participants.

PART II: UTILIZATION OF ICFs-MR AND RELATED MEDICAID PROGRAMS

Method

Since 1976, the Center for Residential Services and Community Living (CRSCL) has been conducting individual facility and state agency surveys that have permitted periodic evaluation of the number, size, and type of facilities participating in the ICF-MR program, the number and characteristics of persons residing in them, and the number of people with mental retardation and related conditions receiving Medicaid waiver services.

Facility Surveys, 1977 and 1982

In 1977-1978 CRSCL, with funding from the Administration on Developmental Disabilities, undertook a survey as of June 30, 1977 of all state-licensed, state-contracted, or state-operated residential facilities in the United States serving persons who were mentally retarded/developmentally disabled. In 1982, CRSCL received primary funding from the Health Care Financing Administration (HCFA), with supplemental support from the Administration on Developmental Disabilities, to replicate the earlier study as of June 30, 1982. In both studies, an identical operational definition of residential facility was employed:

> Any living quarter(s) which provided 24-hour, 7-days-a-week responsibility for room, board, and supervision of mentally retarded people as of June 30, 1977/1982, with the exception of: (a) single family homes providing services to a relative; (b) nursing homes, boarding homes, and foster homes that are not formally state licensed and contracted as mental retardation service providers; and (c) independent living programs that have no staff residing in the same facility.

Both studies gathered data on both ICF-MR certified and non-certified facilities. The specific methods for identifying and surveying these facilities is described in Lakin, Hill, and Bruininks (1985). There were a total of 574 ICF-MR certified facilities in operation in 1977 and 1,853 in operation on June 30, 1982.

State Agency Surveys, 1985 to 1989

Since 1985 statistics on ICF-MR and noncertified facility utilization and related statistics have been gathered as part of the "Recurring Data Set Project," funded by the Administration on Developmental Disabilities. This project actually began in 1978, but data collection until 1985 was limited to state-operated facilities. A 1984 feasibility study indicated that in all but three states, through state mental retardation and/or state Medicaid agencies, it was possible to obtain statistics on the total number of ICF-MR certified facilities and facility residents by state/nonstate facility operation and by size (15 or fewer/16 or more residents), as well as the number of Medicaid waiver recipients and nursing home residents as of June 30, or the last day of the state fiscal year. As part of the feasibility study, key data sources were also identified in each state for the new data elements.

Beginning for Fiscal Year 1985 the Recurring Data Set Project was expanded to include state and nonstate ICFs-MR and noncertified facilities, broken down into size categories of large (16 or more residents) and small (15 or fewer residents). For Fiscal Year 1986 recipients of Medicaid waiver services and nursing home residents with mental retardation and related conditions were also added. In 1988 a third size category (6 or fewer residents) was added to the survey. Response rates for these various data elements have been 98% or greater for every year since 1985. Missing data for a specific year have been estimated by the latest available data from that state. In 1989, response rates were 100% for all data elements.

Findings

General Overview

Growth in use of the ICF-MR program, rapid during the first decade following its enactment, slowed dramatically after 1982. An increase of about 6,500 ICF-MR residents over seven years, from 140,752 on June 30, 1982 to 147,225 on June 30, 1989, contrasted sharply with the increase of over 33,000 in ICF-MR population during the five years between 1977 and 1982. While growth in the use of the ICF-MR program slowed markedly in its second decade, a new program alternative for persons eligible for ICF-MR care contributed to a continuing increase in the total number of ICF-MR eligible Title XIX beneficiaries. Following enactment in 1981, the Title XIX Home and Community Based Services (HCBS) program expanded rapidly. On June 30, 1989, 35,077 persons, 19.2% of the combined 182,302 ICF-MR and Medicaid HCBS recipients with mental retardation and related conditions were receiving Medicaid Home and Community Based ("waiver") Services. By June 30, 1990 HCBS recipients had increased another 13.6% to 39,838.

In addition to a significantly reduced rate of growth in the total number of ICF-MR residents and a rapid increase in the number of waiver services recipients, the number of residents in large (i.e., 16 or more residents) ICFs-MR continued to decline, from 130,767 on June 30, 1982 to 114,954 on June 30, 1989. During the same period, use of small (i.e., 15 or fewer residents) ICFs-MR increased by 22,286 residents, from 9,985 to 32,271 small ICF-MR residents. Of this increase, about 34% (7,633 persons) occurred in ICFs-MR of six or fewer residents. Between June 30, 1982 and June 30, 1989 the total number of people living in ICFs-MR of six or fewer residents nearly quadrupled from 2,572 to 10,205 residents.

Overall, from 1982 to 1989, the nature of Medicaid participation in the service system for persons with mental retardation and related conditions shifted substantially in the direction of community based services. In 1982 the 9,985 small ICF-MR residents and 1,605 Medicaid HCBS recipients made up 8% of the total ICF-MR and HCBS recipients. On June 30, 1989, 67,348 persons lived in small ICFs-MR or received Medicaid HCBS services. Together, these community services were provided to 37% of the total ICF-MR and HCBS waiver recipients.

In the following pages statistics on the status and change in the ICF-MR program are also presented with respect to the state or nonstate operation of facilities. Historically ICF-MR services have been provided primarily in state-operated facilities. On June 30, 1977, 87.5% of 106,166 total ICF-MR service recipients lived in state-operated facilities. On June 30, 1982, 77.2% of 140,752 ICF-MR recipients lived in state-operated facilities. On June 30, 1989, 58.6% of 147,225 ICF-MR recipients lived in state-operated facilities. The steady decrease in the proportion of ICF-MR recipients living in state-operated facilities is a result of substantial depopulation of state institutions over the period and the development of a community based residential care system primarily made up of private service providers.

Most of the statistics in this report are presented on a state by state basis. This reflects the fact that Medicaid ICF-MR and Medicaid HCBS programs are state option programs. States provide them if they

choose, where they choose, and, save the restrictions noted above in HCBS utilization, to as many people as they choose. The "national program" is merely the accumulation of programs which states develop based on their individual perceptions of the benefits of program participation. Because states' perceptions of benefit vary considerably, so too does the nature and size of their ICF-MR programs (see Lakin et al., 1989, and Smith & Gettings, 1989, for summary and discussion of these perceptions). Therefore, as will be discussed later, state participation in the ICF-MR program varies from less than one-third of the total state residential facility population in 10 states to more than two-thirds in 9 states.

The discussion of the status and change in the ICF-MR program that follows is based on the statistics presented in Tables 1 through 6. Tables 1 through 5 present statistics on ICF-MR facilities and residents by state, size, and state/nonstate operation on June 30, 1977, June 30, 1982, June 30, 1986, and June 30, 1989. Table 6 shows the net change among the states in these same categories between 1982 and 1989. Table 7 compares June 30, 1989 ICF-MR utilization with the total residential care system in each of the states on the same date.

Nonstate ICF-MR Certified Facilities

The period from 1977 to 1989 produced a steady and significant shift toward nonstate operation of ICFs-MR. In 1977 the 13,312 nonstate ICF-MR residents made up only 12.5% of all ICF-MR residents. By 1982, 32,044 nonstate ICF-MR residents made up 22.8% of all ICF-MR residents. By 1986, 49,875 nonstate ICF-MR residents made up 34.6% of all ICF-MR residents. On June 30, 1989, 61,016 or 41.4% of all ICF-MR residents were in nonstate ICFs-MR. Growth in the number of nonstate ICF-MR residents has been evident in both large and small nonstate facilities.

Large nonstate facilities. Since 1977 there has been a strong trend toward greater "privatization" of all residential care, including that provided in ICFs-MR. This has happened primarily as people with mental retardation and related conditions have moved from large state institutions to relatively small, overwhelmingly privately operated, community based residences. Still, while growth in the number of residents in small nonstate ICFs-MR between 1977 and 1986 was proportionally more rapid and generally more attended to than the growth in the number of residents in large nonstate ICFs-MR, there was actually a larger net population increase in large ICFs-MR than in small ones from 1977 to 1986 (19,987 and 16,576, respectively). However, from 1982 to 1989, increase of residents in small nonstate ICFs-MR was twice that in large nonstate facilities. Small facilities grew by 19,384 residents, as compared with 9,588 in large ICFs-MR.

Most of the growth in the number of residents in large nonstate certified facilities over the past decade took place between 1977 and 1982 (an increase of 11,728), as states actively pursued certifying existing nonstate institutions. But the certification of large nonstate facilities continued at a high rate until 1986, after which the net increase in number of large nonstate ICFs-MR virtually ceased. From June 30, 1977 to June 30, 1982 states were on the average increasing large nonstate ICF-MR institution populations by 2,340 per year; from June 30, 1982 to June 30, 1986 the average annual increase was 2,060, or only 280 fewer. From June 30, 1986

to June 30, 1988 this increase virtually stopped, averaging less than 70 residents per year. In Fiscal Year 1989, however, there was a notable change in this trend. Between June 30, 1988 and June 30, 1989 the number of large nonstate ICF-MR residents increased by 1,191 people. This increase was primarily driven by the certification for ICF-MR participation of facilities housing persons with mental retardation and related conditions that were previously certified as nursing homes. These "recertifications" were prompted largely by the requirements of the Omnibus Budget Reconciliation Act of 1987 which were designed to eliminate inappropriate nursing home placements of persons with mental retardation and related conditions. Relatedly it should be noted that the net national increase of 9,588 residents in large nonstate ICFs-MR between 1982 and 1989 was substantial, but not truly a national trend, resulting from relatively few states actively certifying existing nonstate mental retardation and nursing facilities as described above. In fact, four states alone accounted for 71.4% of the 1982-1989 increase of residents in large, nonstate ICF-MR institutions: Ohio (2,016), Florida (1,275), Oklahoma (2,026), and Wisconsin (1,527). It is also worthwhile to note that although the average size of large nonstate facilities decreased from 76 to 66 residents between 1977 and 1982, between 1982 and 1989 their average size decreased only from 66 to 63.5 residents.

Small nonstate facilities. Small ICFs-MR (i.e., those with 15 or fewer residents) have been the focus of considerable attention throughout the past decade, primarily because, with the exception of residential services funded under Medicaid HCBS, small ICFs-MR have been the only way for states to use the favorable Medicaid cost-share to support community based residential programs. The vast majority of the small ICFs-MR that have been developed are nonstate facilities. On June 30, 1989 small nonstate ICFs-MR made up 73.6% of all certified facilities, although only 18.8% of all ICF-MR residents lived in small nonstate facilities. These numbers compare with 26% of facilities and 1.3% of residents in 1977, 56% of facilities and 6% of residents in 1982, and 68.5% of facilities and 12.4% of residents in 1986.

Further broken down, on June 30, 1989 of the 27,742 people living in nonstate ICFs-MR of 15 or fewer residents, 9,778 (35%) were living in ICFs-MR of 6 or fewer residents. Of the 41 states (including District of Columbia) with small nonstate ICF-MR facilities, 13 had more of their small ICF-MR residents in ICFs-MR with 6 or fewer residents than in ICFs-MR of 7-15 residents. In comparison, on June 30, 1982 of the 8,358 small nonstate ICF-MR residents, 2,364 (28%) were living in ICFs-MR of 6 or fewer residents, and 4 of 35 states with small nonstate ICF-MR facilities had more residents in nonstate ICFs-MR of 6 or fewer residents than in nonstate ICFs-MR of 7-15 residents. On June 30, 1977 of the 1,354 small ICF-MR residents, 252 lived in ICFs-MR of 6 or fewer residents and no state had more residents in ICFs-MR of 6 or fewer residents than in ICFs-MR of 7-15 residents. As a consequence of the increasing development of ICFs-MR with 6 or fewer residents, the average size of small ICFs-MR dropped from 9.2 residents in 1982 to 7.7 residents in 1989.

TABLE 1: ICF-MR CERTIFIED FACILITIES AND RESIDENTS ON JUNE 30, 1977

	FACILITIES						RESIDENTS					
	STATE			NONSTATE			NONSTATE			ALL BY SIZE		
	1-15	16+	TOTAL	1-15	16+	TOTAL	1-15	16+	TOTAL	1-15	16+	TOTAL
ALABAMA	0	0	0	0	0	0	0	0	0	0	0	0
ALASKA	0	1	1	1	1	2	10	125	135	10	125	135
ARIZONA	0	0	0	0	0	0	0	0	0	0	0	0
ARKANSAS	0	5	5	0	2	2	0	1,385	1,385	0	1,385	1,385
CALIFORNIA	0	4	4	0	0	0	0	0	0	0	0	0
COLORADO	1	3	4	7	5	12	8	8	16	8	8	16
CONNECTICUT	8	7	15	2	0	2	10	7	17	10	7	17
DELAWARE	0	1	1	0	0	0	0	1	1	0	1	1
D.C.	0	0	0	0	0	0	0	0	0	0	0	0
FLORIDA	0	4	4	1	2	3	1	6	7	1	6	7
GEORGIA	0	6	6	0	0	0	0	6	6	0	6	6
HAWAII	0	1	1	0	0	0	0	1	1	0	1	1
IDAHO	0	1	1	0	1	1	0	2	2	0	2	2
ILLINOIS	0	13	13	0	26	26	0	39	39	0	39	39
INDIANA	0	2	2	0	0	0	0	2	2	0	2	2
IOWA	0	2	2	0	0	0	0	2	2	0	2	2
KANSAS	0	4	4	0	6	6	0	10	10	0	10	10
KENTUCKY	0	3	3	0	4	4	0	7	7	0	7	7
LOUISIANA	0	10	10	0	4	4	0	14	14	0	14	14
MAINE	0	2	2	0	4	4	0	6	6	0	6	6
MARYLAND	0	6	6	0	0	0	0	6	6	0	6	6
MASSACHUSETTS	0	7	7	0	0	0	0	7	7	0	7	7
MICHIGAN	0	12	12	0	0	0	0	12	12	0	12	12
MINNESOTA	0	8	8	113	33	146	113	41	154	113	41	154
MISSISSIPPI	0	2	2	0	2	2	0	4	4	0	4	4
MISSOURI	0	5	5	0	4	4	0	9	9	0	9	9
MONTANA	0	0	0	0	0	0	0	0	0	0	0	0
NEBRASKA	0	3	3	0	3	3	0	6	6	0	6	6
NEVADA	0	0	0	0	0	0	0	0	0	0	0	0
NEW HAMPSHIRE	0	1	1	0	1	1	0	2	2	0	2	2
NEW JERSEY	0	5	5	0	0	0	0	5	5	0	5	5
NEW MEXICO	0	2	2	0	0	0	0	2	2	0	2	2
NEW YORK	0	24	24	3	1	4	3	25	28	3	25	28
NORTH CAROLINA	0	6	6	0	1	1	0	7	7	0	7	7
NORTH DAKOTA	0	0	0	0	0	0	0	0	0	0	0	0
OHIO	0	11	11	6	12	18	6	23	29	6	23	29
OKLAHOMA	0	3	3	0	0	0	0	3	3	0	3	3
OREGON	0	2	2	0	4	4	0	6	6	0	6	6
PENNSYLVANIA	0	19	19	0	3	3	0	22	22	0	22	22
RHODE ISLAND	0	1	1	1	0	1	1	1	2	1	1	2
SOUTH CAROLINA	5	7	12	0	2	2	5	9	14	5	9	14
SOUTH DAKOTA	0	2	2	0	0	0	0	2	2	0	2	2
TENNESSEE	0	4	4	0	2	2	0	6	6	0	6	6
TEXAS	27	16	43	7	8	15	34	24	58	34	24	58
UTAH	0	1	1	0	7	7	0	8	8	0	8	8
VERMONT	0	1	1	0	0	0	0	1	1	0	1	1
VIRGINIA	0	5	5	0	1	1	0	6	6	0	6	6
WASHINGTON	0	3	3	0	8	8	0	11	11	0	11	11
WEST VIRGINIA	0	0	0	0	0	0	0	0	0	0	0	0
WISCONSIN	0	3	3	6	11	17	6	14	20	6	14	20
WYOMING	0	0	0	0	0	0	0	0	0	0	0	0
U.S. TOTAL	41	228	269	147	158	305	188	386	574	188	386	574
% ICF-MR TOTALS	7.1	39.7	46.9	25.6	27.5	53.1	32.8	67.2	100.0			

	RESIDENTS											
	STATE			NONSTATE			ALL BY SIZE					
	1-15	16+	TOTAL	1-15	16+	TOTAL	1-15	16+	TOTAL			
ALABAMA	0	0	0	0	0	0	0	0	0			
ALASKA	0	105	105	10	20	30	10	125	135			
ARIZONA	0	0	0	0	0	0	0	0	0			
ARKANSAS	0	1,338	1,338	0	47	47	0	1,385	1,385			
CALIFORNIA	0	0	0	0	0	0	0	0	0			
COLORADO	8	4,158	4,166	65	306	371	73	4,464	4,537			
CONNECTICUT	85	583	668	19	0	19	104	583	687			
DELAWARE	0	477	477	0	0	0	0	477	477			
D.C.	0	0	0	0	0	0	0	0	0			
FLORIDA	0	279	279	15	76	91	15	355	370			
GEORGIA	0	2,369	2,369	0	0	0	0	2,369	2,369			
HAWAII	0	524	524	0	0	0	0	524	524			
IDAHO	0	553	553	0	30	30	0	583	583			
ILLINOIS	0	2,568	2,568	0	2,785	2,785	0	5,353	5,353			
INDIANA	0	1,026	1,026	0	0	0	0	1,026	1,026			
IOWA	0	1,432	1,432	0	0	0	0	1,432	1,432			
KANSAS	0	1,443	1,443	0	367	367	0	1,810	1,810			
KENTUCKY	0	469	469	0	530	530	0	999	999			
LOUISIANA	0	3,221	3,221	0	461	461	0	3,682	3,682			
MAINE	0	197	197	0	113	113	0	310	310			
MARYLAND	0	1,367	1,367	0	0	0	0	1,367	1,367			
MASSACHUSETTS	0	4,242	4,242	0	0	0	0	4,242	4,242			
MICHIGAN	0	5,760	5,760	0	0	0	0	5,760	5,760			
MINNESOTA	0	2,527	2,527	1,052	1,724	2,776	1,052	4,251	5,303			
MISSISSIPPI	0	255	255	0	236	236	0	491	491			
MISSOURI	0	1,842	1,842	0	209	209	0	2,051	2,051			
MONTANA	0	0	0	0	0	0	0	0	0			
NEBRASKA	0	958	958	0	398	398	0	1,356	1,356			
NEVADA	0	0	0	0	0	0	0	0	0			
NEW HAMPSHIRE	0	264	264	0	24	24	0	288	288			
NEW JERSEY	0	525	525	0	0	0	0	525	525			
NEW MEXICO	0	426	426	0	0	0	0	426	426			
NEW YORK	0	18,401	18,401	36	164	200	36	18,565	18,601			
NORTH CAROLINA	0	2,003	2,003	0	70	70	0	2,073	2,073			
NORTH DAKOTA	0	0	0	0	0	0	0	0	0			
OHIO	0	1,696	1,696	44	748	792	44	2,444	2,488			
OKLAHOMA	0	1,978	1,978	0	0	0	0	1,978	1,978			
OREGON	0	1,781	1,781	0	208	208	0	1,989	1,989			
PENNSYLVANIA	0	6,935	6,935	0	420	420	0	7,355	7,355			
RHODE ISLAND	0	756	756	7	0	7	7	756	763			
SOUTH CAROLINA	40	903	943	0	74	74	40	977	1,017			
SOUTH DAKOTA	0	540	540	0	0	0	0	540	540			
TENNESSEE	0	2,111	2,111	0	38	38	0	2,149	2,149			
TEXAS	223	9,497	9,720	54	712	766	277	10,209	10,486			
UTAH	0	849	849	0	344	344	0	1,193	1,193			
VERMONT	0	352	352	0	0	0	0	352	352			
VIRGINIA	0	3,508	3,508	0	50	50	0	3,558	3,558			
WASHINGTON	0	0	0	0	440	440	0	440	440			
WEST VIRGINIA	0	0	0	0	0	0	0	0	0			
WISCONSIN	0	2,280	2,280	52	1,364	1,416	52	3,644	3,696			
WYOMING	0	0	0	0	0	0	0	0	0			
U.S. TOTAL	356	92,498	92,854	1,354	11,958	13,312	1,710	104,456	106,166			
% ICF-MR TOTALS	.3	87.1	87.5	1.3	11.3	12.5	1.6	98.4	100.0			

