

## DOCUMENT RESUME

ED 393 265

EC 304 710

AUTHOR Prouty, Robert, Ed.; Lakin, K. Charlie, Ed.  
 TITLE Residential Services for Persons with Developmental Disabilities: Status and Trends through 1994. Report #46.

INSTITUTION Minnesota Univ., Minneapolis. Research and Training Center on Community Living.

SPONS AGENCY Administration on Developmental Disabilities (DHHS), Washington, D.C.

PUB DATE Jun 95

CONTRACT 90DD0302/02

NOTE 184p.

AVAILABLE FROM Publications Office, Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 (\$10).

PUB TYPE Statistical Data (110) -- Reports - Descriptive (141)

EDRS PRICE MF01/PC08 Plus Postage.

DESCRIPTORS Adults; Community Programs; \*Deinstitutionalization (of Disabled); \*Developmental Disabilities; Federal Aid; Financial Support; Group Homes; Institutionalized Persons; \*Mental Retardation; Residential Care; Residential Institutions; \*Residential Programs; State Programs; \*Trend Analysis

IDENTIFIERS \*Intermediate Care Facilities; \*Medicaid

## ABSTRACT

This report from the ongoing National Residential Information Systems Project provides statistics on persons with mental retardation and related developmental disabilities (MR/DD) receiving residential services in the United States for the year ending June 30, 1994, as well as comparative statistics from earlier years. An executive summary highlights key findings. Section 1 presents statistics on state-operated residential services, in four chapters on: populations of state-operated residential settings in 1994; longitudinal trends in large state-operated residential facilities from 1950 to 1994; characteristics and movement of residents of large state facilities; and large state MR/DD facility closures, 1960-1998. Section 2 presents combined statistics on the total numbers of persons with MR and DD in both state and nonstate residential settings. Individual chapters address services provided by state and nonstate agencies in 1994; number of residential settings and residents by type of living arrangement; and changing patterns in residential service system from 1977-1994. Section 3 focuses on the utilization of the Medicaid program to sponsor long-term care services for persons with MR/DD. Chapters cover: background and summary of Medicaid long-term care programs; utilization of and expenditures for Medicaid institutional, home, and community-based services; status and changes in Intermediate Care Facilities--MR and their residents, and Medicaid community-supported living arrangements. (Contains 47 references, 60 tables, and 30 figures.) (DB)

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# Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1994

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Report 46  
June 1995

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**Residential Services for Persons with Developmental  
Disabilities: Status and Trends Through 1994**

Report #46

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June 1995

Preparation of this report was supported by a grant from the Administration on Developmental Disabilities (Grant No. 90DD0302/02) with supplemental support from the Health Care Financing Administration of the U.S. Department of Health and Human Services. The contents of this report do not necessarily reflect an official position of either agency or the Department of Human Services.

## ACKNOWLEDGMENTS

This report is based on statistics gathered and analyzed as part of the National Residential Information Systems Project on Residential Services (RISP). The authors wish to thank the Administration on Developmental Disabilities (ADD), its Commissioner Bob Williams, and our Project Officer, Rita Stone, for ongoing support of this project and its various activities. We also appreciate the supplemental support received from the Health Care Financing Administration (HCFA) and from Sam Brown and Nancy Miller of HCFA's Office of Research and Demonstrations.

Many people other than the chapter authors played important roles in acquiring, analyzing, and describing the data summarized in this report. Our special thanks to Gary Smith for his invaluable editorial assistance. Laura Lafrenz and Linda Schaefer prepared all text, tables and figures contained in the report. Brian Burwell of the MEDSTAT Group provided ICF-MR expenditure data summarized in Chapter 3. Pete Burdette of HCFA provided valued assistance in acquiring and editing the data in Online Survey Certification and Reporting System on ICF-MR utilization. We are very grateful to Pamela Baker and David Lawson of the Association of Public Developmental Disabilities Administrators for their assistance and support in the survey of all large public residential facilities. That survey had been conducted by Richard Scheerenberger in conjunction with the RISP project until his death in 1992. Although we at the University of Minnesota were pleased to have been able to reactivate this survey during the past year, it will always be "Dick's survey."

As always, we are totally indebted to the more than 300 state and individual facility respondents who provided the statistics used in this report. Clearly this report would not be possible without their knowledge and generous assistance.

Additional copies of this report may be obtained postage-paid for \$10.00 per copy from the Publications Office, Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, (612) 624-4512. Please make checks payable to the University of Minnesota.

The recommended citation for statistics in this report is: [Chapter authors] (1994). [Chapter title]. In R.W. Prouty & K.C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 1994*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

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## TABLE OF CONTENTS

LIST OF TABLES .....	iv
LIST OF FIGURES .....	vi
EXECUTIVE SUMMARY .....	ix
INTRODUCTION .....	xxiii
METHODOLOGY .....	xxv
SECTION I STATUS AND CHANGES IN STATE-OPERATED RESIDENTIAL SERVICES .....	1
CHAPTER 1 POPULATIONS OF STATE-OPERATED RESIDENTIAL SETTINGS IN 1994	3
Number of State-Operated Residential Facilities .....	3
Residents of State-Operated Facilities .....	5
Populations per 100,000 of the General Population .....	5
Change in Average Daily Population; 1980-1994 .....	8
Movement of Residents in Large State MR/DD Facilities .....	8
Admissions .....	8
Discharges .....	8
Deaths .....	8
Expenditures for Care in State-Operated Residential Facilities .....	11
CHAPTER 2 LONGITUDINAL TRENDS IN LARGE STATE-OPERATED RESIDENTIAL FACILITIES, 1950-1994 .....	13
Average Daily Population of Persons with Mental Retardation/	
Developmental Disabilities in Large State MR/DD	
and Psychiatric Facilities .....	13
Average Daily Population of Persons with Mental Retardation/	
Developmental Disabilities in Large State MR/DD and	
Psychiatric Facilities per 100,000 of the General Population .....	15
Movement Patterns in Large State MR/DD Residential Facilities .....	16
Annual Per Resident Expenditures in Large State-Operated MR/DD Facilities .....	18
CHAPTER 3 CHARACTERISTICS AND MOVEMENT OF RESIDENTS OF LARGE STATE FACILITIES .....	20
Characteristics of Residents .....	20
Age of Residents .....	20
Level of Mental Retardation .....	22
Functional Characteristics .....	23
Age by Level of Mental Retardation .....	23
State-by-State Resident Characteristics .....	23
Gender of Residents .....	23
Age Distribution of Residents .....	24
Level of Mental Retardation .....	27
Selected Additional Conditions .....	27
Selected Functional Assistance Needs of Residents .....	29
Residents in Movement .....	32
New Admissions by Age and Level of Mental Retardation .....	32
Readmissions by Age and Level of Mental Retardation .....	33
Discharges by Age and Level of Mental Retardation .....	33
Persons in Movement in 1987, 1989, 1991 and 1994 .....	34
Previous Placement of Admissions .....	34

New residence of discharged residents .....	36
CHAPTER 4 LARGE STATE MR/DD FACILITY CLOSURES, 1960-1998 .....	37
Total Large State MR/DD Facility Closures .....	37
Closures and Projected Closures by States .....	38
Large State MR/DD Residential Facilities Operating and Closing, 1960-1998 .....	38
SECTION II STATUS AND CHANGES IN TOTAL STATE RESIDENTIAL SERVICE SYSTEMS .....	49
CHAPTER 5 SERVICES PROVIDED BY STATE AND NONSTATE AGENCIES IN 1994	51
Number of Residential Settings .....	51
Number of Persons Receiving Residential Services .....	51
Relative Size of Residential Settings .....	54
Average residential settings size .....	54
Percentage living in small residential settings .....	54
Number of Residential Service Recipients Per 100,000 General Population .....	57
CHAPTER 6 NUMBER OF RESIDENTIAL SETTINGS AND RESIDENTS BY TYPE OF LIVING ARRANGEMENT .....	61
"Congregate Care" Settings and Residents .....	61
"Family Foster Care" Settings and Residents .....	61
"Own Home" Settings and Residents .....	62
CHAPTER 7 CHANGING PATTERNS IN RESIDENTIAL SERVICE SYSTEMS: 1977-1994 .....	66
Changing Patterns in Residential Settings .....	66
Changes in Number of Residential Service Recipients .....	66
SECTION III STATUS AND CHANGES IN MEDICAID FUNDED RESIDENTIAL AND RELATED SERVICES .....	71
CHAPTER 8 BACKGROUND AND SUMMARY OF MEDICAID LONG-TERM CARE PROGRAMS .....	73
Federal Involvement Prior to ICFs-MR .....	73
Establishment of the ICF-MR Program .....	73
Small Community ICF-MR Group Homes .....	74
Medicaid Home and Community Based Services (HCBS) .....	75
Community Supported Living Arrangements Programs .....	76
Medicaid Nursing Facilities .....	76
CHAPTER 9 UTILIZATION OF AND EXPENDITURES FOR MEDICAID INSTITUTIONAL AND HOME AND COMMUNITY BASED SERVICES .....	77
ICF-MR Program Utilization on June 30, 1994 .....	77
Number of facilities .....	77
Number of residents .....	79
Nonstate ICF-MR Utilization .....	79
Large nonstate ICFs-MR .....	79
Small nonstate ICFs-MR .....	81
State ICF-MR Utilization .....	81
Large state ICFs-MR .....	81
Small state ICFs-MR .....	82
Large and Small Certified Facilities .....	83
Expenditures for ICF-MR Services .....	87
Interstate Variations in ICF-MR Expenditures .....	90
Per capita cost variations .....	90
Variations due to disproportionate placements .....	90

Variations due to differences in per recipient expenditures . . . . .	90
Medicaid HCBS Recipients . . . . .	90
Expenditures for HCBS Recipients . . . . .	93
Per capita cost variations . . . . .	93
Variations due to disproportionate placements . . . . .	93
Variations due to differences in per recipient expenditures . . . . .	95
HCBS Recipients and Residents of Small ICFs-MR . . . . .	95
Variations in State Financial Benefit for Combined ICF-MR and HCBS Programs . . .	99
Indexed Utilization Rates . . . . .	102
Residential Arrangement of HCBS Recipients . . . . .	108
Persons with Mental Retardation and Related Developmental Disabilities	
in Generic Medicaid Nursing Homes . . . . .	110
CHAPTER 10 STATUS AND CHANGES IN ICFs-MR AND RESIDENTS . . . . .	112
Residents and Facilities in 1992 . . . . .	112
Basic Demographics . . . . .	112
Functional Limitations and Secondary Conditions . . . . .	112
Legal, Medical and Behavioral Practices . . . . .	114
Court-Appointed Guardians . . . . .	114
Court-Ordered Admissions . . . . .	114
Medical care plans . . . . .	114
Drugs to Control Behaviors . . . . .	114
Physical Restraints . . . . .	114
Time Out Rooms . . . . .	114
Medication error rate . . . . .	114
Staffing Characteristics . . . . .	114
State ICF-MR Programs in 1992 . . . . .	115
Resident Level of Mental Retardation . . . . .	115
Number of Residents by Size and Type . . . . .	115
Staffing Characteristics . . . . .	118
Changes in ICFs-MR Between 1982 and 1992 . . . . .	118
Changes in Size and Type, 1982-1992 . . . . .	118
Changes in Resident Ages . . . . .	120
Changes in Level of Mental Retardation . . . . .	121
Discussion . . . . .	121
CHAPTER 11 MEDICAID COMMUNITY SUPPORTED LIVING ARRANGEMENTS . . . . .	124
CSLA Program Enrollment . . . . .	124
Demographic Characteristics of CSLA Recipients . . . . .	125
Primary Disability Conditions of CSLA Participants . . . . .	126
All Conditions . . . . .	126
Cognitive impairments among CSLA participants . . . . .	127
Multiple Disability Conditions . . . . .	129
Living Arrangements . . . . .	131
Major Day Activities . . . . .	132
Services and Providers . . . . .	133
CSLA services . . . . .	133
Provider Agencies . . . . .	135
CSLA Expenditures . . . . .	135

## LIST OF TABLES

Table 1.1	Number of State-Operated Residential Facilities on June 30, 1994 by State . . . . .	4
Table 1.2	Persons with MR/DD Living in State-Operated MR/DD and Psychiatric Settings on June 30, 1994 by State . . . . .	6
Table 1.3	Persons with MR/DD Living in State-Operated MR/DD and Psychiatric Facilities Per 100,000 of the General Population on June 30, 1994 by State . . . . .	7
Table 1.4	Changes in the Average Daily Population of Persons with MR/DD Living in Large State MR/DD Facilities by State, 1980-1994 . . . . .	9
Table 1.5	Movement of Persons with MR/DD In and Out of Large State MR/DD Facilities in Fiscal Year 1994 by State . . . . .	10
Table 1.6	Average per Resident Daily Expenditures in Large State-Operated Facilities in Fiscal Year 1994 by State . . . . .	12
Table 1.7	Average Daily Population of Persons with Mental Retardation/ Developmental Disabilities in Large State MR/DD and Psychiatric Facilities, 1950-1994 . . . . .	14
Table 1.8	Average Daily Population of Persons with Mental Retardation/Developmental Disabilities in Large State MR/DD and Psychiatric Facilities per 100,000 of the General Population, 1950-1994 . . . . .	15
Table 1.9	Movement Patterns in Large State MR/DD Residential Facilities, 1950-1994 . . . . .	17
Table 1.10	Average Annual Per Resident Expenditures for Care in Large State-Operated MR/DD Residential Facilities, 1950-1994 . . . . .	19
Table 1.11	Characteristics of Residents of Large State Facilities on June 30: 1977, 1982, 1987, 1989, 1991, and 1994 . . . . .	20
Table 1.12	Distribution of Residents of Large State Facilities by Level of Mental Retardation and Age on June 30, 1994 . . . . .	24
Table 1.13	Gender Distribution of Residents of Large State Facilities by State on June 30, 1994 . . . . .	25
Table 1.14	Age of Residents of Large State Facilities by State on June 30, 1994 . . . . .	26
Table 1.15	Level of Mental Retardation of Residents of Large State Facilities by State on June 30, 1994 . . . . .	28
Table 1.16	Selected Additional Conditions of Residents of Large State Facilities by State on June 30, 1994 . . . . .	30
Table 1.17	Selected Functional Needs of Residents of Large State Facilities by State on June 30, 1994 . . . . .	31
Table 1.18	New Admissions to Large State Facilities by Age and Level of Mental Retardation in the Year Ending June 30, 1994 . . . . .	32
Table 1.19	Readmissions to Large State Facilities by Age and Level of Mental Retardation in the Year Ending June 30, 1994 . . . . .	33
Table 1.20	Discharges from Large State Facilities by Age and Level of Mental Retardation, Year Ending June 30, 1994 . . . . .	34
Table 1.21	Previous Placement of Persons Admitted or Readmitted to Large State Facilities, Fiscal Years 1985, 1987, 1989, 1991, and 1994 . . . . .	36
Table 1.22	New Place of Residence of Persons Discharged from Large State Facilities, Fiscal Years 1985, 1987, 1989, 1991 and 1994 . . . . .	36
Table 1.23	Summary of Large State MR/DD Facilities and Units Since 1960, including Closures and Planned Closures Between 1960 and 1998 . . . . .	38
Table 1.24	Large State MR/DD Facilities or Units Operating Between 1960 and 1994 with Data and Projections of Closures Through 1998 . . . . .	39
Table 2.1	Residential Settings for Persons with Mental Retardation and Related Developmental Disabilities Served by State and Nonstate Agencies on June 30, 1994 . . . . .	52



Table 2.2	Persons with Mental Retardation and Related Developmental Disabilities Served by State and Nonstate Agencies on June 30, 1994	53
Table 2.3	Summary Statistics on the Size of Residential Settings on June 30, 1994	55
Table 2.4	Persons with Mental Retardation and Related Developmental Disabilities Receiving Residential Services per 100,000 of State General Population by Size of Residential Setting, June 30, 1994	59
Table 2.5	Persons with Mental Retardation and Related Conditions Not Presently Receiving Residential Services Who Are on Waiting Lists for Residential Services on June 30, 1993	60
Table 2.6	Number of "Congregate Care" Residential Settings and Persons with Mental Retardation and Related Developmental Disabilities Living in Them on June 30, 1994 by State	63
Table 2.7	Number of Family Foster Care Settings and Persons with Mental Retardation and Related Conditions Living in Them on June 30, 1994 by State	64
Table 2.8	Number of Homes Owned or Leased By Persons with Mental Retardation and Related Developmental Disabilities and the Number of People Living in Them on June 30, 1994 by State	65
Table 2.9	State and Nonstate Residential Settings for Persons with MR/DD on June 30 of 1977, 1982, 1987, 1992 and 1994	68
Table 2.10	Persons with MR/DD Receiving State and Nonstate Residential Services on June 30 of 1977, 1982, 1987, 1992 and 1994	68
Table 3.1	ICF-MR Certified Facilities on June 30, 1994 by State and Size	78
Table 3.2	Persons with Mental Retardation and Related Developmental Disabilities in ICF-MR Certified Facilities on June 30, 1994 by State and Size	80
Table 3.3	Number and Percentage of Residents in ICF-MR Facilities on June 30, 1994 by State and Size	84
Table 3.4	Summary Statistics on ICF-MR Expenditures by State for Fiscal Year 1994	89
Table 3.5	Persons Receiving Medicaid Home and Community Based Services on June 30, 1982 to June 30, 1994 by State	92
Table 3.6	Summary statistics on HCBS Expenditures by State for Fiscal Year 1994	94
Table 3.7	ICF-MR Residents and Medicaid Home and Community Based Service (HCBS) Recipients with Mental Retardation and Related Developmental Disabilities on June 30, 1994 by State	96
Table 3.8	ICF-MR Residents and HCBS Recipients and ICF-MR and HCBS Expenditures on June 30, 1994 by State	98
Table 3.9	Summary of Combined ICF-MR and HCBS Contributions and State Benefit Ratios by State for Fiscal Year 1994	100
Table 3.10	Utilization Rates per 100,000 of State Population: ICF-MR Residents, HCBS Recipients with MR/DD, and All Residential Service Recipients on June 30, 1994 by State	104
Table 3.11	The Residential Arrangements of Medicaid Home and Community Based Services Recipients in 1994	109
Table 3.12	Persons with Mental Retardation and Related Developmental Disabilities in Nursing Facilities on June 30, 1994 by State	111
Table 3.13	Characteristics of Small and Large ICFs-MR and the People Who Lived in Them in 1992	113
Table 3.14	Percent of ICF-MR Residents in Small and Large Facilities with Each Level of Mental Retardation in 1992	116
Table 3.15	Total Number of ICF-MR Residents in Each Size and Type of ICF-MR in 1992	117
Table 3.16	Number of FTE Direct Service Staff Per Resident in Each Size and Type of ICF-MR in 1992	119
Table 3.17	Number of People in ICFs-MR of Various Sizes and Types, 1982 and 1992	120

Table 3.18 Changes in ICF-MR Populations By Age and Facility Size, 1982-1992: Percent of Residents in Each Age Group .....	122
Table 3.19 Changes in ICF-MR Populations By Level of Mental Retardation and Facility Size, 1982-1992: Percent of Residents with Severe or Profound Mental Retardation .....	123
Table 3.20 CSLA Participants' Demographic Characteristics .....	126
Table 3.21 Primary Disability Conditions of CSLA Participants .....	127
Table 3.22 Living Arrangements of CSLA Participants .....	131
Table 3.23 Major Day Activities of CSLA Participants .....	133
Table 3.24 Services Offered by state CSLA Programs .....	134
Table 3.25 Number of Licensed CSLA Agencies and Average Number of CSLA Participants per State .....	135
Table 3.26 CSLA Expenditures as Reported by States for Fiscal Years 1992, 1993, 1994, and Projected for 1995 .....	136

### LIST OF FIGURES

Figure 1.1 Average Daily Population of Persons with Mental Retardation and Related Conditions in Large MR/DD and Psychiatric Facilities, 1950-1994 .....	14
Figure 1.2 Population of Persons with MR/DD in Large State MR/DD and Psychiatric Facilities per 100,000 of the General Population on June 30 of Years Indicated .....	16
Figure 1.3 Movement Patterns in Large State MR/DD Residential Facilities, 1950-1994 .....	17
Figure 1.4 Average Annual Per Resident Expenditures in Large State-Operated MR/DD Residential Facilities, 1950-1994 .....	19
Figure 1.5 Total and Childhood (0-21 Years) Populations of Large State MR/DD Facilities, 1950-1994 .....	21
Figure 1.6 Level of Retardation of Residents of Large State Facilities on June 30 of Selected Years, 1964-1994 .....	22
Figure 1.7 Distribution of Admissions and Discharges for Large State Facilities by Level of Mental Retardation in Fiscal Years 1987, 1989, 1991 and 1994 .....	35
Figure 1.8 Numbers of Large State MR/DD Facilities and Units Closed and Planned for Closure, 1960-1998 .....	37
Figure 2.1 Average Number of Persons with Mental Retardation and Related Developmental Disabilities per Residential Setting on June 30, 1977, 1982, 1987, 1992, and 1994 .....	54
Figure 2.2 Percentage of All Residential Service Recipients in Settings with 6 or Fewer on June 30, 1994 .....	56
Figure 2.3 Residential Service Recipients per 100,000 of State Gener. I Population in 1994 .....	58
Figure 2.4 Persons with Mental Retardation and Related Development Disabilities in State and Nonstate Residential Settings on June 30 of 1977, 1982, 1987, 1992, and 1994 .....	69
Figure 3.1 ICF-MR Residents as a Proportion of All Residents of State and Nonstate Settings by Size on June 30, 1994 .....	82
Figure 3.2 Residents of ICF-MR Certified Facilities by Size and State/Nonstate Operation on June 30, 1977, 1982, 1987, 1992, and 1994 .....	83

Figure 3.3 Percentage of ICF-MR Residential Service Recipients in Settings with 15 or Fewer Residents on June 30, 1994 .....	85
Figure 3.4 Percentage of All Residential Service Recipients in ICF-MR Certified Facilities on June 30, 1994 .....	86
Figure 3.5 Number of Residents in ICF-MR and Non ICF-MR Residential Settings with 1-15 and 16 or more Total Residents, 1977 to 1994 .....	88
Figure 3.6 Small ICF-MR & HCBS Recipients as a Percentage of all ICF-MR & HCBS Recipients on June 30, 1994 .....	101
Figure 3.7 Residents of Settings with 15 or Fewer and 16 or More Residents Among Medicaid ICF-MR and HCBS Recipients on June 30, 1977, 1982, 1987, 1992, and 1994 .....	102
Figure 3.8 Total ICF-MR Residents per 100,000 of State Population by State on June 30, 1994 .....	105
Figure 3.9 Total Small ICF-MR and HCBS Recipients per 100,000 of State Population by State on June 30, 1994 .....	106
Figure 3.10 ICF-MR and Non ICF-MR Residential Service Recipients per 100,000 of the U.S. Population, 1962 to 1994 .....	107
Figure 3.11 CSLA Participants by State in August 1994 (+/- 2 mos) and Projected for June 30, 1995 .....	125
Figure 3.12 Percentage of CSLA Participants with Cognitive Limitations (among CSLA participants for whom this information was available) .....	128
Figure 3.13 Proportion of CSLA Participants with Cognitive Limitations by Level of Mental Retardation .....	129
Figure 3.14 Percentage of CSLA Participants with Two or More Disabilities .....	130
Figure 3.15 Percentage of CSLA Recipients Who Use Wheelchairs or Need Assistance With Ambulation .....	130
Figure 3.16 Type of Residential Arrangement in Which CSLA Participants Live (8/94) .....	132
Figure 3.17 Amount of Federal CSLA Allocation Per State (\$3.75 million) Reported Expended in Fiscal Year 1994 .....	137
Figure 3.18 A Comparison of Average Per Person Medicaid CSLA and HCBS Expenditures in Fiscal Year 1994 .....	137

## EXECUTIVE SUMMARY

### State-Operated Residential Services

#### *Number and Size of Residential Facilities*

*The number of state-operated facilities continues to grow.* On June 30, 1994 states were directly operating 1,855 residential facilities housing persons with mental retardation and related developmental disabilities (MR/DD), 90 more than in the previous year. Of these 1,750 were facilities primarily serving persons with MR/DD and 105 were facilities primarily serving persons with psychiatric disabilities. Over four-fifths (83.6%) of the state-operated MR/DD facilities had 15 or fewer residents, as compared with 79.6% in 1991 and 83.0% in 1993.

