

Medicaid-financed residential care for persons with mental retardation

by K. Charlie Lakin and Margaret Jean Hall

Two sources of Medicaid support for persons with mental retardation and related conditions (MR/RC) are examined, the intermediate care facility for the mentally retarded (ICF/MR) program and the home and community-based services (HCBS) waiver. Results indicate that Medicaid support through the ICF/MR program has shown little recent growth in terms of

number of persons served, although expenditures continue to increase. Medicaid's HCBS waiver is being used increasingly by States to support residential placement because of its greater flexibility and more individualized approach relative to ICF/MR care. Use of Medicaid to finance care for persons with MR/RC varies considerably across States.

Introduction

Title XIX of the Social Security Act (Medicaid) is the primary source of funding in the United States for residential and other services for persons with mental retardation and related conditions (MR/RC). Braddock (1987) estimated that in fiscal year 1985 more than 46 percent of total Federal spending for persons with MR/RC was through Medicaid. Other major sources of Federal support noted were the Supplemental Security Income program (20 percent) and the Social Security Disability Insurance program (16 percent).

Medicaid services for persons with MR/RC are largely provided through the intermediate care facility for the mentally retarded (ICF/MR) program. ICFs/MR have been the focus of considerable attention from policymakers, program administrators, and advocates in recent years because of the tremendous growth relative to Medicaid in general. From 1977 to 1988 ICF/MR expenditures, State and Federal funds combined, rose from \$1.1 to \$6.0 billion; the number of ICF/MR recipients increased from 106,166 to 146,134; and the average yearly cost per recipient went from \$10,300 to \$41,200. A comparison of these increases to those in the Medicaid program as a whole is shown in Table 1. Although overall Medicaid expenditures more than tripled during the period 1977-88, ICF/MR expenditures increased at almost twice this rate. During this same period, the number of Medicaid recipients increased by only 0.4 percent, but ICF/MR recipients increased by 37.6 percent. The annual cost per recipient for Medicaid as a whole more than tripled, and the ICF/MR average cost quadrupled. For both 1977 and 1988, the average cost of Medicaid care for ICF/MR recipients was considerably higher than the average cost per Medicaid recipient (Health Care Financing Administration, 1990).

Two sources of Medicaid support for residential care for persons with MR/RC are discussed, the ICF/MR program and the home and community-based services waiver (HCBS). Information is included on trends in and projections for the use of these types of Medicaid-funded care for persons with MR/RC. State considerations and

motivations in using ICFs/MR, the Medicaid HCBS waiver, and other funding sources are discussed. The evolution of Medicaid from a program used almost exclusively to fund care in large institutions to one in which increasing numbers of its recipients with MR/RC reside in community-based settings is highlighted. Current and future considerations and problems facing States in funding long-term residential care through Medicaid are addressed.

As Medicaid is the focus of this article, the MR/RC designation, which appears in Medicaid law and regulations, is generally used instead of the more common designation of mentally retarded/developmentally disabled (MR/DD). Both of these terms refer to people who are determined to have mental retardation on the basis of an I.Q. below 70 and concurrent substantial limitation in "adaptive performance," including significant work-related limitation of function, restriction in activities of daily living, and/or difficulties in social functioning; or to people who have related conditions on the basis of severe, chronic disabilities, other than mental illness, which are evident prior to age 22 and result in substantial limitations in three or more of the following areas: self care, understanding and using language, learning, mobility, self-direction, or capacity for independent living (Lakin et al., 1989).

Table 1
Expenditures, recipients, and percent change for intermediate care facilities for the mentally retarded (ICFs/MR) and total Medicaid: Fiscal years 1977 and 1988

Item	1977	1988	Percent change
Expenditures in billions			
ICFs/MR	\$1.1	\$6.0	445.0
Total Medicaid	17.1	54.3	218.0
Recipients			
ICFs/MR	106,166	146,134	37.6
Total Medicaid in millions	22.8	22.9	0.4
Average cost per recipient in dollars			
ICFs/MR	\$10,300	\$41,200	300.0
Total Medicaid	750	2,371	216.0

SOURCE: Health Care Financing Administration, Medicaid Bureau: Data from the Office of Medicaid Management.

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Background

In 1971, Congress authorized the ICF/MR program as an optional service under Medicaid. Section 1905 of the 1972 Amendments to the Social Security Act specified that Federal financial participation (FFP) would be available for care in ICFs/MR which, in addition to meeting the general standards of intermediate care facilities, would provide:

- Health or rehabilitation services to persons with mental retardation and related conditions.
- A program of “active treatment.”
- Assurances that Federal funding would not supplant previously allocated State funding.

Eligibility for ICF/MR services was to be limited to individuals with a diagnosis of mental retardation or a related condition, such as cerebral palsy, whose income and resources qualify them for Medicaid, and who would be determined to be in need of “active treatment” and the ICF/MR level of care.

In establishing the ICF/MR program, Congress helped the States cover the steadily increasing costs of institutional care, growing at an annual real dollar rate of 12 percent from 1965 to 1970 (Lakin, 1979); created incentives for States to maintain minimally adequate residential and habilitative programs in public institutions (Bellman, 1971); and counteracted the rapidly growing practice of placing persons with mental retardation in private nursing homes or of certifying public mental retardation institutions as medical institutions, i.e., skilled nursing facilities (SNFs) in order to obtain Federal financial participation for their care (Boggs, Lakin, and Clauser, 1985; U.S. General Accounting Office, 1970). Congress must also have sought to improve the quality of State institutional care which was generally considered to be deplorable at that time (Blatt, 1970; 1973).

The ICF/MR program was quickly adopted by a number of States, which primarily began their participation by certifying large public facilities as ICFs/MR. By 1977, 43 States were participating in the program with 574 certified ICFs/MR housing 106,166 residents. From 1978-80, about \$750 million in State funds were spent on capital projects alone, primarily needed to enable State institutions to meet ICF/MR requirements (Gettings and Mitchell, 1980).