TABLE 2: ICF-MR CERTIFIED FACILITIES AND RESIDENTS BY STATE AND FACILITY SIZE ON JUNE 30, 1982

	FACILITIES									RESIDENTS												
	STATE			NONSTATE			ALL BY SIZE			STATE				NONSTATE				ALL BY SIZE				
	1-15	16+	TOTAL	1-15	16+	TOTAL	1-15	16+	TOTAL	1-6	7-15	1-15	16+	TOTAL	1-6	7-15	1-15	16+	TOTAL	1-6	7-15	1-15	16+	TOTAL
ALABAMA	0	4	4	0	0	0	0	4	4	0	0	0	1,470	1,470	0	0	0	0	0	0	0	0	1,470	1,470
ALASKA	0	1	1	3	0	3	3	1	4	0	0	0	88	88	0	30	30	0	30	0	30	30	88	118
ARIZONA	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
ARKANSAS	0	5	5	0	2	2	0	7	7	0	0	0	1,354	1,354	0	0	0	66	66	0	0	0	1,420	1,420
CALIFORNIA	0	8	8	0	29	29	0	37	37	0	0	0	7,924	7,924	0	0	0	2,450	2,450	0	0	0	10,374	10,374
COLORADO	36	3	39	25	9	34	61	12	73	0	275	275	989	1,264	6	201	207	546	753	6	476	482	1,535	2,017
CONNECTICUT	21	11	32	9	1	10	30	12	42	0	233	233	1,264	1,497	17	63	80	21	101	17	296	313	1,285	1,598
DELAWARE	0	1	1	0	0	0	0	1	1	0	0	0	513	513	0	0	0	0	0	0	0	0	513	513
D.C.	0	1	1	1	2	3	1	3	4	0	0	0	372	372	4	0	4	60	64	4	0	4	432	436
FLORIDA	0	7	7	6	12	18	6	19	25	0	0	0	1,407	1,407	5	58	63	658	721	5	58	63	2,065	2,128
GEORGIA	0	8	8	0	1	1	0	9	9	0	0	0	2,381	2,381	0	0	0	110	110	0	0	0	2,491	2,491
HAWAII	1	1	2	0	0	0	1	1	2	0	8	8	379	387	0	0	0	0	0	0	8	8	379	387
IDAHO	0	1	1	7	3	10	7	4	11	0	0	0	350	350	11	44	55	77	132	11	44	55	427	482
ILLINOIS	0	15	15	5	38	43	5	53	58	0	0	0	4,500	4,500	0	64	64	3,580	3,644	0	64	64	8,080	8,144
INDIANA	0	7	7	57	3	60	57	10	67	0	0	0	2,296	2,296	200	137	337	165	502	200	137	337	2,461	2,798
IOWA	0	3	3	0	8	8	0	11	11	0	0	0	1,296	1,296	0	0	0	377	377	0	0	0	1,673	1,673
KANSAS	0	4	4	4	11	15	4	15	19	0	0	0	1,371	1,371	0	54	54	653	707	0	54	54	2,024	2,078
KENTUCKY	0	3	3	0	6	6	0	9	9	0	0	0	677	677	0	0	0	573	573	0	0	0	1,250	1,250
LOUISIANA	2	10	12	30	12	42	32	22	54	2	1	3	3,496	3,499	68	177	245	1,105	1,350	70	178	248	4,601	4,849
MAINE	1	2	3	18	5	23	19	7	26	0	12	12	364	376	87	35	122	132	254	87	47	134	496	630
MARYLAND	1	9	10	0	0	0	1	9	10	0	10	10	1,841	1,851	0	0	0	0	0	0	10	10	1,841	1,851
MASSACHUSETTS	0	8	8	9	0	9	9	8	17	0	0	0	3,897	3,897	0	70	70	74	144	0	70	70	3,971	4,041
MICHIGAN	22	11	33	117	0	117	139	11	150	125	8	133	3,165	3,298	641	63	704	0	704	766	71	837	3,165	4,002
MINNESOTA	0	8	8	260	42	302	260	50	310	0	0	0	2,417	2,417	652	1,760	2,412	2,070	4,482	652	1,760	2,412	4,487	6,899
MISSISSIPPI	0	5	5	0	6	6	0	11	11	0	0	0	999	999	0	0	0	615	615	0	0	0	1,614	1,614
MISSOURI	0	5	5	8	0	8	8	5	13	0	0	0	1,813	1,813	0	65	65	0	65	0	65	65	1,813	1,878
MONTANA	0	2	2	2	0	2	2	2	4	0	0	0	273	273	0	17	17	0	17	0	17	17	273	290
NEBRASKA	1	2	3	4	3	7	5	5	10	0	13	13	558	571	0	29	29	380	409	0	42	42	938	980
NEVADA	0	2	2	1	1	2	1	3	4	0	0	0	160	160	0	15	15	0	15	0	15	15	160	175
NEW HAMPSHIRE	0	1	1	0	1	1	0	2	2	0	0	0	317	317	0	0	0	22	22	0	0	0	339	339
NEW JERSEY	0	9	9	0	0	0	0	9	9	0	0	0	4,366	4,366	0	0	0	0	0	0	0	0	4,366	4,366
NEW MEXICO	0	2	2	6	0	6	6	2	8	0	0	0	503	503	0	50	50	0	50	0	50	50	503	553
NEW YORK	44	23	67	254	10	264	298	33	331	31	359	390	12,502	12,892	332	1,567	1,899	786	2,685	363	1,926	2,289	13,288	15,577
NORTH CAROLINA	1	7	8	2	2	4	3	9	12	5	0	5	2,582	2,587	5	10	15	160	175	10	10	20	2,742	2,762
NORTH DAKOTA	0	1	1	2	1	3	2	2	4	0	0	0	183	183	0	24	24	12	36	0	24	24	195	219
OHIO	8	23	31	9	45	54	17	68	85	0	67	67	3,908	3,975	0	90	90	1,975	2,065	0	157	157	5,883	6,040
OKLAHOMA	0	3	3	0	0	0	0	3	3	0	0	0	1,803	1,803	0	0	0	0	0	0	0	0	1,803	1,803
OREGON	2	2	4	3	5	8	5	7	12	0	19	19	1,627	1,646	0	37	37	235	272	0	56	56	1,862	1,918
PENNSYLVANIA	0	20	20	41	15	56	41	35	76	0	0	0	7,128	7,128	75	199	274	1,196	1,470	75	199	274	8,324	8,598
RHODE ISLAND	9	1	10	51	1	52	60	2	62	10	64	74	482	556	143	164	307	18	325	153	228	381	500	881
SOUTH CAROLINA	12	10	22	3	3	6	15	13	28	0	109	109	2,409	2,518	0	24	24	123	147	0	133	133	2,532	2,665
SOUTH DAKOTA	0	2	2	11	0	11	11	2	13	0	0	0	601	601	0	120	120	0	120	0	120	120	601	721
TENNESSEE	0	4	4	9	5	14	9	9	18	0	0	0	2,125	2,125	29	43	72	180	252	29	43	72	2,305	2,377
TEXAS	31	17	48	55	44	99	86	61	147	29	229	258	10,118	10,376	0	610	610	2,973	3,583	29	839	868	13,091	13,959
UTAH	0	1	1	0	7	7	0	8	8	0	0	0	793	793	0	0	0	406	406	0	0	0	1,199	1,199
VERMONT	0	2	2	12	0	12	12	2	14	0	0	0	314	314	71	0	71	0	71	71	0	71	314	385
VIRGINIA	2	6	8	3	1	4	5	7	12	6	12	18	3,506	3,524	0	32	32	60	92	6	44	50	3,566	3,616
WASHINGTON	0	6	6	7	11	18	7	17	24	0	0	0	1,894	1,894	5	52	57	513	570	5	52	57	2,407	2,464
WEST VIRGINIA	0	1	1	1	1	2	1	2	3	0	0	0	156	156	4	0	4	16	20	4	0	4	172	176
WISCONSIN	0	4	4	9	13	22	9	17	26	0	0	0	2,150	2,150	6	93	99	1,299	1,398	6	93	99	3,449	3,548
WYOMING	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
U.S. TOTAL	194	292	486	1,044	359	1,403	1,238	651	1,889	208	1,419	1,627	107,081	108,708	2,361	5,997	8,358	23,686	32,044	2,569	7,416	9,985	130,767	140,752
% ICF-MR Totals	8.5	15.8	24.3	56.3	19.4	75.7	64.9	35.1	100.0	0.1	1.0	1.0	76.2	77.3	1.7	4.3	5.9	16.8	22.8	1.8	5.3	7.1	92.9	100.0

TABLE 3: ICF-MR CERTIFIED FACILITIES AND RESIDENTS BY STATE AND FACILITY SIZE ON JUNE 30, 1986

	FACILITIES									RESIDENTS												
	STATE			NONSTATE			ALL BY SIZE			STATE				NONSTATE				ALL BY SIZE				
	1-15	16+	TOTAL	1-15	16+	TOTAL	1-15	16+	TOTAL	1-15	16+	TOTAL		1-15	16+	TOTAL		1-15	16+	TOTAL		
ALABAMA	0	5	5	3	0	3	3	5	8	0	1,333	1,333		31	0	31		31	1,333	1,364		
ALASKA	0	1	1	5	0	5	5	1	6	0	59	59		40	0	40		40	59	99		
ARIZONA	0	0	0	0	0	0	0	0	0	0	0	0		0	0	0		0	0	0		
ARKANSAS	0	6	6	0	3	3	0	9	9	0	1,284	1,284		0	88	88		0	1,372	1,372		
CALIFORNIA	0	8	8	213	34	247	213	42	255	0	5,043	5,043		1,455	2,918	4,373		1,455	7,961	9,416		
COLORADO	36	3	39	0	6	6	36	9	45	275	694	969		0	346	346		275	1,040	1,315		
CONNECTICUT	27	10	37	15	1	16	42	11	53	537	509	1,046		88	15	103		625	524	1,149		
DELAWARE	0	1	1	8	0	8	8	1	9	0	394	394		61	0	61		61	394	455		
D.C.	0	1	1	51	0	51	51	1	52	0	285	285		306	0	306		306	285	591		
FLORIDA	0	4	4	3	48	51	3	52	55	0	1,303	1,303		42	1,898	1,940		42	3,201	3,243		
GEORGIA	0	8	8	0	1	1	0	9	9	0	1,872	1,872		0	110	110		0	1,982	1,982		
HAWAII	1	1	2	4	0	4	5	1	6	8	221	229		20	0	20		28	221	249		
IDAHO	0	1	1	12	3	15	12	4	16	0	287	287		100	82	182		100	369	469		
ILLINOIS	0	12	12	26	46	72	26	58	84	0	4,475	4,475		338	4,140	4,478		338	8,615	8,953		
INDIANA	0	9	9	229	5	234	229	14	243	0	2,302	2,302		1,450	608	2,058		1,450	2,910	4,360		
IOWA	0	2	2	5	13	18	5	15	20	0	1,143	1,143		37	836	873		37	1,979	2,016		
KANSAS	0	4	4	13	10	23	13	14	27	0	1,345	1,345		166	626	792		166	1,971	2,137		
KENTUCKY	0	3	3	0	6	6	0	9	9	0	690	690		0	513	513		0	1,203	1,203		
LOUISIANA	6	9	15	144	15	159	150	24	174	34	3,042	3,076		874	1,625	2,499		908	4,667	5,575		
MAINE	2	2	4	34	4	38	36	6	42	26	295	321		314	89	403		340	384	724		
MARYLAND	1	7	8	0	0	0	1	7	8	13	2,203	2,216		0	0	0		13	2,203	2,216		
MASSACHUSETTS	0	7	7	38	0	38	38	7	45	0	3,438	3,438		299	0	299		299	3,438	3,737		
MICHIGAN	0	8	8	229	0	229	229	8	237	0	1,930	1,930		1,384	0	1,384		1,384	1,930	3,314		
MINNESOTA	0	7	7	294	53	347	294	60	354	0	1,780	1,780		2,753	2,319	5,072		2,753	4,099	6,852		
MISSISSIPPI	0	5	5	0	5	5	0	10	10	0	967	967		0	605	605		0	1,572	1,572		
MISSOURI	2	9	11	12	3	15	14	12	26	14	1,858	1,872		90	126	216		104	1,984	2,088		
MONTANA	0	2	2	1	0	1	1	2	3	0	257	257		9	0	9		9	257	266		
NEBRASKA	0	1	1	0	4	4	0	5	5	0	468	468		0	393	393		0	861	861		
NEVADA	0	2	2	1	0	1	1	2	3	0	166	166		15	0	15		15	166	181		
NEW HAMPSHIRE	0	2	2	7	1	8	7	3	10	0	226	226		50	23	73		50	249	299		
NEW JERSEY	0	9	9	0	2	2	0	11	11	0	3,809	3,809		0	72	72		0	3,881	3,881		
NEW MEXICO	0	2	2	16	0	16	16	2	18	0	514	514		135	0	135		135	514	649		
NEW YORK	181	28	209	442	35	477	623	63	686	1,664	10,705	12,369		3,647	1,083	4,730		5,311	11,788	17,099		
NORTH CAROLINA	0	6	6	33	4	37	33	10	43	0	2,492	2,492		210	402	612		210	2,894	3,104		
NORTH DAKOTA	0	2	2	58	0	58	58	2	60	0	437	437		441	0	441		441	437	878		
OHIO	0	21	21	121	84	205	121	105	226	0	3,073	3,073		912	3,801	4,713		912	6,874	7,786		
OKLAHOMA	0	3	3	0	17	17	0	20	20	0	1,354	1,354		0	1,647	1,647		0	3,001	3,001		
OREGON	0	2	2	2	6	8	2	8	10	0	1,294	1,294		22	261	283		22	1,555	1,577		
PENNSYLVANIA	0	17	17	80	20	100	80	37	117	0	5,647	5,647		517	1,573	2,090		517	7,220	7,737		
RHODE ISLAND	10	2	12	84	0	84	94	2	96	61	335	396		511	0	511		572	335	907		
SOUTH CAROLINA	11	6	17	27	3	30	38	9	47	101	2,660	2,761		229	110	339		330	2,770	3,100		
SOUTH DAKOTA	0	2	2	16	0	16	16	2	18	0	497	497		166	0	166		166	497	663		
TENNESSEE	0	4	4	12	4	16	12	8	20	0	2,128	2,128		95	188	283		95	2,316	2,411		
TEXAS	57	16	73	93	31	124	150	47	197	502	8,327	8,829		803	2,417	3,220		1,305	10,744	12,049		
UTAH	0	1	1	1	9	10	1	10	11	0	700	700		15	604	619		15	1,304	1,319		
VERMONT	0	1	1	11	0	11	11	1	12	0	195	195		66	0	66		66	195	261		
VIRGINIA	0	5	5	9	3	12	9	8	17	0	2,970	2,970		91	108	199		91	3,078	3,169		
WASHINGTON	0	6	6	21	12	33	21	18	39	0	1,839	1,839		138	618	756		138	2,457	2,595		
WEST VIRGINIA	0	2	2	1	2	3	1	4	5	0	204	204		10	51	61		10	255	265		
WISCONSIN	0	3	3	0	22	22	0	25	25	0	2,030	2,030		0	1,650	1,650		0	3,680	3,680		
WYOMING	0	0	0	0	0	0	0	0	0	0	0	0		0	0	0		0	0	0		
U.S. TOTAL	334	278	612	2,374	515	2,889	2,708	793	3,501	3,235	91,079	94,314		17,930	31,945	49,875		21,165	123,024	144,189		
% ICF-MR TOTALS	9.5	8.0	17.5	68.5	14.9	83.4	77.3	22.7	100.0	2.2	63.2	65.4		12.4	22.2	34.6		14.7	85.3	100.0		

TABLE 4: ICF-MR CERTIFIED FACILITIES ON JUNE 30, 1989 BY SIZE AND STATE

	STATE					NONSTATE					ALL BY SIZE				
	1-6	7-15	1-15	16+	TOTAL	1-6	7-15	1-15	16+	TOTAL	1-6	7-15	1-15	16+	TOTAL
ALABAMA	0	0	0	5	5	0	3	3	0	3	0	3	3	5	8
ALASKA	0	0	0	1	1	2	3	5	0	5	2	3	5	1	6
ARIZONA	0	4	4	1	5	0	0	0	0	0	0	4	4	1	5
ARKANSAS	0	0	0	6	6	0	0	0	4	4	0	0	0	10	10
CALIFORNIA	0	0	0	7	7	283e	49e	332	26	358	283	49	332	33	365
COLORADO	0	36	36	3	39	0	0	0	6	6	0	36	36	9	45
CONNECTICUT	8	28	36	11	47	36	2	38	1	39	44	30	74	12	86
DELAWARE	0	0	0	1	1	0	12	12	0	12	0	12	12	1	13
D.C.	0	0	0	1	1	47	30	77	0	77	47	30	77	1	78
FLORIDA	0	0	0	4	4	0	0	0	51	51	0	0	0	55	55
GEORGIA	0	0	0	8	8	0	0	0	1	1	0	0	0	9	9
HAWAII	0	0	0	2	2	16	1	17	0	17	16	1	17	2	19
IDAHO	0	0	0	1	1	4	21	25	2	27	4	21	25	3	28
ILLINOIS	0	0	0	12	12	0	139	139	46	185	0	139	139	58	197
INDIANA	0	0	0	8	8	144	258	402	8	410	144	258	402	16	418
IOWA	0	0	0	2	2	0	10	10	15	25	0	10	10	17	27
KANSAS	0	0	0	3	3	7	16	23	10	33	7	16	23	13	36
KENTUCKY	0	0	0	3	3	0	0	0	6	6	0	0	0	9	9
LOUISIANA	5	0	5	9	14	264	10	274	16	290	269	10	279	25	304
MAINE	0	2	2	2	4	20	10	30	6	36	20	12	32	8	40
MARYLAND	0	1	1	7	8	0	0	0	0	0	0	1	1	7	8
MASSACHUSETTS	0	27	27	7	34	0	38	38	0	38	0	65	65	7	72
MICHIGAN	0	0	0	7	7	287	0	287	0	287	287	0	287	7	294
MINNESOTA	0	0	0	7	7	106	167	273	46	319	106	167	273	53	326
MISSISSIPPI	0	0	0	5	5	0	0	0	5	5	0	0	0	10	10
MISSOURI	0	2	2	10	12	5	18	23	3	26	5	20	25	13	38
MONTANA	0	0	0	2	2	0	1	1	0	1	0	1	1	2	3
NEBRASKA	0	0	0	1	1	0	1	1	2	3	0	1	1	3	4
NEVADA	0	0	0	2	2	0	1	1	0	1	0	1	1	2	3
NEW HAMPSHIRE	0	0	0	1	1	3	4	7	0	7	3	4	7	1	8
NEW JERSEY	0	0	0	9	9	0	0	0	2	2	0	0	0	11	11
NEW MEXICO	0	0	0	2	2	3	26	29	0	29	3	26	29	2	31
NEW YORK	25	277	302	35	337	120	463	583	23	606	145	740	885	58	943
NORTH CAROLINA	0	0	0	6	6	86	14	100	6	106	86	14	100	12	112
NORTH DAKOTA	0	0	0	1	1	16	45	61	1	62	16	45	61	2	63
OHIO	0	0	0	17	17	15	139	154	93	247	15	139	154	110	264
OKLAHOMA	0	0	0	3	3	0	1	1	22	23	0	1	1	25	26
OREGON	0	0	0	2	2	0	2	2	3	5	0	2	2	5	7
PENNSYLVANIA	0	0	0	13	13	79	69	148	23	171	79	69	148	36	184
RHODE ISLAND	4	0	4	2	6	99	25	124	0	124	103	25	128	2	130
SOUTH CAROLINA	0	1	1	4	5	0	90	90	4	94	0	91	91	8	99
SOUTH DAKOTA	0	0	0	2	2	0	15	15	0	15	0	15	15	2	17
TENNESSEE	0	0	0	4	4	0	1	1	4	5	0	1	1	8	9
TEXAS	36e	45e	81e	18	99	135e	44e	179	28	207	171	89	260	46	306
UTAH	0	0	0	1	1	0	3	3	9	12	0	3	3	10	13
VERMONT	0	0	0	1	1	9	0	9	0	9	9	0	9	1	10
VIRGINIA	0	0	0	5	5	3	11	14	1	15	3	11	14	6	20
WASHINGTON	0	0	0	6	6	14	9	23	10	33	14	9	23	16	39
WEST VIRGINIA	0	0	0	2	2	9	52	61	2	63	9	52	61	4	65
WISCONSIN	0	0	0	3	3	0	5	5	39	44	0	5	5	42	47
WYOMING	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
U.S. TOTAL	78	423	501	275	776	1,812	1,808	3,620	524	4,144	1,890	2,231	4,121	799	4,917
% ICF-MR TOTALS	1.6	8.6	10.2	5.6	15.8	36.9	36.8	73.6	10.7	84.3	38.4	45.4	83.8	16.2	100.0