*On June 30, 1994 every state except New Hampshire, Vermont, Rhode Island and the District of Columbia, was operating at least one large state mental retardation/developmental disabilities facility.* New Hampshire closed its only large (16 or more residents) state MR/DD facility in January 1991. In Fiscal Year 1994 Vermont, Rhode Island and the District of Columbia closed the last of their large state MR/DD facilities. Twelve other states closed at least one large state MR/DD facility in Fiscal Year 1994.

*The number of small state facilities continues to grow substantially, but New York remains by far the largest operator of small state MR/DD residences.* Small state-operated facilities (15 or fewer residents) increased by 6.6% (90 facilities) to a total of 1,463 in Fiscal Year 1994. By the end of Fiscal Year 1994, New York had an estimated 900 small state-operated facilities or 61.5% of the national total.

#### *Number of Residents*

*The population of large state MR/DD facilities continue to fall.* The population of large state MR/DD facilities on June 30, 1994 was 65,735, a decrease of 5.8% from June 30, 1993, continuing a trend first evident in Fiscal Year 1968.

*The population of small state facilities continues to increase.* Persons residing in small state-operated facilities (15 or fewer residents) increased by 4.3% in 1994, to an end of year total of 10,377 persons. New York accounted for 69.9% of all residents of small state facilities.

*The population of persons with MR/DD in all large state residential facilities continues to decline.* On June 30, 1994, the combined population of residents with MR/DD in large state MR/DD and psychiatric facilities was 67,315 a decrease of 6.1% from 1993. The population of persons with MR/DD in state psychiatric facilities dropped from an average daily population of 31,884 in 1970 and 9,405 in 1980 to 1,580 on June 30, 1994.

*Nationally, the population of large state MR/DD facilities per 100,000 of the general population continues to fall.* In 1994 there were 25.5 persons in large state MR/DD facilities per 100,000 of the general U.S. population. This compares with 27.9 in June 1993 and 99.7 in June 1967. Placement rates in 8 states were at 150% or more of the national average, while in 13 states they were less than half the national average.

*Since 1980, large state MR/DD facility depopulation has continued at a steady pace.* Between 1980 and 1994 large state MR/DD facilities' average daily populations decreased by 63,415 individuals (48.4%). Half (25) of all states reduced their average daily populations of large state MR/DD facility populations by 50% or more during the period. The June 30, 1994 population of state MR/DD facilities (65,735) was less than one-half (49.9%) on the June 30, 1980 population of large state MR/DD facilities.

## ***Resident Characteristics***

***The number of children and youth in large state MR/DD facilities continues to decrease rapidly, substantially more rapidly than the state MR/DD facility populations as a whole.*** On June 30, 1994 only 4,001 state MR/DD facility residents (6.1% of the total) were 21 years or younger. This compares with 6,944 persons 21 years or younger living in state MR/DD facilities (8.7% of the total) on June 30, 1991, and 54,130 (35.8% of the total) on June 30, 1977, and 91,590 (48.9% of the total) on June 30, 1965. Children who were 14 years or younger made up only 1.5% of state MR/DD populations in 1994 as compared with 2.3% in 1991. At least 16 states had no state institution residents who were less than 15 years old.

***Large state MR/DD facility populations are overwhelmingly made up of non-elderly adults and increasingly of middle-aged adults.*** On June 30, 1994 86.8% of large state MR/DD facility residents were between 22 and 62 years old. This compares with 60.5% in 1977, 73.1% in 1982, 81.4% in 1987 and 84.3% in 1991. Nearly two-fifths (39.8%) of state MR/DD facility residents in 1994 were in the 40-62 year age range. This compares with 19.2% in 1977, 22.9% in 1982, 27.3% in 1987 and 32.5% in 1991. This reflects the maturing of the "baby boom" cohort into middle age.

***The number of large MR/DD facility residents 63 years and older has declined by nearly 1,000 since 1977, even as the proportion of "aging" residents has increased.*** On June 30, 1977 there were 5,590 persons 63 years or older in large state MR/DD facilities; on June 30, 1994 there were an estimated 4,667. However, as populations of large state MR/DD facilities have been nearly halved over the same period, the proportion of persons 63 years and older has increased substantially (3.7% in 1977, 5.0% in 1982, 6.0% in 1987, 7.0% in 1991 and 7.1% in 1994. At the time of the last (1985) National Nursing Home Survey an estimated 17,946 persons 65 years or older with a primary diagnosis of mental retardation were living in nursing homes.

***The proportion of state MR/DD facility populations made up of persons with the most severe cognitive impairments continues to grow.*** On June 30, 1994, 65.5% of all residents of large state MR/DD facilities are reported to have profound mental retardation. This compares with 45.6% in 1977, 56.2% in 1982, 63.0% in 1987, and 64.8% in 1991. Persons with mild or moderate mental retardation made up 16.0% of state facility residents on June 30, 1994. This compares with 26.8% of state institution residents in 1977, 19.6% in 1982, and 17.0% in 1987. On June 30, 1994 more than one-half of all state MR/DD facility residents (54.3%) were persons with profound mental retardation between the ages of 22 and 54 years.

***Although the proportion of persons with profound mental retardation among large state MR/DD populations continues to grow, their actual numbers continue to decrease.*** Between June 30, 1977 and June 30, 1994 the estimated number of persons with profound mental retardation living in large state MR/DD facilities decreased by about 25,900 (from 68,907 to 43,026). This compares with an increase of nearly 20,000 state facility residents with profound mental retardation in the period between 1964 and 1977.

***The proportion of large state MR/DD residents with significant functional impairments continues to increase.*** On June 30, 1994, 33.4% of state facility residents were reported to be unable to walk without assistance. This compares with 23.3% in 1977, 25.5% in 1982, 29.5% in 1987 and 32.4% in 1991. However, the total number of state facility residents unable to walk without assistance decreased by over 13,000 between 1977 and 1994 (from 35,200 to 22,000). Similarly in 1977, 34.1% of state facility residents were reported to be unable to toilet themselves independently. This compares with 55.3% in 1994. But between 1977 and 1994 the total number of people living in large state facilities who were unable to toilet themselves independently actually decreased by over 15,000 persons. The proportion of large state facility residents reported to need assistance or supervision with toileting increased from 46% to 55% between 1991 and 1994. The proportion reported to need assistance or supervision with dressing increased from 61.1% to 65.9%.

*Most large state facility residents have 2 or more sensory, neurological or behavioral conditions in addition to mental retardation.* On June 30, 1991, 15.3% of large state MR/DD residents were reported to be functionally blind and 7.9% were reported to be functionally deaf. Seizure disorders were reported for 42.5% of residents and 21.4% were reported to have cerebral palsy. Nearly half (47.1%) of all residents were reported to have some form of behavior disorder and 30.6% were reported to have a psychiatric condition. Over three-fifths of all residents (62.4%) were reported to have 2 or more of these conditions. In comparison in 1977, 6.0% of state institution residents were blind, 3.6% were deaf, 32.5% had epilepsy, 19.3% had cerebral palsy, 25.4% were reported to have a behavior disorder and 35.1% to have two or more of these conditions.

*Males remained a substantial majority among large state facility residents.* Males made up 59.3% of state facility populations. Males have made up a majority of state facility residents since the first national survey reporting gender statistics in 1904 when 53.1% of state institution residents were male. That proportion has very gradually increased over the years to 57.0% in 1977, 57.4% in 1982, 57.7% in 1987, and 58.5% in 1991.

#### *Admissions, Discharges, and Deaths*

*Admissions to large state MR/DD facilities decreased in 1994.* In 1994 an estimated total of 2,243 persons with MR/DD were admitted to large state MR/DD facilities. This was equal to 3.3% of the average daily population of these facilities during the year. Twelve states reported no admissions to their large state MR/DD facilities (as compared with 6 in 1993). Four states reported admissions exceeding 10% of their average daily population.

*Discharges from large state MR/DD facilities decreased slightly in 1994.* In 1994 an estimated total of 5,490 persons with MR/DD were discharged from large state MR/DD facilities, equal to 8.1% of the year's average daily population. This compared with 10.0% in 1993. In 1994 ten states reported discharges that equalled 15% or more of the average daily population of their large MR/DD facilities. Twelve states with large state MR/DD facilities had discharges equal to or less than 5% of their average daily population.

*The death rate among residents of large state MR/DD facilities in 1994 (1.5%) remained in the same range evident throughout the past decade.* In 1994 an estimated total of 995 persons with MR/DD died while residing in large state MR/DD facilities. The 1.5% death rate in 1994 is generally consistent with recent rates of 1.6% in 1993, 1.4% in 1992, and 1.34% in 1991. The 995 deaths of state facility residents in 1994 was the first time there were less than 1,000 deaths in state MR/DD institutions since 1915.

*A number of states made very substantial reductions in their large state MR/DD facility populations between 1990 and 1994.* The total number of persons with MR/DD living in large state MR/DD facilities decreased by 19.8% between 1990 and 1994. The largest proportion decreases in large state MR/DD facility populations were, of course, in Vermont, Rhode Island, New Hampshire, and the District of Columbia which closed all their large state MR/DD facilities. In addition, 8 other states reduced their state MR/DD populations by more than 40% over the period.

*Admissions of children and youth continued to decline as a proportion of all admissions to large state MR/DD facilities.* The primary factor in the decrease in children and youth (0-21 years) has been the continuing decrease in their rates of admission. In 1994 26.6% of all new admissions and 16.4% of all readmissions were children and youth. Although this is substantially greater than their 6.1% of the total state facility population, it represents a decline from 1989 when 37.1% of new admissions and 19.0% of all readmissions were children and youth. Fifteen years earlier in 1979, 61.6% of new admissions and 42.5% of readmissions were children and youth.

*Persons discharged from large state facilities were typically young adults and persons with profound mental retardation.* In 1994 46.1% of all discharges were persons between the ages of 22 and 39 years and 29.7% were

between the ages of 40 and 54 years. Persons with profound mental retardation made up 44.5% of all discharges. Over one-third of all discharges (33.7%) were persons between the ages of 22 and 54 years with profound mental retardation. This compares with 31.1% in 1991.

*Most people discharged from large state MR/DD facilities moved to community group homes.* Over half (55.6%) of all persons discharged from state MR/DD facilities in 1994 moved to community group homes of 15 or fewer residents. About 9% moved to foster homes and 9% returned to the homes of their parents or relatives. In comparison in 1985 40% of discharged persons moved to group homes, 7% to foster homes and 17% to the homes of their parents or other relatives; in 1989 49% moved to group homes, 7% to foster homes and 12% to the homes of their parents or other family members.

#### *Expenditures*

*In 1994 expenditures for care in large state MR/DD facilities continued to increase and reached a national annual average of \$82,300 per person.* Between 1993 and 1994 the average annual expenditures for care in large state MR/DD facilities increased slightly from \$81,453 to \$82,256 (an average of \$225.36 per day). Nine states exceeded an average of \$350 per day; 25 states reported annual expenditures per resident exceeding the national average. The 1.0% expenditure increase between 1993 and 1994 was much less than the 5.9% increase between 1992 and 1993. It represented only the second time since 1950 that the annual increase in expenditures has been less than inflation of the Consumer Price Index. The average annual increase since 1977 has been 10.0%.

#### *Facility Closure*

*The closure of large state MR/DD facilities continues.* Between 1992 and 1995, 51 large state MR/DD facilities were closed, an average of 12.75 closures per year. This compares with an average of 1.25 per year between 1976 and 1979, 3.0 per year between 1980 and 1987, and 8.5 per year between 1988 and 1991. States report that between 1995 and 1996 only an additional 20 large state MR/DD facilities are projected to be closed, an average of five closures per year.

### All State and Non-State Residential Services

#### *Number of Size and Residential Settings*

*The number of residential settings for persons with MR/DD is growing very rapidly.* On June 30, 1994 there were 63,654 residential settings in which persons with MR/DD received residential services from state operated or state licensed residential service providers (excluding psychiatric facilities, nursing homes and people receiving services while living with family members). Since 1977 the number of settings in which people receive residential services has grown nearly six-fold. On June 30, 1977 there were 11,008 state licensed or state operated residential service settings; on June 30, 1982 there were 15,632; on June 30, 1987 there were 33,477; on June 30, 1991 there were 46,786 and on June 30, 1993 there were 60,455. Of all residential service settings on June 30, 1994, 1,750 were operated by states, with the remaining 61,904 residential settings served by nonstate agencies.

*Most residences licensed or operated by states for persons with MR/DD were small and almost all people living in small residences were served by nonstate agencies.* Of the 63,654 total residential settings on June 30, 1994, 62,284 had 15 or fewer residents (97.8%) and 55,784 had 6 or fewer residents (87.6%). The 60,821 nonstate settings with 15 or fewer residents made up 97.7% of all settings with 15 or fewer residents. The 52,090 nonstate settings with 6 or fewer residents made up virtually all (99.0%) of the settings with 6 or fewer residents.

*Most large residences were also operated by nonstate agencies.* Nonstate agencies operated 1,083 (79.1%) of the total 1,370 facilities with 16 or more residents. This compares to 80.8% in 1977 and 82.7% in 1987.

#### *Number of Residents*

*Between 1977 and 1994, there was a steady increase in the total number of persons with MR/DD receiving residential services.* Between 1977 and 1994 the total number of residential service recipients grew 25.5%, from 247,780 to 310,911. Total population increases (both nonstate and state settings) were limited to places with 15 or fewer residents, the populations of which increased by 162,865 persons between 1977 and 1994. Total populations of facilities with 16 or more residents decreased by 99,694 persons between 1977 and 1994. Between 1993 and 1994 residents of settings with 15 and fewer residents increased by 9,542 persons, while residents of places with 16 or more residents decreased by 7,575.

*The national average rate of placement in residential settings for persons with MR/DD in 1994 was 120.6 persons per 100,000 of the general population.* Twenty-seven states reported residential placement rates above the national average, with the highest rate (292.0 per 100,000 state residents) in North Dakota. The lowest placement rate (43.8 per 100,000) was reported by Nevada. Eight states reported placement rates 150% or more of the national average and four states reported placement rate 50% or less of the national average. The national average placement rate of 120.6 in 1994 was slightly greater than the rate of 118.8 in 1977, and essentially the same as the 1993 rate of 120.7.

*In 1994 about 65.4% of the persons with MR/DD receiving residential services lived in places with 15 or fewer residents and 47.0% lived in places with 6 or fewer residents.* On June 30, 1994, residences of 15 or fewer persons housed 203,289 people (65.4% of all residents). Settings with 6 or fewer residents housed 145,976 people (47.0% of all residents). Of the 203,289 persons living in places with 15 or fewer residents, 192,957 (94.9%) lived in settings operated by nonstate agencies. The 143,822 persons living in nonstate settings with 6 or fewer residents made up almost all (98.5%) of the 145,976 people living in places with 6 or fewer residents.

*A substantial majority of persons with MR/DD who received residential services from nonstate agencies lived in smaller settings while a substantial majority of persons who lived in state residences lived in large facilities.* More than four-fifths (82.2%) of the 234,844 persons receiving residential services from nonstate agencies lived in settings of 15 or fewer residents, and more than three fifths (61.2%) lived in settings with 6 or fewer residents. Almost nine of ten (86.4%) of the 76,067 persons living in state operated settings were in facilities with 16 or more residents. Of the 107,662 residents of residential settings with 16 or more residents, 65,735 (61.1%) lived in state facilities. In 1977, 74.6% of the 207,356 residents of facilities with 16 or more residents lived in state facilities.

#### *Interstate Variability*

*In 10 states a majority of persons with MR/DD receiving residential services lived in facilities of 16 or more residents.* On June 30, 1994 more than half of the residents of all settings in Alabama, Arkansas, Georgia, Illinois, Louisiana, Mississippi, New Jersey, Oklahoma, Texas, and Virginia lived in facilities with 16 or more residents. In Virginia and Mississippi three-quarters or more of all residential service recipients were in institutional settings of 16 or more residents. Nationally, 34.6% of all residential service recipients lived in settings of 16 or more residents.

*In one-half (25) of all states a majority of persons with MR/DD received residential services in settings with 6 or fewer residents.* On June 30, 1994 more than half of the residents of all settings in Alaska, Arizona, California, Colorado, Connecticut, Delaware, the District of Columbia, Hawaii, Kentucky, Maine, Maryland, Massachusetts, Michigan, Minnesota, Montana, Nevada, New Hampshire, North Dakota, Oregon,



Pennsylvania, Rhode Island, Vermont, Washington, Wisconsin, and Wyoming lived in settings with 6 or fewer residents. Nationally, 47.0% of all residential service recipients lived in settings of 6 or fewer residents.

#### *Waiting Lists*

*The number of persons with MR/DD waiting for residential services in 1993 equalled approximately 18% of the total number of persons receiving residential services.* Based on data from the period 1991-1993, an estimated 56,300 persons with MR/DD were on waiting lists for residential services on June 30, 1993. This was 18.2% of the estimated national total of persons receiving and waiting for residential services on that date, a slight decrease from the 19.3% on waiting lists in 1991.

#### *State and Nonstate Residential Settings by Type*

*Most people receiving residential services receive it in places that provide "congregate care."* Congregate care is provided in settings owned, rented or managed by the residential services provider, or the provider's agents in which paid staff provide care, supervisory instruction and other support. An estimated 236,386 persons with MR/DD lived in congregate care settings on June 30, 1994 (76.0% of all residential service recipients). A majority of these persons (128,764 or 54.5%) lived in settings with 15 or fewer residents and almost one-third (71,564 or 30.3%) lived in settings with 6 or fewer residents.

*The number of people living in "family foster care" has been increasing.* An estimated national total of 31,929 persons with MR/DD lived in family foster care settings on June 30, 1994. Virtually all (99.6%) lived in homes with 6 or fewer residents. Between June 30, 1982 and June 30, 1994 the estimated number of people in foster care settings increased from approximately 17,150 to 31,929 (about 86.2%).

*The number of people living in an "own home" that they own or lease is increasing steadily.* An estimated national total of 42,596 persons with MR/DD receiving residential services and supports lived in homes that they owned or leased for themselves. All of these people lived with five or fewer other persons. Between 1982 and 1994 the estimated number of people living in homes of their own nationally increased by nearly 15,000 persons as the movement toward consumer controlled housing and supported living continued to gain momentum.

#### *Patterns of Change in Residential Service Systems: 1977-1994*

*The number of residential settings in which people received services increased much faster than the total number of service recipients.* Between 1977 and 1994, the total number of residential settings in which people with MR/DD received residential services grew from 11,008 to over 63,654, while total service recipients increased by about 25%, from about 248,000 to 311,000 individuals.

*The nation moved from large facility-centered to small community-based residential services.* In 1977, 84% of all persons with MR/DD receiving residential services lived in residences of 16 or more people. By 1994, 65.4% lived in community settings of 15 or fewer people, and 47.0% lived in residential settings with 6 or fewer people. But only about 13.7% of residential service recipients lived in homes that they themselves owned or rented (12.3% counting persons with MR/DD living in nursing homes).

*The role of the state as a residential service provider dramatically declined.* In 1977, 62.9% of all residential service recipients lived in state-operated residential settings. By 1994, less than one-quarter (24.5%) of all residential service recipients lived in state-operated residential settings.

## Medicaid Funded Services

### *Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR)*

*The total number of ICFs-MR continues to grow, but the average size has decreased dramatically.* On June 30, 1994 there were 7,151 ICFs-MR nationwide. This compares with 574 on June 30, 1977, 1,889 on June 30, 1982, and 3,913 on June 30, 1987. Average ICF-MR size in 1994 was 19.9 residents; this compares with 186 residents in 1977, 74.5 residents in 1982; and 37 residents in 1987.

*In 1994, the population in ICFs-MR evidenced the first notable decrease in the history of the program.* From 1982 to 1993 the ICF-MR program was notable for its stability in the number of persons served. On June 30, 1993 there were 147,729 persons living in all ICFs-MR. This compares with 147,148 persons on June 30, 1989 and 140,684 on June 30, 1982. In 1994 the total ICF-MR population decreased by 5,566 to 142,118. The primary factor in this decrease was New York's conversion of community ICFs-MR housing over 5,000 individuals to Medicaid Home and Community Based Services (HCBS) settings.