At the same time this institutional upgrading was under way, a movement to deinstitutionalize persons with MR/RC was gaining momentum. This trend brought about a shift from reliance on institutional care often provided in large State facilities to increased use of smaller, generally non-State operated community-based facilities. It resulted from the increasing acceptance of a treatment philosophy guided by three important principles: normalization, i.e., affording the rights, benefits, and dignity of culturally typical lifestyles and the improved opportunities to learn the ways of the culture that those lifestyles afforded; placement in the least restrictive environment; and community integration. These principles, along with the growing belief that the most effective services are individualized to respond to the characteristics and life circumstances of the persons in need of services, began to influence the actions of many

State agencies serving people with MR/RC. This trend was reinforced over the years by a substantial and growing body of studies that consistently reported benefits of community versus institutional living in important areas, including development of basic skills and involvement in culturally typical activities (Larson and Lakin, 1989). Despite methodological limitations (Landesman and Butterfield, 1987), data from these studies provided empirical evidence to support the development of smaller residential care settings.

In view of this gradual shift in preferred treatment settings for persons with MR/RC, some States attempted to obtain ICF/MR certification for smaller, community-based, non-State facilities even in the early years of the program. States in some Federal regions, e.g., Region V which includes Minnesota, Michigan, Indiana, Illinois, Ohio, and Wisconsin, had developed hundreds of small ICFs/MR by 1980 (Allard and Toff, 1980). But in other regions, States’ understanding of the option, impressions of Federal receptivity to the creation of small ICFs/MR, and, presumably, judgments about its appropriateness for community-based care, contributed to no, or virtually no, community ICF/MR development, e.g., Region IX, which includes California, Arizona, Hawaii, and Nevada (Allard and Toff, 1980; Toff, 1981; Wood, Loop, and Hitzing, 1980).

In 1981, the Health Care Financing Administration (HCFA) issued “Interpretive Guidelines for Intermediate Care Facilities for the Mentally Retarded (ICF/MR) Serving 15 or Fewer Persons” (Health Care Financing Administration, 1981). These guidelines did not change the program’s existing standards, but they did demonstrate how these standards could be applied to programs delivering the ICF/MR level of care in facilities having from 4 to 15 residents. It was anticipated that these clarifications would assist States in increasing the number of small, community-based, certified settings.

In the succeeding decade, dramatic changes occurred in the types and location of services provided to persons with MR/RC generally, and to ICF/MR residents in particular. Data describing these changes in residential services, the extent to which they have occurred consistently within the various States, and the involvement of two primary Medicaid funding sources for residential and alternative services are the focus of this article.

Data sources

Most of the information contained in this article was gathered in a project funded by HCFA and conducted by the Center for Residential and Community Services (CRCS) of the University of Minnesota. Four national data sources were reviewed along with data gathered by CRCS as part of this and earlier studies.

Data from University of Minnesota

Residential facility surveys

CRCS conducted two census surveys of MR residential facilities, one in mid-1977 and the other in mid-1982.

The earlier census included data from 11,025 facilities, the later, data from 15,633 facilities. In both of these surveys, an MR residential facility was defined as any formally State-licensed or contracted (including State-operated) living quarter(s) which provided 24-hour, 7-days-a-week responsibility for room, board, and supervision of mentally retarded people with the exception of: single family homes providing services to a relative; nursing homes, boarding homes, and foster homes that are not formally State licensed and contracted as mental retardation providers; and independent living programs that have no staff residing in the same facility. Figures furnished by facilities represented counts as of June 30 of the year in which they were surveyed. The specific methods for identifying and surveying these facilities are described in Lakin, Hill, and Bruininks, 1985.

National surveys of State agencies

CRCS conducted two separate surveys of State MR/DD agency directors or their designees in each of the States in 1988 and 1989. Both the 1988 and 1989 surveys of all States gathered statistics for the previous fiscal year (fiscal years 1987 and 1988, respectively) on State recipients of ICF/MR and Medicaid HCBS services by size and operation of facilities and services provided. The 1988 survey also gathered information from State officials on projected use of Medicaid options for persons with mental retardation, factors influencing utilization of those services and other general policy topics related to residential and related services, and obtained relevant State plans and State-sponsored research and other reports (Lakin et al., 1989).

Case studies of 10 States

In 1988, 10 selected States were recruited for detailed case study interviews with directors of or designees from MR/DD agencies regarding their residential and related services for persons with MR/RC. In addition, current policy and planning documents were reviewed. The States included California, Colorado, Connecticut, Florida, Indiana, Minnesota, Mississippi, New York, Oregon, and Texas. States were chosen to ensure geographical distribution as well as on a number of other factors, including preference for large States with the greatest potential or actual impact on Medicaid expenditures (California, New York, and Texas). States were ranked and selected on the basis of intensity of use of the ICF/MR option (Minnesota, New York, and Texas); intensity of use of the Medicaid home and community-based services waiver option (California, Colorado, Florida, Minnesota, and Oregon); and projections of major increases (i.e., more than 50 percent) in community facility residents from 1987 to 1990 (Connecticut and Indiana). Mississippi was also included so that the views of a relatively low user of Medicaid, despite a very favorable Federal/State cost share, could be included (Lakin et al., 1989).

Other national data

In addition to the data mentioned previously, which were gathered by CRCS, information was analyzed from:

- The 1986 Inventory of Long-Term Care Places which was a census of 14,639 MR residential facilities and nursing homes conducted by the Bureau of the Census, U.S. Department of Commerce, and analyzed by the National Center for Health Statistics, Department of Health and Human Services (Sirrocco, 1988; 1989). This census updated information collected in the CRCS 1977 and 1982 census surveys.
- The 1987 National Medical Expenditure Survey (NMES), Institutional Populations Component, which included a national sample survey of 691 MR facilities and 3,618 of their residents; and 810 nursing homes and 133 residents with primary diagnoses of MR/RC. For this survey, samples of MR facilities (as defined previously) and nursing homes and related-care homes, as well as a random sample of residents of these facilities, were selected using a three-stage probability design. Details of the sampling strategy and other definitions used in this survey are reported in Edwards and Edwards (1989).
- The 1977 and 1985 National Nursing Home Surveys which included (respectively) samples of 1,451 nursing homes with 181 sample members with MR, and 1,079 nursing homes with 144 sample members with MR. Details about these surveys can be found in Hing, Sekscenski, and Strahan (1989) and National Center for Health Statistics (1979).