TABLE 5: RESIDENTS OF ICF-MR CERTIFIED FACILITIES ON JUNE 30, 1989 BY SIZE AND STATE

	STATE					NONSTATE					ALL BY SIZE				
	1-6	7-15	1-15	16+	TOTAL	1-6	7-15	1-15	16+	TOTAL	1-6	7-15	1-15	16+	TOTAL
ALABAMA	0	0	0	1,295	1,295	0	31	31	0	31	0	31	31	1,295	1,326
ALASKA	0	0	0	57	57	10	30	40	0	40	10	30	40	57	97
ARIZONA	0	51	51	18	69	0	0	0	0	0	0	51	51	18	69
ARKANSAS	0	0	0	1,302	1,302	0	0	0	139	139	0	0	0	1,441	1,441
CALIFORNIA	0	0	0	6,796	6,796	1,368	434	1,802	2,380	4,182	1,368	434	1,802	9,176	10,978
COLORADO	0	276	276	493	769	0	0	0	346	346	0	276	276	839	1,115
CONNECTICUT	46	220	266	1,813	2,079	188	20	208	48	256	234	240	474	1,861	2,335
DELAWARE	0	0	0	356	356	0	86	86	0	86	0	86	86	356	442
D.C.	0	0	0	171	171	236	234	470	0	470	236	234	470	171	641
FLORIDA	0	0	0	1,247	1,247	0	0	0	1,933	1,933	0	0	0	3,180	3,180
GEORGIA	0	0	0	1,834	1,834	0	0	0	110	110	0	0	0	1,944	1,944
HAWAII	0	0	0	173	173	65	8	73	0	73	65	8	73	173	246
IDAHO	0	0	0	221	221	24	231	255	44	299	24	231	255	265	520
ILLINOIS	0	0	0	4,540	4,540	0	2,116	2,116	4,208	6,324	0	2,116	2,116	8,748	10,864
INDIANA	0	0	0	1,733	1,733	778	2,022	2,800	979	3,779	778	2,022	2,800	2,712	5,512
IOWA	0	0	0	1,016	1,016	0	101	101	701	802	0	101	101	1,717	1,818
KANSAS	0	0	0	1,070	1,070	41	204	245	640	885	41	204	245	1,710	1,955
KENTUCKY	0	0	0	666	666	0	0	0	513	513	0	0	0	1,179	1,179
LOUISIANA	30	0	30	2,728	2,758	1,558	101	1,659	1,650	3,309	1,588	101	1,689	4,378	6,067
MAINE	0	24	24	279	303	120	101	221	144	365	120	125	245	423	668
MARYLAND	0	12	12	1,362	1,374	0	0	0	0	0	0	12	12	1,362	1,374
MASSACHUSETTS	0	198	198	3,026	3,224	0	324	324	0	324	0	522	522	3,026	3,548
MICHIGAN	0	0	0	1,237	1,237	1,722	0	1,722	0	1,722	1,722	0	1,722	1,237	2,959
MINNESOTA	0	0	0	1,410	1,410	636	1,936	2,572	1,787	4,359	636	1,936	2,572	3,197	5,769
MISSISSIPPI	0	0	0	993	993	0	0	0	595	595	0	0	0	1,588	1,588
MISSOURI	0	14	14	1,532	1,546	29	145	174	138	312	29	159	188	1,670	1,858
MONTANA	0	0	0	240	240	0	10	10	0	10	0	10	10	240	250
NEBRASKA	0	0	0	469	469	0	8	8	279	287	0	8	8	748	756
NEVADA	0	0	0	170	170	0	15	15	0	15	0	15	15	170	185
NEW HAMPSHIRE	0	0	0	104	104	18	36	54	0	54	18	36	54	104	158
NEW JERSEY	0	0	0	3,750	3,750	0	0	0	72	72	0	0	0	3,822	3,822
NEW MEXICO	0	0	0	503	503	15	233	248	0	248	15	233	248	503	751
NEW YORK	124	2,877	3,001	8,179	11,180	526	4,608	5,134	1,460	6,594	650	7,485	8,135	9,639	17,774
NORTH CAROLINA	0	0	0	2,097	2,097	430	184	614	462	1,076	430	184	614	2,559	3,173
NORTH DAKOTA	0	0	0	251	251	96	372	468	24	492	96	372	468	275	743
OHIO	0	0	0	2,578	2,578	81	1,321	1,402	3,991	5,393	81	1,321	1,402	6,569	7,971
OKLAHOMA	0	0	0	1,019	1,019	0	15	15	2,026	2,041	0	15	15	3,045	3,060
OREGON	0	0	0	863	863	0	22	22	157	179	0	22	22	1,020	1,042
PENNSYLVANIA	0	0	0	4,082	4,082	416	550	966	2,037	3,003	416	550	966	6,119	7,085
RHODE ISLAND	22	0	22	225	247	480	229	709	0	709	502	229	731	225	956
SOUTH CAROLINA	0	14	14	2,363	2,377	0	762	762	92	854	0	776	776	2,455	3,231
SOUTH DAKOTA	0	0	0	405	405	0	186	186	0	186	0	186	186	405	591
TENNESSEE	0	0	0	1,963	1,963	0	12	12	200	212	0	12	12	2,163	2,175
TEXAS	205e	416e	621	7,933	8,554	741e	551e	1,292	2,235	3,527	946	967	1,913	10,168	12,081
UTAH	0	0	0	470	470	0	43	43	492	535	0	43	43	962	1,005
VERMONT	0	0	0	182	182	54	0	54	0	54	54	0	54	182	236
VIRGINIA	0	0	0	2,673	2,673	16	125	141	20	161	16	125	141	2,693	2,834
WASHINGTON	0	0	0	1,794	1,794	80	71	151	460	611	80	71	151	2,254	2,405
WEST VIRGINIA	0	0	0	212	212	50	416	466	84	550	50	416	466	296	762
WISCONSIN	0	0	0	1,712	1,712	0	71	71	2,826	2,897	0	71	71	4,538	4,609
WYOMING	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
U.S. TOTAL	427	4,102	4,529	81,605	86,134	9,778	17,964	27,742	33,272	61,014	10,205	22,066	32,271	114,877	147,148
% ICF-MR TOTALS	0.3	2.8	3.1	55.5	58.5	6.6	12.2	18.9	22.6	41.5	6.9	15.0	21.9	78.1	100.0

TABLE 6: NET CHANGE IN ICF-MR FACILITIES AND RESIDENTS BY FACILITY SIZE, OPERATION, AND STATE FROM JUNE 30, 1982 TO JUNE 30, 1989

	FACILITIES							RESIDENTS						
	STATE			NONSTATE			ALL BY SIZE	STATE			NONSTATE			ALL BY SIZE
	1-15	16+	TOTAL	1-15	16+	TOTAL	1-15	16+	TOTAL	1-15	16+	TOTAL	1-15	16+	TOTAL
ALABAMA	0	1	1	3	0	3	3	0	0	31	0	31	31	-175	-144
ALASKA	0	0	0	2	0	2	2	0	0	10	0	10	10	-31	-21
ARIZONA	4	1	5	0	0	0	4	0	4	0	0	0	51	18	69
ARKANSAS	0	1	1	0	2	2	0	3	3	73	0	73	0	21	21
CALIFORNIA	0	-1	-1	332	-3	329	332	-4	328	0	73	73	1,802	-1,198	604
COLORADO	0	0	0	-25	-3	-28	-25	-3	-28	-407	-200	-407	-206	-696	-902
CONNECTICUT	15	0	15	29	0	29	44	0	44	155	27	155	161	576	737
DELAWARE	0	0	0	12	0	12	12	0	12	86	0	86	86	-157	-71
D.C.	0	0	0	76	-2	74	76	-2	74	406	-60	406	466	-261	205
FLORIDA	0	-3	-3	-6	39	33	-6	36	30	1,212	1,275	1,212	-63	1,115	1,052
GEORGIA	0	0	0	0	0	0	0	0	0	0	0	0	0	-547	-547
HAWAII	-1	1	0	17	0	17	16	1	17	73	0	73	65	-206	-141
IDAHO	0	0	0	18	-1	17	18	-1	17	167	33	167	200	-162	38
ILLINOIS	0	-3	-3	134	8	142	134	5	139	2,680	628	2,680	2,052	668	2,720
INDIANA	0	1	1	345	5	350	345	6	351	3,277	814	3,277	2,463	251	2,714
IOWA	0	-1	-1	10	7	17	10	6	16	425	324	425	101	44	145
KANSAS	0	-1	-1	19	-1	18	19	-2	17	178	-13	178	191	-314	-123
KENTUCKY	0	0	0	0	0	0	0	0	0	-60	-60	-60	0	-71	-71
LOUISIANA	3	-1	2	244	4	248	247	3	250	1,959	545	1,959	1,441	-223	1,218
MAINE	1	0	1	12	1	13	13	1	14	111	12	111	111	-73	38
MARYLAND	0	-2	-2	0	0	0	0	-2	-2	0	0	0	2	-479	-477
MASSACHUSETTS	27	-1	26	29	0	29	56	-1	55	180	-74	180	452	-945	-493
MICHIGAN	-22	-4	-26	170	0	170	148	-4	144	1,018	0	1,018	885	-1,928	-1,043
MINNESOTA	0	-1	-1	13	4	17	13	3	16	-123	-283	-123	160	-1,290	-1,130
MISSISSIPPI	0	0	0	0	-1	-1	0	-1	-1	-20	-20	-20	0	-26	-26
MISSOURI	2	5	7	15	3	18	17	8	25	109	138	247	123	-143	-20
MONTANA	0	0	0	-1	0	-1	-1	0	-1	-7	0	-7	-7	-33	-40
NEBRASKA	-1	-1	-2	-3	-1	-4	-4	-2	-6	-122	-101	-122	-34	-190	-224
NEVADA	0	0	0	0	-1	-1	0	1	1	0	0	0	0	10	10
NEW HAMPSHIRE	0	0	0	7	-1	6	7	-1	6	32	-22	32	54	-235	-181
NEW JERSEY	0	0	0	0	2	2	0	2	2	72	72	72	0	-344	-344
NEW MEXICO	0	0	0	23	0	23	23	0	23	198	0	198	198	0	198
NEW YORK	258	12	270	329	13	342	587	25	612	3,909	674	3,909	5,846	-3,649	2,197
NORTH CAROLINA	-1	-1	-2	98	4	102	97	3	100	901	302	901	594	-183	411
NORTH DAKOTA	0	0	0	59	0	59	59	0	59	456	12	456	444	80	524
OHIO	-8	-6	-14	145	48	193	137	42	179	1,328	2,016	3,328	1,245	686	1,931
OKLAHOMA	0	0	0	1	22	23	1	22	23	2,041	2,026	2,041	15	1,242	1,257
OREGON	-2	0	-2	-1	-2	-3	-3	-2	-5	-93	-78	-93	-34	-842	-876
PENNSYLVANIA	0	-7	-7	107	8	115	107	1	108	1,533	841	1,533	692	-2,205	-1,513
RHODE ISLAND	-5	1	-4	73	-1	72	68	0	68	384	18	384	330	-275	75
SOUTH CAROLINA	-11	-6	-17	87	1	88	76	-5	71	707	-31	707	643	-77	566
SOUTH DAKOTA	0	0	0	4	0	4	4	0	4	66	0	66	66	-196	-130
TENNESSEE	0	0	0	-8	-1	-9	-8	-1	-9	-60	20	-40	-60	-142	-202
TEXAS	50	1	51	124	-16	108	174	-15	159	-56	-738	-56	1045	-2,923	-1,878
UTAH	0	0	0	3	2	5	3	2	5	129	86	129	43	-237	-194
VERMONT	0	-1	-1	-3	0	-3	-3	-1	-4	-17	0	-17	91	-132	-149
VIRGINIA	-2	-1	-3	11	0	11	9	-1	8	69	-40	69	91	-873	-782
WASHINGTON	0	0	0	16	-1	15	16	-1	15	94	-53	41	94	-153	-59
WEST VIRGINIA	0	1	1	60	1	61	60	2	62	530	68	530	462	124	586
WISCONSIN	0	-1	-1	-4	26	22	4	25	21	-28	1,527	1,499	-28	1,089	1,061
WYOMING	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
U.S. TOTAL	307	-17	290	2,576	165	2,741	2,883	148	3,031	19,384	9,586	28,970	22,286	-15,890	6,396

The development of small nonstate ICFs-MR has varied considerably from state-to-state since passage of the ICF-MR legislation. The extreme of the tendency was most evident in 1977 when Minnesota, the earliest adopter of the small ICF-MR option, had within its residential care system 77% of all small nonstate ICF-MR group homes nationwide (113) and 78% of all small nonstate ICF-MR residents. By 1982, small nonstate ICFs-MR were no longer predominantly a Minnesota program, but there remained a strong tendency toward concentration in a few states. On June 30, 1982, Minnesota and New York together had a majority (51.5%) of all residents nationally (28.8% and 22.7%, respectively).

The five states which were the most intense users of small nonstate ICF-MR programs in 1982 (Minnesota, New York, Michigan, Indiana, and Rhode Island) together had 67.6% of all residents, as compared with only 21.5% of residents of all ICF-MR certified facilities. By 1989, the five most intense users of small nonstate ICF-MR programs in 1982 (Minnesota, New York, Michigan, Indiana, and Rhode Island) had less than half of all small nonstate ICF-MR residents (46.6%) and facilities (46.1%), while their share of all ICF-MR residents increased slightly to 22.4%. On June 30, 1989 the six states with the greatest number of small nonstate ICF-MR residents (New York, Indiana, Minnesota, Illinois, California and Michigan) had 58.3% of all small nonstate ICF-MR residents, and nine states (California, Illinois, Indiana, Louisiana, Michigan, Minnesota, New York, Ohio, and Texas) together accounted for about three fourths (73.9%) of all small nonstate ICF-MR residents. New York alone accounted for 19%. In contrast, half of the states (25) with the lowest utilization of small nonstate ICFs-MR had only 2.3% of all residents on June 30, 1989.

State ICF-MR Certified Facilities

Although the proportion of ICF-MR residents living in nonstate facilities has been increasing steadily, ICF-MR services are still delivered primarily in state-operated facilities (58.6% of all ICF-MR residents). Similarly, federal ICF-MR reimbursements, although increasingly shifting toward nonstate facilities, still primarily go to state-operated facilities (73.6% of all federal reimbursements in 1988). Even though there has been substantial growth in small state-operated ICFs-MR in recent years, from 2,960 residents on June 30, 1986 to 4,529 residents on June 30, 1989, state-operated ICF-MR services remained largely institutional, with only 5.3% of the June 30, 1989 populations living in facilities of 15 or fewer residents.

Large state facilities. Nationally on June 30, 1989, the population of state mental retardation institutions was 87,071, or at about the same number as in 1934 (Lakin, 1979; White, Lakin, Bruininks, & Li, 1991). Although the percentage of state institution residents living in ICF-MR certified units increased from 88% to 93.7% between 1982 and 1989, there was an overall reduction in the population of large state ICF-MR institutions. From June 30, 1982 to June 30, 1989 there was a net decrease of about 25,401 residents of ICF-MR certified state institutions in the U.S. This trend toward lower numbers of residents in ICF-MR certified state institutions was evident in the vast majority of states. Only 6 states increased the number of ICF-MR service recipients in state institutions (Arizona, 18; Connecticut, 549; Illinois, 40; Nevada, 10; North Dakota,

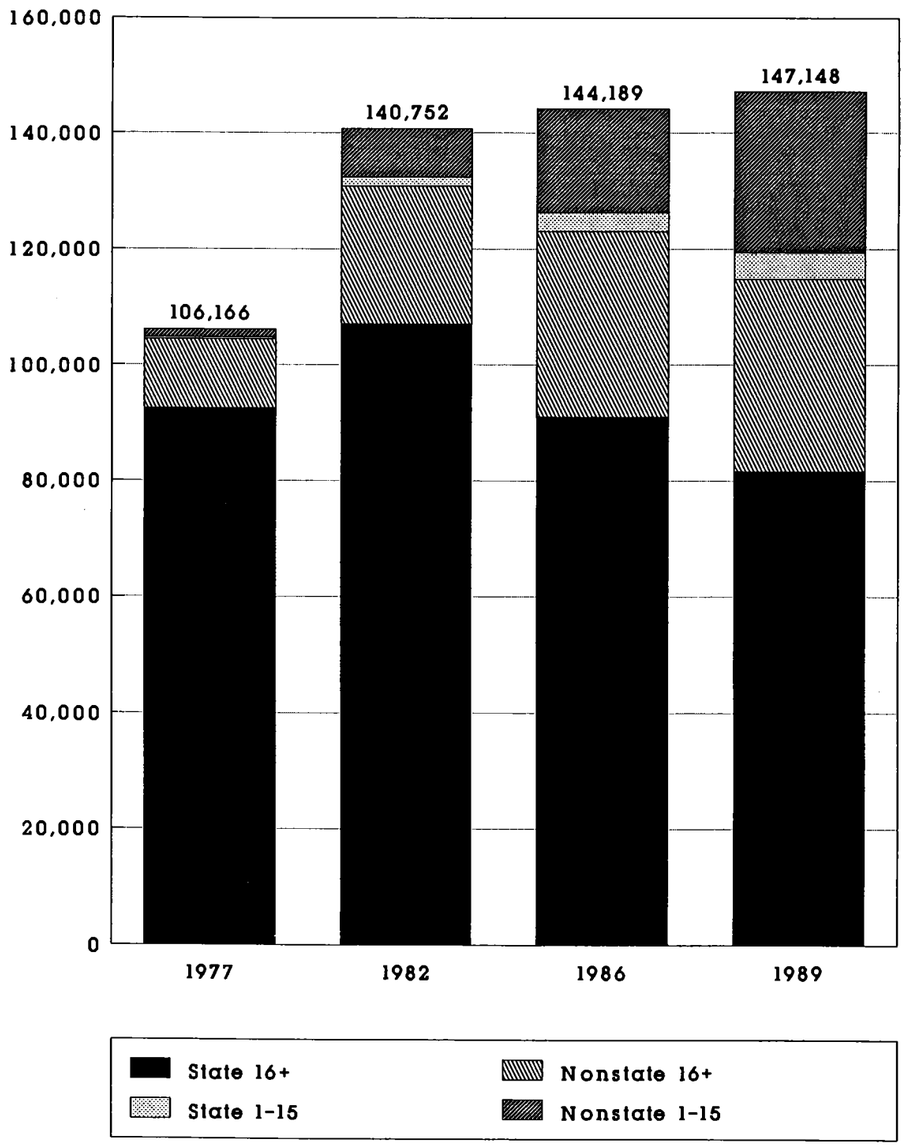
68; and West Virginia, 56). In this regard, it is important to note that of these 6 states only Illinois reported an actual increase in state institution residents (irrespective of ICF-MR certification) between June 30, 1988 and June 30, 1989. Arizona began participation in the ICF-MR program for the first time during Fiscal Year 1989.

In contrast to the recent overall decreases in large state ICF-MR populations, there was a net increase between June 30, 1977 and June 30, 1982 of about 15,000 residents in ICF-MR certified units. Two major factors affected the rather notable change from an average increase of about 3,000 per year between 1977 and 1982 to an average decrease of about 3,700 per year between 1982 and 1989. First, between June 30, 1977 and June 30, 1982 states were increasing the proportion of state institution capacity in compliance with ICF-MR standards from about 60% of the national total to about 88%. Therefore, although states were decreasing their state institution populations over the period by about a quarter, the number of newly certified facilities led to an overall increase in persons living in ICF-MR certified state institutions. However, by 1982, with the vast majority of institution beds already ICF-MR certified, the ongoing depopulation of state institutions caused substantial decreases in the number of residents in ICF-MR certified state institutions. Despite the decreasing populations in state institutions, which continues to reduce the extent to which the ICF-MR program has been predominantly a state institution-centered program, clearly it remains such. In June 1989, 55.5% of all ICF-MR residents were in large state institutions; but this compares with 63.4% in 1986, 76.3% in 1982 and 87.1% in 1977.

Small state facilities. On June 30, 1989 there was a total of 501 small state-operated, ICF-MR certified group homes operating in the United States. In all, only 3.1% (4,529) of all ICF-MR residents lived in these facilities. While the number of small ICFs-MR, and the number of residents in them, grew rapidly from 1982 to 1989, growth in the number of small state-operated facilities was largely confined to three states (New York, Massachusetts, and Texas) which had 93% of all new facilities and 95.8% of new residents. Of the total 501 small state ICFs-MR operating on June 30, 1989, 302 (60.3%) were in New York, 81 (16%) were in Texas, both Colorado and Connecticut had 36 (7.2%), and Massachusetts had 27 (5.4%), for a combined total of 96.2% of all small state-operated ICFs-MR. In general, small state-operated ICFs-MR are larger than small nonstate ICFs-MR. Only 15.6% of the former were facilities of 6 or fewer residents as compared to the 50.1% of the latter.

Figure 1 shows the distribution of residents among the four types of facilities described above. The substantial growth in the number of residents in ICFs-MR other than state institutions is clear, but so, too, is the extent to which large state institutions remain the predominant setting for delivering ICF-MR residential services.

FIGURE 1: RESIDENTS OF ICF-MR CERTIFIED FACILITIES BY SIZE AND STATE/NONSTATE OPERATION ON JUNE 30TH OF 1977, 1982, 1986 AND 1989



Large and Small Certified Facilities

Since the early years of the ICF-MR program the single most pronounced trend has been its evolution from an almost exclusively state facility program to a program increasingly delivered by nonstate providers. However, the state/nonstate distinction is not frequently seen as the most significant factor in categorizing residential facilities. Today policy considerations regarding the ICF-MR program much more often focus on facility size rather than operation. Increasingly facility size is seen as the most significant policy manipulable factor associated with qualities considered important in residential settings, notably normalized, integrated living, development of increased independence, and opportunities for social relationships and community participation. Although facilities with 15 residents are not particularly small by contemporary standards, they are frequently classified as small because of historical distinctions between 15 and smaller and 16 and more residents in fire safety codes and in the original ICF-MR standards, although for some unknown reason the revised 1988 ICF-MR regulations distinguish between facilities of 16 and fewer residents and 17 and more residents. In this report, we have retained the 15 and fewer/16 and more resident dichotomy for longitudinal comparative purposes. However, we have also provided breakdowns of "small" facilities into places with 6 or fewer and 7-15 residents in Tables 4 and 5.

With respect to the broad distinction between large and small ICFs-MR, Table 7 reports the total number of persons with mental retardation and related conditions in large and small ICFs-MR, the number of persons with mental retardation in all large and small facilities licensed or operated by the various states for persons with mental retardation (irrespective of ICF-MR certification), and the percentages of all residents of large and small mental retardation facilities residing in ICF-MR certified settings on June 30, 1989.