*Populations of large ICFs-MR with 16 or more residents have continued to decrease steadily over the past several years.* On June 30, 1994 there were 93,779 persons in ICFs-MR of 16 or more residents. (66.0% of all ICF-MR residents). This represented a 22.4% decrease from the 120,822 persons in large ICFs-MR in 1987 and a 28.3% decrease from 130,767 large ICF-MR residents in 1982. The 1994 population of large ICFs-MR included 62,599 residents of state ICFs-MR and 31,180 residents in nonstate ICFs-MR. Between June 30, 1987 and June 30, 1994, large state ICF-MR populations decreased 29.2% (from 88,424), while large nonstate ICF-MR populations decreased only 3.8% (from 32,398). In 1994, 87.1% of persons living in all large state and nonstate facilities lived in ICF-MR units, and 95.3% of people living in state facilities of 16 or more residents lived in ICF-MR units.

*In 1994, a minority of ICF-MR residents were living in state-operated facilities.* On June 30, 1994, 48.1% of all ICF-MR residents were living in state-operated facilities. This compares with 63.2% on June 30, 1987; 77.2% on June 30, 1982 and 87.5% on June 30, 1977. The deconcentration of ICF-MR residents from state-operated facilities is associated with the general depopulation of large state MR/DD facilities and the increase in the number of small ICFs-MR, 89.8% of which in 1994 were nonstate facilities. On June 30, 1994 there were 62,599 persons in ICF-MR units of large state MR/DD facilities (44.0% of all ICF-MR residents). This compares with 88,424 persons on June 30, 1987 (61.2% of all ICF-MR residents), and 107,081 persons in June 30, 1982 (76.3% of all ICF-MR residents).

*Most residents of private ICFs-MR lived in facilities operated by private non-profit agencies.* In 1992 about 65,700 people were living in private ICFs-MR. Of these individuals 61.5% were in ICFs-MR operated by private non-profit agencies, and 38.5% lived in facilities operated by private for-profit agencies. In 1982 52.3% of private ICF-MR residents lived in settings operated by private non-profit agencies.

*For the first time since 1977 the number of residents of ICFs-MR of 15 or fewer residents decreased in 1994, even with the large decrease in total ICF-MR residents.* On June 30, 1994 there were 48,339 persons with MR/DD living in ICFs-MR with 15 or fewer residents. This represents a decrease of .7% from June 30, 1993. Still small ICFs-MR continued to house many more people than the 23,528 persons on June 30, 1987, and the 9,985 on June 30, 1982. On June 30, 1994, 40.6% of residents of small ICFs-MR lived in facilities with 6 or fewer residents. Between June 30, 1982 and June 30, 1994 the total number of persons with MR/DD living in ICFs-MR of six or fewer residents increased from 2,572 to 19,698. The number of people living in ICFs-MR of 6 or fewer residents actually increased between June 30, 1993 and June 30, 1994 by 1,881 residents.

*A relatively small proportion of persons with MR/DD living in the community settings live in ICF-MR certified residences.* Nationally, on June 30, 1994 48,339 (23.3%) of the 207,184 persons in settings with 15 or

fewer residents lived in ICFs-MR. Persons living in settings with 7 to 15 residents were far more likely to be found in ICF-MR certified facilities than are persons living in settings of 6 or fewer residents. In 1994, 28,641 (47.5%) of the 60,234 persons living in settings with 7 to 15 residents were in ICF-MR certified residences while only 19,698 (13.4%) of the 207,184 persons living in settings with 6 or fewer residents lived in ICFs-MR.

*In 1994 total ICF-MR expenditures did not increase for the first time in program history.* In Fiscal Year 1994 total federal and state expenditures for ICF-MR services were 9.2 billion dollars, the same as in Fiscal Year 1993. This compares with \$8.8 billion dollars in 1992, \$5.6 billion in 1987 and \$3.6 billion in 1982. The stability in expenditures was the result of a decrease in ICF-MR residents.

*Per resident ICF-MR expenditures in 1994 continued to increase.* In 1994 the average expenditure for end-of-year ICF-MR residents was \$64,891. This compares with the average 1993 per recipient expenditure of \$62,180. The average 1994 expenditure was \$19,945 or 44.4% more than the 1989 per recipient expenditure of \$44,946. States varied substantially in expenditures per ICF-MR recipient, from over \$100,000 per year in nine states to under \$40,000 per year in one state. Total ICF-MR expenditures per day per person in the general population averaged \$35.76 per year nationally. Two states averaged over twice the national average, while fourteen states averaged less than half the national average.

#### *Characteristics of ICF-MR Residents*

*Children and youth (0-21 years) make up only about 11.0% of ICF-MR residents.* In contrast to 1982 when children and youth made up 22.7% of all ICF-MR residents, in 1992 children and youth made up 11.0% of ICF-MR residents. In 1982 in only three states were 10% or less of ICF-MR residents 21 years or younger; in 1992, 24 states.

*In 1992 a majority of ICF-MR residents (50.7%) had profound mental retardation.* In 1992, 11.1% of ICF-MR residents had mild mental retardation, 14.0% had moderate mental retardation; 22.7% had severe mental retardation and 50.7% had profound mental retardation. In most states the proportion of persons with profound mental retardation was higher in the largest ICFs-MR.

*Between 1982 and 1992 there was movement of persons with profound mental retardation from large to small ICFs-MR.* In 1992 large ICFs-MR served 19,999 fewer persons with profound mental retardation than in 1982. In 1992 small ICFs-MR (15 or fewer residents) housed 20,121 more persons with profound mental retardation than in 1982.

*Most ICF-MR residents have physical and/or sensory impairments in addition to mental retardation.* Nearly half (47.8%) of all ICF-MR residents are reported to require mobility assistance, including 49.1% of large (16 or more residents) ICF-MR residents and 42.7% of residents of ICFs-MR with 6 or fewer residents. Nearly one-fifth (18.8%) of ICF-MR residents were reported to have cerebral palsy, including 20.3% of residents of large ICFs-MR. Eight percent of ICF-MR residents were reported to be functionally blind and 2.9% to be functionally deaf, with prevalences of each about 25% higher in large ICFs-MR than in small ICFs-MR.

*Medications were used to control behavior of more than a quarter of ICF-MR residents.* Psychoactive drugs were used to control the behavior of 28.5% of all ICF-MR residents. Only small differences were evident among ICFs-MR of different sizes.

#### *Medicaid Home and Community Based Services (HCBS)*

*Growth in HCBS recipients continued at a rapidly accelerated rate in Fiscal Year 1994.* On June 30, 1994 there were 122,075 persons with MR/DD receiving HCBS, and increase of 41.0% over the 86,604 recipients on June 30, 1993. In the five years between June 30, 1989 and 1994, the number of HCBS recipients grew by

3½ times from 35,077 and the number of states providing HCBS increased from 35 to 49. Twenty-two states increased their number of HCBS recipients by 1,000 or more between 1989 and 1994.

*Utilization of HCBS to fund small residential services (other than room and board) is greater than the small ICF-MR program.* Of the 49 states with HCBS recipients, 38 were able to report the residential arrangements of their recipients. These states reported residential arrangements for 74,851 individuals, 61.3% of 122,075 HCBS recipients on June 30, 1994. More than three-quarters (76.2%) of these HCBS recipients were receiving residential services outside their family home. Applying this statistic to all 122,075 HCBS recipients on June 30, 1994 would yield an estimated 93,007 persons receiving residential services funded by HCBS, almost twice the 48,339 persons served in all small ICFs-MR.

*Expenditures for Medicaid HCBS recipients continue to grow and show substantial interstate variability.* In Fiscal Year 1994 expenditures for Medicaid HCBS recipients were 3.0 billion dollars for 122,075 recipients, a per recipient average of \$24,343 per year. This represents a 14.6% increase over the per recipient average in Fiscal Year 1990 (\$21,246). The states with the highest per recipient expenditures in 1994 were Connecticut (\$57,236) and Pennsylvania (\$57,521). The states with the lowest per recipients expenditures in 1994 were Alabama (\$10,517), Idaho (\$6,111), Indiana (\$7,592), Iowa ((\$4,579), Florida (\$10,538), and California (\$10,089).

#### *ICF-MR and HCBS Combined*

*Despite decreasing numbers of ICF-MR residents, growth in the total number of ICF-MR and HCBS recipients has continued at a rapidly accelerating rate.* Between 1982 and 1987 combined totals of ICF-MR and HCBS recipients increased at an annual average of about 6,200. Between 1987 and 1992 there was a combined average annual increase of approximately 8,000 ICF-MR and HCBS recipients. Between 1992 and 1994 total ICF-MR and HCBS recipients increased at an annual rate of about 24,000 per year. On June 30, 1994, HCBS recipients made up 46.2% of the combined total of ICF-MR and HCBS recipients, compared with just 13.6% on June 30, 1987.

*ICF-MR and HCBS recipients living in small (15 or fewer residents) residential settings make up nearly two-thirds of the combined total of ICF-MR and HBCS recipients.* On June 30, 1994 residents of small ICFs-MR and HCBS recipients made up 64.5% of all ICF-MR and HCBS recipients. That compares with 57.7% on June 30, 1993, 49.7% on June 30, 1992, and 27.7% on June 30, 1987. In 39 states most of the combined ICF-MR and HCBS recipients were in small residential settings.

*There remains remarkable variation among states in ICF-MR and HCBS utilization rates.* On June 30, 1994 there was a national ICF-MR utilization rate of 55.1 ICF-MR residents per 100,000 persons in the United States. The highest individual state ICF-MR utilization rates were 124.9 in District of Columbia and 140.4 in Louisiana. The highest utilization of large ICFs-MR were in Illinois (69.3), Louisiana (81.7), Mississippi (72.7), Oklahoma (69.8), and Wisconsin (73.1). State utilization rates of smaller ICFs-MR were more than 50 residents per 100,000 in 6 states, in contrast to the 24 states with rates of fewer than 6 residents per 100,000 citizens. On June 30, 1994 nationally there was an average of 102.4 ICF-MR and HCBS recipients per 100,000 of the population. Individual state utilization rates for the combined programs varied from the highest rates in North Dakota (324.4), South Dakota (210.6), Minnesota (204.2) and New York (192.1) to the lowest rates in Alaska (18.4), Nevada (27.1) and Georgia (35.5).

*Expenditures are disproportionately greater in ICFs/MR than for persons receiving HCBS.* The average annual expenditures for ICF-MR services were \$66,720 per person as compared to \$24,343 per each HCBS recipient. Nationally, for Fiscal Year 1994, HCBS recipients were 46.2% of the total HCBS and ICF-MR recipient population but were beneficiaries of only 24.4% of the total HCBS and ICF-MR expenditures. Only in Arizona and West Virginia did HCBS per person expenditures exceed ICF-MR per person expenditures.

*Current proposals to block grant Medicaid present significant issues in establishing interstate equity.* Almost any measure of each states' fair share of total Medicaid funding will produce significant interstate disparities. For example, if 1994 Medicaid long-term care benefits paid to each state for persons with MR/DD are indexed by federal income tax paid by citizens of each state, major disparities are formed in relative state benefits. Five states receive over twice their relative contributions through federal income tax back in benefits (North Dakota, \$3.27 in benefits per \$1.00 contributed; Louisiana, \$2.31; South Dakota, \$2.51; New York and Rhode Island, \$2.02). Six states receive back less than half their relative contributions (Alaska, California, Florida, Hawaii, Nevada, Virginia). Establishing block grants according to state population would exhibit similar problems because of large differences among states in Medicaid expenditures for persons with MR/DD. For example, in Fiscal Year 1994, New York, the District of Columbia and Rhode Island spent more than \$100 for Medicaid long-term care programs for persons with MR/DD per state resident. Alaska, California, Georgia, Hawaii, Nevada and West Virginia spend less than \$25.

#### *Nursing Home Residents*

*The number of persons with MR/DD in Nursing Facilities continues to decrease slowly.* States reported that on June 30, 1994 there were 36,197 persons with MR/DD in nursing homes. This compares with 38,564 on June 30, 1992 and 38,177 on June 30, 1993. Nationwide, in 1994 10.4% of all persons with MR/DD receiving residential services and 12.2% of all with MR/DD receiving services through Medicaid ICF-MR, HCBS or Nursing Facility programs were in Medicaid nursing homes. Seven states reported Nursing Facility residents to make up one-fourth or more of their citizens with MR/DD receiving residential services and six states reported Nursing Facility residents to make up one-fourth or more Medicaid long-term service recipients with MR/DD.

#### *Medicaid Community Supported Living Arrangements (CSLA)*

In August 1994 the 8 CSLA states were supporting a total of 3,308 individuals with MR/DD. The 8 CSLA states projected that there would be 3,971 participants in June 1995.

*CSLA states varied considerably in the number of persons supported.* States with relatively low numbers of persons supported included Maryland (168), Colorado (249), and California (253). States with relatively high numbers of persons supported included Florida (720), Illinois (652), and Michigan (515). Rhode Island served 398 persons and Wisconsin served 353 persons.

*Over 60% of CSLA participants were between the ages of 22 and 39 years.* In every state CSLA program a majority of participants were in the 22 to 39 year age range. The proportion of participants between 22 and 39 years ranged from 55% in Illinois to 76% in California.

*A substantial majority (over 75%) of CSLA participants had mental retardation as a primary disability.* In every state a substantial majority (over 60%) had mental retardation as a primary disability. In the seven CSLA states able to distinguish level of mental retardation, 60% or more of CSLA participants had mild or moderate mental retardation.

*Most CSLA participants lived in their own homes.* In 6 of the 8 CSLA states a majority of CSLA participants lived in their own homes. In 2 states (Colorado and Rhode Island) the majority of CSLA participants lived with other family members.

*Only 3 of the 8 CSLA states used 85% or more of their authorized federal funding.* The CSLA program provided states the opportunity to spend up to \$4.375 million federal dollars in FY 1995, provided the required state Medicaid matching funds were expended. Only 3 states spent at 85% or more of the authorized level

(California, Illinois and Michigan). Two states (Florida and Maryland) spent at less than 40% of the authorized level.

*CSLA expenditures varied considerably from state-to-state.* Florida had the lowest per participant CSLA expenditures (\$3,872 per year). California and Maryland had the highest per participant expenditures (over \$20,000 per year). Factors associated with CSLA expenditures included the nature and intensity of supports needed by people, the proportion of participants who lived with and received partial support from family members, restriction/openness of program access for persons with unusually high cost needs, availability and access of services from non-CSLA agencies and programs (e.g., Medicaid personal care, vocational rehabilitation, school programs, etc.).

*CSLA played a major role in changing the goals and standards in Medicaid Home and Community Based Services in most CSLA states.* Although CSLA will end in September 1995, it leaves an important legacy of redefined purposes and policies for Medicaid Home and Community Based Services (HCBS) in most states. State officials in most CSLA states observed that CSLA allowed "seeds" of supported living to be planted throughout their states. These seeds are now viewed as the foundation for integrating supported living approaches throughout state services systems, especially through community support programs financed by Medicaid HCBS.

**INTRODUCTION  
AND  
METHODOLOGY**

## INTRODUCTION

The National Residential Information Systems Project (RISP) on Residential Services of the Research and Training Center on Residential Services and Community Living began in 1977. It has operated on a nearly continuous basis since then. This project gathers and reports statistics on persons with mental retardation and related developmental disabilities (MR/DD) receiving residential services state-operated, nonstate and Medicaid-funded programs in the United States, including residential services operated specifically for persons with MR/DD, as well as persons with MR/DD who are living in nursing homes, and state psychiatric facilities. This particular report provides such statistics for the year ending June 30, 1994, as well as comparative statistics from earlier years.

Section 1 of this report presents statistics on state-operated residential services for Fiscal Year 1994, with comparative trend data from earlier years. Chapter 1 presents statistics that were compiled and reported by various state agencies, with the exception of four states for which state statistics were obtained from individual state facilities. The data collection in Chapter 1 represents a continuation of a statistical program originated by the Office of Mental Retardation Coordination (now the Administration on Developmental Disabilities) in 1968 which gathered statistics on state MR/DD institutions (places with 16 or more residents). It has since been expanded to include statistics on smaller state MR/DD residential settings (those with 15 or fewer residents) and on state-operated psychiatric facilities which house persons with mental retardation and related conditions. The addition of state psychiatric facilities was begun for Fiscal Year 1978, and the smaller state-operated residential settings were added in Fiscal Year 1986. As is indicated at various points throughout this report the statistics gathered as part of the National Residential Information Systems Project since Fiscal Year 1977 have also been linked to a longitudinal data base developed by the project. That data base begins with the first census of state MR/DD institutions carried out as part of the U.S. Census of 1880.

Section I, Chapter 2 presents the Fiscal Year 1994 statistics as part of the longitudinal trends in state institution populations, resident movement, and expenditures for state institution care since 1950. A brief historical review of these and other preceding surveys since 1950 can be found in Lakin, Hill, Street, and P. uininks (1986). For a more detailed review, including surveys and statistics since 1880, see Lakin (1979).

Section I, Chapter 3 presents statistics on the characteristics and movement of residents of large state MR/DD residential institutions (16 or more residents) in Fiscal Year 1994. These statistics were gathered through a survey of 239 individual state institutions for persons with mental retardation and related conditions with 16 or more residents. These facilities included traditional state MR/DD institutions and MR/DD units contained within other state-operated institutions. Previous surveys of state institutions were conducted in conjunction with this project in 1977, 1979, 1981, 1982, 1985, 1987, 1989, and 1991. As in the past these statistics were gathered in cooperation with the Association of Public Developmental Disabilities Administrators (formerly the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded). The procedures for this survey were developed by the late Richard Scheerenberger.

Section I, Chapter 4 presents information on patterns of state institution closure. It provides a listing of all state institutions that have operated since 1960, including those that closed on or before 1994, and those that are scheduled to close by 1998.

Section II of this report presents combined statistics on the total numbers of persons with mental retardation and related developmental disabilities in both state and nonstate residential settings. Statistics in this section have been compiled and reported by individual state MR/DD agencies. This data set was designed in cooperation with state agencies to permit the most comprehensive possible data collection while maintaining congruence with administrative data sets maintained in each of the states. It should be noted that in certain states a significant amount of



state effort is required to compile the requested statistics, including frequently separate surveys of substate/regions. Occasionally the demands of such data collection activities are greater than can be managed by a state in a particular year, or data system problems preclude a state's reporting for a particular year. This was again the case with three states in 1994. In such states statistics from the most recent data collection point have been substituted for Fiscal Year 1994 data. When earlier data are substituted, they are so indicated in the tables presented.

Section II provides 1994 and longitudinal trend statistics on total (i.e., state-operated and nonstate-operated) MR/DD residential service systems on the individual state and national levels. Section II, Chapter 5 provides data on total state residential services systems (i.e., services provided by both state and nonstate agencies). These statistics are reported by state/nonstate operation and by size of residential settings on June 30, 1994. State-operated services include those described in Chapter 1 with the exception of the psychiatric institutions, which are excluded in Section II's focus on the individual state and national MR/DD residential services systems. Although nonstate facilities are almost entirely privately operated, in a few states local government agencies operate residential programs. These local government programs are included with private programs in a nonstate category because typically their relationship with the state with respect to licensing, monitoring and funding is more like that of a private agency than that of a state-operated program. In addition to state/nonstate operation, three residential setting size distinctions are provided: 1 to 6 residents, 7 to 15 residents and 16 or more residents. Again these size categories were established because they were most congruent with the data that the individual states were able to report.

Chapter 6 presents statistics reported by the various states on residents living in different types of residential settings of state and nonstate operation. Four separate categories of residential settings are identified. These were developed after consultation with state respondents during a 1986 feasibility study of states' abilities to report residents by setting type. Without question this area presents states with the greatest reporting challenge. States have in total literally hundreds of

different names for residential programs and many of these programs have aspects which make them subtly different from similarly named programs in other states. Even in using just the four broad residential setting categories identified below, a few state data systems do not permit the breakdowns requested. Therefore in some states some residential settings and their residents must be subsumed in the statistics of another setting type.

Chapter 7 presents Fiscal Year 1994 statistics along with longitudinal statistics with statistics from earlier years to show the changing patterns of residential services for persons with MR/DD from 1977 to 1994. This presentation of statistics focuses on overall residential service utilization as well as the utilization of residential settings of different state/nonstate operation, size and type.

Section III focuses on the utilization of the Medicaid program to sponsor long-term care services for persons with mental retardation and related developmental disabilities. Chapter 8 describes the evolution of Medicaid involvement in services for person with mental retardation and related conditions and the specific programs funding residential services for persons with MR/DD. Chapter 9 provides statistics on June 30, 1994 utilization of these Medicaid programs. It also presents Fiscal Year 1994 statistics within the longitudinal context of changing Medicaid utilization. This presentation also includes Medicaid residential services program utilization within the entire system of residential services for persons with mental retardation and related conditions.

Chapter 10 provides descriptive data on Medicaid Intermediate Care Facility [for persons who are] Mentally Retarded (ICF-MR) residents and programs, by size and operation. It is based on special analyses of carefully edited data tapes from the Online Survey, Certification and Reporting System maintained by the Health Care Financing Administration. Comparative data are also provided from a 1982 RISP survey of all ICFs-MR. Finally, Chapter 11 presents summary statistics on the implementation of the Medicaid Community Supported Living Arrangements (CSLA) program, created by Congress in 1990. This program operated in 8 states, and the data reported on it is from a survey of CSLA coordinators in those 8 states.

## METHODOLOGY

The statistics in this report primarily derive from four data collection activities. The first is a three-part survey of designated state agencies and key respondents to gather aggregated state statistics. The second is a survey of administrators of all large (16 or more residents) state MR/DD facilities. The third is an analysis of edited data tapes from HCFA's Online Survey, Certification and Reporting System (OSCAR). The fourth is a survey of all state CSLA coordinators. These are described below.

### *State Survey Data Collection*

A three-part survey questionnaire for state agency statistics for Fiscal Year 1994, was mailed with a cover letter to each state's mental retardation/developmental disabilities program director or the state's designated "key data manager" in August 1994. Part 1 of the questionnaire was on state-operated residential services. Part 2 gathered statistics on nonstate residential settings and persons with mental retardation and related developmental disabilities residing in Medicaid nursing facilities. Statistics on ICFs-MR were integrated into Parts 1 and 2. Part 3 contained questions on Medicaid Home and Community Based Services. Telephone follow-up began two weeks after the questionnaires were mailed to confirm the individual(s) in each state agency who had accepted responsibility for compiling the statistics for each part of the survey. Direct contacts were then made with each key data manager to answer questions about the data requested.

Additional follow-up telephone calls to promote initial response and to clarify and edit the statistics on returned questionnaires continued until March 1994. In April summaries of the data from each state were returned to each state for verification. Corrections and special notes on state data were completed by the end of May 1994. Compiling statistics from states on the three-part survey took an average of four telephone conversations involving up to four different people in each state. In several states contacts were made with two or more of the mental retardation/developmental disabilities, mental health and Medicaid agencies to gather the

required statistics. In two states data on state MR/DD institutions were obtained from individual state institutions.