Findings

One of the major objectives of the CRCS research was to track the role of the ICF/MR program over time relative to the overall system of residential care for the MR/RC population. The following discussion summarizes some of the major findings related to this issue. Addressed will be the number of persons in ICFs/MR and their proportion of the overall MR/RC residential population over time, the share of residents in various sizes of ICFs/MR, and ICF/MR expenditures. Additional detail related to these findings can be found in Lakin et al. (1989).

Intermediate care for mentally retarded

More than one-half of the persons with MR/RC in residential care were living in ICFs/MR in 1988. In 1977, 43 percent of all residents with MR/RC living in facilities operated or licensed by States for persons with MR/RC were in ICFs/MR. This figure rose to 58 percent in 1982, and decreased somewhat to 56 percent in 1987 and to 54 percent in 1988 (Lakin et al., 1989).

The overall number of persons in ICFs/MR has increased in recent years, but is expected to either stabilize or decline slightly in the future. The period from 1977 to 1982 witnessed growth of 32 percent in the number of participants in the ICF/MR program nationwide, bringing the total number of ICF/MR

residents from 106,166 to 140,682. In the 6 years that followed, the number of ICF/MR residents increased by only 5.452, or less than 4 percent, thereby totaling 146,134 (Figure 1). However, in a majority of States (27), the number of ICF/MR recipients actually decreased as States deinstitutionalized their large State institutions where most of the ICF/MR residents were housed, without commensurate growth in certification of other types of facilities (Lakin et al., 1990). In fact, as a whole, States projected that the number of ICF/MR residents would decline slightly in future years as States continue to depopulate State institutions while exploring alternatives to ICFs/MR for the replacement housing (Lakin et al., 1989).

ICF/MR care is increasingly provided in small community facilities rather than in large State institutions. The percentage of all ICF/MR residents living in large State institutions decreased from 87 percent in 1977 to 58 percent in 1988. This is evidence of the influence of the deinstitutionalization movement on ICF/MR care. From 1977 to 1988, the number of residents in small ICFs/MR increased by 1,600 percent (derived from Figure 1).

Two broad-size categories were used in this study to differentiate facilities: those with 15 or fewer residents (small) and those with 16 or more residents (large). This particular distinction between small and large facilities is found in the original ICF/MR standards, in the Life Safety Code of the National Fire Protection Association, in other Federal standards, and is commonly used in the MR/RC field. Small facilities are assumed to be in the

community or community-based. Large facilities are assumed to be institutional. In fact, some small facilities may be more institutional and less community-based than some large facilities. Nevertheless, because of its recognition in policy and general convention, and the observable and documented differences in lifestyles of residents of facilities so categorized, the above dichotomy remains one of the most useful ways of differentiating facilities.

Although the findings show substantial movement toward deinstitutionalizing ICF/MR care, other data gathered in this study and illustrated in Figure 2 indicate that the ICF/MR program continued to support an overwhelming proportion of persons within large institutions, and that the movement toward community-based care was much slower in the ICF/MR program than in other settings supported by other funding sources (Lakin et al., 1989 and 1990).

The average size of ICFs/MR has decreased. In 1977, the average number of residents per ICF/MR was 186 and by 1988 it was 32. This dramatic decrease was accomplished primarily through the development of new, smaller ICFs/MR, but also involved downsizing existing ones. In spite of the progress in reducing the average size of ICFs/MR, they were still much larger than MR residential facilities as a whole, which averaged 22 residents in 1977 and decreased to 7 residents, on average, in 1987 (Lakin et al., 1989).

Total ICF/MR expenditures have been increasing and are expected to continue to do so. From 1977 to 1988, total ICF/MR expenditures rose from \$1.1 to \$6.0 billion.

Figure 1
Residents of certified ICFs/MR, by size and State and non-State operation:
June 30, 1977, 1982, 1986, and 1988