Table 7 shows a total of 32,271 persons in small ICFs-MR nationwide on June 30, 1989. These persons made up only 21.9% of all ICF-MR residents on that day. These figures represent an increase of some 11,000 residents and 7.2% of total ICF-MR residents since 1986. However, states varied greatly in their particular use of large and small ICFs-MR. States with at least 40% of their total ICF-MR population in small facilities included Alaska (41.2%), Arizona (73.9%), Indiana (50.8%), District of Columbia (73.3%), Idaho (49.0%), Michigan (58.2%), Minnesota (44.6%), New York (45.8%), North Dakota (63.0%), Rhode Island (76.5%), and West Virginia (61.2%). In contrast, 6 states actually participating in the ICF-MR program (7 states altogether) had no small ICFs-MR.

The "All Residents" columns of Table 7 present statistics on combined ICF-MR and non-ICF-MR (state and nonstate) residential facilities in the various states. These data serve as a point of comparison for facilities with ICF-MR certification. The "% in 1-15" column provides the percentage of residents in all facilities who were in small residential facilities in each state on June 30, 1989. Nationally, 51.4% of all residents of state and nonstate facilities were in "small" facilities. The "Percentage in ICF-MR" indicates the percentage of all state residents and the percentage of residents of small and large facilities specifically who

TABLE 7: NUMBER AND PERCENTAGE OF RESIDENTS IN ICF-MR CERTIFIED FACILITIES BY STATE AND FACILITY SIZE ON JUNE 30, 1989

	ICF-MR RESIDENTS					ALL RESIDENTS					PERCENTAGE IN ICF-MR				
	1-6	7-15	1-15	16+	TOTAL	1-6	7-15	%in1-15	1-6	7-15	1-15	16+	TOTAL
ALABAMA	0	31	31	1,295	1,326	440	337	23	0.0	9.2	4.0	92.2	60.8
ALASKA	10	30	40	57	97	244	45	41.2	4.1	66.7	13.8	100.0	28.0
ARIZONA	0	51	51	18	69	1,930	65	73.9	0.0	78.5	2.6	4.7	2.9
ARKANSAS	0	0	0	1,441	1,441	202	432	0.0	0.0	0.0	0.0	100.0	69.4
CALIFORNIA	1,368	434	1,802	9,176	10,978	15,339	3,052	16.4	8.9	14.2	9.8	69.8	34.8
COLORADO	0	276	276	839e	1,115	664	1,581	24.8	0.0	17.5	12.3	100.0	36.2
CONNECTICUT	234	240	474	1,861	2,335	2,680	557	20.3	8.7	43.1	14.6	97.9	45.5
DELAWARE	0	86	86	356	442	239	86	19.5	0.0	100.0	26.5	100.0	64.9
D.C.	236	234	470	171	641	533	298	73.3	44.3	78.5	56.6	72.8	60.1
FLORIDA	0	0	0	3,180	3,180	0.0	1,491	0.0	0.0	0.0	0.0	66.6	37.4
GEORGIA	0	0	0	1,944	1,944	0.0	1,362	0.0	0.0	0.0	0.0	83.8	52.8
HAWAII	65	8	73	173	246	29.7	917	8	7.1	100.0	7.9	100.0	22.4
IDAHO	24	231	255	265	520	49.0	108	794	22.2	29.1	28.3	76.8	41.7
ILLINOIS	0	2,116	2,116	8,748	10,864	19.5	2,310	3,024	0.0	70.0	39.7	78.0	65.6
INDIANA	778	2,022	2,800	2,712	5,512	50.8	1,687	2,022	46.1	100.0	75.5	87.5	80.9
IOWA	0	101	101	1,717	1,818	5.6	1,065	1,325	0.0	7.6	4.2	80.0	40.1
KANSAS	41	204	245	1,710	1,955	12.5	885	1,019	4.6	20.0	12.9	100.0	54.1
KENTUCKY	0	0	0	1,179	1,179	0.0	483	137	0.0	0.0	0.0	94.7	63.2
LOUISIANA	1,588	101	1,689	4,378	6,067	27.8	1,888	101	84.1	100.0	84.9	99.7	95.1
MAINE	120	125	245	423	668	36.7	1,451	52	81.9	240.4	16.3	72.2	32.0
MARYLAND	0	12	12	1,362	1,374	0.9	2,919	12	0.0	0.4	0.4	94.5	31.4
MASSACHUSETTS	0	522	522	3,026	3,548	14.7	2,224	2,780	0.0	18.8	10.4	92.3	42.8
MICHIGAN	1,722	0	1,722	1,237	2,959	58.2	6,012	0	77.2	28.6	28.6	69.5	38.0
MINNESOTA	636	1,936	2,572	3,197	5,769	44.6	3,543	1,949	62.3	18.0	99.3	96.0	65.4
MISSISSIPPI	0	0	0	1,588	1,588	0.0	262	74	13.9	0.0	0.0	76.4	65.8
MISSOURI	29	159	188	1,670	1,858	10.1	1,058	1,778	81.7	50.0	46.7	24.6	32.8
MONTANA	0	10	10	240	250	4.0	513	559	0.0	1.8	0.9	100.0	19.1
NEBRASKA	0	8	8	748	756	1.1	1,698	8	69.5	100.0	0.5	100.0	30.8
NEVADA	0	15	15	170	185	8.1	340	15	67.6	100.0	4.2	100.0	35.2
NEW HAMPSHIRE	18	36	54	104	158	34.2	809	199	89.5	18.1	5.4	88.1	14.0
NEW JERSEY	0	0	0	3,822	3,822	0.0	1,747	1,573	38.9	0.0	0.0	73.3	44.8
NEW MEXICO	15	233	248	503	751	33.0	318	414	22.4	50.0	33.9	95.3	59.6
NEW YORK	650	7,485	8,135	9,639	17,774	45.8	5,827	11,625	77.2	64.3	46.6	99.6	65.5
NORTH CAROLINA	430	184	614	2,559	3,173	19.4	1,771	265	58.1	38.0	30.2	77.1	59.2
NORTH DAKOTA	96	372	468	275	743	63.0	752	670	72.3	55.5	32.9	87.0	42.8
OHIO	81	1,321	1,402	6,569	7,971	17.6	2,877	2,828	43.7	81.8	46.7	89.5	61.1
OKLAHOMA	0	15	15	3,045	3,060	0.5	509	372	22.4	100.0	4.0	100.0	77.9
OREGON	0	22	22	1,020	1,042	2.1	1,340	477	62.8	64.3	11.2	94.7	36.0
PENNSYLVANIA	416	550	966	6,119	7,085	13.6	7,015	873	52.9	64.4	46.6	87.2	47.5
RHODE ISLAND	502	229	731	225	956	76.5	747	337	81.7	69.4	24.3	93.0	72.1
SOUTH CAROLINA	0	776	776	2,455	3,231	24.0	587	833	36.6	100.0	68.0	100.0	83.4
SOUTH DAKOTA	0	186	186	405	591	31.5	313	769	72.8	93.2	67.4	100.0	39.7
TENNESSEE	0	12	12	2,163	2,175	0.6	569	1,136	0.0	24.2	17.2	100.0	55.9
TEXAS	946e	967e	1,913e	10,168e	12,081	15.8	1,183	967	80.0	100.0	89.0	100.0	98.1
UTAH	0	43	43	962	1,005	4.3	325	568	0.0	7.6	4.8	100.0	54.2
VERMONT	54	0	54	182	236	22.9	465	0	100.0	-	11.6	100.0	36.5
VIRGINIA	16	125	141	2,693	2,834	5.0	223	386	7.2	32.4	23.2	97.4	84.0
WASHINGTON	80	71	151	2,254	2,405	6.3	2,642	834	57.8	8.5	4.3	88.9	40.0
WEST VIRGINIA	50	416	466	296	762	61.2	266	416	18.8	100.0	68.3	72.5	69.9
WISCONSIN	0	71	71	4,538	4,609	1.5	3,632	1,576	0.0	4.5	1.4	99.0	47.1
WYOMING	0	0	0	0	0	-	76	202	0.0	0.0	0.0	0.0	0.0
U.S. TOTAL	10,205	22,066	32,271	114,877	147,148	21.9	88,480	51,664	140,144	132,619	272,763	51.4	86.6	53.9

were living in facilities with ICF-MR certification. It shows that 53.9% of all residents nationally were in ICF-MR facilities but that only 23.0% of all small facility residents were living in small ICFs-MR. It is also notable that a total of 32 states reported more than half their total residents in small facilities on June 30, 1989, but only 7 states (Arizona, District of Columbia, Michigan, Indiana, North Dakota, Rhode Island, and West Virginia) reported more than half their ICF-MR residents in small facilities.

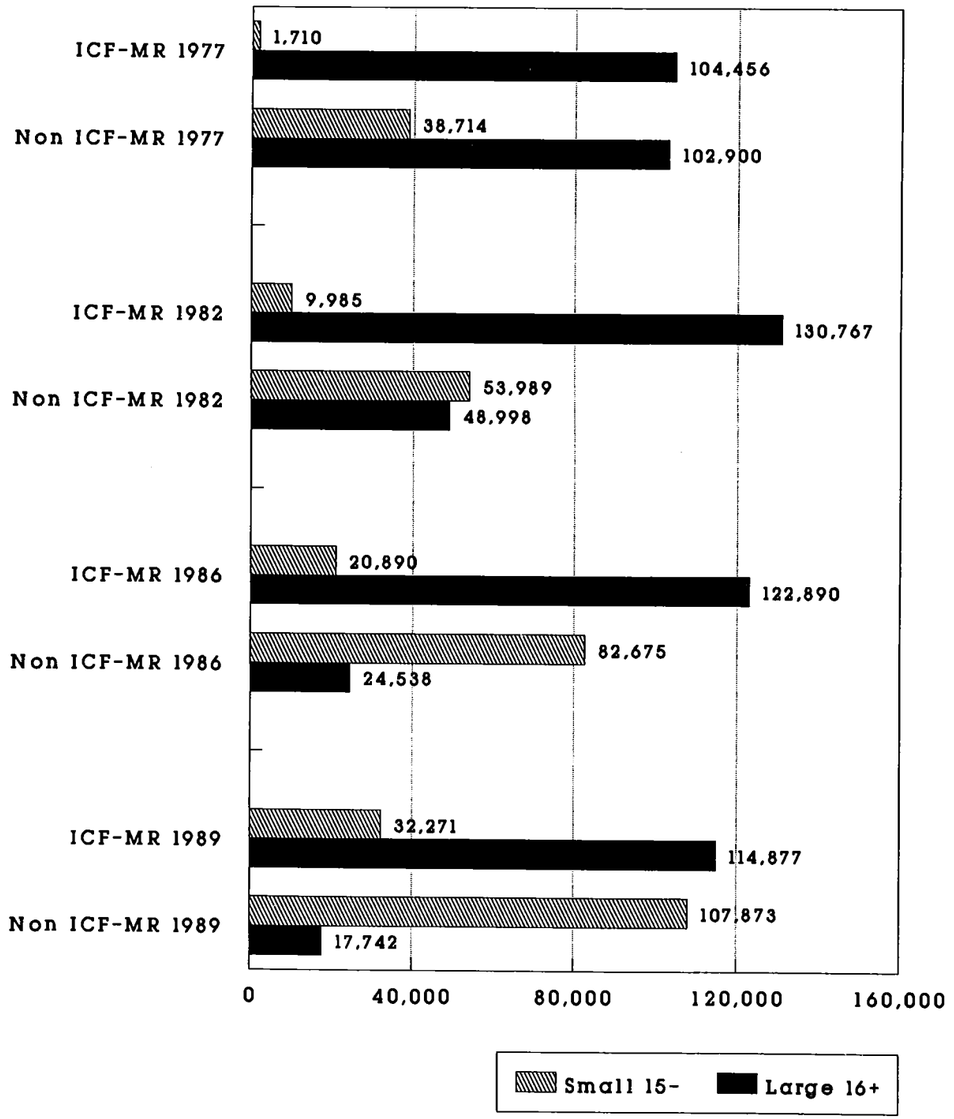
On June 30, 1989 five states had approximately two-thirds or more of their small facility residents in ICFs-MR (Indiana, 75.5%; Louisiana, 84.9%; Rhode Island, 67.4%; Texas, 89.0% and West Virginia, 68.3%). At the other extreme, 6 states using the ICF-MR program had no small ICFs-MR and 24 states had less than 10% of their small facility residential populations in ICFs-MR. Indeed, excluding the five states with more than two-thirds of their small facility population in certified facilities (and which together had 23.5% of the total small ICF-MR population nationally), only 18.9% of residents in small facilities in the remaining 46 states were in facilities with ICF-MR certification.

Use of small ICF-MR facilities on June 30, 1989 was dominated by nine states, each having 1,000 or more residents in small ICFs-MR, and together serving 74.8% of all small ICF-MR residents. However, this reflects much more balanced utilization than on June 30, 1977 when two states had 77% of all residents of small ICFs-MR. Further, 28 states reported 100 or more small ICF-MR residents in 1989, as compared with only 3 states serving more than 100 residents in small ICFs-MR in 1977.

Between 1982 and 1989, 36 states showed a net increase in the number of residents of small ICFs-MR and 24 states showed net increases of 100 or more. But 71% (15,894) of the total net increase (22,286) in small ICF-MR residents occurred in seven states (California, Illinois, Indiana, Louisiana, New York, Ohio, and Texas). Seven states showed net decreases ranging from 7 to 206 persons. Despite these clear trends toward increased numbers of persons in small ICFs-MR and participation by greater numbers of states in the option of using the ICF-MR program to fund services in small residential facilities, ICF-MR services remain predominantly concentrated in institutions in most states.

Figure 2 shows the proportion of large and small facilities among the facilities certified as ICFs-MR and facilities that were not ("non-ICF-MR") in 1977, 1982, 1986, and 1989. This figure shows the absolute and proportional growth of small facilities among both the ICFs-MR and noncertified facilities. It also shows that while the ICF-MR program continues to be primarily concentrated in institutions, there has been some shift over time to greater total and proportional use of Title XIX funding in small facilities. For example, in 1977, only 4.2% (1,710) of the total 40,400 persons in small residential settings were in ICFs-MR. In 1982, 15.7% (9,985) of 63,700 persons in small residential facilities were in ICFs-MR. By 1986, 20.4% (21,165) of 103,500 residents in smaller residential settings were in ICFs-MR and by 1989, 23.0% (32,271) of 140,144 persons in small residential settings were in ICFs-MR. It is also notable that in 1977 barely half (50.5%) of the people living in all state and nonstate facilities of 16 or more residents ("large") lived in ICFs-MR. By 1989 86.6% of the people living in large facilities lived in ICFs-MR.

FIGURE 2: NUMBER OF RESIDENTS
IN LARGE AND SMALL FACILITIES BY ICF-MR CERTIFICATION



Characteristics of ICF-MR and Non ICF-MR Residents

Tables 8 and 9 present data on the characteristics of residents of ICFs-MR and non-ICF-MR facilities broken down by the state/nonstate and small/large distinctions used throughout this report. These data derive from CRSCL secondary analyses of the Institutional Populations Component of the 1987 National Medical Expenditure Survey (the National Medical Expenditure Survey is conducted under the auspices of the Agency for Health Care Policy and Research, Department of Health and Human Services). Descriptions of study methods and limitations can be found in Edwards and Edwards (1989) and Lakin, Hill, Chen & Stephens (1989).

Primary and Secondary Conditions

Table 8 presents estimates of the level of mental retardation and secondary conditions of residents ICFs-MR, noncertified residential facilities (non-ICFs-MR) and all residential facilities by state and nonstate operation. It should be noted that estimates for state facilities of 1-6 and 7-15 residents, both ICF-MR and non-ICF-MR, may be unreliable because of the small sample sizes of their resident population. The four most notable aspects of these statistics are 1) there are major differences between ICF-MR and non-ICF-MR populations, 2) there is considerable similarity between small ICF-MR and small non-ICF-MR residents, 3) there are major differences between large ICF-MR and large non-ICF-MR residents, and 4) there are major differences between large state ICF-MR and large non-state ICF-MR populations.

Residents of ICFs-MR have more severe impairments than residents of non-ICFs-MR. Estimates from the National Medical Expenditure Survey indicate that nearly half of all ICF-MR residents (48.5%) have profound mental retardation (i.e., an I.Q. below 20 with corresponding functional limitations). Among the residents of non-ICFs-MR only 14% were indicated to have profound mental retardation. The estimated proportion of residents with severe or profound mental retardation was 70% and 33% respectively. Residents of ICF-MR had significantly higher prevalences of epilepsy, cerebral palsy and blindness than residents of non-ICFs-MR (34% vs. 21%, 13.5% vs. 8%, and 7% vs. 3%, respectively). The residents primarily contributing to these differences are those living in the overwhelmingly (92% in 1987) ICF-MR certified state institutions. An estimated 60% of persons living in state institutions were profoundly retarded in the 1987 NMES as compared with 36% of all residents of mental retardation facilities.

Residents of small ICFs-MR are as a group similar to residents of small ICFs-MR. Estimates from the National Medical Expenditure Survey indicate that despite the generally more severe cognitive impairments among ICF-MR residents than non-ICF-MR residents, among resident populations of small residential facilities, ICF-MR and non-ICF-MR residents are generally similar. For example, among facilities with 6 or fewer residents persons with severe and profound mental retardation made up 40% of ICF-MR residents and

TABLE 8: PERCENTAGE OF ICF-MR AND NON-ICF-MR RESIDENTS WITH MENTAL RETARDATION AND RELATED CONDITIONS BY LEVEL OF MENTAL RETARDATION AND TYPE OF SECONDARY CONDITION

		State Facilities by Size				Nonstate Facilities by Size				All Facilities by Size			
		1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total
ICF-MR Residents	Level of Mental Retardation												
	Border/Mild	38.8	19.9	8.6	9.2	28.5	34.4	22.9	26.2	29.5	31.9	12.3	15.1
	Moderate	28.0	13.8	10.6	10.9	29.7	28.3	21.0	24.0	29.5	25.8	13.3	15.4
	Severe	19.0	27.4	19.8	19.9	21.8	27.3	19.0	21.2	21.5	27.3	19.6	20.4
	Profound	14.2	38.9	60.7	59.8	19.2	9.7	35.6	27.5	18.7	14.7	54.2	48.5
	No MR/Other	-	-	-	0.2	0.9	0.3	1.5	1.2	0.8	0.3	0.6	0.6
	Secondary Conditions												
	Epilepsy	9.5	28.3	40.2	39.6	19.9	21.4	25.4	23.7	18.8	22.5	36.4	34.1
	Cerebral Palsy	4.7	11.4	12.1	12.0	6.9	6.5	21.9	16.2	6.7	7.3	14.7	13.5
	Autism	-	-	2.6	2.5	1.8	3.3	2.5	2.6	1.7	2.7	2.5	2.5
	Spina Bifida	-	-	0.6	0.6	-	0.6	1.0	0.8	-	0.5	0.7	0.7
	Deaf	9.5	5.7	2.6	2.8	0.7	0.9	0.9	0.9	1.6	1.7	2.2	2.1
	Blind	14.2	5.4	8.0	8.0	3.7	0.7	6.5	4.8	4.8	1.5	7.6	6.9
	Deaf and/or Blind	14.2	11.1	9.9	10.0	4.4	1.6	7.1	5.5	5.4	3.3	9.2	8.4
Non-ICF-MR Residents	Level of Mental Retardation												
	Border/Mild	21.7	25.7	19.4	22.2	32.1	38.9	41.3	38.2	31.4	37.0	48.9	36.5
	Moderate	18.1	16.5	27.0	21.6	28.5	37.4	26.6	30.2	27.8	34.5	26.6	29.3
	Severe	54.6	30.8	26.7	32.4	21.0	18.2	15.2	17.6	23.2	19.9	16.5	19.2
	Profound	5.6	27.1	26.9	23.8	16.8	4.6	15.1	12.5	16.1	7.7	16.4	13.7
	No MR/Other	-	-	-	-	1.6	0.9	1.9	1.5	1.5	0.8	1.6	1.4
	Secondary Conditions												
	Epilepsy	27.3	16.6	41.2	29.5	25.4	13.0	20.7	19.7	25.5	13.5	23.0	20.7
	Cerebral Palsy	16.4	21.7	11.3	16.1	7.6	6.6	7.7	7.4	8.2	8.7	8.1	8.3
	Autism	4.2	-	-	0.6	5.4	1.9	9.0	6.0	5.3	1.6	8.0	5.4
	Spina Bifida	-	-	-	-	0.7	0.2	0.2	0.4	0.7	0.2	0.2	0.3
	Deaf	-	-	3.1	1.4	0.2	3.1	1.7	1.7	0.2	2.6	1.9	1.7
	Blind	-	1.8	10.9	5.7	1.9	3.2	2.3	2.4	1.7	3.0	3.2	2.8
	Deaf and/or Blind	-	1.8	14.1	7.1	2.1	5.7	3.6	3.8	1.9	5.1	4.7	4.2
Total Residents	Level of Mental Retardation												
	Border/Mild	28.6	23.5	9.1	10.3	31.0	37.4	32.3	33.3	30.8	35.3	18.5	22.9
	Moderate	22.1	15.4	11.4	11.8	28.8	34.3	23.9	27.7	28.3	31.5	16.4	20.5
	Severe	40.3	29.5	20.1	21.0	21.2	21.2	17.1	19.1	22.7	22.5	18.9	20.0
	Profound	9.1	31.7	59.3	56.6	17.5	6.3	25.1	18.6	16.9	10.1	45.5	35.8
	No MR/Other	-	-	0.2	0.2	1.4	0.7	1.7	1.4	1.3	0.6	0.8	0.8
	Secondary Conditions												
	Epilepsy	20.1	21.1	40.3	38.8	23.8	15.8	23.0	21.3	23.5	16.6	33.3	29.2
	Cerebral Palsy	11.7	17.7	12.1	12.4	7.4	6.6	14.7	11.0	7.7	8.2	13.1	11.6
	Autism	2.5	-	2.4	2.3	4.3	2.3	5.8	4.6	4.2	2.0	3.8	3.5
	Spina Bifida	-	-	0.6	0.5	0.5	0.4	0.6	0.5	0.5	0.3	0.6	0.5
	Deaf	3.8	2.2	2.6	2.6	0.4	2.3	1.3	1.4	0.6	2.3	2.1	2.0
	Blind	5.7	3.2	8.1	7.8	2.4	2.4	4.3	3.4	2.7	2.5	6.6	5.4
	Deaf and/or Blind	5.7	5.4	10.1	9.7	2.8	4.3	5.3	4.5	3.0	4.5	8.2	6.9

39% of non-ICF-MR residents. Among facilities with 7-15 residents there was a small, but significant difference with 42% of ICF-MR residents and 28% of non-ICF-MR residents reported to have severe or profound mental retardation. Reported prevalences of secondary conditions were also similar for small ICFs-MR and non-ICF-MR.