Limitations are encountered when gathering statistics at the state level. Most notable among these are the variations that sometimes exist in the types of statistics maintained by the various states and the specific operational definitions governing certain data elements. For example, in a few states data on first admissions, readmissions, and releases were not available according to the specific survey definitions. In a few other states the state statistical systems were not wholly compatible with the uniform data collection of this project. General problems in the collection of the data are presented in the discussion accompanying each table in the body of the report and/or in notes at the foot of tables.

### *Individual State Institution Survey*

Data in Chapter 3 of this report result from a survey of each large (16 or more residents) state MR/DD residential facility or unit operating on June 30, 1994. This survey included questions on demographic, diagnostic, and functional characteristics of each facility's residents, on patterns of resident movement, including previous place of residence of new admissions and readmissions to each state-operated residential facility, and on program administration, staffing and expenditures.

The facilities included in this study were 238 large state residential facilities for persons with MR/DD or specifically designated units for persons with MR/DD within other institutions. Data collection was carried out primarily by mail with telephone follow-up to nonrespondents. Two instruments were used in this survey. They included a long form (22 categories of information) initially mailed to all facilities (returned by 191 facilities, 80.3% of responding facilities), and a short form (10 categories of information) mailed to all nonrespondents to the long form (returned by 31 facilities, 13.0%). Sixteen (6.7%) facilities failed to respond to either the long or short form of this survey. Statistics were obtained from these institutions on their number of residents on June 30, 1994 and their average daily population during Fiscal Year 1994. Specific item response rates are indicated at the foot of each table. These report

the percentage of all state MR/DD institution residents who are housed in the facilities that reported the specific statistic.

#### *ICF-MR Data Base Analyses*

The descriptive statistics on ICF-MR residents, facilities and programs in Chapter 10 of this report are based on analyses of edited data tapes from the Medicaid Online Survey Certification and Reporting System (OSCAR). This data base contains basic statistics about ICF-MR facility, program and resident characteristics gathered at the time of the annual survey and certification review of each ICF-MR, as well as the specific findings of the survey regarding compliance with ICF-MR regulations. (The purpose of survey and certification reviews is to insure that each ICF-MR is in compliance with federal regulations.)

The statistics used in this report are taken from the "cover sheet" completed for each facility in cooperation with the ICF-MR staff. It includes basic facility information (number of residents, ownership, living units), resident characteristics (ages, level of mental retardation, functional characteristics), staffing information (number of employees and staff-resident ratios by category), and other information.

The data tapes analyzed were constructed in January 1994. There is a "rolling" effective date of these statistics because data are gathered at the time of each facility's survey. The effective date of the data are viewed here as June 30, 1992, with 77.1% of the data gathered in 1992, 17.4% in the first 4 months of 1993, and except for one ICF-MR, the remainder in 1991.

A major challenge in preparing these data for analysis was the large number of sub-facility units entered into the data base as though they were

independent facilities. This required ordering all facilities by zip and manual screening for potential multiple units from the same facility, based on same address, phone number and so forth. Potential multiple units of the same facility were followed by phone, with subsequent editing and data merging as appropriate. Other editing was based on comparison of the total ICF-MR residents reported by state agencies and aggregated totals derived from the OSCAR data set. This, and subsequent telephone follow-up with specific facilities, permitted discovery of keypunching errors in the OSCAR data set (most dramatically a group home with 6 residents indicated to have 1,006 residents). Details of the OSCAR methodology, editing and analysis is described in Larson, Lakin, and Moore (1995). Comparative data on changes in ICF-MR programs and service recipients over the previous decade were derived from the University of Minnesota's 1982 census of all ICFs-MR (Lakin, Hill, and Bruininks, 1985).

#### *CSLA Survey*

The statistics on state Medicaid Community Supported Living Arrangements (CSLA) programs reported in Chapter 11 derive from a survey of the individuals designated as "CSLA coordinator" in each of the 8 states providing CSLA services. This survey was one part of the CSLA evaluation being conducted by the MEDSTAT Group, the Research and Training Center on Community Living/University of Minnesota and the University of Maryland at Baltimore. All 8 states providing CSLA services responded to the survey, which requested information about participants, expenditures and services provided in the CSLA program.

**SECTION I**

**STATUS AND CHANGES IN  
STATE-OPERATED RESIDENTIAL SERVICES**

**CHAPTER 1**  
**POPULATIONS OF STATE-OPERATED RESIDENTIAL SETTINGS IN 1994**

**Troy Mangan**  
**Robert W. Prouty**  
**Barbara Polister**  
**K. Charlie Lakin**

The statistics in this chapter on resident populations, resident movement, and costs in state-operated residential settings for persons with mental retardation and related developmental disabilities (MR/DD) in Fiscal Year 1994 were gathered in a survey of all states. Statistics are provided for persons residing in state-operated MR/DD settings of 6 or fewer residents, 7-15 residents and 16 or more residents, and for persons with MR/DD residing in state-operated psychiatric facilities. A state-operated setting is defined as one in which the persons providing direct support to the residents of the setting are state employees.

*Number of State-Operated Residential Facilities*

Table 1.1 presents statistics by state on the number of state-operated residential facilities serving persons with MR/DD in the United States on June 30, 1994. The statistics are broken down for state-operated MR/DD settings with 6 or fewer residents, 7-15 residents, and 16 or more residents; and for state-operated psychiatric facilities and total state-operated facilities.

On June 30, 1994, states reported a total of 1,855 state-operated residential settings serving persons with MR/DD, an increase of 90 over the previous year. Of these, 1,750 (94.3%) were settings primarily for persons with MR/DD. Of the 1,750 state MR/DD facilities, 1,463 (83.6%) had 15 or fewer residents; 287 (16.4%) had 16 or more residents. All states except New Hampshire,

Vermont, Rhode Island, and the District of Columbia operated at least one large state MR/DD facility on June 30, 1994. Eighteen states reported at least one psychiatric facility housing persons with a primary diagnosis of mental retardation or a related developmental disability in units other than special MR/DD units. States reported a total of 105 state psychiatric facilities with residents with MR/DD as compared with 110 on June 30, 1993.

On June 30, 1994, 15 states were serving persons with MR/DD in state-operated settings with 15 or fewer total residents. The total of 1,463 small residential settings staffed by state employees on June 30, 1994 represented an increase of 6.6% (90 settings) between June 30, 1993 and June 30, 1994. By far the greatest portion of that growth came among settings with 6 or fewer residents, which grew by 15.8% (78 settings). Seven states increased their number of small state-operated settings during this period.

The greatest number of small state-operated residential settings was in New York (900 settings). New York operated 61.5% of all such settings in the United States on June 30, 1994. Most (78%) of New York's state-operated community residential facilities had between 7 and 15 residents. Other states which have been active in developing state-operated community residential settings have focused on developing settings with no more than 6 residents. In fact, two thirds (67%) of the 563 state-operated community residential settings outside of New York in 1994 had 6 or fewer residents.

**Table 1.1 Number of State-Operated Residential Facilities on June 30, 1994 by State**

State	Size of State MR/DD facilities					Psychiatric Facilities	Total Large (16+)	Total State-Operated Facilities
	1-6	7-15	1-15	16+	Total			
AL	0	0	0	5	5	0	5	5
AK	0	0	0	1	1	0	1	1
AZ	23	10	33	7	40	0	7	40
AR	0	0	0	6	6	0	6	6
CA	0	0	0	7	7	0	7	7
CO	3	36	39	2	41	0	2	41
CT	118	38	156	12	168	3	15	171
DE	0	0	0	1	1	0	1	1
DC	3*	0	0	0	0	2	2	2
FL	0	0	0	24	24	0	24	24
GA	0	0	0	12	12	8	20	20
HI	0	0	0	2	2	0	2	2
ID	0	0	0	1	1	0	1	1
IL	0	0	0	12	12	6	18	18
IN	0	0	0	11	11	0	11	11
IA	0	0	0	2	2	6	8	8
KS	0	0	0	3	3	0	3	3
KY	0*	0*	0*	2*	2*	3*	5*	5*
LA	11	0	11	9	20	0	9	20
ME	0*	1	1	2	3	0	2	3
MD	0	0	0	5	5	9	14	14
MA	37	61	98	8	106	11	19	117
MI	0	0	0	3	3	0*	3	3
MN	34	0	34	6	40	0	6	40
MS	91	24	115	5	120	0**	5	120
MO	0	0	0	6	6	6	12	12
MT	0	0	0	2	2	0	2	2
NE	0	0	0	1	1	0	1	1
NV	4	0	4	2	6	0	2	6
NH	11	0	11	0	11	0	0	11
NJ	0	0	0	8	8	7	15	15
NM	0	0	0	2	2	0	2	2
NY	196*	704*	900*	25*	925*	20**	45*	945*
NC	0	0	0	6	6	3	9	9
ND	0	1	1	1	2	1	2	3
OH	0	0	0	12	12	0	12	12
OK	0	0	0	3	3	0	3	3
OR	7	0	7	2	9	0	2	9
PA	0	0	0	12	12	14	26	26
RI	36	13	49	0	49	0	0	49
SC	0	0	0	5	5	0	5	5
SD	0	0	0	2	2	1	3	3
TN	0	0	0	5	5	0	5	5
TX	1	3	4	16	20	DNF	16	20
UT	0	0	0	1	1	0	1	1
VT	0	0	0	0	0	1	1	1
VA	0	0	0	15	15	0	15	15
WA	0	0	0	7	7	2	9	9
WV	0*	0*	0*	1*	1*	2*	3*	3*
WI	0	0	0	3	3	0	3	3
WY	0	0	0	2	2	0	2	2
<b>U.S. Total</b>	<b>572</b>	<b>891</b>	<b>1,463</b>	<b>287</b>	<b>1,750</b>	<b>105</b>	<b>392</b>	<b>1,855</b>

e indicates estimate

\* indicates 1993 data

\*\* indicates 1992 data

DNF indicates data not furnished

### *Residents of State-Operated Facilities*

Table 1.2 presents the number of persons with MR/DD living in state-operated MR/DD residential settings and psychiatric facilities on June 30, 1994. On June 30, 1994 there were 77,692 persons with MR/DD living in state-operated residential settings. This represented a decrease of about 5% from the 81,649 residents on June 30, 1993. Of this population, 76,112 persons (98.0%) were residents of settings specifically designated for persons with MR/DD and 1,580 persons (2.0%) were in psychiatric facilities.

Of the 76,112 persons in state-operated MR/DD facilities, 2,154 (2.8%) were in settings of six or fewer residents, 8,223 (10.8%) were in facilities of seven to 15 residents, and 65,735 (86.4%) were in large facilities of 16 or more residents. Nationally, the populations of large state-operated facilities decreased 5.8% between June 30, 1993 and June 30, 1994 from 69,760 residents on June 30, 1993. All residents with MR/DD living in state-operated psychiatric facilities were in settings of 16 or more residents.

The 2,154 persons with MR/DD in state-operated MR/DD settings of six or fewer residents were in thirteen states, with 1,371 (63.6%) concentrated in three states (Connecticut, Mississippi, and New York). Of the 8,223 persons in MR/DD facilities of seven to 15 residents, all were from one of 10 states and 6,554 (79.7%) were from New York. Of the 65,735 persons living in large state MR/DD facilities, 27,427 (41.7%) were concentrated in six states (California, Illinois, New Jersey, New York, Pennsylvania, and Texas). Of the 1,580 persons with MR/DD reported as residents of psychiatric facilities by 18 states, 1,124 (71.1%) were in three states (New Jersey, New York, and Pennsylvania).

The decrease in the number of residents of large state MR/DD facilities continued a trend first evident in Fiscal Year 1968. The 5.8% rate of decrease between Fiscal Years 1993 and 1994

compares with a 6.4% decrease between Fiscal Years 1992 and 1993 and a 7.5% decrease between Fiscal Years 1991 and 1992. In the two years between Fiscal Years 1992 and 1994 a decrease in the average daily population of large state facilities was evident in every state in the United States.

### *Populations per 100,000 of the General Population*

Table 1.3 indexes the population of persons with MR/DD living in state-operated residential settings by 100,000 of each state's general population on June 30, 1994. This statistic is referred to here as the "placement rate." On June 30, 1994 the national placement rate for all state-operated residential settings was 30.1 residents per 100,000 of state population. This represented a reduction from 31.9 on June 30, 1993. This decrease in national placement rate for all state-operated residential services was due to the decrease in national placement rate for large state MR/DD facilities, from 27.3 on June 30, 1993 to 25.5 on June 30, 1994. During the same period the placement rate for small state-operated MR/DD residential settings increased slightly from 3.9 to 4.0 per 100,000 of the total population.

States with over twice the average placement rate in large state MR/DD facilities on June 30, 1994 were Arkansas, Mississippi, New Jersey, and South Carolina. States with less than one-third the average placement rate in large state MR/DD facilities on June 30, 1994 included Alaska, Arizona, Colorado, District of Columbia, Hawaii, Michigan, New Hampshire, Rhode Island, Vermont, and West Virginia. Connecticut, New York, and Rhode Island had the highest placement rates in state-operated community settings of 15 or fewer residents (each over five times the national average). Rhode Island, Connecticut, and Mississippi had the highest placement rates in small state-operated settings of 6 or fewer residents (20.6, 13.1, and 9.2 per 100,000 of the state population, respectively).

Table 1.2 Persons with MR/DD Living in State-Operated  
MR/DD and Psychiatric Settings on June 30, 1994 by State

State	Size of State MR/DD Facilities					Psychiatric Facilities	Total Large (16+)	All State-Operated Facilities
	1-6	7-15	1-15	16+	Total			
AL	0	0	0	1,113	1,113	0	1,113	1,113
AK	0	0	0	38	38	0	38	38
AZ	106	171	277	123	400	0	123	400
AR	0	0	0	1,258	1,258	0	1,258	1,258
CA	0	0	0	6,343	6,343	0	6,343	6,343
CO	8	264	272	248	520	0	248	520
CT	428	302	730	1,342	2,072	52	1,394	2,124
DE	0	0	0	320	320	0	320	320
DC	0	0	0	0	0	54	54	54
FL	0	0	0	1,535	1,535	0	1,535	1,535
GA	0	0	0	1,991	1,991	41	2,032	2,032
HI	0	0	0	84	84	0	84	84
ID	0	0	0	143	143	0	143	143
IL	0	0	0	3,726	3,726	20	3,746	3,746
IN	0	0	0	1,384	1,384	0	1,384	1,384
IA	0	0	0	752	752	30	782	782
KS	0	0	0	806	806	0	806	806
KY	0*	0*	0*	620*	620*	92**	712*	712*
LA	58	0	58	2,126	2,184	0	2,126	2,184
ME	0	15	15	137	152	0	137	152
MD	0	0	0	822	822	11	833	833
MA	144	488	632	2,119	2,751	16	2,135	2,767
MI	0	0	0	411	411	0*	411	411
MN	170	0	170	751	921	0	751	921
MS	242	235	477	1,439	1,916	0**	1,439	1,916
MO	0	0	0	1,500	1,500	47	1,547	1,547
MT	0	0	0	163	163	0	163	163
NE	0	0	0	439	439	0	439	439
NV	24	0	24	145	169	0	145	169
NH	26	0	26	0	26	0	0	26
NJ	0	0	0	4,363	4,363	691*	5,054	5,054
NM	0	0	0	349	349	0	349	349
NY	701*	6,554*	7,255*	3,933*	11,188*	219**	4,152*	11,407*
NC	0	0	0	2,378	2,378	19	2,397	2,397
ND	0	12	12	146	158	17	163	175
OH	0	0	0	2,179	2,179	0	2,179	2,179
OK	0	0	0	658	658	0	658	658
OR	35	0	35	489	524	0	489	524
PA	0	0	0	3,563	3,563	214	3,777	3,777
RI	206	147	353	0	353	0	0	353
SC	0	0	0	1,885	1,885	0	1,885	1,885
SD	0	0	0	351	351	22	373	373
TN	0	0	0	1,784	1,784	0	1,784	1,784
TX	6	35	41	6,124	6,165	DNF	6,124	6,165
UT	0	0	0	362	362	0	362	362
VT	0	0	0	0	0	1	1	1
VA	0	0	0	2,298	2,298	0	2,298	2,298
WA	0	0	0	1,346	1,346	32	1,378	1,378
WV	0*	0*	0*	109*	109*	2*	111*	111*
WI	0	0	0	1,384	1,384	0	1,384	1,384
WY	0	0	0	156	156	0	156	156
U.S. Total	2,154	8,223	10,377	65,735	76,112	1,580	67,315	77,692

\* indicates 1993 data

\*\* indicates 1992 data

DNF indicates data not furnished



**Table 1.3 Persons with MR/DD Living in State-Operated MR/DD and  
Psychiatric Facilities Per 100,000 of the General  
Population on June 30, 1994 by State**

State	Population (100,000)	Size of State MR/DD Facilities					Psychiatric Facilities	Total Large (16+)	All State- Operated Facilities
		1-6	7-15	1-15	16+	Total			
AL	41.87	0.0	0.0	0.0	26.6	26.6	0.0	26.6	26.6
AK	5.99	0.0	0.0	0.0	6.3	6.3	0.0	6.3	6.3
AZ	39.36	2.7	4.3	7.0	3.1	10.2	0.0	3.1	10.2
AR	24.24	0.0	0.0	0.0	51.9	51.9	0.0	51.9	51.9
CA	312.11	0.0	0.0	0.0	20.3	20.3	0.0	20.3	20.3
CO	35.66	0.2	7.4	7.6	7.0	14.6	0.0	7.0	14.6
CT	32.77	13.1	9.2	22.3	41.0	63.2	1.6	42.5	64.8
DE	7.00	0.0	0.0	0.0	45.7	45.7	0.0	45.7	45.7
DC	5.78	0.0	0.0	0.0	0.0	0.0	9.3	9.3	9.3
FL	136.79	0.0	0.0	0.0	11.2	11.2	0.0	11.2	11.2
GA	69.17	0.0	0.0	0.0	28.8	28.8	0.6	29.4	29.4
HI	11.72	0.0	0.0	0.0	7.2	7.2	0.0	7.2	7.2
ID	10.99	0.0	0.0	0.0	13.0	13.0	0.0	13.0	13.0
IL	116.97	0.0	0.0	0.0	31.9	31.9	0.2	32.0	32.0
IN	57.13	0.0	0.0	0.0	24.2	24.2	0.0	24.2	24.2
IA	28.14	0.0	0.0	0.0	26.7	26.7	1.1	27.8	27.8
KS	25.31	0.0	0.0	0.0	31.8	31.8	0.0	31.8	31.8
KY	37.89	0.0*	0.0*	0.0*	16.4*	16.4*	2.4**	18.8*	18.8*
LA	42.95	1.4	0.0	1.4	49.5	50.8	0.0	49.5	50.8
ME	12.39	0.0	1.2	1.2	11.1	12.3	0.0	11.1	12.3
MD	49.65	0.0	0.0	0.0	16.6	16.6	0.2	16.8	16.8
MA	60.12	2.4	8.1	10.5	35.2	45.8	0.3	35.5	46.0
MI	94.78	0.0	0.0	0.0	4.3	4.3	0.0*	4.3	4.3
MN	45.17	3.8	0.0	3.8	16.6	20.4	0.0	16.6	20.4
MS	26.43	9.2	8.9	18.0	54.4	72.5	0.0**	54.4	72.5
MO	52.34	0.0	0.0	0.0	28.7	28.7	0.9	29.6	29.6
MT	8.39	0.0	0.0	0.0	19.4	19.4	0.0	19.4	19.4
NE	16.07	0.0	0.0	0.0	27.3	27.3	0.0	27.3	27.3
NV	13.89	1.7	0.0	1.7	10.4	12.2	0.0	10.4	12.2
NH	11.25	2.3	0.0	2.3	0.0	2.3	0.0	0.0	2.3
NJ	78.79	0.0	0.0	0.0	55.4	55.4	8.8*	64.1	64.1
NM	16.16	0.0	0.0	0.0	21.6	21.6	0.0	21.6	21.6
NY	181.97	3.9*	36.0	39.9*	21.6*	61.5*	1.2**	22.8*	62.7*
NC	69.45	0.0	0.0	0.0	34.2	34.2	0.3	34.5	34.5
ND	6.35	0.0	1.9	1.9	23.0	24.9	2.7	25.7	27.6
OH	110.91	0.0	0.0	0.0	19.6	19.6	0.0	19.6	19.6
OK	32.31	0.0	0.0	0.0	20.4	20.4	0.0	20.4	20.4
OR	30.32	1.2	0.0	1.2	16.1	17.3	0.0	16.1	17.3
PA	120.48	0.0	0.0	0.0	29.6	29.6	1.8	31.3	31.3
RI	10.00	20.6	14.7	35.3	0.0	35.3	0.0	0.0	35.3
SC	36.43	0.0	0.0	0.0	51.7	51.7	0.0	51.7	51.7
SD	7.15	0.0	0.0	0.0	49.1	49.1	3.1	52.2	52.2
TN	50.99	0.0	0.0	0.0	35.0	35.0	0.0	35.0	35.0
TX	180.31	0.0	0.2	0.2	34.0	34.2	DNF	34.0	34.2
UT	18.60	0.0	0.0	0.0	19.5	19.5	0.0	19.5	19.5
VT	5.76	0.0	0.0	0.0	0.0	0.0	0.2	0.2	0.2
VA	64.91	0.0	0.0	0.0	35.4	35.4	0.0	35.4	35.4
WA	52.55	0.0	0.0	0.0	25.6	25.6	0.6	26.2	26.2
WV	18.20	0.0*	0.0*	0.0*	6.0*	6.0*	0.1*	6.1*	6.1*
WI	50.38	0.0	0.0	0.0	27.5	27.5	0.0	27.5	27.5
WY	4.70	0.0	0.0	0.0	33.2	33.2	0.0	33.2	33.2
U.S. Total	2,579.04	0.8	3.2	4.0	25.5	29.5	0.6	26.1	30.1

\* indicates 1993 data

\*\* indicates 1992 data

DNF indicates data not furnished

### *Change in Average Daily Population; 1980-1994*

Table 1.4 presents summaries of the average daily population of large state MR/DD facilities by state for 1980, 1985, 1990, and 1994 and the percentage of change in average daily population between 1994 and 1980, 1985 and 1990, respectively. The total decrease in populations of large state MR/DD facilities between 1980 and 1994 was 63,415 average daily residents (48.4%). Half of all states (25) reduced their populations in large state MR/DD facilities by more than 50% during the period. In nine states the decrease was 80% or more: Arizona, Colorado, District of Columbia, Hawaii, Michigan, New Hampshire, North Dakota, Rhode Island, and Vermont.