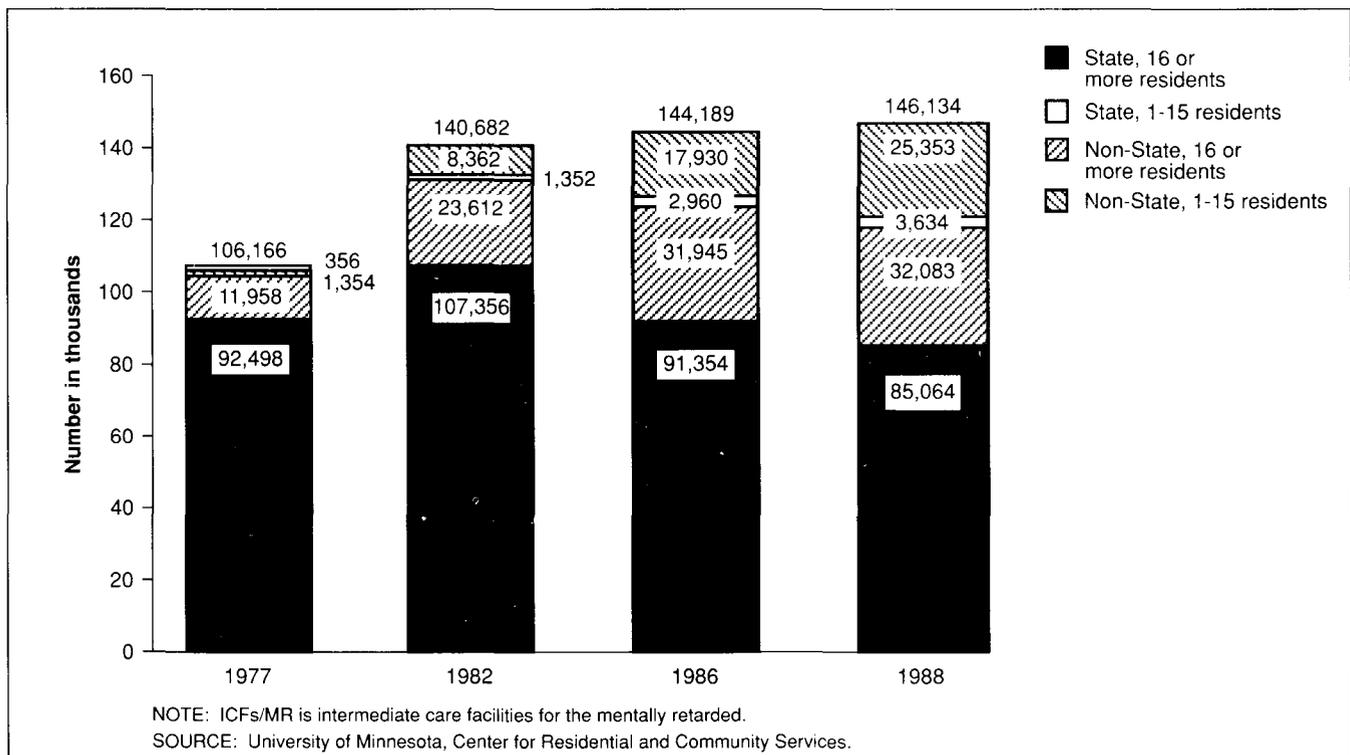
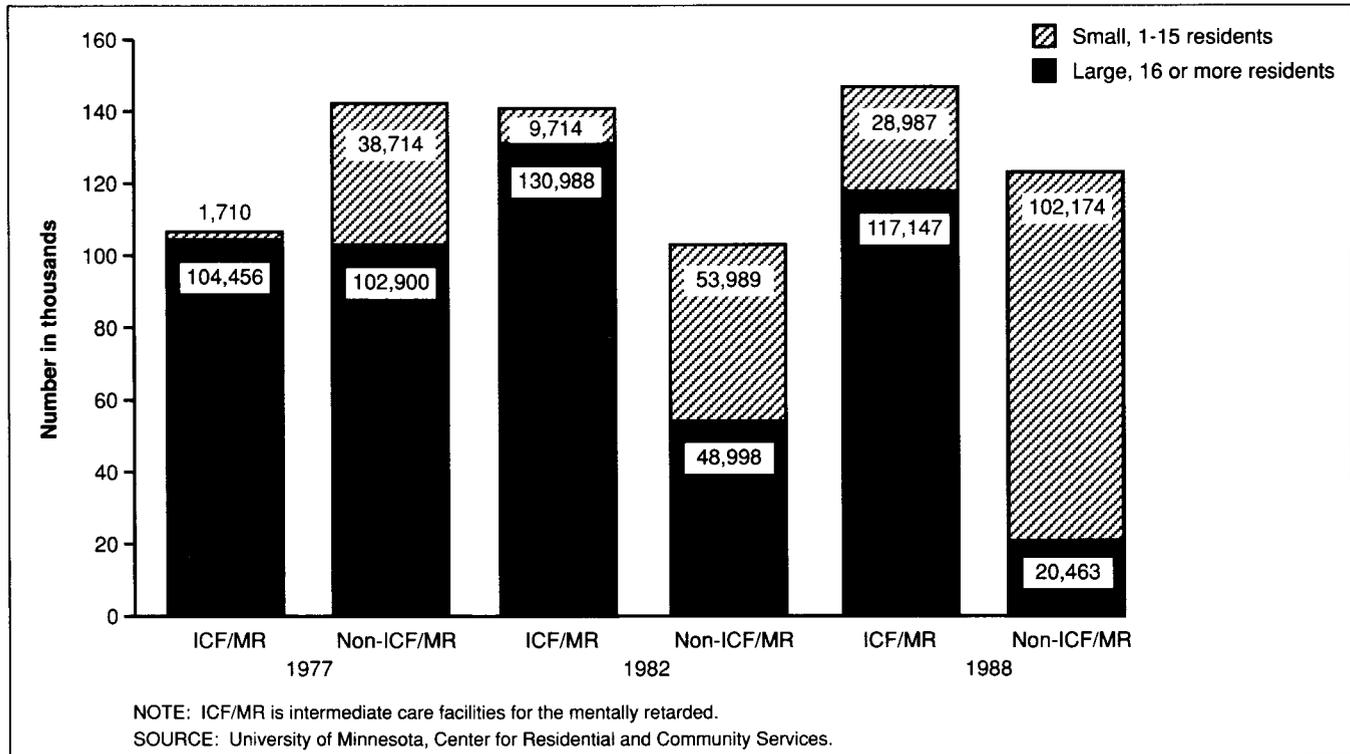


Figure 2
Number of residents in large and small facilities, by ICF/MR certification:
June 30, 1977, 1982, and 1988



Real per capita ICF/MR expenditures continued to increase although the rate of increase has slowed. A number of reasons have been advanced to explain these cost increases. First, as was indicated previously, many individuals in ICFs/MR were in large State institutions. As the populations of these institutions decreased sharply, the fixed institutional costs for administration, maintenance, housekeeping, etc., continued to rise and had to be spread among fewer and fewer people. At the same time, ICF/MR active treatment and other certification requirements required costly upgrading in program, physical plant, and staffing. For example, from 1977 to 1987, the number of State institution residents per full-time equivalent direct care staff position decreased from 1.6 to 0.7 nationwide. In recent years, the residents of large institutions are increasingly more severely cognitively, physically, and behaviorally impaired, and increased costs are incurred in providing the more intensive and specialized professional and direct care they require (Lakin et al., 1989; Lakin et al., 1990).

State variation

The previous discussion of national trends obscures the considerable variability among the States with regard to use of the ICF/MR program and the size of the settings in which residents with MR/RC are housed. Choices available to States and factors that influence their decisions about their MR/RC residential care program are discussed, and data illustrating the resulting State variation follow.

Factors influencing State variability

In order to place persons with MR/RC in residential care, States must choose a treatment setting and source(s) of funding. Among the most common residential settings used were State institutions, large private institutions, large or small ICFs/MR, group homes, semi-independent living alternatives, and personal care homes. Funding sources used to support care in these settings include the Medicaid ICF/MR and the HCBS waiver programs, Federal income maintenance programs, i.e., Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI), State supplements to these maintenance programs, other State and/or county funds, and client contributions.

The State MR/DD officials who furnished information for the CRCS case studies indicated that variability within the total State systems of care for persons with MR/RC, and specifically in their use of the ICF/MR option, results from a complex range of philosophical, historical, economic, and political differences among States. Other influential factors noted by State officials in these studies include court actions, MR/RC population growth, oversight activities of the Health Care Financing Administration, State legislative actions (including those affecting payment rates and limitation of residential facility development), and the anticipated impact of possible Federal reform proposals.