Notable differences were observed between residents of large ICFs-MR and residents of large non-ICFs-MR. Residents of large ICFs-MR were much more likely than non-ICF-MR residents to have more severe intellectual impairments and more frequent secondary conditions. An estimated 74% of large ICF-MR residents had severe or profound mental retardation as compared with 33% of large non-ICF-MR residents. About 36% of large ICF-MR residents were reported to have epilepsy as compared with 23% of large non-ICF-MR residents. About 15% of large ICF-MR residents were reported to have cerebral palsy and 8% were reported to be blind; comparable statistics for large non-ICF-MR residents were 8% and 3% respectively.

Substantial differences were found between the residents of state-operated ICFs-MR and non-state ICFs-MR. Residents of state-operated ICFs-MR, primarily large state institutions were substantially more severely impaired than residents of non-state ICFs-MR. For example, while 57% of state ICF-MR residents were reported to have profound mental retardation and 21% were reported to have severe mental retardation, among non-state ICF-MR residents the comparable statistics were 19% and 19%, respectively. About 30% of state ICF-MR residents were reported to have epilepsy as compared with 20% of non-state ICF-MR residents. About 16% of state-ICF-MR residents were estimated to have cerebral palsy and 6% were reported to be blind. Comparable estimates for non-state ICF-MR residents were 8% and 2%. Non-state ICF-MR residents were, on the other hand, more likely to be reported as autistic (6% as compared with 1% of state-ICF-MR residents).

Physical, Functional, and Health Limitations

Table 9 presents estimates of selected physical, functional and health limitations among residents of ICF-MR and non-ICF-MR facilities. In general it shows that persons living in ICFs-MR more frequently have limitations of mobility and activities of daily living than persons living in non-ICFs-MR. Persons living in small facilities more frequently have limitations of mobility and activities of daily living than persons living in non-ICFs-MR.

In the area of mobility the National Medical Expenditure Survey estimated that 23% of residents of mental retardation facilities required assistance in walking across a room and 19% used wheelchairs. These estimates included 30% of all ICF-MR residents reported to need assistance walking across a room and 25% using wheelchairs, and 11% of all non-ICF-MR residents needing assistance in walking across a room and 8% using a wheelchair. Among large facility residents an estimated 29% needed assistance walking across a room and 24% used a wheelchair. Comparable statistics for small facilities were 11% and 7%, respectively, for

TABLE 9: PERCENTAGE OF ICF-MR AND NON-ICF-MR RESIDENTS WITH SELECTED PHYSICAL, FUNCTIONAL AND HEALTH LIMITATIONS BY STATE/NONSTATE OPERATION AND FACILITY SIZE

Type of Limitation		State Facilities by Size				Nonstate Facilities by Size				All Facilities by Size			
		1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total
ICF-MR Residents	Physical Limitations												
	Needs help walking across a room	28.4	7.8	34.8	34.1	11.1	3.3	30.6	21.6	12.8	4.0	33.7	29.7
	Uses a wheelchair	19.0	5.7	30.6	29.9	5.4	-	22.4	14.9	6.8	1.0	28.5	24.7
	Functional Limitations												
	Needs help bathing	37.9	62.6	78.5	77.8	58.1	34.3	69.0	59.9	56.0	39.1	76.1	71.5
	Needs help dressing	23.7	57.5	73.2	72.4	44.5	30.4	54.6	47.8	42.4	35.0	68.4	63.8
	Needs help toileting	9.5	22.0	32.1	31.6	17.2	6.4	26.6	20.8	16.5	9.1	30.6	27.8
	Health Conditions												
	Circulatory Conditions	4.7	15.2	10.2	10.2	13.0	11.4	12.7	12.4	12.1	12.0	10.8	11.0
	Arthritis or rheumatism	4.7	-	4.3	4.2	4.3	5.2	4.6	4.7	4.3	4.3	4.3	4.3
	Diabetes	9.5	4.1	1.5	1.6	1.6	1.4	3.1	2.5	2.4	1.9	1.9	1.9
	Cancer	0	0	1.4	1.4	2.3	2.2	0.8	1.3	2.1	1.8	1.2	1.4
	Frequent constipation	0	16.3	32.2	31.5	16.4	8.3	21.1	17.6	14.7	9.6	29.3	26.6
Non-ICF-MR Residents	Physical Limitations												
	Needs help walking across a room	17.1	19.9	20.1	19.6	9.9	7.5	11.3	9.8	10.4	9.2	12.3	10.9
	Uses a wheelchair	6.1	14.3	19.8	15.6	7.7	3.3	8.9	6.9	7.6	4.8	10.1	7.9
	Functional Limitations												
	Needs help bathing	45.1	58.9	59.6	57.2	47.4	33.2	41.1	40.4	47.3	36.8	43.1	42.3
	Needs help dressing	29.0	41.9	62.3	49.3	46.7	27.7	35.8	36.3	45.6	29.6	38.7	37.7
	Needs help toileting	16.6	5.6	19.7	13.7	16.6	7.0	12.5	11.9	16.6	6.8	13.3	12.1
	Health Conditions												
	Circulatory Conditions	17.1	11.9	13.1	13.2	12.8	12.6	9.8	11.4	13.0	12.5	10.2	11.6
	Arthritis or rheumatism	3.3	9.5	13.0	10.2	6.6	4.0	3.6	4.5	6.4	4.7	4.7	5.1
	Diabetes	7.4	2.8	3.4	3.8	1.0	2.6	2.3	2.0	1.4	2.6	2.5	2.2
	Cancer	4.4	1.1	6.0	3.9	0.7	0.2	0.9	0.6	0.9	0.4	1.5	1.0
	Frequent constipation	33.5	28.9	17.8	24.5	9.6	9.0	9.8	9.5	11.2	11.8	10.7	11.1
Total Residents	Physical Limitations												
	Needs help walking across a room	21.7	15.2	34.2	32.2	10.3	6.1	20.7	14.6	11.1	7.4	28.7	22.9
	Uses a wheelchair	11.3	11.0	30.1	28.7	7.1	2.2	15.5	10.2	7.4	3.5	24.2	18.6
	Functional Limitations												
	Needs help bathing	42.2	60.4	77.7	76.0	50.6	33.6	54.8	48.3	49.9	37.6	68.4	60.9
	Needs help dressing	26.9	48.0	72.7	70.4	46.1	28.6	45.0	41.0	44.6	31.5	61.5	54.3
	Needs help toileting	13.8	12.0	31.5	30.1	16.8	6.8	19.5	15.6	16.6	7.6	26.7	22.2
	Health Conditions												
	Circulatory Conditions	12.1	13.2	10.3	10.5	12.8	12.2	11.2	11.8	12.8	12.4	10.7	11.2
	Arthritis or rheumatism	3.9	5.9	4.7	4.7	5.9	4.4	4.1	4.6	5.8	4.6	4.4	4.6
	Diabetes	8.2	3.3	1.6	1.8	1.1	2.2	2.7	2.2	1.7	2.3	2.0	2.0
	Cancer	2.6	0.7	1.6	1.6	1.2	0.9	0.8	0.9	1.3	0.9	1.3	1.2
	Frequent constipation	20.0	24.0	31.6	30.9	11.6	8.8	15.4	12.8	12.2	11.0	25.0	21.0

people living in facilities with 6 or fewer residents and 7% and 4%, respectively for persons living in facilities with 7-15 residents.

Functional limitations in activities of daily living residents were also most often identified for residents of ICFs-MR and of large facilities. While 61% of all mental retardation facility residents were reported to need the assistance of another person in bathing, estimated rates for persons in ICFs-MR were 72% as compared with 42% for residents of non-ICFs-MR. Comparable differences were noted in the areas of dressing and toileting. Regarding the latter, while 22% of all residents were estimated to need assistance in toileting, 28% of all ICF-MR residents were said to need assistance as compared with 12% of all non-ICF-MR. Among the ICFs-MR the proportion of residents needing assistance with toileting (16% of residents in facilities of 6 and fewer and 9% in facilities with 7-15 residents) was less than half the proportion in large ICFs-MR (31%). Among non-ICFs-MR there were no differences between large and small facilities, but there were statistically significant differences between non-ICFs-MR of 6 or fewer residents (17%) and those of 7-15 residents (7%).

In the area of health conditions, comparing prevalence circulatory conditions, arthritis or rheumatism, diabetes, cancer and frequent constitution yielded differences only in the latter. As expected due to general associations with severity of intellectual impairment and mobility impairments, frequent constipation was much more frequently reported in ICFs-MR (27%), particularly large ICFs-MR (29%) than in non-ICFs-MR (11%). No statistically significant differences were found among small ICFs-MR and small non-ICFs-MR.

Medicaid HCBS Recipients

Medicaid Home and Community Based Services are associated with the ICF-MR program through its dedication to persons who but for the services available through the waiver program would be placed in an ICF-MR. Table 10 presents information on states' utilization of the Medicaid HCBS option on June 30, 1989, the same date as the ICF-MR statistics presented earlier. It also summarizes the combined utilization of the Medicaid HCBS and small ICF-MR options to provide community based services and total utilization of ICF-MR and waiver services by the individual states on June 30, 1989.

Between enactment of the Medicaid waiver in 1981 and June 30, 1989 a total of 42 states had at one time availed themselves of the opportunity to provide home and community based services as an alternative to ICF-MR care. On June 30, 1986, 33 states were operating approved programs for persons with mental retardation and related conditions; by June 30, 1989 there were 41. On June 30, 1990 the number of states with HCBS programs remained at 41. The number of HCBS program participants on June 30, 1982 was estimated to be 1,605. By June 30, 1986 the number was 23,053. On June 30, 1989 there were 35,077 persons reported to be receiving Medicaid waiver services. By June 30, 1990 that number had further increased to 39,828 (see Table 11).

In comparing the numbers of HCBS recipients on June 30, 1986 and June 30, 1989, 38 states had a combined increase of 16,594 recipients. Arkansas had received Medicaid waiver approval but was serving no

TABLE 10: BENEFICIARIES OF MEDICAID HOME AND COMMUNITY BASED SERVICES (HCBS) AND ICF-MR SERVICES FOR PERSONS WITH MENTAL RETARDATION ON JUNE 30, 1989

State	State Had HCBS on 6/30/89	Number Receiving HCBS on 6/30/89	Total ICF-MR Residents on 6/30/89	Total Medicaid Recipients (ICF-MR + HCBS)	Total Community Medicaid (HCBS+ICF-MR 15)	% Medicaid Beneficiaries in Community on 6/30/89	Total Small Community ICF-MR (1-15) Residents on 6/30/89	Total Community Medicaid (HCBS+ICF-MR 15)	% Medicaid Beneficiaries in Community on 6/30/89
ALABAMA	Y	1,830	1,326	3,156	1,861	59.0	31	1,861	59.0
ALASKA	N	N/A	97	97	40	41.2	40	40	41.2
ARIZONA	N	N/A	69	69	51	73.9	51	51	73.9
ARKANSAS	N	0	1,441	1,441	0	0.0	0	0	0.0
CALIFORNIA	Y	3,355	10,978	14,333	5,157	36.0	1,802	5,157	36.0
COLORADO	Y	1,679	1,115	2,794	1,955	70.0	276	1,955	70.0
CONNECTICUT	Y	1,127	2,335	3,462	1,601	46.2	474	1,601	46.2
DELAWARE	Y	100	442	542	186	34.3	86	186	34.3
D.C.	N	N/A	641	641	470	73.3	470	470	73.3
FLORIDA	Y	2,542	3,180	5,722	2,542	44.4	0	2,542	44.4
GEORGIA	Y	25	1,944	1,969	25	1.3	0	25	1.3
HAWAII	Y	70	246	316	143	45.3	73	143	45.3
IDAHO	Y	270	520	790	525	66.5	255	525	66.5
ILLINOIS	Y	680	10,864	11,544	2,796	24.2	2,116	2,796	24.2
INDIANA	N	N/A	5,512	5,512	2,800	50.8	2,800	2,800	50.8
IOWA	Y	14	1,818	1,832	115	6.3	101	115	6.3
KANSAS	Y	314	1,955	2,269	559	24.6	245	559	24.6
KENTUCKY	Y	728	1,179	1,907	728	38.2	0	728	38.2
LOUISIANA	N	N/A	6,067	6,067	1,689	27.8	1,689	1,689	27.8
MAINE	Y	453	668	1,121	698	62.3	245	698	62.3
MARYLAND	Y	813	1,374	2,187	825	37.7	12	825	37.7
MASSACHUSETTS	Y	1,210	3,548	4,758	1,732	36.4	522	1,732	36.4
MICHIGAN	Y	1,292	2,959	4,251	3,014	70.9	1,722	3,014	70.9
MINNESOTA	Y	2,068	5,769	7,837	4,640	59.2	2,572	4,640	59.2
MISSISSIPPI	N	N/A	1,588	1,588	0	0.0	0	0	0.0
MISSOURI	Y	338	1,858	2,196	526	24.0	188	526	24.0
MONTANA	Y	274	250	524	284	54.2	10	284	54.2
NEBRASKA	Y	540	756	1,296	548	42.3	8	548	42.3
NEVADA	Y	136	185	321	151	47.0	15	151	47.0
NEW HAMPSHIRE	Y	762	158	920	816	88.7	54	816	88.7
NEW JERSEY	Y	3,170	3,822	6,992	3,170	45.3	0	3,170	45.3
NEW MEXICO	Y	135	751	886	383	43.2	248	383	43.2
NEW YORK	N	N/A	17,774	17,774	8,135	45.8	8,135	8,135	45.8
NORTH CAROLINA	Y	553	3,173	3,726	1,167	31.3	614	1,167	31.3
NORTH DAKOTA	Y	1,063	743	1,806	1,531	84.8	468	1,531	84.8
OHIO	Y	240	7,971	8,211	1,642	20.0	1,402	1,642	20.0
OKLAHOMA	Y	500	3,060	3,560	515	14.5	15	515	14.5
OREGON	Y	1,218	1,042	2,260	1,240	54.9	22	1,240	54.9
PENNSYLVANIA	Y	1,930	7,085	9,015	2,896	32.1	966	2,896	32.1
RHODE ISLAND	Y	449	956	1,405	1,180	84.0	731	1,180	84.0
SOUTH CAROLINA	N	N/A	3,231	3,231	776	24.0	776	776	24.0
SOUTH DAKOTA	Y	683	591	1,274	869	68.2	186	869	68.2
TENNESSEE	Y	474	2,175	2,649	486	18.3	12	486	18.3
TEXAS	Y	417	12,081	12,498	2,330	18.6	1,913	2,330	18.6
UTAH	Y	1,124	1,005	2,129	1,167	54.8	43	1,167	54.8
VERMONT	Y	280	236	516	334	64.7	54	334	64.7
VIRGINIA	N	N/A	2,834	2,834	141	5.0	141	141	5.0
WASHINGTON	Y	1,084	2,405	3,489	1,255	35.4	151	1,255	35.4
WEST VIRGINIA	Y	224	762	986	690	70.0	466	690	70.0
WISCONSIN	Y	913	4,609	5,522	984	17.8	71	984	17.8
WYOMING	N	N/A	0	0	0		0	0	
U.S. TOTAL	Y=41	35,077	147,148	182,225	67,348	37.0	32,271		

recipients on June 30, 1989. Two states (Florida and New Mexico) reported a combined total of 4,570 fewer HCBS recipients on June 30, 1989 than on June 30, 1986. These changes were due variously to the effects of recipient eligibility revised by the state agency, removal of certain residents/facilities from waiver coverage, or changes in reporting criteria. The net increase in HCBS recipients for all states from 1986 to 1989 was 12,024 persons. Between 1986 and 1990 the net increase was 16,785 or about 73%.

Because the HCBS waiver represents another means in addition to developing small ICF-MR residences for providing community based care under Medicaid, it may be instructive to combine the recipients of the two programs to examine total Title XIX beneficiaries receiving institutional (16 or more residents) and community based services for persons with mental retardation and related conditions. On June 30, 1989 there were 32,271 persons living in small ICFs-MR and 35,077 receiving Medicaid HCBS services. When combined the total proportion of Medicaid service recipients (ICF-MR and HCBS) being served in community based settings was 37% of the 182,225 total Title XIX (ICF-MR and HCBS) recipients, a more favorable assessment of Title XIX utilization for community based services when compared with the 21.9% of total ICF-MR residents residing in small ICFs-MR. Combining ICF-MR and HCBS service recipients also shows 18 states to be serving the majority of their Title XIX mental retardation services recipients in community programs. The same could be said with only 7 states when only ICF-MR services were considered. While in 3 states there was still no Medicaid participation in providing community based services for persons with mental retardation, that number was four fewer than with ICF-MR services alone.

Figure 3 shows the total institutional ICF-MR service recipients (large state and large nonstate ICF-MR residents) and community recipients (small state and nonstate ICF-MR residents and HCBS recipients) for 1977, 1982 and 1989. It shows the dramatic increase in community based Title XIX service recipients from 1977 to 1989, an increase from 1,710 to 67,348. It also shows the substantial decrease in institutional recipients from 1982 to 1989, a decrease from 130,767 to 114,877.

Utilization of and Expenditures for Specific HCBS

Table 11 shows the number of HCBS recipients in states providing HCBS in June 1990 with Fiscal Year 1990 costs for HCBS and the average HCBS FY 90 expenditures per recipient. In all, the 41 states providing HCBS reported 39,838 HCBS recipients. Estimated state-federal expenditures totalled $846,404,031. Table 12 summarizes utilization by states of the specific services authorized under the Medicaid Home and Community Based Services option in June 1990. There are seven basic services that the states are specifically authorized to offer under their HCBS program: 1) case management, 2) homemaker services, 3) home health aid services, 4) personal care services, 5) adult day health services, 6) habilitation services, and 7) respite care. Specific operational definitions of these services were not provided in the regulations (general descriptions were), with states given wide latitude in defining the services for their own purposes. In addition, the statute indicates that other services may be approved if the state demonstrates that these services are necessary to avoid institutionalization and that they are cost effective. Most frequently reported HCBS services were residential and day habilitation and case management.