In the first five years of this period (1980-1985) average daily populations of large state MR/DD facilities decreased by 21,474 (16.4%) or an annual average of about 4,300 residents (or 3.3% per year). In the next five years of this period (1985-1990) large state MR/DD facilities' average daily populations decreased by 25,225 (23.0%) or an annual average of about 5,045 residents (or 4.6% per year). In the four years between 1990 to 1994 the average daily population of large state MR/DD facilities decreased by 16,716 (19.8%) or about 4,200 residents per year (or 5.0% per year). Every state reduced its average daily population of large state MR/DD facilities between 1990 and 1994, and in all but 8 states the decrease was at least 10%.

#### *Movement of Residents in Large State MR/DD Facilities*

Table 1.5 presents statistics on the admissions, discharges, and deaths among residents of large state MR/DD facilities during Fiscal Year 1994. Admissions, discharges, and deaths are also indexed as a percentage of the average daily residents of those settings. It should be noted that there are small differences between these state level movement statistics and the related movement statistics reported in Part 3 of this

chapter, which are based on the reports of individual large state MR/DD facilities.

**Admissions.** During Fiscal Year 1994, an estimated total of 2,243 persons with MR/DD were admitted to large state MR/DD residential facilities. This number was equal to 3.3% of the year's average daily population of those same settings. Twelve states reported no admissions to large state MR/DD residential facilities (Alaska, Arizona, Delaware, District of Columbia, Hawaii, Idaho, Kansas, New Hampshire, New Mexico, Rhode Island, Vermont, and Wyoming). Four states reported admissions exceeding 10% of the year's average daily population (Georgia, Maine, Montana, and Nevada).

**Discharges.** During Fiscal Year 1994 an estimated total of 5,490 persons with MR/DD were discharged from large state MR/DD residential facilities. Discharges equaled 8.1% of the average daily population of large state MR/DD residential facilities during the year. Four states reported discharges equal to 20% or more of their large state MR/DD residential facilities average daily residents (Indiana, Maine, Minnesota, and North Dakota). Eighteen states reported discharges of 10% or more of the year's average daily population of large MR/DD state facilities.

**Deaths.** During Fiscal Year 1994 an estimated total of 995 people with MR/DD died while residing in large state MR/DD residential facilities. Deaths equaled 1.5% of the average daily population of the large state MR/DD residential facilities. The 1994 death rate of 1.47% was slightly less than the 1993 rate of 1.63% and slightly greater than the 1992 rate of 1.42%. Four states reported no deaths during the year (Alaska, Hawaii, Idaho, and Nevada). Fiscal Year 1994 was the first year since 1910 that fewer than 1,000 people died while residents of large state MR/DD facilities.

**Table 1.4 Changes in the Average Daily Population of Persons with MR/DD  
Living in Large State MR/DD Facilities by State, 1980-1994**

State	1980	1985	1990	1994	% Change 1980-1994	% Change 1985-1994	% Change 1990-1994
AL	1,651	1,422	1,305	1,159	-29.8%	-18.5%	-11.2%
AK	86e	76	58	42	-51.2%	-44.7%	-27.6%
AZ	672	538	360e	124	-81.5%	-77.0%	-65.6%
AR	1,550	1,254	1,260	1,254	-19.1%	-0.0%	-0.5%
CA	8,812	7,524	6,768	6,563	-25.5%	-12.8%	-3.0%
CO	1,353	1,125	466e	250	-81.5%	-77.8%	-46.4%
CT	2,944	2,905	1,799	1,378	-53.2%	-52.6%	-23.4%
DE	518	433	345e	320	-38.2%	-26.1%	-7.2%
DC	775	351	309e	0	-100.0%	-100.0%	-100.0%
FL	3,750	2,268	1,992e	1,640	-56.3%	-27.7%	-17.7%
GA	2,535	2,097	2,069	2,021	-20.3%	-3.6%	-2.3%
HI	432	354	162	85	-80.3%	-76.0%	-47.5%
ID	379	317	210	146	-61.5%	-53.9%	-30.5%
IL	6,067	4,763	4,493	3,794	-37.5%	-20.3%	-15.6%
IN	2,592	2,248	1,940e	1,405	-45.8%	-37.5%	-27.6%
IA	1,225	1,227	986	784	-36.0%	-36.1%	-20.5%
KS	1,327	1,309	1,017e	834	-37.2%	-36.3%	-18.0%
KY	907	671	709	627*	-30.9%	-6.6%	-11.6%
LA	2,914	3,375	2,622	2,232	-23.4%	-33.9%	-14.9%
ME	460	340	283	170	-63.0%	-50.0%	-39.9%
MD	2,527	1,925	1,289	858	-66.0%	-55.4%	-33.4%
MA	4,531	3,580	3,000	2,119	-53.2%	-40.8%	-29.4%
MI	4,888e	2,191	1,137e	448	-90.8%	-79.6%	-60.6%
MN	2,692	2,065	1,392	787	-70.8%	-61.9%	-43.5%
MS	1,660	1,828	1,498	1,445	-13.0%	-21.0%	-3.5%
MO	2,257	1,856	1,860e	1,496	-33.7%	-19.4%	-19.6%
MT	316	258	235	161	-49.2%	-37.8%	-31.7%
NE	707	488	466	447	-36.8%	-8.4%	-4.1%
NV	148	172	170	145	-2.0%	-15.7%	-14.7%
NH	578	267	87	0	-100.0%	-100.0%	-100.0%
NJ	7,262	5,705	5,069	4,386	-39.6%	-23.1%	-13.5%
NM	500	471	500	403	-19.4%	-14.4%	-19.4%
NY	15,140	13,932	7,694	4,307*	-71.6%	-69.1%	-44.0%
NC	3,102	2,947	2,654	2,364	-23.8%	-19.8%	-10.9%
ND	1,056	763	232	156	-85.2%	-70.6%	-32.8%
OH	5,045	3,198	2,665e	2,209	-56.2%	-30.9%	-17.1%
OK	1,818	1,505	935	662	-63.6%	-56.0%	-29.2%
OR	1,724	1,488	838	506	-70.6%	-66.0%	-39.6%
PA	7,290	5,980	3,986	3,616	-50.4%	-39.5%	-9.3%
RI	681	415	201	0	-100.0%	-100.0%	-100.0%
SC	3,043	2,893e	2,286	2,120	-30.3%	-26.7%	-7.3%
SD	678	557	391	351	-48.2%	-37.0%	-10.2%
TN	2,074	2,107	1,932	1,800	-13.2%	-14.6%	-6.8%
TX	10,320	9,638	7,320e	6,211	-39.8%	-35.6%	-15.2%
UT	778	706	462	365	-53.1%	-48.3%	-21.0%
VT	331	200	180	0	-100.0%	-100.0%	-100.0%
VA	3,575	3,069	2,650	2,375	-33.6%	-22.6%	-10.4%
WA	2,231	1,844	1,758	1,404	-37.1%	-23.9%	-20.1%
WV	563	498	304e	113*	-79.9%	-77.3%	-62.8%
WI	2,151	2,058e	1,678e	1,426	-33.7%	-30.7%	-15.0%
WY	473	413	367	166	-64.9%	-59.8%	-54.8%
U.S. Total	131,088	109,614	84,389	67,673	-48.4%	-38.3%	-19.8%

e indicates estimate  
\* indicates 1993 data

**Table 1.5 Movement of Persons with MR/DD In and Out of Large State  
MR/DD Facilities in Fiscal Year 1994 by State**

State	Average Daily Population	Admissions		Discharges		Deaths	
		16+ Total	% Average Daily Pop.	16+ Total	% Average Daily Pop.	16+ Total	% Average Daily Pop.
AL	1,159	78	6.7	183	15.8	16	1.4
AK	42	0	0.0	6	14.3	0	0.0
AZ	124	0	0.0	6	4.8	4	3.2
AR	1,254	54	4.3	40	3.2	5	0.4
CA	6,563	260	4.0	615	9.4	84	1.3
CO	250	24	9.6	32	12.8	8	3.2
CT	1,378	33	2.4	67	4.9	22	1.6
DE	320	0	0.0	4	1.3	2	0.6
DC	0	0	0.0	0	0.0	0	0.0
FL	1,640	6	0.4	176e	10.7	39e	2.4
GA	2,021	204	10.1	201	9.9	11	0.5
HI	85	0	0.0	0	0.0	0	0.0
ID	146	0	0.0	0	0.0	0	0.0
IL	3,794	105	2.8	304	8.0	56	1.5
IN	1,405	32	2.3	282	20.1	13	0.9
IA	784	66	8.4	81	10.3	20	2.6
KS	834	0	0.0	62	7.4	8	1.0
KY	627*	62*	9.9	79e	12.6	1*	0.2
LA	2,234	51	2.3	62	2.8	31	1.4
ME	170	21	12.4	76	44.7	1	0.6
MD	858	61	7.1	111	12.9	22	2.6
MA	2,119	1	0.0	105	5.0	48	2.3
MI	448	20e	4.5	43e	9.6	10e	2.2
MN	787	33	4.2	206	26.2	3	0.4
MS	1,445	92	6.4	89	6.2	28	1.9
MO	1,496	126	8.4	98	6.6	20	1.3
MT	161	18	11.2	1 <sup>1</sup>	6.9	2	1.2
NE	447	1	0.2	7	1.6	6	1.3
NV	145	18	12.4	18	12.4	0	0.0
NH	0	0	0.0	0	0.0	0	0.0
NJ	4,386	113	2.6	101	2.3	61	1.4
NM	403	0	0.0	68	16.9	4	1.0
NY	4,307*	114a	2.6	642a	14.9	68*	1.6
NC	2,364	63	2.7	134	5.7	30	1.3
ND	156	13	8.3	37	23.7	7	4.5
OH	2,209	51	2.3	85	3.8	27	1.2
OK	662	39	5.9	120	18.1	6	0.9
OR	506	48	9.5	86	17.0	1	0.2
PA	3,616	17	0.5	128	3.5	65	1.8
RI	0	0	0.0	19	0.0	0	0.0
SC	2,120	60	2.8	204	9.6	52	2.5
SD	351	20	5.7	16	4.6	5	1.4
TN	1,800	65	3.6	118	6.6	33	1.8
TX	6,211	152e	2.4	368	5.9	101	1.6
UT	365	3	0.8	14	3.8	7	1.9
VT	0	0	0.0	0	0.0	0	0.0
VA	2,375	99	4.2e	152	6.4	33	1.4
WA	1,404	2	0.1	109	7.8	11	0.8
WV	113*	11*	9.7	19*	16.8	1*	0.9
WI	1,426	7	0.5	77	5.4e	19	1.3
WY	166	0	0.0	29	17.5	4	2.4
U.S. total	67,673	2,243	3.3	5,490	8.1	995	1.5

e indicates estimate

\* indicates 1993 data

a indicates data from survey of each state MR/DD facility

*Expenditures for Care in State-Operated  
Residential Facilities*

Table 1.6 summarizes the expenditures for state-operated MR/DD residential facilities. These expenditures are reported for individual states as an average daily expenditure per resident. The national averages presented are the average daily expenditure per resident reported by each state weighted by that state's average daily resident population. For Fiscal Year 1994, data on the average daily expenditures for large state MR/DD residential facilities was available for all but seven states. Eleven of the 19 states reporting residents with MR/DD in state psychiatric facilities reported daily expenditures for those facilities. All states with small state MR/DD facilities reported an average daily expenditure per resident for those facilities.

Average expenditures for care in large state MR/DD residential facilities varied considerably across the United States with a national average of \$225.36. Nine states reported costs in large state MR/DD residential facilities that exceeded \$350.00 per day in Fiscal Year 1994 (Alaska, Connecticut, Hawaii, Idaho, Maine, Massachusetts, New York, Oregon, and West Virginia). Among the 47 states with large state MR/DD residential facilities 25 reported annual expenditures per resident above the national average of \$225.36 per person per year. Mississippi reported the lowest average daily expenditure per resident for large state MR/DD residential facilities (\$127.33). From Fiscal Year 1993 to 1994 the average daily expenditure per resident of large state MR/DD residential facilities increased only 1.0% from \$223.16. This compares with 5.9% increase between 1992 and 1993 and an average annual increase since 1977 has been 10.1%. When changes in state-operated MR/DD large residential facility costs are controlled for inflation in the Consumer Price Index they

increased by only 2.4% in the 5 year period between 1989 and 1994. A major factor in the stabilizing of per resident expenditures in large state MR/DD facilities was the closure of 85 large state-operated MR/DD residential facilities and special MR/DD units between 1988 and 1995. Prior to 1988 state expenditure increases for large state-operated MR/DD residential facilities were substantially affected by fewer and fewer residents sharing the fixed costs of a stable number of facilities. Closure and consolidation of large state MR/DD facility programs have reduced the effects of these fixed costs on average per resident expenditures. (These closures are described in Chapter 4.)

The 11 states providing for persons with MR/DD in state psychiatric facilities and reporting the expenditures for them reported average daily expenditures per resident of \$202.11. It should be noted that the reported psychiatric facility expenditures are usually the average daily expenditure per resident for the entire facility, not specifically the expenditures for residents with MR/DD. State psychiatric facility populations have been stable for several years nationwide, so that per resident expenditures have not been driven up as much by the spreading of fixed facility costs over fewer and fewer residents as had been occurring in the large state MR/DD residential facilities.

National average expenditures for small state-operated MR/DD residential facilities were \$257.30 per resident per day. This average rate of expenditure is above that of large state MR/DD residential facilities nationwide, but the difference is related to the states providing small facility services. Of the 12 states reporting both small and large state MR/DD facility expenditures, the per person expenditures in large state-operated MR/DD facilities were less than those of small state-operated MR/DD facilities in only two.

**Table 1.6 Average per Resident Daily Expenditures in Large State-Operated Facilities in Fiscal Year 1994 by State**

	State MR/DD Facilities		Psychiatric Facilities
	1-15 Residents	16+ Residents	
AL	NA	\$204.00	NA
AK	NA	\$397.25	NA
AZ	\$294.81e	\$232.85e	NA
AR	NA	\$154.00	NA
CA	NA	\$219.00	NA
CO	\$235.27e	\$235.27e	NA
CT	\$297.00**	\$353.00**	DNF
DE	NA	\$219.19	NA
DC	NA	NA	DNF
FL	NA	\$186.56	NA
GA	NA	\$196.86**	\$216.00*
HI	NA	\$365.22*	NA
ID	NA	\$373.21	NA
IL	NA	\$196.00	\$210.00
IN	NA	\$219.00	NA
IA	NA	\$202.00	\$166.00
KS	NA	\$232.41	NA
KY	NA	\$155.00e*	\$170.00*
LA	\$167.73	\$163.71	NA
ME	\$170.00	\$365.00	NA
MD	NA	\$249.89	\$327.00
MA	\$284.19	\$406.94	DNF
MI	NA	\$303.77	NA
MN	\$249.50	\$310.00	NA
MS	\$65.18	\$127.33	NA
MO	NA	\$184.11	\$185.00e
MT	NA	\$233.00	NA
NE	NA	\$174.71	NA
NV	\$231.00	\$264.00	NA
NH	\$339.71	NA	NA
NJ	NA	\$249.00	DNF
NM	NA	\$324.00	NA
NY	\$264.75**	\$350.00**	DNF
NC	NA	\$224.49	DNF
ND	NA	\$346.05	\$300.00
OH	NA	\$242.00	NA
OK	NA	\$281.97	NA
OR	\$447.00	\$411.25	NA
PA	NA	\$224.70	DNF
RI	\$322.84	NA	NA
SC	NA	\$145.33	NA
SD	NA	\$196.38	\$188.54
TN	NA	\$155.82	NA
TX	\$124.14	\$138.44	DNF
UT	NA	\$180.00	NA
VT	NA	NA	\$412.27
VA	NA	\$187.41	NA
WA	NA	\$303.03	\$225.00e
WV	NA	\$363.80*	\$365.19*
WI	NA	\$242.00	NA
WY	NA	\$304.00	NA
U.S. weighted average	\$257.30	\$225.36	\$202.11

DNF indicates Data Not Furnished

e indicates estimates

\* indicates 1993 data

\*\* indicates 1992 data

**CHAPTER 2**  
**LONGITUDINAL TRENDS IN LARGE STATE-OPERATED**  
**RESIDENTIAL FACILITIES, 1950-1994**

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This chapter presents a longitudinal view of changing patterns in the placement of persons with MR/DD in state-operated residential facilities with 16 or more residents during the period from 1950 to 1994. Although in recent years there has been substantial development in small state-operated residential facilities, the vast majority of residents of state-operated facilities remain in large facilities (i.e., those with 16 or more residents). As the once overwhelmingly predominant model of residential care (large state MR/DD facilities housed 90.4% of all persons with MR/DD in residential settings in 1967), few statistics have served as better broad indicators of the changing patterns of residential services for persons with MR/DD than the changes taking place in the populations of large state residential facilities.

The longitudinal data presented here are derived from several sources. Data for both state MR/DD and psychiatric facilities for the years 1950 to 1968 are from the National Institute of Mental Health's surveys of "Patients in Institutions". Data on the state mental retardation/developmental disabilities facilities for Fiscal Year 1969 and 1970 come from surveys conducted by the Office on Mental Retardation Coordination, now the Administration on Developmental Disabilities. Data on large state MR/DD facilities for 1971 through 1977 come from the surveys of the National Association of Superintendents of Public Residential Facilities for Persons with Mental Retardation, now the Association of Public Developmental Disabilities Administrators. Data on psychiatric facilities for 1969 to 1977 come from the National Institute of Mental Health's surveys of "Patients in State and County Mental Hospitals". Data on both large state MR/DD and psychiatric facilities for the years 1978 through 1994 come from the ongoing data collection of this project. Data for 1994, the latest survey in this series, are presented in detail in Part 1 of this chapter. The list of "References and Data Sources" includes

specific citations for the surveys and statistical summaries used to complete the longitudinal data set. A detailed description of the methodologies used in these surveys can be found in Lakin (1979).

*Average Daily Population of Persons with  
Mental Retardation and Developmental Disabilities  
in Large State MR/DD and Psychiatric Facilities*

The gradual depopulation of large state residential facilities for persons with MR/DD has been occurring on a national basis since 1967. Nationally, there has been a decreasing total residential population of large state residential facilities for all types of mental disability (i.e., psychiatric and MR/DD) since 1956. Although the total population in state psychiatric facilities peaked in 1955, the number of persons with a primary diagnosis of mental retardation in state psychiatric facilities continued to increase until 1961. In 1961, there were nearly 42,000 persons with a primary diagnosis of mental retardation in such facilities. The combined total of persons with MR/DD in both large state MR/DD and psychiatric facilities in 1961 was 209,114. By 1967 the number of persons with MR/DD in state psychiatric facilities had decreased to 33,850, but the total number of persons with MR/DD in all large state-operated facilities had increased to 228,500, 194,650 of whom were in large state MR/DD facilities. This was the highest total ever.

Since 1967 the number of persons with MR/DD in all large state residential facilities has decreased to less than one-third of the 1967 total (32.0%). During this period the numbers of persons with MR/DD in state psychiatric facilities decreased much more rapidly than did the number of persons in large state MR/DD facilities. The different rates of depopulation reflect a number of factors. For one, the overall rate of depopulation of state psychiatric facilities has been much more rapid than the rate of depopulation of state

MR/DD facilities. Since 1965 the total populations of state psychiatric facilities decreased by more than 75% (Zappolo, Lakin and Hill, 1990). This rapid depopulation and frequent closing of facilities has contributed to major reductions in residents with all types of mental disability, including MR/DD. Relatedly over the years, many large state residential facilities became primarily dedicated to populations with MR/DD or developed independent MR/DD units on the grounds of what were historically public psychiatric facilities.

A driving force in the reduction of residents with MR/DD in state psychiatric facilities has been the general movement toward deinstitutionalization and specific concerns about the appropriateness of placement in psychiatric facilities. It was also important that Medicaid legislation in the late 1960s and early 1970s allowed states to obtain federal cost-sharing of institutional services to persons with MR/DD in Intermediate Care

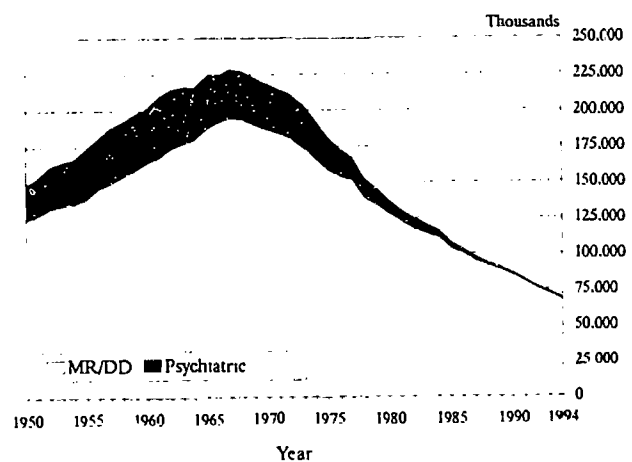
Facilities-Mental Retardation (ICFs-MR) and in nursing homes, but excluded residents of facilities for "mental diseases" from participation in Medicaid, except for children and elderly residents. Distinct units for persons with MR/DD within those facilities could become ICF-MR certified. Many did and those units within the definitions employed in this study are now classified among the large state MR/DD residential facilities.

Figure 1.1 shows the relative contribution of state MR/DD and state psychiatric facilities to the total average daily population of persons with MR/DD in all large state-operated residential facilities. The average daily number of persons with MR/DD in large state MR/DD facilities in Fiscal Year 1994 (67,673) was only 34.8% of the average number in large state MR/DD facilities in 1967, and the total number of persons with MR/DD in all large state residential facilities (69,286) was only 30.3% of the 1967 total.