Taking these factors into consideration, each State makes decisions about critical future directions with regard to the rate of continued deinstitutionalization, the

nature and extent of support for small, community-based residential programs including those under the Medicaid home and community-based services waiver, and the degree of commitment they have to provide more individualized and client-centered residential alternatives. However, even States that shared similar program objectives and whose officials identified similar issues with regard to the above factors, often made very different decisions about the development and funding of residential and related services.

Data on State variability

Intermediate care utilization—States' utilization of the ICF/MR program varies greatly. In 1988, six States had three-quarters or more of their total MR/RC facility residents in ICF/MR units; four States had less than one-quarter. These statistics have changed relatively little since 1982. Among the case study States included in this research, ICF/MR utilization in 1987 ranged from 28 percent of MR/RC residents in Connecticut to 92 percent in Texas (Lakin et al., 1989; Lakin et al., 1990).

Utilization of small facilities—States also differed generally in the sizes of their residential facilities and specifically in those with ICF/MR certification. In 1988, 49 percent of all MR/RC facility residents, i.e., those in ICFs/MR and in noncertified facilities, were in facilities of 15 or fewer residents, but the percentage across States ranged from 14 percent (Mississippi) to 87 percent (New Hampshire). In this same year, 12 States had more than 70 percent of their residents in small facilities (Alaska, Arizona, Colorado, District of Columbia, Idaho, Maine, Michigan, Montana, New Hampshire, North Dakota, Rhode Island, and South Dakota). More than one-half of all States (28) had reached the point at which more than one-half of their MR/RC residential population was in small residential facilities. Three States (Mississippi, Texas, and Oklahoma) had less than 20 percent of their residents in small facilities (Lakin et al., 1990).

The percentage of ICF/MR residents in smaller facilities in 1988 varied to an even greater extent across the States. Nationally, 20 percent of ICF/MR residents were living in small ICFs/MR, with the percentages ranging from less than 1 percent in six States with at least one ICF/MR to more than 50 percent in five States (District of Columbia, Indiana, Michigan, North Dakota, and Rhode Island) (Lakin et al., 1990). The complexities States face in making placement and funding decisions have been increased in recent years by new options and requirements under Medicaid for serving people with MR/RC. In the following section one new option, the HCBS waiver program, is discussed.

Home and community-based waiver

Considering the dramatic shift in treatment philosophy and in preferred sites of care in the years following passage of the original ICF/MR provisions, the program increasingly has been considered out of step with the prevailing standards for residential and related services for persons with MR/RC. Its original focus was on

improving conditions in institutions, and its regulations were oriented toward the organization, service provision, practices, and environmental conditions of large institutions. Data presented earlier in this article indicated the decreasing utilization of such facilities for persons with MR/RC.

When Congress enacted the Omnibus Budget Reconciliation Act (OBRA) of 1981 (Public Law 97-35), it provided an important new way for States to support the evolution of their system of services for persons with MR/RC. This legislation granted the Secretary of Health and Human Services the authority to waive certain statutory requirements to permit States to finance a number of noninstitutional services through the Medicaid program. To receive these services recipients were required to be Medicaid-eligible and to need institutional services (i.e., nursing home or ICF/MR) in the absence of the noninstitutional services provided under this waiver. States are permitted to exercise considerable flexibility in the services they provide under an approved plan, but total Federal funds are restricted to the savings in institutional expenditures made possible by the alternative services (i.e., "cost neutrality" must be demonstrated). Final waiver regulations were published in March 1985.

The noninstitutional services that can be provided under the waiver include case management, homemaker services, home health aide services, personal care services, adult day health services, habilitation services, respite care, or any other service that the State demonstrates is cost effective and necessary to avoid institutionalization. Although the waiver may not be used to pay for room and board, virtually all States that use the waiver for persons with MR/RC provide some form of residential service under the categories of personal care, habilitation, and homemaker services to people in supervised residential settings.

By June 1988, a total of 41 States were providing HCBS to persons with MR/RC. States nearly universally offer day habilitation services, residential facility-based training, behavioral intervention services, and early intervention services under their MR waivers. Respite care, case management, and personal care including direct care in residential settings, were authorized for more than 80 percent of States with these waivers. Specific transportation services were approved for one-third of applicants.

In 1988, a total of 28,689 persons were receiving home and community-based services through the MR waiver at a cost of about \$450 million. This figure includes care provided for recipients both in residential care (excluding room and board) and those who reside at home. It has been estimated that about 50 percent of waiver expenditures (Clinkscale, 1988) and 60 percent of waiver recipients (Clinkscale and Ray, 1987) are in residential care. However, in this study's seven case-study States with waiver programs, it was estimated by State officials that 81 percent of their 10,276 total waiver recipients with MR/DD were in out-of-home residential care in 1987.

The average cost per recipient under the Medicaid waivers in 1988 was about \$15,700, or about \$8,800 in Federal Medicaid funds. These costs are not directly

comparable to average costs of the ICF/MR program for the following reasons. Research has found that the overall ICF/MR population tends to be older and more severely impaired than the waiver population (Clinkscale and Ray, 1987; Laudicina and Burwell, 1988), and waiver services, by definition, do not include payment for room and board (usually paid for by SSI or SSDI), and therefore represent only part of the costs of maintaining these individuals in the community. Family members also make significant contributions to housing costs and care provided for persons with MR/RC in their own homes, which are not included in the above costs of care.

According to the State officials responding to the CRCS surveys, States have welcomed the new Federal commitment to individualized, community-based services represented by the waiver program. The waiver is of significant and growing importance to States' MR/RC service systems. Respondents generally considered it a much more appropriate model for Federal participation in providing services to individuals with MR/RC than the less flexible, more standardized ICF/MR model. State respondents indicated that with the waiver program they are better able to develop services that are compatible with the contemporary goals and values of service delivery. A large number of States specifically noted the important role of the HCBS waivers in sustaining their deinstitutionalization efforts.

Medicaid intermediate and waiver care

The overall total of persons served by ICFs/MR and the HCBS waiver has grown steadily. In 1985, there were 164,955 persons in both programs combined. This number rose to 174,956 in 1988. The average increase per year was 2 percent. Combined expenditures have increased at a more rapid rate (10 percent per year), rising from \$4.9 billion to \$6.5 billion during the same 3-year period (Table 2).