FIGURE 3: INSTITUTIONAL AND COMMUNITY RECIPIENTS OF MEDICAID ICF-MR AND HCBS BENEFITS ON JUNE 30TH OF 1977, 1982, 1986 AND 1989

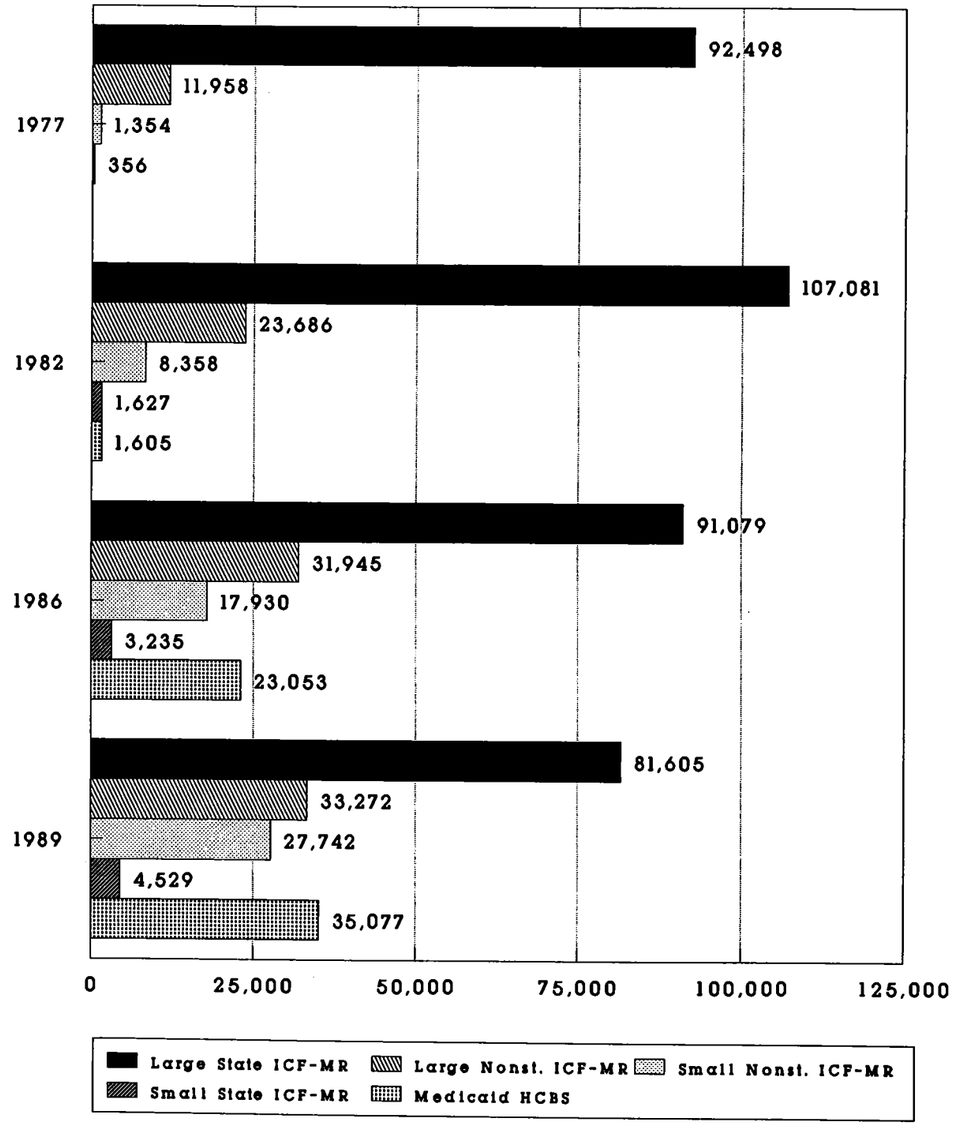


TABLE 11: NUMBER OF HCBS RECIPIENTS WITH MR/RC IN JUNE 1990, STATE FISCAL YEAR 1990 COSTS FOR HCBS AND AVERAGE HCBS COST PER RECIPIENT

State	No. of HCBS Recipients in June 1990	Combined state and federal $: HCBS SFY 90	Average HCBS expenditure (1990) per recipient
AL	1,839	$10,503,596	5,712
AR	91	425,000	4,670
CA	3,628	50,496,572 [1]	13,919
CO	1,841	38,720,290	21,032
CT	1,555	59,179,791	38,058
DE	196	3,585,131	18,291
FL	2,615	17,766,000	6,794
GA	160	3,819,509 +	23,847
HI	123	1,915,378	15,572
ID	346	1,648,019 [2]	4,763
IL	724	19,100,000	26,381
IA*	5	41,998	8,400
KS	361	4,372,992	12,114
KY	743	10,066,379 +	13,548
ME	454	15,000,000	33,040
MD	858	34,346,756	40,031
MA	1,539	47,183,000	30,658
MI	1,658	41,500,000	25,030
MN	2,184	55,185,013	25,268
MO	989	13,817,994	13,972
MT	276	5,235,640	18,970
NE	658	18,185,838	24,589
NV	133	1,587,500	11,938
NH	822	31,564,800	38,400
NJ	3,270	78,600,000	24,037
NM	160	2,400,000	15,000
NC	731 [3]	6,826,343	9,338
ND	1,055	13,360,819	12,664
OH	245	4,070,507	16,614
OK	621	5,499,237	8,855
OR	1,282	34,838,377	27,175
PA	2,221	107,984,235	48,620
RI	277	14,336,750 +	51,757
SD	721	10,388,196	14,408
TN	581	7,909,045	13,613
TX	485	12,139,200	25,029
UT	1,200	13,308,843	11,091
VT	323	7,959,645	24,643
WA	1250 [3]	18,464,904	14,772
WV	316	4,504,258 +	14,254
WI	1,302	18,566,476 [4]	14,260
Total	39,838 **	$846,404,031 **	$21,246 ++

* Iowa provided Medicaid HCBS for persons with MR/RC under a "model" waiver only.
** Forty-one states
+ Data from HCFA-64 report for fiscal year October 1, 1989 to September 30, 1990.
++ Average cost per participant (total HCBS cost/total # recipients) nationally.

TABLE 12: TYPES OF HCBS SERVICES AND NUMBER OF RECIPIENTS/SERVICE TYPE

State	No. of HCBS Recipients in June 1990	No. of HCBS recipients receiving indicated HCBS in June 1990***							
		Case mgt.	Home-maker	Home health aide	Personal care	Habil., resid.	Habil., day	Respite care	Other services
AL	1,839						1,839		See below
AR	91	91			10	45	83	45	See below
CA	3,628		1	5	3,259	329		25	See below
CO	1,841	1,841				1,751	686	83	
CT	1,555	1,555				1,555	684		
DE	196	196				196	72	30	See below
FL	2,615	330						39	See below
GA	160		64	32	32	93	123	64	See below
HI	123	123			46	77		1	See below
ID	346				346				
IL	724	724				643	609	46	
IA*	5		5	3			2		
KS	361	361	10		43	289	282	18	See below
KY	743	Not available							
ME	454	Not Available							
MD	858	858				858	858		
MA	1,539	1,539				1,062	427	36	See below
MI	1,658					1,605			See below
MN	2,184	2,184	69			1,722	1,112	423	See below
MO	989					937	512		See below
MT	276	102	NA			167	120	NA	See below
NE	658	658				658	658		
NV	133	133				133	91		See below
NH	822	822			822		245		See below
NJ	3,270	3,270			1,917		2,664		
NM	160	160	36			77	76	69	See below
NC	731 [3]	421	2		142		379	117	See below
ND	1,055	1,055	10	10	90	514	298	57	See below
OH	245	223	1		206	182	120		See below
OK	621	621				196		61	
OR	1,282					1,282 [6]	1,089 [6]		
PA	2,221	2,221				2,220	1,573	37	See below
RI	277	Not Available							
SD	721	721				584	721		
TN	581	543			38	543	543	28	
TX	485	485	NA			NA	NA	485	See below
UT	1,200	1,200				788	830	42	See below
VT	323	323				323	323	66	See below
WA	1250 [3]	Not available							
WV	316	Not available							
WI	1,302	Not available							
Total	39,838 **	22,773	198	50	6,951	18,829	17,019	1,772	

* Iowa provided Medicaid HCBS for persons with MR/RC under a "model" waiver only.
** Forty-one states
*** Thirty-five of 41 states (with a total of 35,496 HCBS recipients) reporting.

Notes.
[1]As of 11/28/90
[2]1-1-89 to 12-31-89
[3]Approximate
[4]Calender year 89 (1100 persons)
[5]includes education services
[6]includes prevocational and supported employment services

OTHER SERVICES: (# of recipients in 6/90)
Note. NA means # of recipients is not available.

Alabama
- residence-group home (136)
- residence - SCLA (60)

Arkansas
- combined homemaker/home health aide/personal care (10)
- transportation (91)
- adaptive equipment (27)
- consultative services (18)

California
- adult day services (205)
- non-medical transportation (548)

Delaware
- supported employment (38)
- pre-vocational (66)

Florida
- transportation (1172)
- training and therapies (1049)
- developmental training (1378)
- family placement (4)
- diagnosis and evaluation (63)
- case management by direct care staff (243)

Georgia
- supported employment

Hawaii
- adult day/health (123)

Kansas
- wellness monitoring (7)
- Med alert (7)

Massachusetts
- transportation (185)

Michigan
- non-vocational (out-of- home) day habilitation (142)
- pre-vocational day habilitation (444)
- supported employment (160)
- transportation to day habilitation (477)

Minnesota
- adaptive aids (111)

Missouri
- occupational therapy (87)
- physical therapy (90)
- speech therapy (95)
- home modification (3)
- transportation (93)
- behavior therapy (44)

Montana
- transportation (145)

New Hampshire
- supported employment (99)
- adult day activities (281)

New Mexico
- companion home (9)
- behavior management (26)
- behavior implementation (16)
- family education and training (1)
- occupational therapy (30)
- physical therapy (29)
- speech therapy (46)

North Carolina
- screening (11)
- home mobility aides (1)
- mr waiver supplies (104)
- adult day health (2)

North Dakota
- adult day care (47)
- supported employment (37)
- infant development (40)

Ohio
- equipment (150)
- transportation (74)
- nursing respite/LPN (10)
- private duty nursing/LPN (17)

Oregon
- residential habilitation includes educational service
- day habilitation includes prevocational and supported employment services

Pennsylvania
- transportation (1121)
- special therapies (1635)
- physical adaptations (90)
- prevocational supported employment
- permanency planning (1)

Texas
- occupational therapy (NA)
- physical therapy (NA)
- speech therapy (NA)
- audiology therapy (NA)
- psychological therapy (NA)
- social services (NA)
- nursing services (RN, LVN) (NA)
- age appropriate day programming (485)

Vermont
- day activities (2)

Utah
- family support (25)
- supported employment (154)

Characteristics and Place of Residence of HCBS Recipients

Table 13 shows place of residence by level of disability of HCBS recipients in 11 states reporting this data. While HCBS recipients with mild/moderate mental retardation made up only about 35% of all persons with MR/RC reported living in family homes, they were 80% of those living in their own homes.

TABLE 13: HCBS RECIPIENTS BY RESIDENCE AND PRIMARY DIAGNOSIS

Type of Residence with Support Services	Level of Mental Retardation				Other Related Cond.	Total	% of Total
	Mild	Mod	Sev	Prof			
Natural/adoptive family home	152	409	419	602	6	1,588	15%
Own home	277	106	55	41	0	479	5%
Other supervised residence	1,660	2,257	2,656	1,613	52	8,238	80%
Total	2,089	2,772	3,130	2,256	58	10,305*	100%

Note. Eleven states with 10,588 HCBS recipients reporting; excludes 283 unclassified HCBS recipients.

Ages and Place of Residence of HCBS Recipients

Table 14 shows the place of residence by age group of HCBS recipients with MR/RC in the 22 states reporting this data. Most HCBS recipients were over 21 years of age and living outside their family or own home in an "other supervised residence" in the community. Even a majority (55.4%) of HCBS recipients under 22 years of age lived in supervised residences, other than their own or family home.

TABLE 14: HCBS RECIPIENTS BY RESIDENCE AND AGE GROUP

Type of Residence	Age (Years)		Total
	0-21	22+	
Natural/adop. family home with supp. services	1,067	2,271	3,338
Own home with supp. services	49	500	549
Other supv. resid. with supp. services	977	13,495	14,472
Residence type unclassified	407	955	1,362
TOTAL	2,500	17,221	19,721

Note. Twenty-two states provided the data presented in Table 14.

Utilization Rates for Institutional and Community Services

Statistics presented to this point have shown states to vary remarkably in the total number of persons with mental retardation and related conditions in the various types and sizes of ICF-MR and non-ICF-MR residences and receiving HCBS. Such statistics can be difficult to compare because of the great variability in the size of states. Therefore, Table 15 was developed to index these statistics by the population of states in 100,000s of the general population.

Table 15 shows that the average number of ICF-MR residents per 100,000 of the U.S. population on June 30, 1989 was 59.3. That included 13.0 persons per 100,000 in small ICFs-MR (4.1 in size 1-6, 8.9 in size 7-15) and 46.3 persons per 100,000 in large ICFs-MR. Remarkable variation in utilization is evident among the states. Louisiana had the highest utilization rate nationally, with 138.5 ICF-MR residents per 100,000 of the state's population, followed closely by Minnesota with 132.5/100,000. A total of 9 other states had more than 150% of the national rate. In contrast 8 states were less than 50% of the national rate, including Wyoming which does not participate in the program.

States with the highest utilization rates for large ICFs-MR included Louisiana (99.9/100,000, and Oklahoma (94.5/100,000), and Wisconsin (93.2/100,000). Eight states reported rates below 25/100,000. But by far the greatest interstate variability was evident in the small ICF-MR utilization rates. These rates ranged from 77.8 per 100,000 in the District of Columbia and 73.3 in Rhode Island, to less than 3.0 in 19 states. Of the 26 states with ICFs-MR of 6 or fewer residents, rates ranged from 50.3/100,000 in Rhode Island to less than 5.0 in 13 states.

Overall Title XIX utilization of Title XIX services for persons with mental retardation and related conditions shows similarly high interstate variability. Nationally on June 30, 1989 there were 73.4 ICF-MR and HCBS recipients per 100,000 of the nation's population. Three states were over double the national utilization rate: North Dakota (273.6/100,000), Minnesota (180.0/100,000), and South Dakota (178.2/100,000). At the other extreme, 5 states had total Title XIX utilization rates that were less than half the national rate. The very high and very low states with respect to total Title XIX utilization rates (ICF-MR and HCBS) were generally the same as the very high and very low states with respect to ICF-MR utilization alone.

Utilization rates for Title XIX community based care (HCBS plus small ICF-MR) also showed great variation around the national average utilization rate of 27.1 per 100,000. Three states provided Title XIX funded community based care to less than 1 person with mental retardation and related conditions per 100,000 of the states' total population. At the other extreme, nine states provided Medicaid community based care to 54 or more persons with mental retardation per 100,000 of the state's total population.

In noting the extreme variability among states in the utilization of Medicare ICF-MR and HCBS services, it is important to recognize that some of that variability is a reflection of the size of state residential systems in general. On June 30, 1989 states had an average total utilization of all residential placements (ICF-MR and non-ICF-MR) for persons with mental retardation and related conditions of 109.9 per 100,000. States varied from 47.3 placements per 100,000 in Nevada to 263.3 in North Dakota, although only 3 states had less than half the national placement rate (Alabama, Nevada, and Kentucky) and only North Dakota had double the national rate. In all 30 states fell in the range of 74 to 146 placements per 100,000, or the national average, 110, plus or minus 33%. Generally, then, states vary substantially in their total utilization of residential placements for persons with mental retardation, but their utilization of Title XIX to finance those placements varies considerably more.

TABLE 15: UTILIZATION RATES PER 100,000 OF STATE POPULATION: LARGE AND SMALL ICF-MR AND TOTAL RESIDENTIAL FACILITIES ON JUNE 30, 1989

State	7/1/89 State Pop. (100,000)	ICF-MR (1-15) and Waiver	Waiver Rate	All ICF-MR and Waiver	ICF-MR and Non-ICF-MR 1-6	7-15	1-15	16+	Total
ALABAMA	41.18	45.19	44.44	76.64	10.68	8.18	18.87	34.12	52.99
ALASKA	5.27	7.59	0.00	18.41	46.30	8.54	54.84	10.82	65.65
ARIZONA	35.56	1.43	0.00	1.94	54.27	1.83	56.10	10.69	66.79
ARKANSAS	24.06	0.00	0.00	59.89	8.40	17.96	26.35	59.89	86.24
CALIFORNIA	290.63	17.74	11.54	49.32	52.78	10.50	63.28	45.22	108.50
COLORADO	33.17	58.94	50.62	84.23	20.02	47.66	67.68	25.29	92.98
CONNECTICUT	32.39	49.43	34.79	106.88	82.74	17.20	99.94	58.66	158.60
DELAWARE	6.73	27.64	14.86	80.53	35.51	12.78	48.29	52.90	101.19
D.C.	6.04	77.81	0.00	106.13	88.25	49.34	137.58	38.91	176.49
FLORIDA	126.71	20.06	0.00	45.16	11.77	17.60	29.37	37.68	67.05
GEORGIA	64.36	0.39	0.00	30.59	21.16	0.06	21.22	36.03	57.26
HAWAII	11.12	5.85	0.00	28.42	82.46	0.72	83.18	15.56	98.74
IDAHO	10.14	2.57	0.00	22.78	25.15	26.13	51.28	71.67	122.98
ILLINOIS	116.58	0.00	0.00	18.15	18.15	75.04	93.19	48.76	141.95
INDIANA	55.93	13.91	0.00	36.15	30.16	18.49	48.49	98.55	147.04
IOWA	28.40	0.49	0.00	4.05	64.51	37.50	46.65	84.15	75.53	159.68
KANSAS	25.13	1.63	0.00	12.50	90.29	35.22	40.55	75.77	68.05	143.81
KENTUCKY	37.27	0.00	0.00	19.53	51.17	12.96	3.68	16.64	33.40	50.04
LOUISIANA	43.82	36.24	0.00	38.54	138.45	43.09	2.30	45.39	100.18	145.57
MAINE	12.22	9.82	0.00	10.23	91.73	118.74	4.26	123.00	47.95	170.95
MARYLAND	46.94	0.00	0.00	0.26	46.59	62.19	0.26	62.44	30.72	93.16
MASSACHUSETTS	59.13	0.00	0.00	8.83	80.47	37.61	47.02	84.63	55.42	140.05
MICHIGAN	92.73	18.57	0.00	8.83	45.84	64.83	0.00	64.83	19.20	84.03
MINNESOTA	43.53	14.61	44.48	18.57	180.04	81.39	44.77	126.17	76.48	202.64
MISSISSIPPI	26.21	0.00	0.00	59.09	60.59	10.00	2.82	12.82	79.28	92.10
MISSOURI	51.59	0.56	3.08	3.64	20.51	34.46	54.97	54.95	109.92
MONTANA	8.06	0.00	1.24	1.24	63.65	69.35	133.00	29.78	162.78
NEBRASKA	16.11	0.00	0.50	0.50	105.40	0.50	105.90	46.43	152.33
NEVADA	11.11	0.00	1.35	1.35	30.60	1.35	31.95	15.30	47.25
NEW HAMPSHIRE	11.07	1.63	3.25	4.88	73.08	17.98	91.06	10.66	101.72
NEW JERSEY	77.36	0.00	0.00	0.00	22.58	20.33	42.92	67.41	110.33
NEW MEXICO	15.28	0.98	15.25	16.23	20.81	27.09	47.91	34.55	82.46
NEW YORK	179.50	3.62	41.70	45.32	32.46	64.76	97.23	53.92	151.15
NORTH CAROLINA	65.71	6.54	2.80	9.34	26.95	4.03	30.98	50.54	81.52
NORTH DAKOTA	6.60	14.55	56.36	70.91	99.02	164.24	263.26	10.07	273.33
OHIO	109.07	0.74	12.11	12.85	99.35	101.52	215.45	47.88	263.33
OKLAHOMA	32.24	0.00	0.47	0.47	15.79	25.93	52.31	67.31	119.61
OREGON	28.20	0.00	0.78	0.78	110.42	11.54	27.33	94.45	121.77
PENNSYLVANIA	120.40	3.46	4.57	8.02	47.52	16.91	64.43	38.19	102.62
RHODE ISLAND	9.98	50.30	22.95	73.25	58.26	7.25	65.51	58.26	123.77
SOUTH CAROLINA	35.12	0.00	22.10	22.10	74.85	33.77	108.62	24.25	132.87
SOUTH DAKOTA	7.15	0.00	26.01	26.01	16.71	23.72	40.43	69.90	110.34
TENNESSEE	49.40	0.00	0.24	0.24	43.78	107.55	151.33	56.64	207.97
TEXAS	169.91	5.57	5.69	11.26	6.96	5.69	12.65	59.84	72.50
UTAH	17.07	0.00	2.52	2.52	19.04	33.27	52.31	56.36	108.67
VERMONT	5.67	9.52	0.00	9.52	82.01	0.00	82.01	32.10	114.11
VIRGINIA	60.98	0.26	2.05	2.31	3.66	6.33	9.99	45.34	55.33
WASHINGTON	47.61	1.68	1.49	3.17	46.47	22.40	36.73	21.97	58.70
WEST VIRGINIA	18.57	2.69	22.40	25.09	20.22	113.46	107.01	94.16	201.17
WISCONSIN	48.67	0.00	1.46	1.46	74.63	32.38	58.53	86.53	145.05
WYOMING	4.75	0.00	0.00	0.00	16.00	42.53	0.00	0.00	0.00
U.S. TOTAL	2482.43	4.11	8.89	13.00	46.28	14.13	27.13	73.41	35.64	20.81	56.45	53.42	109.88

Costs of ICF-MR Services

Statistics on total recipients and expenditures for FY 1989 (presented in Table 16) are useful in examining longitudinal change in ICF-MR program costs as well as interstate variations in expenditures for ICF-MR services. Three general observations regarding changes over time in the cost of the ICF-MR program are presented below.

Total ICF-MR costs have been increasing rapidly. ICF-MR expenditures have been one of the fastest growing elements of the Medicaid program over the past 15 years. Between Fiscal Year 1971 and 1989 ICF-MR expenditures grew from zero (not covered) to 6.6 billion dollars. Between 1977 and 1989 ICF-MR expenditures grew almost exactly 500% or at over twice the rate of total Medicaid expenditures (a 220% increase over the same period). Although the rate of growth in ICF-MR expenditures slowed notably from Fiscal Year 1982 to Fiscal Year 1989, expenditures still increased 3.0 billion dollars over the period (from 3.6 billion in 1982). Before 1982 the ICF-MR program costs were pushed upward by two factors, increased number of recipients and increased costs per recipient. Since 1982 the greater costs per recipient has been by far the most significant factor in the increasing costs of providing ICF-MR services to each individual, accounting for about 95% of total increase, as the total number of ICF-MR residents has increased by less than 6,500.

Early cost increases were primarily due to growth in certified capacity. Much of the growth in ICF-MR expenditures since the inception of the program in 1971 was attributable to the expansion of state ICF-MR programs (i.e., increasing numbers of recipients). By the end of 1975, 38 states were participating, including all large states except Indiana and New Jersey. By 1982 only 2 small states, Arizona and Wyoming, were not participating. In addition to program growth as a function of increasing numbers of states participating, participating states also increased their "certified capacity." Between Fiscal Years 1971 and 1976, the total number of persons receiving ICF-MR services grew from 0 to 89,000. Between Fiscal Years 1976 and 1989, the number of persons receiving ICF-MR services grew from 89,000 in 1976 to 140,000 in 1982 and to 147,000 on June 30, 1989. Most of the increases in cost of the ICF-MR program between 1971 and 1977 were attributable to increasing numbers of recipients.