**Table 1.7 Average Daily Population of Persons with Mental Retardation/ Developmental Disabilities in Large State MR/DD and Psychiatric Facilities, 1950-1994**

Year	MR/DD	Psychiatric	Total
1950	124,304	23,905	148,209
1955	138,831	34,999	173,830
1960	163,730	37,641	201,371
1965	187,305	36,825	224,130
1967	194,650	33,850	228,500
1970	186,743	31,884	218,627
1973	173,775	30,237	204,012
1977	151,532	15,524	167,056
1980	128,058	9,405	137,463
1982	117,160	7,865	125,026
1984	111,333	5,096	116,429
1986	100,190	3,106	103,296
1988	91,582	1,933	93,515
1989	88,691	1,605	90,296
1990	84,732	1,487	86,219
1991	80,269	1,594	81,863
1992	75,151	1,561	76,712
1993	71,477	1,741	73,218
1994	67,673	1,613	69,286

**Figure 1.1 Average Daily Population of Persons with Mental Retardation and Related Conditions in Large MR/DD and Psychiatric Facilities, 1950-1994**





*Average Daily Population of Persons with Mental Retardation/Developmental Disabilities in Large State MR/DD and Psychiatric Facilities per 100,000 of the General Population*

Since 1967 there has been a substantial decrease in the number of people with MR/DD in large state-operated residential facilities. But as notable as the reduction in total residents, it is even more substantial when adjusted for the growing total population of the United States. Indexing the population of large state facilities by the general population of the U.S. permits a better picture of the relative use of these settings for persons with MR/DD. The average annual placement rates per 100,000 of the total U.S. population for large state MR/DD and psychiatric facilities are shown in Figure 1.2.

The trends in the placement rates of persons with MR/DD in all large state residential facilities are generally similar to trends for the total populations. However, the rate of decrease in the placement rate has been substantially faster because the U.S. population has grown as the population of the large state facilities has decreased. The placement rate of persons with MR/DD in all large state facilities (MR/DD and psychiatric) peaked in 1965 at 115.8 per 100,000 of the general population. This compares with 26.87 in Fiscal Year 1994. The highest placement rate in large state MR/DD facilities was in 1967. That year's placement rate of 98.6 was almost four times greater than the 1994 rate of 26.2.

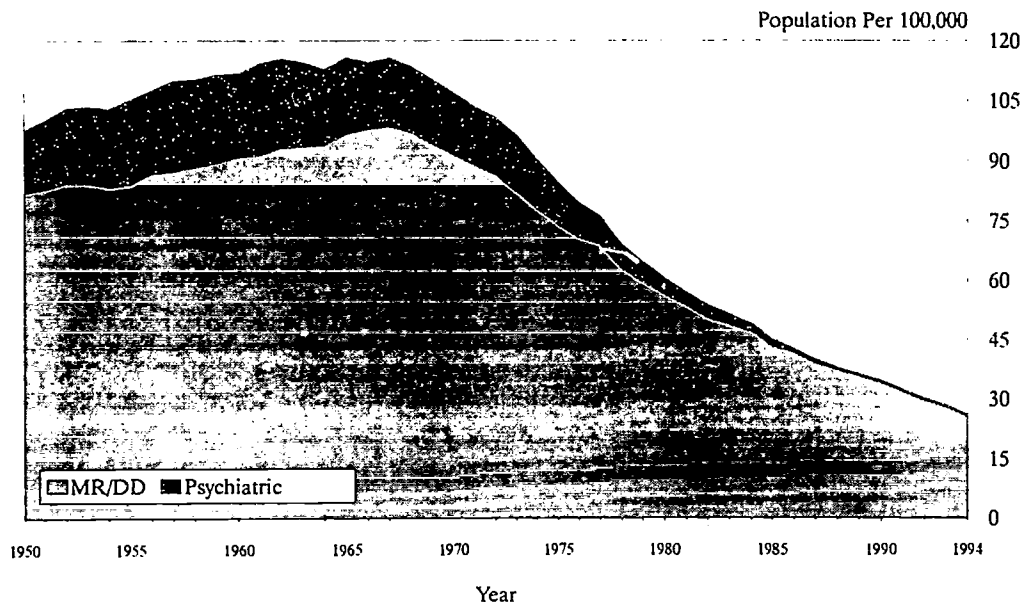
As noted earlier, some of the decrease in the placement rate in large state psychiatric facilities between 1973 and 1994 reflects changing definitions. During that period some settings historically serving psychiatric populations either through official or operational designation became facilities primarily serving persons with MR/DD. Others developed specific administratively distinct MR/DD units within

traditional psychiatric facilities. But by far the most important factors in the decreasing numbers of persons with MR/DD in psychiatric facilities have been the major changes in philosophy and federal sharing of the costs of care for persons living in large MR/DD facilities certified to participate in the Intermediate Care Facility for Persons with Mental Retardation (ICF-MR) program (258 of 287 large state MR/DD facilities nationwide). The statistics in Figure 1.2 show clearly a substantial decrease in the rate of placement of persons with MR/DD in state-operated residential facilities. The placement rate in 1994 for all large state facilities (26.9) was less than one quarter of the 1965 placement rate (115.8).

**Table 1.8 Average Daily Population of Persons with Mental Retardation/Developmental Disabilities in Large State MR/DD and Psychiatric Facilities per 100,000 of the General Population, 1950-1994**

Year	U.S. Population in 100,000s			
	on July 1	MR/DD	Psychiatric	Total
1950	1,518.68	81.85	15.75	97.59
1955	1,650.69	84.10	21.20	105.30
1960	1,799.79	90.97	20.91	111.88
1965	1,935.26	96.79	19.03	115.82
1967	1,974.57	98.58	17.14	115.72
1970	2,039.84	91.55	15.63	107.18
1973	2,113.57	82.22	14.31	96.53
1980	2,272.36	56.35	4.14	60.49
1984	2,361.58	47.14	2.16	49.30
1986	2,387.70	41.96	1.30	43.26
1989	2,482.43	35.73	0.65	36.38
1990	2,487.09	34.07	0.58	34.65
1991	2,521.77	31.83	0.63	32.46
1992	2,540.02	29.58	0.61	30.20
1993	2,559.50	27.93	0.68	28.61
1994	2,579.04	26.24	0.63	26.87

**Figure 1.2**  
**Population of Persons with MR/DD in Large State MR/DD and Psychiatric**  
**Facilities per 100,000 of the General Population on June 30 of Years Indicated**



***Movement Patterns in Large State MR/DD Residential Facilities***

From the beginning of this century until the mid-1960's, resident movement statistics of large state MR/DD residential facilities indicated relatively stable movement patterns. During that period first admissions and discharges both steadily increased, but populations of large state MR/DD facilities grew as first admissions substantially outnumbered discharges. During this same period readmissions remained relatively low because once placed in a state facility, people tended to remain there. From 1903 to 1965 the annual number of deaths in large state MR/DD facilities increased substantially, but death rates (deaths as a percentage of average daily population) decreased steadily from 4.1% to 1.9%.

By the mid-1960s these historical patterns began to change. In 1965 the number of first admissions to large state MR/DD facilities began to decrease, dropping below the increasing number of discharges by 1968. The number of readmissions increased substantially throughout the 1970s as return to the facility was a frequently used solution to problems in community placements. From 1980 to 1994, readmissions were reduced

fairly steadily, but remained a substantial proportion of total admissions (35.7% in 1991 and 30.7% in 1994). Over this same period total admissions (first admissions and readmissions) generally remained fairly consistently between 2,000 and 3,000 fewer than the number of discharges. In general, however, distinctions are no longer being made in this state survey for new admissions and readmissions, because the increasing rates of large state MR/DD facility closures, consolidations, and resident transfers have made such distinctions less easily obtained from state reporting systems. (Statistics on patterns of new admissions and readmissions based on the reports of individual state MR/DD facilities from 1985 to 1994 are provided in Chapter 3 in this Section.) Figure 1.3 shows that between Fiscal Year 1993 and Fiscal Year 1994 overall admissions to large state MR/DD facilities decreased from 2,949 to 2,243 persons.

In recent years, the number of discharges has fallen far below the numbers apparent in the first 12 years of large state MR/DD facility depopulation (i.e., until 1980). The period of the greatest number of discharges was the decade of the 1970s when discharges were consistently between 14,000 and 17,000 per year. In the six

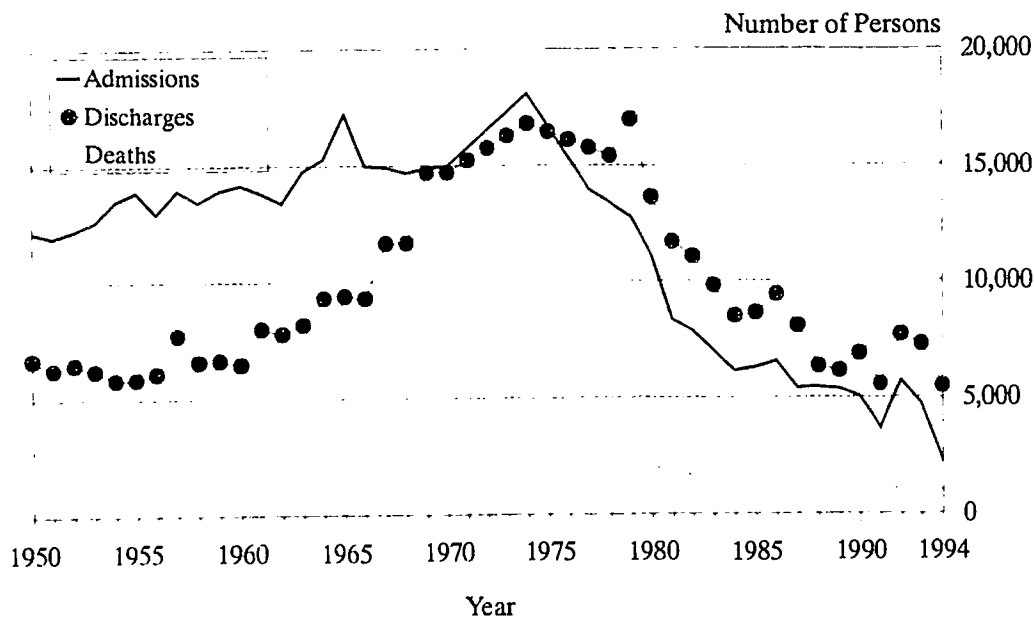
year period including fiscal years 1989 through 1994 discharges have remained in a range between 5,490 and 6,877 per year. In 1994 there were 5,490 total discharges.

Deinstitutionalization literally connotes a process of discharging people from large residential facilities, but Figure 1.3 shows clearly that it has also encompassed important successes in reducing initial placements in such facilities. The resident movement patterns shown in Figure 1.3 indicate that this latter "preventative" policy (i.e., reducing admissions to large state MR/DD facilities) has actually accounted for relatively more of the reduction in large state MR/DD facility populations over the past decade than has the number of discharges, although both clearly have played important roles. As shown in Figure 1.3 there had been a generally steady decrease in both admissions and discharges over the past two decades. Total deaths reported for 1994 decreased slightly from 1993. In 1994 the number of deaths as a percentage of average daily residents was 1.47% as compared with 1.63% in 1993 and 1.42% in 1992.

**Table 1.9 Movement Patterns in Large State MR/DD Residential Facilities, 1950-1994**

Year	Admissions	Discharges	Deaths
1950	12,197	6,672	2,761
1955	13,906	5,845	2,698
1960	14,182	6,451	3,133
1965	17,225	9,358	3,585
1967	14,904	11,665	3,635
1970	14,979	14,702	3,496
1974	18,075	16,807	2,913
1978	10,508	15,412	2,154
1980	11,141	13,622	2,019
1984	6,123	8,484	1,555
1986	6,535	9,399	1,322
1989	5,337	6,122	1,180
1990	5,034	6,877	1,207
1991	3,654	5,541	1,077
1992	4,349	6,316	1,075
1993	2,947	5,536	1,167
1994	2,243	5,490	995

**Figure 1.3 Movement Patterns in Large State MR/DD Residential Facilities, 1950-1994**



### *Annual Per Resident Expenditures in Large State-Operated MR/DD Facilities*

The per person expenditures for people with MR/DD living in large state-operated MR/DD facilities have increased dramatically since 1950, when the average per person annual expenditures for care was \$745.60 per person per year. Even in dollars adjusted for changes in the Consumer Price Index over this period, expenditures for care in 1994 (\$82,256 per year) were about 18 times as great as in 1950. Figure 1.4 shows the trends in large state MR/DD facility expenditures in both actual and adjusted dollars (\$1=1983) between 1950 and 1994. In terms of 1983 "real dollar" equivalents, the average annual per person expenditures for care in large state MR/DD facilities increased from just over \$3,000 to over \$55,500 during the 44 year period. That rate of increase represents an annual, after inflation, compounded growth of 10% per person per year. However, in the last five years, the rate increases have slowed substantially. Between Fiscal Year 1989 and 1994 states reported a 2.4% real dollar increase in large state MR/DD facility expenditures. This compares to an average real dollar increase of 8.1% per year during the 1980's.

A major factor in controlling large state MR/DD facility expenditures has been the large number of recent facility closures described in Chapter 4 of this report. Prior to this period, a number of factors had been contributing to the steady increases in the large state MR/DD facility expenditures. One contributing factor has been the continuing increase in the proportion of persons with severe impairments in their resident populations. As one indicator of this, in 1940 about 65% of all residents of large state MR/DD facilities had borderline, mild, or moderate retardation and 16% had an equivalent of profound mental retardation. In 1964, 40% of residents were classified as having borderline, mild or moderate mental retardation and 27% as having profound mental retardation. By 1994, the proportion of persons with borderline, mild or moderate mental retardation had decreased to 15%, while the proportion of persons with profound mental retardation had increased to 65.5%. Associated with these changes have been increased staff to resident ratios and increased numbers of professional staff employed to serve remaining residents.

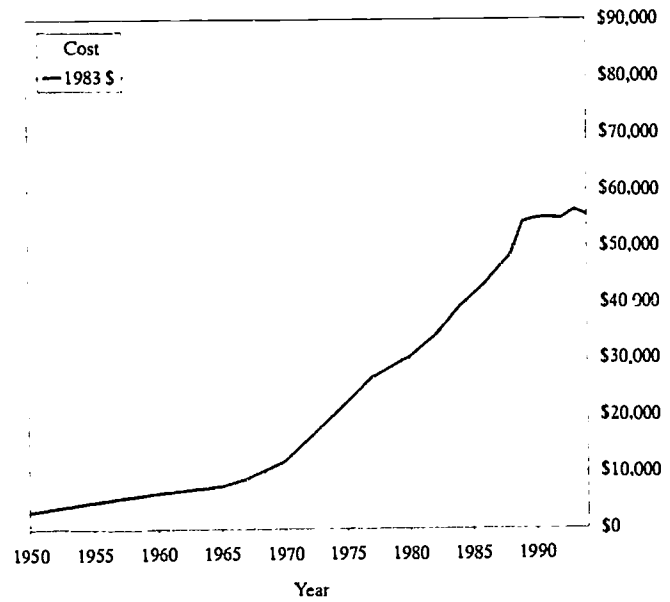
Two major factors began to exercise considerable upward pressure on expenditures in the early 1970's. The first of these was the Intermediate Care Facility for Persons with Mental Retardation (ICF-MR) program enacted in 1971 (described in Section III). This program offers Federal cost-sharing through Medicaid of 50-80% of the expenditures for residential and "active treatment" services, depending on the per capita income in states, under the condition that facilities meet specific program, staffing, and physical plant standards. In 1994, 19 of every 20 large state MR/DD facility residents lived in units with ICF-MR certification. The ICF-MR program has significantly cushioned the impact of rapidly increasing large MR/DD facility costs for the states. For example, in 1970, one year before enactment of the ICF-MR program, the average annual per resident real dollar (\$1=1983) expenditure in large state MR/DD facilities was about \$12,000. In 1994, the average annual per resident real dollar cost was \$ 55,500. Over that period state large MR/DD residential facility real dollar expenditures grew by 4.65 times, but the states' share of the increased real dollar expenditures for state institution care "only" doubled because of the new federal ICF-MR cost-sharing that began in 1971. Court decisions and settlement agreements have also had significant impact on expenditures with their frequent requirements for upgrading staffing levels, adding programs, improving physical environments, and frequently, reducing resident populations.

From the late 1960's until the late 1980's, the steady decrease in large state MR/DD facility populations with neither reductions in facility budgets nor substantially reduced number of facilities led to steady increases in per resident expenditures. As states moved more and more of their former large state MR/DD facility residents to community residential arrangements, the fixed costs of underutilized physical plants and specialized professional staff played a major role in pushing up the per resident expenditures. The greatly increased number of closures of state MR/DD facilities in the second half of the 1980s and the first half of the 1990s has played an important role in the remarkably reduced rate of growth of state MR/DD facility expenditures.

**Table 1.10 Average Annual Per Resident Expenditures for Care in Large State-Operated MR/DD Residential Facilities, 1950-1994**

Year	Cost	Cost (\$1=1983)
1950	\$ 745.60	\$ 3,094.99
1955	1,285.50	4,797.49
1960	1,867.70	6,299.75
1965	2,361.08	7,475.18
1967	2,965.33	8,875.23
1970	4,634.85	11,930.10
1974	9,937.50	20,163.19
1977	16,143.95	26,621.31
1980	24,944.10	30,307.08
1982	32,758.75	33,905.31
1984	40,821.60	39,229.56
1986	47,555.85	43,418.49
1988	57,221.05	48,409.01
1989	67,200.15	54,230.52
1990	71,660.45	54,891.90
1991	75,051.30	55,087.65
1992	76,945.65	54,862.25
1993	81,453.40	56,365.71
1994	82,256.40	55,523.07

**Figure 1.4 Average Annual Per Resident Expenditures in Large State-Operated MR/DD Residential Facilities, 1950-1994**



**CHAPTER 3  
CHARACTERISTICS AND MOVEMENT OF RESIDENTS  
OF LARGE STATE FACILITIES**

Robert W. Prouty  
K. Charlie Lakin  
Nohoon Kwak  
Stacey Moore

This chapter provides information about the characteristics and movement of large state MR/DD facility residents in Fiscal Year 1994 based on a survey of all large state facilities operating in the United States on June 30, 1994. Large state facilities included state-operated facilities for persons with MR/DD with 16 or more residents or distinct units for 16 or more persons with MR/DD within large state facilities primarily serving other populations. A description of the state facility survey is provided in the "Methodology" section ("Individual Large State Facility Survey").

*Characteristics of Residents*

Table 1.11 presents a summary of selected age, diagnostic and functional characteristics of residents of large (16 or more residents) state facilities for persons with MR/DD (hereafter "large state facilities") on June 30 of 1977, 1982, 1987, 1989, 1991, and 1994.

*Age of Residents*

There has been continuing aging of the population of residents of large state facilities since

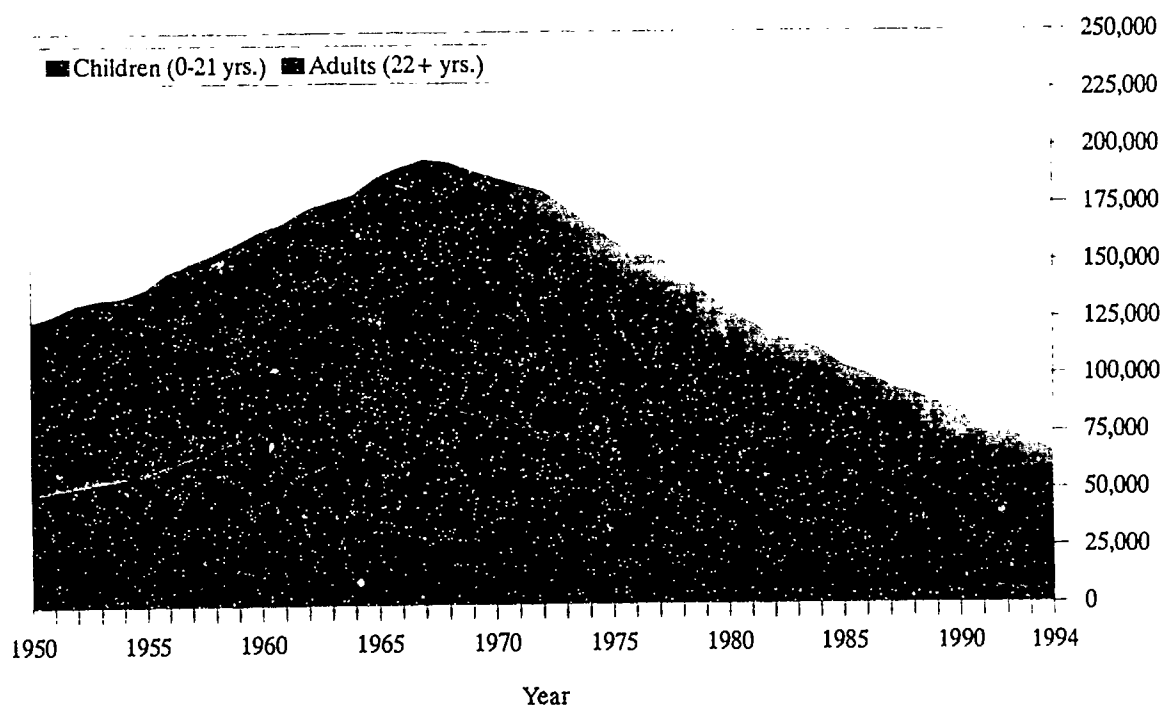
**Table 1.11 Characteristics of Residents of Large State Facilities  
on June 30: 1977, 1982, 1987, 1989, 1991, and 1994**

Characteristic		June 30 of the Year					
		1977 (N= 151,112)	1982 (N= 119,335)	1987 (N= 94,695)	1989 (N= 87,071)	1991 (N= 79,407)	1994 (N= 65,735)
Age	0-21 years	35.8%	22.0%	12.7%	10.6%	8.7%	6.1%
	22-39 years	41.3	50.2	54.1	52.4	51.8	47.1
	40-62 years	19.2	22.9	27.3	30.3	32.5	39.7
	63+ years	3.7	5.0	6.0	6.8	7.0	7.1
Level of Retardation	Mild/No MR	10.4	7.1	7.2	6.7	6.9	7.0
	Moderate	16.4	12.5	9.8	10.1	9.2	9.0
	Severe	27.6	24.2	20.0	19.5	19.1	18.5
	Profound	45.6	56.2	63.0	63.7	64.8	65.5
Functional Limitations	Needs assistance or supervision in walking	23.3	25.5	29.5	31.2	32.4	33.4
	Cannot communicate basic desires verbally	43.5	49.1	54.8	55.3	57.1	56.0
	Needs assistance or supervision in toileting	34.1	38.0	46.6	45.4	45.9	55.3
	Needs assistance or supervision in eating	21.4	35.0	37.8	38.2	37.8	49.7
	Needs assistance or supervision in dressing self	55.8	60.9	60.5	60.4	61.1	65.6

1977. Age statistics are based on reporting large state facilities for 1977, 1982, 1987, 1989, 1991, and 1994. These statistics are based on the reports of large state facilities housing 77% of all residents on June 30, 1994 (and between 76% and 84% in the earlier years). As shown in Table 1.11 the proportion of children and youth (birth to 21 years) living in large state facilities declined from 35.8% of all residents in 1977 to 6.1% in 1994, while the proportion of residents 63 years and older increased from 3.7% of all residents in June 1977 to 7.1% of all residents in June 1994. Despite the substantial increase in the proportion of residents 63 years and older in large state facilities, the total number of residents 63 years and older actually decreased by 938 residents (to 4,653) between 1977 and 1994. The most notably changing age cohort of large state facility residents was the middle age group (40-62 years). It grew from 32.5% to 40.7% of the large state facility populations, as the demographics of the "baby boom" became increasingly evident. In fact the number of "middle aged" (40-62) large state facility

residents actually increased between 1991 and 1994. As will be evident from admission statistics presented later, this was primarily because the stable population of large state facilities aged out of the young adult category (22-39 years) and into the middle aged category and less so because middle-aged individuals were being admitted to large state facilities. As shown in Figure 1.5, the June 30, 1994 estimate of 4,001 children and youth (0-21 years) making up 6.1% of the large state facility population nationwide reflects dramatic decreases during the second half of this century and particularly the past quarter century. In 1950, 48,354 of the 124,304 large state facility residents (38.9%) were 21 years or younger. By 1965 the population of children and youth had increased by 91,592, and made up 48.9% of all large state facility residents. Subsequent annual decreases brought the population of children and youth to 54,130 (35.8%) in 1977, to 9,230 (10.6%) in 1989, 6,944 (8.7%) in 1991, and eventually to 4,001 (6.1%) in June 30, 1994.