In prior sections of this article, the increase in ICF/MR care provided in community-based relative to institutional settings has been discussed. To get a more complete picture of the extent of Medicaid funding for care in community-based settings it is useful to combine utilization figures from both small ICFs/MR and waiver service recipients. Although not all the waiver recipients were in residential settings, in order to qualify for this program they are required to be people who in the

absence of waiver services would require institutional services. On June 30, 1988, 33 percent of combined ICF/MR and waiver service recipients were in community settings, compared with 20 percent of ICF/MR residents only (derived from data in Figure 3). Seventeen States had more than one-half of their total ICF/MR and waiver recipients in small residential facilities or in their own homes (Lakin et al., 1990).

Among Medicaid-funded alternatives for community-based services from 1982 to 1988, total waiver service recipients increased by about 27,100 while small ICF/MR residents increased by about 19,300. These data suggest that the waiver option has generally provided a number of States with an alternative to ICF/MR development, but it has by no means replaced it. From 1982 to 1988, combined ICF/MR and Medicaid waiver recipients increased from 142,287, including 11,319 small ICF/MR and waiver service recipients, to 174,823, including 57,676 small ICF/MR and waiver service recipients (derived from data in Figure 3).

Data on trends in the use of large and small ICFs/MR and the HCBS waiver are shown in Figure 3. In this figure, the large State and non-State ICF/MR residents are considered to be in institutional settings; the small State and non-State ICF/MR residents and waiver recipients are considered to be in community settings. The figure shows the dramatic increase in Medicaid recipients in community settings from 1977 to 1988—from 1,710 to 57,676. It also shows the substantial decrease in institutional recipients from 1982 to 1988—from 130,968 to 117,147 (Lakin et al., 1990).

Critical issues facing States

Despite the progress States have made in achieving the nearly universally held goals of deinstitutionalization and increased development of small facilities, two broad problem areas were consistently noted by State officials participating in the CRCS case studies: insufficient financial resources to develop additional small facilities, and, related to this, extensive waiting lists for residential care in small facilities and other adult services.

One of the problems frequently noted by case-study respondents in discussions of these funding limitations was that expenditures for large institutions continue to increase despite decreasing populations. Although people who have been in institutions are being placed in small facilities, funds are not released by their deinstitutionalization to support them. Nor is there support for others who have lived at home into their adult years who now seek community-living opportunities. Furthermore, respondents of the CRCS case studies reported that these funding limitations have led to inadequate compensation of small facilities which has contributed to an underpaid, inadequately trained work force, frequent staff turnover (averaging more than 50 percent per year, nationally), and growing evidence of chronic personnel shortages. This latter problem can be expected to increase in the future without substantially improved resources for these services as the low birth rates of the sixties and seventies produce serious labor shortages in the coming decades. It seems inevitable that

Table 2

Recipients and expenditures for intermediate care facilities for the mentally retarded (ICFs/MR) and home and community-based services (HCBS) waiver: 1985 and 1988

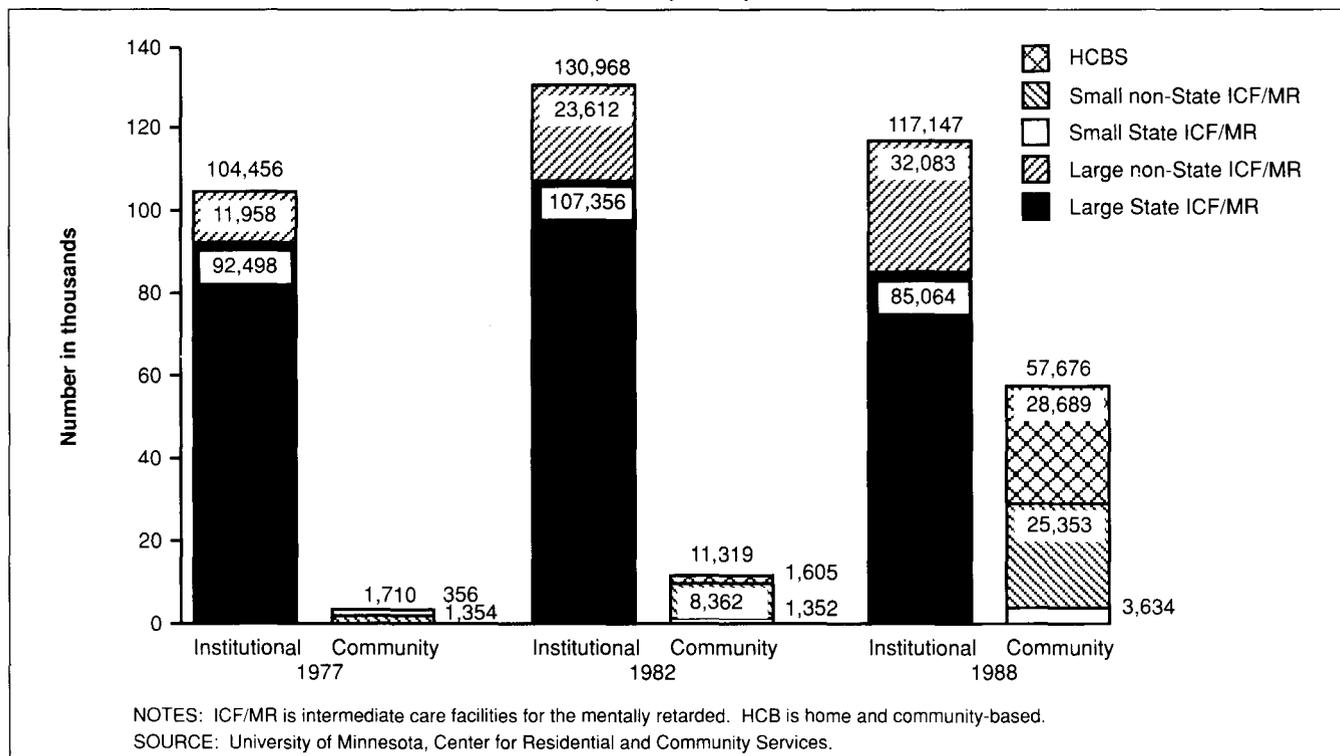
Year	ICF/MR and HCBS recipients ¹	Expenditures in billions ²
1985	164,955	\$4.9
1988	174,956	6.5

¹Recipient data are as of June 30, 1985 and 1988.