Recent rates of increase have slowed as increases have become only a function of increasing costs per recipient. Total ICF-MR costs have been increasing in recent years almost exclusively because of increasing costs per service recipient. Because a single factor has been responsible for cost increases of recent years, cost analysis has become much more straightforward. It has also seemed less urgent, as a stable number of recipients has led to a considerably lower *rate* of growth (the average annual increase of about 400 million dollars between 1982 and 1989 was actually slightly greater than the average from 1973 to 1982). In addition to the reduction in the total growth rate of program costs, there has also been a reduction in recent years in the per resident rate of increase in the cost of ICF-MR care. While per recipient costs between 1975 and 1980 increased from

$5,530 to $20,040 per year, or at an average annual rate of 29%, from 1980 to 1989 those increases were from $20,040 to $44,946, or just under 10% annually. Between 1986 and 1989, cost per ICF-MR resident increased by almost $4,000 per year. The worst fears of geometrically increasing costs may have abated with the stabilization of the total number of ICF-MR residents, but the cost per resident continues to climb steadily. Still for the most part attention now given to the program by federal policymakers is directed toward issues of the quality, equity, and systemwide effects of the program rather than what was perceived as runaway costs in the early 1980s. However at the state level cost management remains a major concern (Lakin et al., 1989).

Interstate Variations in ICF-MR Costs

Earlier in this report statistics were provided on the substantial interstate variations in the utilization of the ICF-MR option. Not surprisingly, there were also major variations in the costs of the ICF-MR programs in the various states. The variability in state ICF-MR expenditures, and federal contributions to those expenditures, is by no means predictable solely by general factors such as total ICF-MR recipients or state size. Presented below are general observations regarding the interstate variability in program costs, particularly where the variability may reflect on the quality, equity, and nationwide effects of the ICF-MR program.

Table 16 presents Fiscal Year 1989 statistics for ICF-MR expenditures across the states in total expenditures, federal expenditures, per recipient average annual costs, per capita annual ICF-MR expenditures (ICF-MR expenditures per resident of the state), 1989 ICF-MR recipients per 100,000 of state population, each state's proportion of the total ICF-MR population, and the relative "payback" to states for ICF-MR services for each dollar of individual income tax contributed by the states to support the program. The cost statistics provided in Table 16 derive from analyses of HCFA 2082 data provided by Brian Burwell of Systemetrics/McGraw-Hill.

One indicator of the variation among states in ICF-MR expenditures is the average expenditure for ICF-MR service per citizen of the state. Table 16 shows the great variation with respect to these expenditures among the states. While nationally in Fiscal Year 1989 the average annual cost of ICF-MR services was $26.64 per state resident, the average varied from over twice the national average in New York ($75.28), North Dakota ($63.32), Rhode Island ($62.34), and Minnesota ($53.55), to less than half the national average in California ($12.84), New Hampshire ($12.13), Florida ($10.49), Nevada ($9.42), West Virginia ($8.07), Hawaii ($5.30), and, of course, Wyoming ($0.00). The variability in total and per citizen expenditures among states is affected by two major factors, the extent to which placements are made into ICF-MR facilities and the amount of money spent per placement.

TABLE 16: SUMMARY STATISTICS ON EXPENDITURES FOR ICF-MR CARE BY STATE AN FOR FISCAL YEAR 1989

State	ICF-MR Costs	% Federal Cost Share	Total Federal Payments for ICF-MR	ICF-MR Costs per Recipient	Total ICF-MR Expenditures per State Resident	ICF-MR Recipients per 100,000 Population	State % of Federal ICF-MR	Federal Income Tax (in millions)	State % of Total Income Tax	State Benefit Ratio ICF-MR%/Tax%
ALABAMA	58,157,693	73.10	42,513,274	43,859	14.12	32.20	1.14	4,422	1.17	0.98
ALASKA	11,339,343	50.00	5,669,672	116,900	21.52	18.41	0.15	1,088	0.29	0.53
ARIZONA	N/A*	N/A	N/A	N/A	N/A	1.94	N/A	4,600	1.21	N/A
ARKANSAS	63,265,809	74.14	46,905,271	43,904	26.30	59.89	1.26	2,205	0.58	2.16
CALIFORNIA	373,079,895	50.00	186,539,948	33,984	12.84	317.77	5.00	47,690	12.58	0.40
COLORADO	45,924,113	50.00	23,462,057	42,084	14.15	33.61	0.63	5,074	1.34	0.47
CONNECTICUT	142,375,254	50.00	71,187,627	60,974	43.96	72.09	1.91	8,736	2.30	0.83
DELAWARE	16,846,873	52.60	8,861,455	38,115	25.03	65.68	0.24	1,122	0.30	0.80
D.C.	31,655,924	50.00	15,827,962	49,385	52.41	106.13	0.42	1,398	0.37	1.15
FLORIDA	132,871,092	55.18	73,318,269	41,783	10.49	25.10	1.96	20,901	5.51	0.36
GEORGIA	94,283,005	62.78	59,178,315	48,489	14.65	30.21	1.59	8,597	2.27	0.70
HAWAII	5,897,873	53.99	3,184,262	23,975	5.30	22.12	0.09	1,517	0.40	0.21
IDAHO	27,436,664	72.71	19,949,198	52,763	27.06	51.28	0.53	901	0.24	2.25
ILLINOIS	305,317,191	50.00	152,658,596	28,104	26.19	93.19	4.09	20,194	5.33	0.77
INDIANA	101,940,118	63.71	64,946,049	18,494	18.23	98.55	1.74	7,595	2.00	0.87
IOWA	100,349,967	62.95	63,170,304	55,198	35.33	64.01	1.69	3,229	0.85	1.99
KANSAS	68,779,317	54.93	37,780,479	35,181	27.37	77.80	1.01	3,492	0.92	1.10
KENTUCKY	53,305,251	72.89	38,854,197	45,212	14.30	31.63	1.04	3,933	1.04	1.00
LOUISIANA	171,141,863	71.07	121,630,522	28,209	39.06	138.45	3.26	4,777	1.26	2.59
MAINE	43,621,246	66.68	29,086,647	65,301	35.70	54.66	0.78	1,489	0.39	1.98
MARYLAND	72,556,038	50.00	36,278,019	52,806	15.46	29.27	0.97	8,710	2.30	0.42
MASSACHUSETTS	222,282,890	50.00	111,141,445	62,650	37.59	60.00	2.98	12,383	3.27	0.91
MICHIGAN	197,430,214	54.75	108,093,042	66,722	21.29	31.91	2.90	14,921	3.93	0.74
MINNESOTA	233,090,315	53.07	123,701,030	40,404	53.55	132.53	3.31	6,309	1.66	1.99
MISSISSIPPI	38,892,283	79.80	31,036,042	24,491	14.84	60.59	0.83	2,101	0.55	1.50
MISSOURI	76,004,401	59.96	45,572,239	40,907	14.73	36.01	1.22	7,378	1.95	0.63
MONTANA	10,971,843	70.62	7,748,316	43,887	13.61	31.02	0.21	785	0.21	1.00
NEBRASKA	29,478,197	60.37	17,795,988	38,992	18.30	46.93	0.48	1,955	0.52	0.92
NEVADA	10,461,368	50.00	5,230,684	56,548	9.42	16.65	0.14	1,855	0.49	0.29
NEW HAMPSHIRE	13,422,900	50.00	6,711,450	84,955	12.13	14.27	0.18	2,190	0.58	0.31
NEW JERSEY	253,874,333	50.00	126,937,167	66,424	32.82	49.41	3.40	18,336	4.84	0.70
NEW MEXICO	25,935,085	71.34	18,503,960	34,534	16.97	49.15	0.50	1,561	0.41	1.21
NEW YORK	1,351,196,585	50.00	675,598,293	76,021	75.28	99.02	18.10	34,044	8.98	2.02
NORTH CAROLINA	181,919,313	68.01	123,723,325	57,334	27.69	48.29	3.31	7,933	2.09	1.58
NORTH DAKOTA	41,789,491	66.53	27,802,548	56,244	63.32	112.58	0.74	744	0.20	3.80
OHIO	323,711,074	58.98	190,924,791	40,611	29.68	73.08	5.11	15,332	4.04	1.27
OKLAHOMA	97,426,834	66.06	64,360,180	31,839	30.22	94.91	1.72	3,738	0.99	1.75
OREGON	81,421,645	62.44	50,839,675	78,140	28.87	36.95	1.36	3,325	0.88	1.55
PENNSYLVANIA	424,030,537	57.42	243,478,334	59,849	35.22	58.85	6.52	17,701	4.67	1.40
RHODE ISLAND	62,213,016	55.88	34,764,633	65,076	62.34	95.79	0.93	1,580	0.42	2.24
SOUTH CAROLINA	110,153,977	73.08	80,500,526	34,093	31.37	92.00	2.16	3,651	0.96	2.24
SOUTH DAKOTA	23,498,408	71.02	16,688,569	39,760	32.86	82.66	0.45	679	0.18	2.50
TENNESSEE	81,959,241	70.17	57,510,799	37,682	16.59	44.03	1.54	6,072	1.60	0.96
TEXAS	390,099,177	59.04	230,314,554	32,290	22.96	71.10	6.17	25,078	6.61	0.93
UTAH	33,587,976	73.86	24,808,079	33,421	19.68	58.88	0.66	1,633	0.43	1.54
VERMONT	12,689,890	63.92	8,111,378	53,771	22.38	41.62	0.22	728	0.19	1.13
VIRGINIA	136,800,812	51.20	70,042,016	48,271	22.43	46.47	1.88	9,852	2.60	0.72
WASHINGTON	128,515,613	53.06	68,190,384	53,437	26.99	50.51	1.83	7,012	1.85	0.99
WEST VIRGINIA	14,985,825**	76.14	11,410,207	19,666	8.07	41.03	0.31	1,846	0.49	0.63
WISCONSIN	84,798,984	59.31	50,294,277	18,399	17.42	94.70	1.35	6,168	1.63	0.83
WYOMING	0	62.61	0		0.00	0.00	0.00	659	0.17	0.00
U.S. TOTAL	6,613,766,776		3,732,886,052	44,946	26.64	59.28	100.00	379,219	100.00	1.00

* Cost data for Arizona's ICF-MR program not available for this period.
** Data used are 1990 annualized cost data from HCFA Form 64.

Variations due to disproportionate placements. Variations in ICF-MR utilization rates across states have been discussed in some detail earlier in this report. These variations have an important direct effect on interstate differences in total costs and federal contributions to the total costs of residential programs in the various states. As an example of the variability, on June 30, 1989, 5 states had placed more than 80% of their total residential care population in ICF-MR certified facilities, while 18 states had 40% or less of their residents of state and nonstate residential settings in ICFs-MR. Obviously those states with disproportionately high placement rates into ICFs-MR tended to account for disproportionate amounts of total ICF-MR expenditures.

Variations due to differences in per recipient cost. Placement rates are not the only factor accounting for interstate differences in ICF-MR expenditures. Obviously the average number of dollars expended per ICF-MR resident is also a key factor. Table 15 also shows the enormous variations among states in the average per resident cost of ICF-MR care. The national average cost of ICF-MR care per recipient in Fiscal Year 1989 (total ICF-MR expenditures in the year divided by total recipients) was $44,946 per year. Among the states with the highest per recipient costs in 1989 were Alaska ($116,900 per person per year), New Hampshire ($84,955), Oregon ($78,140), and New York ($76,021). Among the states with the lowest per recipient costs were West Virginia ($19,666), Indiana ($18,494), and Wisconsin ($18,399). The effects of relatively high per resident costs are straightforward. For example, New York, New Hampshire, Oregon, and Alaska had 13.0% of all ICF-MR residents on June 30, 1989, but accounted for 22.2% of total FY 1989 ICF-MR expenditures. Obviously, when a state is both a high user of the ICF-MR option and has high cost per recipient, its total expenditures become particularly notable. New York stands out in this regard. Although New York had only 7.2% of the total U.S. population and 12.1% of the ICF-MR population on June 30, 1989, in FY 1989 it accounted for 20.5% of all ICF-MR expenditures.

Variations in state financial benefit. It was noted in the general description of the ICF-MR program that, like all Medicaid programs, the federal government shares the costs of ICF-MR services with the states as a function of the state per capita income relative to national per capita income. Relatively rich states share total costs on an equal basis with the federal government; relatively poor states may have federal involvement in financing Medicaid services up to 83%. (Mississippi's 79.8% was the highest federal share in 1989.) It is often presumed, therefore, that the extent to which states benefit from ICF-MR program participation tends to be related to their general need for assistance as reflected in the federal Medicaid cost share ratio. However, because states vary considerably in their ICF-MR utilization rates, in the proportions of their licensed facilities participating in the ICF-MR program, and in their costs per recipient, some deviation should be expected between total benefit in federal dollars from the ICF-MR program and the proportion of total ICF-MR costs reimbursed by the federal government.

To assess the extent of variance a "state benefit ratio" was computed. The state benefit ratio in Table 15 represents a ratio of federal ICF-MR reimbursements paid to each state for each dollar contributed to the program through personal income tax. Obviously such an index masks certain realities: first, federal revenues for the Medicaid program do not come exclusively through personal income tax; second, expenditures for federal programs in recent years have not been equal to the revenues generated for those programs (i.e., the federal government has had substantially greater total expenditures than revenues). Despite the oversimplifications, such an index is one way of assessing the balance between state contributions to the federal government for the ICF-MR program and federal reimbursements back to the states for ICF-MR services. Table 15 shows that in Fiscal Year 1989, North Dakota got back over three dollars in federal reimbursements for every dollar contributed, and 7 other states exceeded two dollars received for each dollar paid (Arkansas, $2.16, Louisiana, $2.59; Idaho, $2.25; New York, $2.02; North Dakota, $3.80; Rhode Island, $2.24; South Carolina, $2.24; and South Dakota, $2.50). In contrast six states got back less than $.50 in reimbursements for every dollar contributed (California, $.40; Colorado, $.47; Florida, $.36; Hawaii, $.21; Maryland, $.42; Nevada, $.29; and New Hampshire, $.31).

Of the 25 states showing a favorable "State Benefit Ratio" (state's % of total Federal ICF-MR reimbursements divided by state's % of total Federal income tax payments being greater than 1.00), eight of the 13 poorest states (with federal Medicaid matching rates of 70% or greater) were included. Only two of the twelve richest states (i.e., with the highest per capita incomes) with federal Medicaid matching rates of 50.0% had a favorable "state benefit ratio." Therefore, while differential ICF-MR utilization and average costs may cause a number of poorer states to be subsidizers of ICF-MR services in a number of relatively wealthy states (e.g., Minnesota, New York, Rhode Island), the highly favorable Medicaid federal-state cost share for the poorer states does establish a general tendency for them to receive more federal funds from ICF-MR reimbursements than they contribute to them.

Nursing Home Residents with Mental Retardation

Table 17 presents the number of people with mental retardation and related conditions reported by states to be in Medicaid certified nursing homes (ICFs, SNFs), other than ones specifically licensed for persons with mental retardation and related conditions. This was the second year that statistics were obtained from all states on nursing home residents with mental retardation. The primary factor in states' improved capacity to report an actual or estimated count was the new requirement under the Omnibus Budget Reconciliation Act of 1987 (OBRA-87), that states screen nursing home residents with mental handicaps for the appropriateness of their placement.

In all, states indicated 37,143 persons with mental retardation to be in nursing homes. This statistic is remarkably consistent with the 1987 National Medical Expenditure Survey estimate of 37,005 persons with a primary diagnosis of mental retardation in ICF and/or SNF certified nursing homes (see Table 18). Nationwide the total reported number of persons with mental retardation in nursing homes was 20.4% of the

TABLE 17: PERSONS WITH MENTAL RETARDATION AND RELATED CONDITIONS IN NURSING FACILITIES ON JUNE 30, 1989

State	Nursing Home(NH) Residents with MR	Total ICF-MR/ Waiver Recipients	NH Residents as % of ICF-MR/Waiver Recipients	Total MR Residents	NH Residents as % of Total MR Residents
ALABAMA	1,650e	3,156	52.3	2,182	75.6
ALASKA	50	97	51.5	346	14.5
ARIZONA	33	69	47.8	2,375	1.4
ARKANSAS	600e	1,441	41.6	2,075	28.9
CALIFORNIA	880	14,333	6.1	31,534	2.8
COLORADO	459	2,794	16.4	3,084	14.9
CONNECTICUT	436	3,462	12.6	5,137	8.5
DELAWARE	89	542	16.4	681	13.1
D.C.	55	641	8.6	1,066	5.2
FLORIDA	126	5,722	2.2	8,496	1.5
GEORGIA	2,500e	1,969	127.0	3,685	67.8
HAWAII	39	316	12.3	1,098	3.6
IDAHO	48e	790	6.1	1,247	3.8
ILLINOIS	3,000e	11,544	26.0	16,549	18.1
INDIANA	2,200	5,512	39.9	6,810	32.3
IOWA	986	1,832	53.8	4,535	21.7
KANSAS	35	2,269	1.5	3,614	1.0
KENTUCKY	720	1,907	37.8	1,865	38.6
LOUISIANA	1,200	6,067	19.8	6,379	18.8
MAINE	162	1,121	14.5	2,089	7.8
MARYLAND	300	2,187	13.7	4,373	6.9
MASSACHUSETTS	1,279	4,758	26.9	8,281	15.4
MICHIGAN	1,900e	4,251	44.7	7,792	24.4
MINNESOTA	1,223	7,837	15.6	8,821	13.9
MISSISSIPPI	280e	1,588	17.6	2,414	11.6
MISSOURI	440	2,196	20.0	5,671	7.8
MONTANA	231	524	44.1	1,312	17.6
NEBRASKA	353	1,296	27.2	2,454	14.4
NEVADA	40	321	12.5	525	7.6
NEW HAMPSHIRE	11	920	1.2	1,126	1.0
NEW JERSEY	962	6,992	13.8	8,535	11.3
NEW MEXICO	88e	886	9.9	1,260	7.0
NEW YORK	800e	17,774	4.5	27,131	2.9
NORTH CAROLINA	316	3,726	8.5	5,357	5.9
NORTH DAKOTA	194	1,806	10.7	1,738	11.2
OHIO	2,950	8,211	35.9	13,046	22.6
OKLAHOMA	1,200	3,560	33.7	3,926	30.6
OREGON	434	2,260	19.2	2,894	15.0
PENNSYLVANIA	466	9,015	5.2	14,902	3.1
RHODE ISLAND	250e	1,405	17.8	1,326	18.9
SOUTH CAROLINA	94	3,231	2.9	3,875	2.4
SOUTH DAKOTA	155	1,274	12.2	1,487	10.4
TENNESSEE	900	2,649	34.0	3,894	23.1
TEXAS	3,500e	12,498	28.0	12,318	28.4
UTAH	360e	2,129	16.9	1,855	19.4
VERMONT	100e	516	19.4	647	15.5
VIRGINIA	1,448	2,834	51.1	3,374	42.9
WASHINGTON	564	3,489	16.2	6,012	9.4
WEST VIRGINIA	36	986	3.7	1,090	3.3
WISCONSIN	817	5,522	14.8	9,791	8.3
WYOMING	184	0	-	689	26.7
U.S. TOTAL	37,143	182,225	20.4	272,763	13.6

total number receiving ICF-MR and Medicaid waiver services. In 5 states the reported number of nursing home residents with mental retardation was at least 50% of the number of people receiving ICF-MR and waiver services. Nationwide, the reported number of nursing home residents with mental retardation equalled 13.6% of the nation's total population of persons in state licensed or operated mental retardation facilities. Two states (Alabama and Georgia) reported nursing home residents equal to 50% or more of mental retardation facility residents.

Characteristics of Nursing Home Residents with Mental Retardation and Related Conditions

Table 18 presents estimates from the 1987 National Medical Expenditure Survey on the diagnostic characteristics and ages of persons with mental retardation and related conditions in Medicaid certified (ICF and/or SNF) and all nursing and related care homes as included in the 1987 National Medical Expenditure Survey. In all there were a total of 204 sample members with mental retardation or related conditions or related conditions among the 3,347 total sample members in the nursing and related care facility sample of the 1987 National Medical Expenditure Survey. Of course, such a small sample substantially affects the reliability of the population estimates obtained. The NMES yielded an estimate of 90,387 total persons with mental retardation and related conditions in all types of nursing and related care homes. This estimate included 73,423 persons with mental retardation and related conditions in Medicaid certified nursing homes. In Table 18 population estimates for Medicaid certified nursing homes and all nursing and related care homes have been broken down into 3 groups: 1) persons whose primary diagnosis in their medical records (i.e., the reason for placement) was mental retardation or a related condition; 2) persons whose primary diagnosis was mental illness, but who were also indicated to have mental retardation; and 3) persons whose primary diagnosis was a medical condition, but who were also indicated to have mental retardation or a related condition.

Level/Type of condition. In 1987 residents of nursing and related care homes with mental retardation or a related condition as a primary diagnosis were estimated to number 57,849. About 78% of these persons were indicated to have mental retardation as a primary diagnosis (an estimated 45,261 individuals). About 19% (10,900) were estimated to be people with a primary diagnosis of cerebral palsy. Although no level of mental retardation was specified in the records of 28% of the individuals with a primary diagnosis of mental retardation, the largest group by level of mental retardation was made up of persons with mild or "borderline" mental retardation (33.4% of persons with level of mental retardation indicated). About 24.6% of persons with level of mental retardation reported were indicated to be moderately retarded; 20.9% severely retarded, and 21.1% profoundly mentally retarded. There were an estimated 32,538 persons in nursing homes with primary diagnoses of mental illness or medical conditions who were reported also to have mental retardation or a related condition. The majority of these persons for whom the level of mental retardation was known were reported to be mildly or borderline mentally retarded, including 86% of those with mental illness and 60.5% of those with medical conditions.