**Figure 1.5**  
**Total and Childhood (0-21 Years) Populations of Large State MR/DD Facilities, 1950-1994**

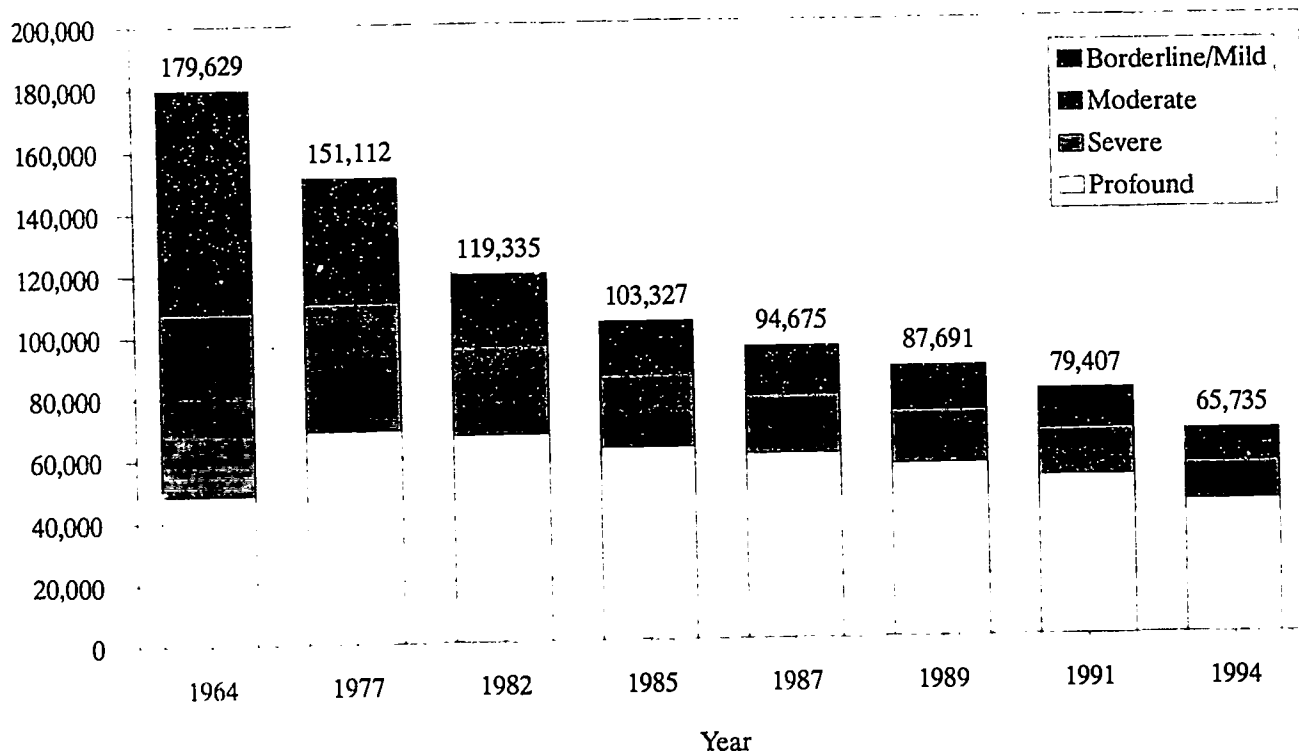


**Level of Mental Retardation**

Table 1.11 also presents a breakdown of the diagnosed level of mental retardation of residents of large state facilities on June 30 of 1977, 1982, 1987, 1989, 1991, and 1994. These statistics show the continuing trend toward reduced numbers and proportions of persons in the mild (or no), moderate and severe ranges of mental retardation and increased proportions (but reduced numbers) of persons with profound mental retardation in large state facilities. In 1994, based on the reports of facilities housing 76.4% of all large state facility residents, there were an estimated 4,608 large state facility residents who had mild or no mental retardation (7.0% of all residents) as compared with an estimated 15,700 in 1977 and 5,479 in 1991. In contrast, the proportion of large state facility residents with profound mental retardation increased substantially from 1977 to 1994, from 45.6% of all residents to 65.5% of all residents. Despite these proportional increases, the actual

number of persons with profound mental retardation in large state facilities decreased by 25,800 people between 1977 and 1994, from 68,907 to 43,121 people. In just the five years between June 30, 1989 and June 30, 1994 the number of large state facility residents with profound mental retardation decreased by over 12,300 people (or 22%). Figure 1.6 shows the same basic statistics as those in Table 1.11 with the addition of data from 1964 and 1985 surveys (Scheerenberger, 1965, 1986). It shows that while large state facility populations decreased by about 38,500 residents between 1964 and 1977, the number of residents with profound mental retardation actually increased by about 20,000. During the same period the number of large state facility residents with mild, moderate, severe or no mental retardation decreased nearly 50,000 people from 131,100 to 82,200. In June 1994 there were 22,713 large state facility residents with mild, moderate, severe or no mental retardation, only about one-sixth of the number 30 years earlier.

**Figure 1.6**  
**Level of Retardation of Residents of Large**  
**State Facilities on June 30 of Selected Years, 1964-1994**





### *Functional Characteristics*

Table 1.11 also shows the percentage of residents of large state facilities reported to have functional limitations in certain important activities of daily living. In this study, each of the large state facilities surveyed was asked to report the number of their residents who: 1) "cannot walk without assistance or supervision," 2) "cannot communicate basic desires verbally," 3) "cannot use the toilet without assistance or supervision," 4) "cannot feed self without assistance or supervision." and 5) "cannot dress self without assistance or supervision." National tables for 1994 are shown in Table 1.7 with comparable statistics from 1977, 1982, 1987, 1989, and 1991. There was the continued expected association with the slightly increasing proportion of profoundly intellectually impaired populations of large state facilities and higher proportion of residents reported to have certain functional limitations. In 1994, 33.4% of large state facility residents were reported to need assistance or supervision in walking and 56.1% to be unable to communicate basic desires verbally. For the first time ever a majority (55.3%) of large state facility residents were reported to be unable to use the toilet independently without assistance or supervision. About half of large state facility residents are reported to need assistance or supervision in feeding themselves, nearly two-thirds in getting dressed. In the five years between 1989 and 1994 there were rather substantial increases in the percentage of residents with substantial limitations in toileting themselves (45.4% to 55.3%), feeding themselves (38.2% to 49.7%) and dressing themselves (60.4% to 65.4%). As will be shown subsequently, there continued to be considerable inter-state variability in these patterns.

#### *Age by Level of Mental Retardation*

Table 1.12 shows the distribution of large state facility residents by age and level of mental retardation groupings. Facilities housing 76.6% of

all large state facility residents on June 30, 1994 reported statistics on this distribution. Clearly within large state facilities, residents who are older less often have profound cognitive limitations than residents who are relatively younger. Only 56.1% of residents 55 years or older had profound mental retardation as compared with 66.9% of all residents 54 years or younger. Conversely the youngest large state facility residents tended most often to have profound cognitive impairments. Three-quarters (74.7%) of large state facility residents 14 years and younger had profound mental retardation as compared with 65.3% of the large state facility population older than 14 years. Remarkably a majority of large state facility residents (53.7%) are now persons with profound mental retardation between the ages of 22 and 54 years.

#### *State-by-State Resident Characteristics*

State-by-state statistics on resident characteristics are based on aggregated data on all reporting large state facilities in each state. State breakdowns are provided only for states in which the reporting facilities for any specific characteristic housed at least 60% of all large state facility residents.

#### *Gender of Residents*

Table 1.13 shows the distribution of large state facility residents by gender. In all states but Wyoming, males made up the majority of large state facility residents. Nationally 59.3% of residents were male, with states ranging from a low of 47.5% (Wyoming) to a high of 71.3% (Michigan). For the most part the proportion of male large state facility residents has remained relatively stable in recent years (57.0% in 1977, 57.4% in 1982, 59.0% in 1989, 58.5% in 1991 and 59.3% in 1994).

**Table 1.12 Distribution of Residents of Large State Facilities by Level of Mental Retardation and Age on June 30, 1994**

Level of Mental Retardation	Chronological Age							Total
	0-9	10-14	15-21	22-39	40-54	55-62	63+	
Mild or No MR	17 (7.2%) [0.5%]	26 (4.9%) [0.7%]	206 (8.9%) [5.8%]	1,545 (6.5%) [43.5%]	1,271 (7.6%) [35.8%]	226 (6.7%) [6.4%]	264 (7.4%) [7.4%]	3,555 (7.0%) [100.0%]
Moderate	9 (3.8%) [0.2%]	35 (6.5%) [0.8%]	296 (12.7%) [6.5%]	1,930 (8.1%) [42.4%]	1,551 (9.3%) [34.1%]	323 (9.6%) [7.1%]	413 (11.5%) [9.1%]	4,547 (9.0%) [100.0%]
Severe	25 (10.6%) [0.3%]	80 (15.0%) [0.9%]	373 (16.1%) [4.0%]	3,878 (16.4%) [41.6%]	3,160 (18.9%) [33.9%]	795 (23.5%) [8.5%]	1,018 (28.4%) [10.9%]	9,319 (18.5%) [100.0%]
Profound	184 (78.3%) [0.6%]	382 (73.4%) [1.2%]	1,447 (63.3%) [4.4%]	16,372 (69.1%) [49.6%]	10,709 (64.2%) [32.4%]	2,015 (59.6%) [6.1%]	1,885 (52.7%) [5.7%]	33,006 (65.5%) [100.0%]
Total	235 (100.0%) [0.5%]	523 (100.0%) [1.0%]	2,322 (100.0%) [4.6%]	23,715 (100.0%) [47.0%]	16,681 (100.0%) [33.1%]	3,371 (100.0%) [6.7%]	3,580 (100.0%) [7.1%]	50,427 (100.0%) [100.0%]

Note: The percentage in parentheses indicates the distribution of persons by age with different levels of mental retardation. The percentage in brackets indicates the distribution of persons by level of mental retardation within the different age categories. Statistics are based on the reports of large state facilities housing 50,427 (76.7%) of the 65,735 residents of large state facilities on June 30, 1994.

#### Age Distribution of Residents

Table 1.14 presents the state-by-state age distribution of residents in large state facilities on June 30, 1994. The table shows the great variability across states in the ages of residents. Differences were particularly notable in the number of children and youth (0-21 years) and the number of older residents (63 years and older). Nationwide, 6.1% of all large state facility residents were 21 years or younger. However, in 15 states less than 3% of large state facility residents were 21 years or younger (as compared with 9 states in June 1991). In contrast 9 states reported more than 10% of their large state facility residents as being in the 0-21 year age range (as compared with 15 in June 1994). In the 5 years between 1989 and 1994 in the 39 states with facilities housing 60% of the total large state facility population reporting in both years, there was a reduction in the proportion of residents 21 years and younger in 36, no change in one and a slight increase in two. More importantly in all 39 states there was a decrease in the actual number of children and youth residing in large state facilities.

Nationally 13.8% of large state facility residents were 55 years and older. Individual states ranged from more than a quarter of all residents being 55 years and older to virtually no residents in this age range. Northeastern states typically had more than a quarter of their large state facility populations made up of persons 55 years old or older. In Massachusetts and New York over 29% of large state facility residents were 55 years or older, while in 14 states over 15% of large state facility residents were 55 years or older. In only 4 of the 40 reporting states were less than 5% of state institution residents 55 years or older. It is notable that while the largest group of large state facility residents on June 30, 1994 (46.7%) were between the ages of 22 and 39 years, that proportion decreased from 51.8% in 1989. In the same 5 year period (1989-1994) the proportion of residents 40 years or older increased from 36.0% to 47.3% nationally. The proportion of large state facility residents who are 40 or older is substantially greater than the 32% of the general U.S. population in this age range, but is clearly being influenced by the same demographic trend - the aging of the "baby boom" generation.

**Table 1.13 Gender Distribution of Residents  
of Large State Facilities by State on June 30, 1994**

State	Gender of Residents		Total
	Male	Female	
ALABAMA	60.9%	39.1%	100.0%
ALASKA	63.2	36.8	100.0
ARIZONA	50.0	50.0	100.0
ARKANSAS	62.1	37.9	100.0
CALIFORNIA	61.1	38.9	100.0
COLORADO	*	*	*
CONNECTICUT	58.8	41.2	100.0
DELAWARE	56.9	43.1	100.0
D.C.	NA	NA	NA
FLORIDA	60.3	39.7	100.0
GEORGIA	58.3	41.7	100.0
HAWAII	68.7	31.3	100.0
IDAHO	61.5	38.5	100.0
ILLINOIS	63.4	36.5	100.0
INDIANA	64.8	35.2	100.0
IOWA	65.5	34.5	100.0
KANSAS	63.2	36.8	100.0
KENTUCKY	59.3	40.7	100.0
LOUISIANA	56.0	44.0	100.0
MAINE	62.8	37.2	100.0
MARYLAND	59.3	40.7	100.0
MASSACHUSETTS	54.6	45.4	100.0
MICHIGAN	71.3	28.7	100.0
MINNESOTA	65.6	34.4	100.0
MISSISSIPPI	59.4	40.6	100.0
MISSOURI	61.0	39.0	100.0
MONTANA	63.2	36.8	100.0
NEBRASKA	58.5	41.5	100.0
NEVADA	65.1	34.9	100.0
NEW HAMPSHIRE	NA	NA	NA
NEW JERSEY	57.7	42.3	100.0
NEW MEXICO	58.1	41.9	100.0
NEW YORK	57.0	43.0	100.0
NORTH CAROLINA	57.4	42.6	100.0
NORTH DAKOTA	53.4	46.6	100.0
OHIO	63.9	36.1	100.0
OKLAHOMA	65.7	34.3	100.0
OREGON	*	*	*
PENNSYLVANIA	58.4	41.6	100.0
RHODE ISLAND	NA	NA	NA
SOUTH CAROLINA	59.2	40.8	100.0
SOUTH DAKOTA	60.4	39.6	100.0
TENNESSEE	59.1	40.9	100.0
TEXAS	55.4	44.6	100.0
UTAH	57.5	42.5	100.0
VERMONT	NA	NA	NA
VIRGINIA	58.8	41.2	100.0
WASHINGTON	51.2	48.8	100.0
WEST VIRGINIA	62.6	37.4	100.0
WISCONSIN	61.4	38.6	100.0
WYOMING	47.5	52.5	100.0
U.S. Total	59.3	40.7	100.0

*Note.* Data in this table are based on the reports of large state facilities which housed 55,679 (84.7%) of the 65,735 large state facility residents on June 30, 1994. Specific state data are omitted (\*) where the reporting facilities in a specific state housed less than 60% of the total large state facility residents. NA is used to indicate states which did not operate large state facilities on June 30, 1994.

Table 1.14 Age of Residents of Large State Facilities by State on June 30, 1994

State	Age of Residents in Years						Total
	0-14	15-21	22-39	40-54	55-62	63+	
ALABAMA	0.6%	5.0%	43.5%	35.4%	6.0%	9.5%	100.0%
ALASKA	*	*	*	*	*	*	*
ARIZONA	0.0	0.8	30.2	62.9	5.0	1.3	100.0
ARKANSAS	2.5	10.6	50.2	34.2	7.4	0.2	100.0
CALIFORNIA	3.7	6.6	48.5	36.6	5.0	4.6	100.0
COLORADO	*	*	*	*	*	*	*
CONNECTICUT	0.3	1.0	35.6	41.5	8.9	12.6	100.0
DELAWARE	*	*	*	*	*	*	*
D.C.	0.0	0.0	NA	NA	NA	NA	NA
FLORIDA	0.0	2.0	59.5	34.0	3.4	1.1	100.0
GEORGIA	5.1	4.8	49.7	27.2	9.3	3.9	100.0
HAWAII	0.0	8.8	48.8	36.3	2.5	2.5	100.0
IDAHO	2.8	6.3	46.2	32.2	5.6	7.0	100.0
ILLINOIS	0.9	4.4	52.3	30.8	5.7	5.9	100.0
INDIANA	0.0	5.3	45.4	34.5	10.7	4.1	100.0
IOWA	2.4	4.7	49.8	33.1	4.8	5.2	100.0
KANSAS	4.9	12.4	51.8	24.1	3.9	2.9	100.0
KENTUCKY	1.0	7.0	65.1	25.5	1.5	0.0	100.0
LOUISIANA	2.9	8.7	52.4	24.3	5.8	5.8	100.0
MAINE	*	*	*	*	*	*	*
MARYLAND	*	*	*	*	*	*	*
MASSACHUSETTS	0.0	0.0	27.4	43.2	14.5	14.9	100.0
MICHIGAN	0.2	6.9	53.9	27.1	6.9	5.0	100.0
MINNESOTA	0.0	2.7	44.6	37.2	6.9	8.6	100.0
MISSISSIPPI	4.8	10.2	48.4	26.8	5.5	4.3	100.0
MISSOURI	*	*	*	*	*	*	*
MONTANA	*	*	*	*	*	*	*
NEBRASKA	1.6	2.1	41.7	38.0	7.3	9.3	100.0
NEVADA	*	*	*	*	*	*	*
NEW HAMPSHIRE	0.0	0.0	NA	NA	NA	NA	NA
NEW JERSEY	0.0	1.4	43.6	33.6	8.0	13.4	100.0
NEW MEXICO	3.6	6.5	58.1	26.2	3.6	2.0	100.0
NEW YORK	0.0	1.0	36.6	32.9	9.7	19.7	100.0
NORTH CAROLINA	0.3	2.7	46.1	36.8	7.5	6.7	100.0
NORTH DAKOTA	2.7	8.2	46.6	27.4	8.2	6.9	100.0
OHIO	0.0	1.6	40.4	40.5	7.8	9.7	100.0
OKLAHOMA	3.1	16.9	68.1	12.0	0.0	0.0	100.0
OREGON	0.0	0.6	48.9	41.3	4.5	4.7	100.0
PENNSYLVANIA	0.0	1.0	38.4	38.2	10.6	11.7	100.0
RHODE ISLAND	0.0	0.0	NA	NA	NA	NA	100.0
SOUTH CAROLINA	*	*	*	*	*	*	*
SOUTH DAKOTA	0.8	4.3	41.6	27.8	9.8	15.7	100.0
TENNESSEE	2.8	7.3	42.2	32.0	7.7	8.0	100.0
TEXAS	0.5	3.2	48.5	32.7	8.2	6.9	100.0
UTAH	0.6	7.5	57.2	29.0	4.7	1.1	100.0
VERMONT	0.0	0.0	NA	NA	NA	NA	100.0
VIRGINIA	0.7	4.6	48.2	32.8	6.7	7.0	100.0
WASHINGTON	0.9	3.8	44.8	37.7	8.1	4.8	100.0
WEST VIRGINIA	*	*	*	*	*	*	*
WISCONSIN	3.0	5.4	54.7	29.5	3.5	3.9	100.0
WYOMING	0.0	2.6	42.3	35.9	3.9	15.4	100.0
U.S. Total	1.5	4.6	46.7	33.5	6.7	7.1	100.0

Note. Data in this table are based on the reports of large state facilities which housed 50,280 (76.5%) of the 65,735 large state facility residents on June 30, 1994. Specific state data are omitted (\*) where the reporting facilities in a specific state did not house at least 60% of the state's total state facility residents. NA is used to indicate states which did not operate a large state facility on June 30, 1994 except that 0.0% is reported for the percentage of total residents who were children (0-14 years) and youth (15-24 years) in these states without large state facilities.

In contrast, children and youth (birth to 21 years), made up 32% of the U.S. population, but only 6.1% of the large state facility population. Persons 63 years and older made up 18% of the U.S. population, but only 7.1% of the large state facility population. One reason for the disproportionately low rates of large state facility placement among children and youth are the relatively low overall rates of out-of-home placement of children and youth. (Only an estimated 18% of all persons with MR/DD in all public and private out-of-home placements are between birth and 21 years.) A more specific factor with respect to large state facilities is the concerted effort by most states to restrict the admission of children and youth to them. This is particularly evident in the youngest ages. For example, nationwide 21% of the U.S. population is made up of persons 14 years and younger, but only 1.5% of large state facility populations and 7.1% of all admissions to large state facilities in Fiscal Year 1994 were persons 14 years and younger. As a comparison in 1965 the majority of persons admitted to large state facilities were 11 years or younger (NIMH, 1966).

The primary reason for the lower proportion of persons 63 years and older in large state facilities than in the general population is the continuing high use of nursing homes for long-term care of older persons with a primary diagnosis of mental retardation and related conditions. In fact, the estimated 4,674 persons 63 years and older in large state facilities in 1994 was considerably less than the estimated 11,600 persons 65 years and older with a primary diagnosis of mental retardation in nursing homes (based on the total 1994 nursing home residents in this survey and the age characteristics of nursing home residents with a primary diagnosis of mental retardation from the 1985 National Nursing Home Survey; Lakin, Hill & Anderson; 1991).