²Expenditure data are for fiscal years 1985 and 1988.

SOURCES: Recipient data: University of Minnesota, Center for Residential and Community Services. Expenditure data: Health Care Financing Administration, Medicaid Bureau; Data from the Office of Medicaid Management.

Figure 3
Number of institutional and community Medicaid recipients of ICF/MR and HCB walver services:
June 30, 1977, 1982, and 1988



the industries that will suffer most from these shortages are ones that pay the least, demand the most, and draw their personnel primarily from among young adults. The current labor force in residential care fits each of these conditions (Lakin, 1988).

Waiting lists for placement in small residential care settings, estimated by the Association for Retarded Citizens to be more than 50,000 people (Davis, 1987), have resulted from the limited growth in total residential capacity in the past 11 years (an average well below 1 percent per year) and substantial growth in the MR/RC population in the young adult years, during which most persons seek entry into the residential care system. Other factors that State respondents felt were contributing to the waiting lists are increasing longevity of persons with MR/RC and increased demand stimulated by court orders, legislation, and State policies focused on transferring residents from institutions to community settings. In addition, they note that parents who have seen their children benefit from the appropriate education guaranteed to all children under the Education for All Handicapped Children Act (Public Law 94-142) seek settings that will maintain the community lifestyles their children have always known and reject settings that are perceived likely to diminish the skills their children have acquired. These parents generally refuse placements in the large facilities, which frequently have the only unused capacity in the residential care system, thereby adding their children to the growing waiting lists for placement in smaller community facilities.

In their efforts to address these serious and growing problems, States cannot overlook the potential of the Federal Government, and specifically Medicaid, to assist them with increased funding to support MR/RC care in small facilities.

Future Medicaid support

Intermediate care for mentally retarded

The ICF/MR program is used by all States to finance care in large State institutions. It is also used in virtually all States, to widely varying degrees, to finance residential services in large non-State facilities and/or in small facilities. Nearly all States seek to retain Federal financial participation (FFP) at least at current levels, for example, by avoiding ICF/MR decertification of State institutions, by concentrating de-institutionalization of State facilities to noncertified units, by certifying large non-State facilities, and by balancing decreases in ICF/MR capacity with increasing Medicaid waiver utilization and other strategies.

The desire of States to maximize FFP is counterbalanced by the assessment of whether or not individuals would be better and/or more cost-effectively served in a less restrictive, less specialized, and usually less expensive setting. In the CRCS case studies, States mentioned that, despite the Federal contribution, the State share required to support ICF/MR care can, in some cases, be more than the State would pay for an

individual's care using State funds along with the individual's contributions from SSI or SSDI. A number of State respondents interviewed indicated that the ICF/MR option must be used more judiciously in the future or it will add significantly to the overall cost of providing appropriate residential services. This usually involves efforts to avoid the initial placement of people not needing an ICF/MR level of care, but, in three case study States, it also involved considering alternatives for moving present community ICF/MR residents not needing ICF/MR care to alternative settings.

Respondents also noted two additional factors that are likely to have considerable influence on their States' decisions on future expansion of the ICF/MR program: HCFA enforcement activities in the wake of the 1988 revised ICF/MR regulations; and legislation requiring many MR persons inappropriately placed in nursing homes to be relocated.

Enforcement of 1988 regulations

In October 1988, new ICF/MR regulations went into effect. These represented substantially revised rules for program participation. State respondents considered them to be more in keeping with the current philosophy of care for the MR/RC population. According to the respondents questioned in the CRCS study, States had not yet had sufficient opportunity to evaluate the practical implications of the 1988 amended standards for ICFs/MR at the time this study was conducted. Most State respondents expressed concern about the possibility that ICF/MR residents in facilities reviewed by HCFA would be found to be inappropriately placed and be considered ineligible for Medicaid ICF/MR support. Other continuing concerns mentioned by State respondents were that institutions reviewed, particularly with respect to providing "active treatment," would not meet ICF/MR standards, would require reforms which would further divert funds used for small facilities, or could even face termination of the provider agreement. Much of this concern is because of the results of increased Federal oversight of State Medicaid survey and certification activities, including those focused on the ICF/MR program authorized by OBRA 1981. The reviews that followed, referred to as "look behind" reviews, found numerous examples of facilities failing to meet ICF/MR standards, including facilities with deficiencies of sufficient severity that they were threatened with decertification as ICF/MR facilities and termination from the Medicaid program. However, in practice, few terminations have taken place to date.

Mentally retarded nursing home residents

The Omnibus Budget Reconciliation Act (OBRA) of 1987 (Public Law 100-203) provided restrictions on the circumstances under which persons with MR/RC can be placed in Medicaid-reimbursed nursing facilities. This legislation followed more than a decade of concern about the appropriateness of nursing homes as residential environments for persons with MR/RC. It states that individuals with MR/RC placed in nursing homes must require the medical or nursing services offered, and that,

in addition, the facility must assure that the individual's needs for active treatment are being currently met. Current residents not in need of nursing service must be moved to "more appropriate" residential facilities. Exceptions can be made for individuals who have resided in a facility for 30 months or more, provided the individual chooses to stay, and that his or her "active treatment" needs are met.

Data reviewed for this article indicated a relatively stable population of about 40,000 to 45,000 nursing home residents with a primary condition of mental retardation during the period 1977-87 (National Center for Health Statistics, 1979; Hing, Sekscenski, and Strahan, 1989). The 1987 NMES yields an estimate of 45,261 people with a primary diagnosis of mental retardation in nursing homes, about 34 percent of whom were 65 years of age or over. Therefore, people with MR as their primary condition appear to make up about 3 percent of the overall nursing home population. But, States vary substantially in their individual use of nursing homes as a residential care option for people with MR/RC, and therefore, in the expected consequences of this legislation. Many States have reduced use of nursing homes for this population during the past few years and have already initiated preadmission screening activities. In the 10 case-study States, initial estimates were that 30-40 percent of the nursing home residents with MR/RC might be expected to require transfer to a more appropriate placement.