Among Medicaid certified nursing homes the distribution of residents by level of mental retardation or a related condition was similar to that of all nursing and related care homes. Of the 47,266 estimated residents with a primary diagnosis of mental retardation or a related condition, 37,005 had a primary diagnosis of mental retardation. Among persons with a primary diagnosis of mental retardation and a reported level of mental retardation, 34.2% had borderline or mild mental retardation, 19.3% had moderate mental retardation, 20.9% had severe mental retardation and 25.6% had profound mental retardation. Comparative statistics from the mental retardation facilities (see Table 8) were 23.1%, 20.7%, 20.1% and 36.1%, respectively. An estimated 10,261 Medicaid nursing home residents had primary diagnoses of related conditions, but were reported not to have mental retardation. Persons with cerebral palsy made up the vast majority (87%) of these individuals. As was noted in the entire nursing and related care homes sample, Medicaid nursing home residents with primary diagnoses of mental health conditions who were also indicated to have mental retardation (an estimated 4,250 persons) had a strong tendency to have borderline or mild mental retardation, with slightly more persons reported to have borderline mental retardation than mild mental retardation. With respect to the estimated 21,905 Medicaid nursing home residents with primary diagnosis of health/medical conditions who were also indicated to have developmental disabilities, 95% were indicated to have mental retardation and, based on sample members with reported level of mental retardation, 63% of those had borderline or mild mental retardation.

Age. Persons with mental retardation or a related condition living in all nursing and related care homes tended to be much older than the general population and much older than the population of persons in mental retardation facilities (see Table 18). An estimated 54% of the persons with primary diagnoses of mental retardation and related conditions living in nursing homes were 55 years or older as compared with 13.2% of those living in mental retardation facilities. Among persons with mental retardation or a related condition as a primary diagnosis the estimated median age was 56 years. Only an estimated 10.4% of nursing home residents with a primary diagnosis of mental retardation or a related condition were 21 years and younger. Of these children and youth 65.8% were reported to have profound mental retardation, 19.4% to have severe mental retardation, 7.4% were reported to have mild or moderate mental retardation and 7.4% had related conditions. On the other end of the age cycle there were an estimated 19,877 persons 65 years or older with a primary diagnosis of mental retardation or a related condition (34.4% of the total). The older group was much more likely to be mildly or moderately retarded than the younger groups. For example 31.1% of the 65 to 72 year olds with a reported level of retardation were reported to have mild or borderline mental retardation; 22% were reported to have moderate mental retardation; 23.3% had related conditions. Among persons with primary diagnoses of mental retardation or related conditions who were over 72 years, 39.4% of those with a specific level of retardation or related conditions indicated were mildly or borderline mentally retarded. An estimated 66.4% of persons with mental retardation or related conditions with primary diagnoses

TABLE 18: PERSONS WITH MENTAL RETARDATION AND RELATED CONDITIONS IN MEDICAID-CERTIFIED (ICF AND SNF) AND ALL NURSING AND RELATED CARE FACILITIES AS ESTIMATED IN THE 1987 NATIONAL MEDICAL EXPENDITURE SURVEY

Characteristics	Medicaid (ICF, SNF) Nursing Homes								All Nursing and Related Care Facilities							
	Primary Diagnosis of MR or RC		Primary Diagnosis of MI, also MR/RC		Primary Diagnosis of Medical Cond., also MR/RC		All Residents with MR/RC		Primary Diagnosis of MR or RC		Primary Diagnosis of MI, also MR/RC		Primary Diagnosis of Medical Cond., also MR/RC		All Residents with MR/RC	
	Est. No.	Est. %	Est. No.	Est. %	Est. No.	Est. %	Est. No.	Est. %	Est. No.	Est. %	Est. No.	Est. %	Est. No.	Est. %	Est. No.	Est. %
CONDITION																
Mental Retardation																
Borderline/Mild	9,138	19.3	2,639	62.1	10,291	47.0	22,068	30.1	10,849	18.8	4,655	60.5	10,990	44.2	26,494	29.3
Moderate	5,158	10.9	69	1.6	2,975	13.6	8,202	11.1	7,998	13.9	759	9.9	4,022	16.2	12,779	14.1
Severe	5,588	11.8	-	-	-	-	5,588	7.6	6,794	11.7	-	-	-	-	6,794	7.5
Profound	6,858	14.5	-	-	2,113	9.6	9,671	13.2	6,858	11.9	-	-	2,113	8.5	8,971	9.9
Unspecified	10,263	21.7	1,543	36.3	5,482	25.0	16,588	22.6	12,762	22.1	2,275	29.6	6,680	26.9	21,717	24.0
Total MR	37,005	78.3	4,252	100.0	20,861	95.2	62,188	84.6	45,261	78.2	7,689	100.0	23,805	95.8	76,755	84.9
Related Conditions Only																
Cerebral Palsy	8,912	18.9	-	-	-	-	8,912	12.1	10,902	18.8	-	-	-	-	10,902	12.1
Others*	1,349	2.9	-	-	1,044	4.8	2,393	3.3	1,686	2.9	-	-	1,044	4.2	2,730	3.0
Total	10,261	21.7	-	-	1,044	4.8	11,205	15.4	12,588	21.8	-	-	1,044	4.2	13,632	15.1
Total MR/RC	17.266	100.0	4,252	100.0	21,905	100.0	73,423	100.0	57,849	100.0	7,689	100.0	24,849	100.0	90,387	100.0
AGE																
0-12 Years	2,797	5.9	-	-	1,170	5.3	3,697	5.4	2,797	4.8	-	-	1,170	4.7	3,967	4.4
13-21 Years	2,787	5.9	-	-	585	2.7	3,372	4.6	3,232	5.6	-	-	585	2.4	3,817	4.2
22-54 Years	16,079	34.0	1,955	46.0	1,485	6.8	19,519	26.6	20,473	35.4	4,366	56.8	2,398	9.7	27,237	30.1
55-64 Years	9,407	19.9	-	-	4,017	18.3	13,424	18.3	11,470	19.8	739	9.6	4,465	18.0	16,674	18.4
65-72 Years	11,722	24.8	-	-	4,383	20.0	17,510	23.8	13,950	24.1	670	8.7	4,473	18.0	19,093	21.1
73+ Years	4,474	9.5	2,297	54.0	10,265	46.9	15,078	20.5	5,927	10.2	1,914	24.9	11,758	47.3	19,599	21.7
Total All Ages	47,266	100.0	4,252	-	21,905	100.0	73,423	100.0	57,849	100.0	7,689	100.0	24,849	100.0	90,387	100.0

* Includes Autism, Spina Bifida, and a diagnosis of multiple handicaps, but with no indication of mental retardation.

of mental illness were between 22 and 64 years. An estimated 83.3% of those with primary diagnoses of medical conditions were 55 years or older, with an estimated 47.3% reported to be 73 years and older.

TABLE 19: COMPARISON OF AGES OF NURSING HOME AND MENTAL RETARDATION FACILITY RESIDENTS WITH PRIMARY DIAGNOSIS OF MENTAL RETARDATION OR RELATED CONDITIONS

Age	Nursing Home Residents	ICF-MR Residents	Non-ICF-MR Residents	All MR Facility Residents
0-12	4.8%	4.0	5.6	4.6
13-21	5.6	9.7	12.8	10.8
22-54	35.4	72.9	68.8	70.4
55-64	19.8	7.6	8.0	7.8
65+	34.3	5.8	4.8	5.4

Among Medicaid certified nursing homes the estimates of age distribution of residents with developmental disabilities were generally similar to those for residents of all nursing and related care homes. As was noted with the total nursing and related care home population estimates, Medicaid nursing home residents with developmental disabilities tended to be much older than the resident populations of mental retardation facilities (44.3% vs. 5.4%) were 65 years or older. Even among Medicaid nursing home residents with a primary diagnosis of mental retardation or a related condition, an estimated more than one-third (34.3%) were 65 years or older. Persons with mental retardation or related conditions in Medicaid nursing homes with primary diagnoses of health/medical conditions were much older than those with primary diagnoses of mental retardation and related conditions (66.9% vs. 34.3% 65 years or older). The 67% of nursing home residents with mental retardation and related conditions 65 years or older was still significantly less than the estimated 88% of all nursing home residents who were 65 years or older.

SUMMARY AND CONCLUSIONS

This report has summarized basic utilization and resident characteristics data on Medicaid ICF-MR, HCBS waiver and nursing home program participants. One of the most striking findings of this study, although by no means a new phenomenon, was the high variability in states' ICF-MR utilization and in the associated federal reimbursements to states for services provided under the program. However, the variability noted was not found in all types of facilities. With respect to services offered in large state institutions, the consistently high rates of state utilization (93.7% nationally) suggest a high degree of agreement on the part of states that the program is appropriate and beneficial for public institution residential care. Similar conclusions are apparently being made about care in large nonstate facilities, in which the proportion of all residents living in ICF-MR units has increased from 23% in 1977 to 41% in 1982 to 70% in 1988 to 73% in 1989.

The ICF-MR program is obviously judged by states as suitable for financing institutional care. But institutional care is decreasing, down from 147,463 to 132,619 residents of 16 or more person facilities in just the three years between June 30, 1986 and June 30, 1989. This trend will continue. It is the utilization of the ICF-MR option for community services which raises the primary questions about the program's future benefits, both in terms of projected utilization of the current ICF-MR program and also the possible need for major reform of Medicaid in order to provide the most appropriate and cost-effective community services to persons with mental retardation and related conditions.

In 1989 the ICF-MR program remained primarily an institutional program. About 78% of ICF-MR service recipients lived in facilities of 16 or more residents. On the other hand, utilization statistics did indicate that nationally states continued to certify a substantial number of community-based facilities as ICFs-MR. Between 1986 and 1989 small ICFs-MR went from housing 20% of all small facility residents to 23%, an increase of 11,000 total residents. However, this represented only 30% of the growth in community-based housing, as the number of residents of noncertified community facilities increased by about 25,600. These statistics reflect the ambivalence of states regarding the usefulness and appropriateness of the ICF-MR option for community settings. At present, despite very attractive federal cost-sharing of ICF-MR service expenditures, states vary considerably in their use of the ICF-MR option for community-based residences. At present only 14 states have certified the homes of at least 25% of their community facility residents for ICF-MR participation. Increasingly states are utilizing the HCBS option to obtain federal cost-sharing of residential services for persons with mental retardation and related conditions, with reports from 22 states indicating that 79% of HCBS recipients whose place of residence could be identified were in some form of supervised residential setting.

Data from the 1987 National Medical Expenditure Survey (NMES) also reflect this ambiguity among states in decisions about developing smaller community ICFs-MR. They suggest strongly that ICF-MR

placements are more driven by policy decisions regarding financing strategies than by the establishment of the programmatic needs of potential residents. National estimates from NMES show small ICF-MR and small non-ICF-MR populations to be very similar. For example, 30% and 33% of residents, respectively, were estimated to have mild retardation, 16 and 12%, respectively, to have profound mental retardation. Among small ICF-MR populations an estimated 21% had epilepsy and 7% had cerebral palsy. Among small noncertified facility populations, estimates for epilepsy and cerebral palsy were 19% and 8%, respectively. Independently bathing was reported for 54% of small ICF-MR residents and 48% of small non-ICF-MR residents; independent dressing for 62% and 60%, respectively; independent toileting for 87% and 86%, respectively. There were no statistically significant differences between the two populations in ambulatory abilities or health conditions.

Despite these similarities in resident characteristics, the 1987 National Medical Expenditure Survey estimated that small ICFs-MR averaged 0.92 direct care staff members per resident, while the small non-ICFs-MR averaged 0.63 direct care staff members per resident. Staffing and other differences were in turn reflected in costs of care. While 68% of small ICF-MR residents were living in facilities that cost more than $55 per day, and 33% were in facilities that cost more than $80 a day, only 25% of residents of small non-ICFs-MR were living in places that cost more than $55 per day and 16% were in places that cost more than $80 a day. These differences are ones that state officials have identified in previous surveys as causing them to question whether sufficient benefit is derived from these different levels of expenditure (Lakin et al., 1989).

The substantially higher costs of providing ICF-MR versus non-ICF-MR community-based residential services to similar populations are recognized by state mental retardation/developmental disabilities officials (Lakin et al., 1989). These same officials note also that beyond the additional costs of ICFs-MR, there is a required intensity of supervision and "active treatment" that is viewed as counter productive to increased independence for many ICF-MR residents. It is interesting, therefore, to note that the number of people living in small ICFs-MR continued to increase from June 1986 to June 1989 at a rate nearly equal to the rate of increase of persons receiving Medicaid HCBS (an increase of 11,106 ICF-MR recipients and 12,024 HCBS recipients). In interviews (Lakin et al., 1989), state officials are generally quite clear about their preference for the flexibility and individualizability of the HCBS option for providing community services. However, most also noted that they experienced considerable difficulty in increasing the number of people to whom they were able to provide home and community based services because of access and cost restrictions in the Medicaid HCBS regulations. The approach taken in a majority of states between 1986 and 1989 was to increase utilization of both the small ICF-MR and the HCBS options for increasing federal participation in financing community based services. Consequently between June 1986 and June 1989 there was substantially increased utilization of Medicaid ICF-MR and waiver services in community settings. From June 30, 1986 to June 30, 1989 the combined small ICF-MR and Medicaid recipients increased from 43,943 to 67,348 (53%). But

despite this rapid increase, a very substantial majority of the new community service recipients were provided services that were not supported through federal Medicaid cost share.

As per person costs of ICF-MR services were increased by 56% between 1982 and 1989 (from $61.89 to $123.14 per person per day) as compared with a 16% increase in the Consumer Price Index), not only did the bulk of total ICF-MR expenditures continue to go to institutional care (86% in 1988), but so did about two-thirds of the total dollar increase in ICF-MR expenditures since 1982. This continued pouring of funds into institutional services in the absence of a strong federal commitment to promote access to community services has brought many efforts to reform Medicaid services for persons with mental retardation and related conditions. The case for redesign of federal support for residential and related services becomes more compelling each year with crises in community service access growing in most states. States are unwilling to comprehensively utilize ICF-MR services in community settings because of prohibitive costs and, increasingly, a belief that the otherwise eligible persons would benefit from less prescriptive residential service approaches. States are unable to utilize the HCBS option as fully as they desire. As a result the most common federal support for community based services remains Supplemental Security Income (S.S.I.) and Social Security Disability Insurance (S.S.D.I.) programs, which provide people with about 13 federal dollars per day, as compared with an average of about 70 dollars in daily federal contributions for people living in ICFs-MR.

Clearly, the present Medicaid program is contributing to the increased community presence of persons with mental retardation and related conditions. In FY 1989 about 1.7 billion dollars were spent for community services for 67,348 ICF-MR and HCBS recipients. This represents nearly a quarter (23%) of total ICF-MR and HCBS expenditures and more than a third (37%) of all ICF-MR and HCBS recipients and a dramatic improvement of over 6% of expenditures and 8% of total ICF-MR and HCBS recipients in 1982. In general, then, the trends are positive, but perhaps more significant is the fact that access to services is falling increasingly behind demand, with "openings" existing only in the institutional settings which fewer and fewer people are willing to consider, and with individuals with mental retardation and their families typically waiting years between application and access to community residential services. Although improvement is clearly evident in Medicaid's participation in the provision of community services, it must be recognized that the present long-term care system is extremely inefficient in resources allocation and has not shown substantial improvement in recent years. The bulk of funding goes to facilities which offer less promise of exhibiting habilitative "productivity," but whose per person costs are growing far more rapidly than the demonstrably more effective community-based models of service (Larson & Lakin, 1989). Most notably state institutions, which received over 60% of the total federal funds for ICF-MR and HCBS services in 1989, had average annual per person cost increases from $57,220 to $67,200 between Fiscal Years 1988 and 1989. But perhaps of most basic concern is that present Medicaid policy, save the extremely limited funding available to 8 states in late 1991 to provide Community Supported Living Arrangements services simply cannot be construed as changing in the direction of widely espoused social values.

Congress found in the 1990 Developmental Disabilities Act that, "it is in the national interest to offer persons with developmental disabilities the opportunity, to the maximum extent feasible, to make decisions for themselves and to live in typical homes and communities where they can exercise their full rights and responsibilities as citizens" (p. 3). While most states are making good progress in these directions, the present Medicaid program does not represent a serious national commitment to advance this interest. The current Medicaid policy remains primarily reflected in the ICF-MR program which was developed in 1971 to assure certain minimal standards of care and treatment to residents of large state institutions. Two decades later it seems essentially out of step with contemporary goals and standards for services to persons with mental retardation and related conditions, the vast majority of whom today receive those services while living in community-based residential settings or their own homes.

REFERENCES

Boggs, E., Lakin, K.C., & Clauser, S. (1985). Medicaid coverage of residential service. In K.C. Lakin, B.K. Hill, & R.H. Bruininks (Eds.), *An analysis of Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) Program* (Report No. 20). Minneapolis: University of Minnesota, Department of Educational Psychology.

Davis, R., Silverstein, B., Uehara, E., & Sadden, L. (1987). *Evaluation and service identification for developmentally disabled residents of intermediate care and skilled nursing facilities.* Chicago: Taylor Institute.

Edwards, W.S., & Edwards, B. (1989). *National Medical Expenditure Survey questionnaire and data collection methods for the Institutional Population Component: Methods 1.* Hyattsville, MD: National Center for Health Services Research.

General Accounting Office. (1970). *Report to Congress: Questionable claims under Medicaid program for care of persons in state institutions for mentally retarded in California.* Washington, DC: General Accounting Office.

Gettings, R.M., & Mitchell, D. (1980). *Trends in capital expenditures for mental retardation facilities: A state-by-state survey.* Washington, DC: National Association of State Mental Retardation Program Directors.

Greenberg, J., Lakin, K.C., Hill, B.K., Bruininks, R.H., & Hauber, F.A. (1985). Costs of residential care in the United States. In K.C. Lakin, B.K. Hill, & R.H. Bruininks (Eds.), *An analysis of Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) program* (Report No. 20). Minneapolis: University of Minnesota, Department of Educational Psychology.

Lakin, K.C. (1979). *Demographic studies of residential facilities for mentally retarded people: A historical review of methodologies and findings* (Report No. 3). Minneapolis: University of Minnesota, Department of Educational Psychology.

Lakin, K.C., Bruininks, R.H., Doth, D., Hill, B.K., & Hauber, F.A. (1982). *Sourcebook on long-term care for developmentally disabled people* (Report No. 17). Minneapolis: University of Minnesota, Department of Educational Psychology.

Lakin, K.C., Hill, B.K., & Anderson, D.J. (1991). Persons with mental retardation in nursing homes in 1977 and 1985: A comparison of the findings of the 1977 and 1985 National Nursing Home Surveys. *Mental Retardation, 29*(1), 25-33.

Lakin, K.C., Hill, B.K., & Bruininks, R.H. (Eds.). (1985). *An analysis of Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) program* (Report No. 20). Minneapolis: University of Minnesota, Department of Educational Psychology.

Lakin, K.C., Hill, B.K., Chen, T.H., & Stephens, S.A. (1989). *Persons with mental retardation and related conditions in mental retardation facilities: Selected findings from the National Medical Expenditure Survey.* Minneapolis: University of Minnesota, Center for Residential and Community Services.

Lakin, K.C., Jaskulski, T.M., Hill, B.K., Bruininks, R.H., Menke, J.M., White, C.C., & Wright, E.A. (1989). *Medicaid services for persons with mental retardation and related conditions.* Minneapolis: University of Minnesota, Center for Residential and Community Services.

Larson, S.A., & Lakin, K.C. (1989). Deinstitutionalization of persons with mental retardation: The impact on daily living skills. *Journal of The Association for Persons with Severe Handicaps, 14*(4), 324-332.

National Institute of Mental Health. (1975). *Changes in the age, sex, and diagnostic composition of the resident population of state and county mental hospitals in the United States, 1964-1973* (Statistical Note 112). Rockville, MD: National Institute of Mental Health, Division of Biometry. DHEW Publication No. (ADM) 75-158.

Smith, G., & Gettings, R. (1989). *Medicaid Home and Community Based Services for persons with developmental disabilities.* Alexandria, VA: National Association of State Mental Retardation Program Directors.

U.S. Bureau of the Census. (1990). *Statistical abstract of the United States, 1990.* Washington, DC: U.S. Government Printing Office.

U.S. Senate. (1967). *Senate Report on H.R. 12080,* Senate Reports 744, November 14, pp. 188-189.

White, C.C., Lakin, K.C., & Bruininks, R.H. (1989). *Persons with mental retardation and related conditions in state-operated residential facilities: Year ending June 30, 1988 with longitudinal trends from 1950 to 1988* (Report No. 30). Minneapolis: University of Minnesota, Department of Educational Psychology.

Prouty, R.W., & Lakin, K.C. (1992). A summary of states' efforts to positively affect the quality of Medicaid Home and Community-Based Services for persons with Mental Retardation and Related Conditions. Minneapolis: University of Minnesota, Center for Residential and Community Services.

Hill, B.K., & Lakin, K.C. (1984). Classification of residential facilities for mentally retarded people. Mental Retardation, 24, 107-115.