Most States included in the CRCS case studies were not yet sure of the magnitude of the effects of this legislation on their residential service system in general or their ICF/MR and other Medicaid utilization in particular. Many States noted that the implementation of OBRA 1987 may impede further deinstitutionalization of State institution residents. This is because the limited number of available community placements may be allocated to discharged nursing home residents. Other possible placements for former nursing home residents mentioned by State respondents were State institutions (most of which are ICF/MR-certified) or small ICF/MR facilities. Some States will convert some units now certified as SNFs, ICFs, or both to ICFs/MR, but the HCBS waiver was the most common option under consideration because nursing home population reductions can be directly linked to waiver service authorizations.

Future utilization of the waiver

Growth under the waiver is likely to continue as States seeking to renew their programs expand the number of persons to be served and as additional States participate for the first time. However, increases will continue to be limited by the statutory and regulatory restrictions on the population that can be served under the waiver. A number of States in the CRCS studies believed that the current restrictions that tie dollars available under the waiver directly to projected costs of institutional services prevent the full potential of the approach from being realized. In these State respondents' views, sufficient evidence exists of the overall cost effectiveness of the waiver approach, and they would like to have the waiver

made a general Medicaid option. It should be noted that States' assessment of the cost effectiveness of the waiver option is arrived at after considering budget restraints and service access issues and is contrary to evaluations of cost effectiveness based solely on total Medicaid expenditures. These evaluations have generally found that the types of services covered by the waiver are not cost effective relative to traditional Medicaid settings (Weissert, 1985; Weissert and Cready, 1989).

Legislative proposals

During the past few years, various legislative proposals have been introduced in Congress to reform Medicaid funding for care of the MR/RC population. Many of the provisions included in proposed legislation would greatly improve access to Federal funding for a wide range of smaller residential settings, and would thereby provide resources for interested States to expand needed services. Proposed legislation would place emphasis on meeting individual needs rather than purchasing care in specialized facilities. A great deal of flexibility in program options is included.

This client-centered approach is already available under Medicaid, in a limited sense, in the HCBS waiver. Proposed changes of this nature would equalize the funding that is available for smaller residential care settings, and thereby eliminate what many have considered the bias toward support of large facilities in most Medicaid funding for MR/RC care.

Other proposed provisions would promote the phasedown of large institutions by capping total FFP available for their support. This highly controversial proposal is advocated by many who feel that services in many large facilities do not meet contemporary standards of appropriate services. Many also feel that Federal contributions of 50 to 80 percent are allowing States to put off politically difficult but needed decisions regarding the consolidation or closing of inefficient or costly settings, and the redirecting of resources to smaller residential care settings.

Such legislation would include family and individual support, specialized vocational services, case management, and protective interventions under mandated Medicaid services. Other proposed measures would make all community habilitation and supportive services an option that the States might elect under Medicaid.

A particularly controversial area in proposed legislative changes is quality assurance. A number of respondents to CRCS surveys stated that Federal participation in quality assurance beyond that provided by the waiver program is needed. States were generally in favor of FFP to support quality assurance activities. Yet, respondents noted that there is a great deal of opposition among States to developing a set of Federal standards or expanding the Federal role in the area of home and community-based services. The opposing States feel such standards would interfere with their goals of individualization of services and would often conflict with or confound existing State standards for non-ICF/MR services. Although not found among the State officials interviewed, proponents of the need for Federal standards cite instances of perceived

failure by the States to adequately enforce ICF/MR regulations, which led to the "look behind" reviews referred to earlier in this article.

Congress will ultimately determine whether and what kinds of additional Medicaid participation will be available for the majority of persons with MR/RC who now live in small residential settings. Among the key decisions remaining to be addressed is how active a role the Federal Government can or should play in setting standards for services, primarily community-based, that will be provided to persons with MR/RC in the future.

Conclusion

In this article, trends have been reviewed in the utilization of and expenditures for primarily two sources of Medicaid funds for persons with MR/RC in residential settings: ICFs/MR and the HCBS waiver. The evidence presented suggests that the period of substantial growth in the number of persons served through the ICF/MR program has ended. Although this program continues to be used by States, particularly to support care in large institutions, States increasingly find the Medicaid HCBS waiver to be a more flexible funding source for the care of persons with MR/RC in community residential placements. Persons served and expenditures under the waiver are expected to increase as States expand their existing programs and new States begin waiver programs. The HCBS program has increased and is expected to continue to cause an increase in the number of persons supported by Medicaid in community versus institutional settings. Through the waiver and the increase of small ICFs/MR, the Medicaid program has evolved from a program used almost exclusively to fund care for people with MR/RC in State institutions to one in which about one-third of the recipients with MR/RC are in community-based settings.

States continue to seek expanded funding sources to assist them in their efforts to increase the number of community residential placements. Considerable support was found in the CRCS studies for expansion of the HCBS waiver or for initiation of other flexible person-centered, rather than facility-centered, Medicaid funding. Many State respondents said that the addition of such a Medicaid provision would further update coverage under this program to reflect the fact that community-based services have replaced institutions as the primary model of care for persons with MR/RC.

States face a number of other challenges in the immediate future regarding MR/RC residential care. In order to retain the substantial support they now receive for ICF/MR care, they must meet the revised rules for program participation contained in the October 1988 regulations. The expenditures needed to meet these requirements will reduce the dollars available to expand much-needed community placements. Most States face increasing demand for care in these settings, and demand is likely to be increased by the addition of discharged nursing home patients seeking the same placement alternatives.

Other legislative changes that have been proposed have potential for significantly altering the system of care. The

most dramatic of these would be freezing Federal nominal dollar support (i.e., reducing real dollars) for care delivered in each State's institutional settings, while creating an open-ended entitlement for a full range of family and community services. Without such legislation, it is likely that change to greater use of small, community-based alternatives rather than institutions will continue at a steady pace. However, a number of State respondents felt that this pace might be slower than has been experienced in recent years.

Especially in view of the possibility of greater Federal support of a full range of family and community-based services, a very critical issue will be whether the Federal Government will continue to rely largely on States for the review of the quality of care in community-based non-ICFs/MR, or will, instead, undertake new responsibilities for assuring quality of care for services in primarily noninstitutional settings.

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