#### *Level of Mental Retardation*

Table 1.15 presents the state-by-state distributions of residents of large state facilities by reported level of mental retardation. Thirty seven states are reported; 4 states are not reported because they operated no large state facilities on

June 30, 1994 and 10 states are not reported because this statistic was not reported by facilities housing at least 60% of the state's total large state facility population. In Table 1.15 persons reported not to have mental retardation (or to have "borderline" mental retardation) have been included in the "mild" mental retardation group. Nationally 65.5% of large state facility residents were indicated to have profound mental retardation. In all but one of the reporting states (Michigan) a majority of large state facility residents were reported to have profound mental retardation. In 12 of the 37 reporting states more than 70% of large state facility residents were reported to have profound mental retardation.

A great deal of variability was also found in states' use of large state facilities to house persons with mild and moderate mental retardation. Nationwide, 16.0% of residents were reported to have mild or moderate mental retardation. In four of the reporting states persons with mild or moderate mental retardation made up more than a quarter of large state facility populations; in four states less than 10% of state institution populations were made up of persons with mild or moderate mental retardation.

#### *Selected Additional Conditions*

Table 1.16 presents the reported prevalence of selected secondary conditions of large state facility residents. Nationwide, 15.3% of large state facility residents were reported to be functionally blind in 1994 (defined as having little or no useful vision). This compares with 11.8% in 1989. Seven states reported 20% or more residents to be functionally blind; 11 states reported less than 10% of large state facility residents were blind. Nationally, 7.9% of large state facility residents were reported to be functionally deaf (having little or no useful hearing). Prevalence rates varied from more than 14% in 3 states to less than 7% in 13 states.

Nationwide, 42.5% of large state facility residents were reported to have epilepsy. This is the same reported prevalence as 5 years earlier. Only 5 states reported rates outside the range of 34% to 56%, with the highest report being 63.5% (Arizona) and the lowest 21.9% (Mississippi).

Table 1.15 Level of Mental Retardation of Residents of Large State Facilities by State on June 30, 1994

State	Level of Mental Retardation				Total
	Mild+	Moderate	Severe	Profound	
ALABAMA	7.3%	8.4%	16.3%	68.0%	100.0%
ALASKA	*	*	*	*	*
ARIZONA	3.1	6.3	24.5	66.0	100.0
ARKANSAS	2.6	7.2	23.0	67.3	100.0
CALIFORNIA	10.3	8.4	14.1	67.3	100.0
COLORADO	*	*	*	*	*
CONNECTICUT	6.6	12.6	24.2	56.7	100.0
DELAWARE	*	*	*	*	*
D.C.	NA	NA	NA	NA	NA
FLORIDA	15.8	10.4	11.5	62.2	100.0
GEORGIA	5.5	11.1	21.7	61.8	100.0
HAWAII	6.3	11.2	16.2	66.3	100.0
IDAHO	7.0	5.6	18.9	68.5	100.0
ILLINOIS	5.7	12.9	18.4	63.0	100.0
INDIANA	18.2	12.1	15.7	53.9	100.0
IOWA	12.1	15.2	18.4	54.2	100.0
KANSAS	9.0	6.6	13.1	71.2	100.0
KENTUCKY	4.3	9.9	30.8	55.1	100.0
LOUISIANA	5.4	5.3	17.8	71.5	100.0
MAINE	*	*	*	*	*
MARYLAND	*	*	*	*	*
MASSACHUSETTS	5.1	7.8	17.8	65.6	100.0
MICHIGAN	27.5	13.3	15.7	43.5	100.0
MINNESOTA	15.9	7.7	17.8	58.6	100.0
MISSISSIPPI	5.0	9.1	19.4	66.4	100.0
MISSOURI	*	*	*	*	*
MONTANA	*	*	*	*	*
NEBRASKA	7.3	6.4	12.1	74.3	100.0
NEVADA	*	*	*	*	*
NEW HAMPSHIRE	NA	NA	NA	NA	NA
NEW JERSEY	8.8	8.8	17.9	64.5	100.0
NEW MEXICO	0.5	2.4	11.7	85.5	100.0
NEW YORK	11.3	8.8	18.4	61.5	100.0
NORTH CAROLINA	2.3	6.1	16.5	75.1	100.0
NORTH DAKOTA	13.7	6.2	7.5	72.6	100.0
OHIO	4.5	14.4	19.7	61.4	100.0
OKLAHOMA	7.7	10.9	22.4	59.0	100.0
OREGON	9.2	8.4	8.0	74.4	100.0
PENNSYLVANIA	5.3	7.8	18.0	68.9	100.0
RHODE ISLAND	NA	NA	NA	NA	NA
SOUTH CAROLINA	*	*	*	*	100.0
SOUTH DAKOTA	5.1	6.9	9.0	78.9	100.0
TENNESSEE	2.9	6.3	17.2	73.5	100.0
TEXAS	3.9	7.8	26.2	62.2	100.0
UTAH	4.4	6.1	12.4	77.1	100.0
VERMONT	NA	NA	NA	NA	NA
VIRGINIA	4.0	10.1	20.1	65.8	100.0
WASHINGTON	4.5	11.4	17.3	66.7	100.0
WEST VIRGINIA	*	*	*	*	*
WISCONSIN	2.2	4.4	17.9	75.5	100.0
WYOMING	3.2	6.4	13.5	76.9	100.0
U.S. Total	7.0	9.0	18.5	65.5	100.0

Note. Data in this table are based on the reports of large state facilities which housed 50,280 (76.5%) of the 65,735 large state facility residents on June 30, 1994. Specific state data are omitted (\*) where the reporting facilities in a specific state housed less than 60% of the total large state facility residents. NA is used to indicate states which did not operate large state facilities on June 30, 1994.

Nationwide 21.4% of large state facility residents were indicated to have cerebral palsy. This compares to a reported rate of 21.3% five years earlier in 1989. The reported prevalence of cerebral palsy varied considerably from state to state. In 9 states the prevalence of cerebral palsy among large state facility residents was indicated to be less than 14% and in 6 other states it was indicated to be greater than 30%.

Individual large state facilities were asked to report the number of their residents with behavior disorders. "Behavior disorder" was defined simply as behavior that is sufficiently problematic as to require special staff attention. The absence of a definition expressed in behavioral terms of frequency or severity may account for some of the deviation among states from the national average of 47.1%. In 2 states two-thirds or more of large state facility residents were reported to have behavior disorders; in 6 states less than one-third of the large state facility residents were reported to have behavioral disorders.

Individual facilities were asked how many of their residents had psychiatric disorders requiring the attention of psychiatric personnel. Nationwide 30.6% of large state facility residents were reported to be receiving psychiatric attention for psychiatric conditions. The aggregated statistics for 26 of the 33 states providing these data for at least 60% of all residents were in the range between 20% and 45% of all residents.

In all 62.4% of large state facility residents were reported to have two or more of the above conditions in addition to mental retardation. This included 75% or more of residents in 10 states and less than 50% in 4 states.

#### *Selected Functional Assistance Needs of Residents*

Table 1.17 presents selected functional limitations of residents of large state MR/DD facilities. Nationwide 33.4% of residents large state facilities were reported to need assistance or supervision in walking. This represented a slight increase from the 31.3% reported in 1989.

Reported rates varied from 57.5% in Hawaii to 20.2% in Nevada. In 5 states half of the large state facility residents were reported to need assistance in walking. In 5 states less than a quarter of large state facility residents were reported to need assistance in walking.

Nationwide, 65.6% of large state facility residents were reported to need assistance or supervision in dressing. This compares with 61.0% in 1989. In 12 states 70% or more of large state facility residents were reported to need assistance dressing. Only Oklahoma reported less than 50% of its large state facility residents in need of assistance or supervision in dressing.

Nationwide, 49.7% of large state facility residents were reported to need assistance or supervision in feeding themselves. This compares with 37.9% reported to need assistance in feeding themselves in 1989. Seven states reported that 60% or more of their large state facility residents needed help or supervision in eating while 2 states indicated that 30% or less of their large state facility populations needed assistance or supervision with eating. Thirteen of the 47 states operating large state facilities had insufficient reports on this skill (i.e., less than 60% of all residents) to compute a state statistic.

Nationwide 55.3% of large state facility residents were reported to need assistance or supervision with toileting. This was a substantial increase from the 45.7% reported in 1989. Seven states reported more than two-thirds of large state facility residents needing assistance with toileting; 3 states reported less than 40% of large state facility residents needing assistance or supervision in toileting.

A total 56.0% of large state facility residents were reported to be unable to communicate their basic desires verbally. This compares with 55.9% in 1989. Three states reported that more than 75% of their large state facility residents could not communicate verbally; 6 states reported that less than 50% of their large state facility residents could not communicate verbally.

Table 1.16. Selected Additional Conditions of Residents of Large State Facilities by State on June 30, 1994

State	Blind <sup>1</sup>	Deaf <sup>2</sup>	Epilepsy	Cerebral Palsy	Behavior Disorder <sup>3</sup>	Psychiatric Disorders <sup>4</sup>	Multiple Conditions <sup>5</sup>
ALABAMA	9.6%	5.0%	41.8%	13.2%	30.6%	21.1%	66.0%
ALASKA	*	*	*	*	*	*	*
ARIZONA	11.3	1.3	63.5	43.4	33.9	11.3	78.6
ARKANSAS	7.1	6.3	44.1	31.0	29.2	30.3	57.7
CALIFORNIA	24.5	14.7	40.6	31.6	44.3	24.2	57.7
COLORADO*	*	*	*	*	*	*	*
CONNECTICUT	8.0	1.5	*	*	*	27.0	*
DELAWARE	*	*	*	*	*	*	*
D.C.	NA	NA	NA	NA	NA	NA	NA
FLORIDA	4.8	5.8	30.0	12.4	51.8	29.6	47.2
GEORGIA	13.5	9.1	42.2	19.4	36.6	14.9	68.2
HAWAII	30.0	17.5	55.0	28.8	52.5	47.5	78.7
IDAHO	17.5	9.1	35.7	21.7	27.3	20.3	53.1
ILLINOIS	18.1	7.5	41.7	13.4	45.6	37.8	67.4
INDIANA	12.5	14.3	43.1	26.5	56.0	37.4	78.3
IOWA	17.6	10.3	44.6	11.0	61.4	72.9	78.9
KANSAS	8.7	4.2	40.6	11.8	61.4	20.2	81.0
KENTUCKY	*	8.9	43.0	12.7	*	*	*
LOUISIANA	10.9	12.8	28.7	10.9	43.3	23.5	73.3
MAINE	*	*	*	*	*	*	*
MARYLAND	13.6	20.0	43.6	14.6	30.4	33.7	47.0
MASSACHUSETTS	9.7	4.3	45.7	25.8	*	*	*
MICHIGAN	5.5	3.8	35.9	14.3	66.7	44.2	80.5
MINNESOTA	11.3	7.8	45.0	16.0	63.6	39.2	48.3
MISSISSIPPI	7.5	4.1	21.9	17.4	35.1	30.3	67.6
MISSOURI	*	*	*	*	*	*	*
MONTANA	*	*	*	*	*	*	*
NEBRASKA	29.8	5.5	55.1	14.6	49.7	37.1	88.4
NEVADA*	*	6.1	48.5	*	*	*	*
NEW HAMPSHIRE	NA	NA	NA	NA	NA	NA	NA
NEW JERSEY	15.9	3.3	40.0	20.0	43.5	*	47.1
NEW MEXICO	23.8	1.8	49.2	29.0	44.4	25.8	56.8
NEW YORK	20.6	13.2	34.4	16.7	52.2	30.6	61.8
NORTH CAROLINA	21.6	7.7	47.4	25.8	27.2	23.0	33.5
NORTH DAKOTA	27.4	*	50.0	33.6	45.2	28.8	79.5
OHIO	10.8	4.7	48.0	10.0	60.1	50.7	51.3
OKLAHOMA	16.3	4.9	44.9	32.3	44.3	*	82.0
OREGON	*	*	*	*	*	*	*
PENNSYLVANIA	8.4	4.1	41.7	19.4	33.4	27.7	57.8
RHODE ISLAND	NA	NA	NA	NA	NA	NA	NA
SOUTH CAROLINA	*	7.6	47.5	17.4	44.7	10.7	53.4
SOUTH DAKOTA	8.5	8.1	43.1	15.4	73.8	8.1	58.1
TENNESSEE	7.5	4.4	52.7	41.1	58.6	21.1	61.1
TEXAS	15.1	4.2	44.0	28.5	44.3	28.9	52.9
UTAH	9.4	5.0	48.6	8.1	58.0	42.3	100.0
VERMONT	NA	NA	NA	NA	NA	NA	NA
VIRGINIA	9.1	5.7	44.4	18.2	65.3	*	57.7
WASHINGTON	17.2	8.3	42.4	21.8	60.2	40.9	63.1
WEST VIRGINIA	*	*	*	*	*	*	*
WISCONSIN	10.9	9.8	61.9	34.0	52.8	35.5	78.0
WYOMING	11.5	2.6	55.8	22.4	32.7	7.7	100.0
U.S. Total	15.3	7.9	42.5	21.4	47.1	30.6	62.4

Note. Data in this table are based on the reports of large state facilities which housed between 50,209 (76.4% for blind and deaf) to 43,640 (66.4% for multiple conditions) of the 65,735 large state facility residents on June 30, 1994. Specific state data are omitted (\*) where the reporting facilities in a specific state housed less than 60% of the total large state facility residents. NA is used to indicate states which did not operate large state facilities on June 30, 1994.

<sup>1</sup> Defined as having little or no useful vision.

<sup>2</sup> Defined as having little or no useful hearing.

<sup>3</sup> Defined as challenging behavior requiring special attention of staff.

<sup>4</sup> Defined as a disorder requiring the attention of psychiatric specialists.

<sup>5</sup> Defined as having two or more of the indicated conditions in addition to mental retardation.

50



Table 1.17 Selected Functional Needs of Residents of Large State Facilities by State on June 30, 1994

State	Functional Limitations				
	Needs Others' Assistance/Supervision in Walking	Needs Others' Assistance/Supervision with Dressing	Needs Others' Assistance/Supervision in Eating	Needs Others' Assistance/Supervision with Toileting	Cannot Communicate Verbally
ALABAMA	23.0%	56.8%	49.3%	47.9%	62.8%
ALASKA	*	*	*	*	*
ARIZONA	33.9	80.0	77.9	75.5	82.4
ARKANSAS	23.7	56.5	28.0	39.2	47.2
CALIFORNIA	40.9	65.0	49.2	64.5	51.3
COLORADO	*	*	*	*	*
CONNECTICUT	39.5	*	*	*	*
DELAWARE	*	*	*	*	*
D.C.	NA	NA	NA	NA	NA
FLORIDA	20.2	52.4	28.2	35.1	55.2
GEORGIA	41.1	71.2	64.5	60.8	68.6
HAWAII	57.5	57.5	48.7	56.2	53.7
IDAHO	45.4	56.6	32.9	71.3	73.4
ILLINOIS	26.4	65.7	40.7	45.1	57.1
INDIANA	34.5	69.3	35.9	63.8	55.3
IOWA	32.5	63.2	36.8	42.7	24.2
KANSAS	36.2	60.6	44.8	39.6	56.0
KENTUCKY	23.6	*	*	*	*
LOUISIANA	36.6	55.5	46.4	42.9	48.1
MAINE	*	*	*	*	*
MARYLAND	39.4	74.2	*	*	*
MASSACHUSETTS	36.2	73.3	63.1	66.3	67.8
MICHIGAN	39.4	69.8	75.1	60.8	43.9
MINNESOTA	41.3	75.9	66.7	62.2	68.4
MISSISSIPPI	26.8	57.1	40.8	49.5	46.1
MISSOURI	*	*	*	*	*
MONTANA	*	*	*	*	*
NEBRASKA	44.0	86.1	55.1	68.8	59.9
NEVADA	*	*	*	*	*
NEW HAMPSHIRE	NA	NA	NA	NA	NA
NEW JERSEY	26.0	67.9	46.7	46.6	51.5
NEW MEXICO	53.2	76.2	52.0	63.7	60.9
NEW YORK	32.7	63.4	51.7	64.2	51.8
NORTH CAROLINA	33.9	74.8	55.7	71.5	60.1
NORTH DAKOTA	56.2	77.4	79.4	69.2	76.7
OHIO	23.1	58.7	44.3	47.1	58.2
OKLAHOMA	26.3	40.6	42.9	41.1	62.9
OREGON	*	*	*	*	*
PENNSYLVANIA	32.3	72.7	44.3	48.0	55.1
RHODE ISLAND	NA	NA	NA	NA	NA
SOUTH CAROLINA	39.9	77.1	59.1	70.7	62.3
SOUTH DAKOTA	27.3	80.0	47.7	63.1	63.5
TENNESSEE	49.8	67.1	50.8	60.8	55.2
TEXAS	35.2	57.7	49.0	48.2	58.5
UTAH	28.5	64.6	*	48.6	71.8
VERMONT	NA	NA	NA	NA	NA
VIRGINIA	34.1	64.2	50.0	58.5	44.5
WASHINGTON	30.7	59.5	46.2	48.6	65.8
WEST VIRGINIA	*	*	*	*	*
WISCONSIN	31.9	88.7	85.5	68.3	74.4
WYOMING	54.5	83.9	59.6	80.7	81.4
U.S. Total	33.4	65.6	49.7	55.3	56.0

Note. Data in this table are based on the reports of large state facilities which housed 50,280 (76.5%) of the 65,735 large state facility residents on June 30, 1994. Specific state data are omitted (\*) where the reported facilities in a specific state housed fewer than 60% of the total large state facility residents. NA is used to indicate states which did not operate large state facilities on June 30, 1994.

## *Residents in Movement*

### *New Admissions by Age and Level of Mental Retardation*

Table 1.18 presents the distribution of persons newly admitted to large state facilities in Fiscal Year 1994 by their age and level of mental retardation. Data reported in Table 1.14 were supplied by large state facilities housing 77.3% of large state facility residents. As shown in Table 1.18 persons newly admitted to large state facilities in FY 1994 presented a considerably different profile than the general large state facility population on June 30, 1994. In general they were considerably younger and less severely cognitively impaired than the general population. For example, 1.5% of the total large state facility population was 0-14 years old as compared with 8.3% of the new admissions. While 4.6% of the general large state facility population was persons 15-21 years, 18.3% of new admissions were in this age group. In contrast, while persons 40 years or older made up 46.8% of the large state facility population, they made up only 24.4% of the new admissions. Between 1989 and 1994 new admissions of persons 21 years and younger decreased from 37.1% to 26.6% of all new admissions. Of course, the relatively higher proportion of young people in the new admission

category as compared with general facility population reflects the fact that most people entering residential programs do so in adolescence or young adulthood.

Newly admitted large state facility residents in Fiscal Year 1994 were also considerably more likely to have mild mental retardation or no mental retardation and considerably less likely to have profound mental retardation than was the case with the general large state facility population. Persons with mild or no mental retardation made up 27.7% of new admissions as compared with 7.0% of the general large state facility population (this compares with 27.8% of new admissions in Fiscal Year 1989). Persons with profound mental retardation made up only 34.3% of new admissions as opposed to 65.5% of the total large state facility population (persons with profound mental retardation made up 35.2% of new admissions in Fiscal Year 1989). Children and young adults (birth to 39 years) with mild or no mental retardation made up 22.3% of all new admissions as compared with 3.6% of the general large state facility population. As will be seen in Table 1.20 they also make up a disproportionately high proportion of discharges, indicating that large state facilities continue to function as relatively short-term entry and/or "crisis response" points for residential services for this population.

**Table 1.18 New Admissions to Large State Facilities by Age and Level of Mental Retardation in the Year Ending June 30, 1994**

Level of Retardation	Chronological Age								Total(%)
	0-4	5-9	10-14	15-21	22-39	40-54	55-62	63+	
Mild and No MR	5	8	15	115	227	69	9	10	458 (27.7%)
Moderate	2	5	10	72	148	46	11	6	300 (18.1%)
Severe	5	11	16	51	143	72	16	14	328 (19.8%)
Profound	7	7	48	64	292	105	23	22	568 (34.3%)
Total	19	32	89	302	810	292	59	52	1,654
%	1.1%	1.9%	5.3%	18.3%	49.0%	17.7%	3.6%	3.1%	100.0%

*Note.* New admissions in this table are persons admitted for the first time to individual large state facilities. This statistic reflects the number of persons who were admitted to a specific large state facility for the first time in Fiscal Year 1994. Statistics in this table represent 1,654 (77.3%) of the estimated 2,139 new admissions to individual large state facilities in Fiscal Year 1994.

### Readmissions by Age and Level of Mental Retardation

Table 1.19 presents the distribution of persons readmitted to specific large state facilities in Fiscal Year 1994 by their age and level of mental retardation. The large state facilities reporting data for Table 1.19 housed 77.3% of all residents of large state facilities in Fiscal Year 1994. The profile of readmissions shown in Table 1.19 is more similar to that of new admissions than of the general large state facility population, although as would be expected, it is somewhat older than the new admissions. As with new admissions there was a relatively high proportion of persons with mild or no mental retardation (34.3% vs. 7.0% in the general large state facility population) and a relatively low proportion of persons with profound mental retardation (24.9% vs. 65.5% in the general large state facility population). There was a notable decrease between 1989 and 1994 in the number and the proportion of persons with profound mental retardation among readmissions (from 33.7% of readmissions in 1989 to 24.9% in 1994). With the increasing numbers of persons with profound mental retardation living in community settings, this apparently reflects an improving capacity of community services to meet the needs of persons with the most severe cognitive limitations. While readmissions were somewhat older than new admissions, they tended to be younger than the general large state facility population (e.g., 16.4% vs. 6.1% were 21 years or

younger; 4.5% vs. 7.1% were 63 years or older). The proportion of children and youth (0-21 years) among all readmissions decreased from 19.0% in 1989 to 16.4% in 1994. The actual number of children and youth readmitted to large state facilities decreased from the estimated 292 in 1989 to an estimated 155 in 1994, as total readmissions were substantially reduced.

### Discharges by Age and Level of Mental Retardation

In the year ending June 30, 1994, there were an estimated 5,542 total discharges from large state facilities. About 9% of these "discharges" involved persons who were actually transferred to other large state facilities of 64 or more residents. Table 1.20 presents the distribution of persons discharged from large state facilities in Fiscal Year 1994 by age and level of mental retardation. It is based on the reports of facilities with 73.6% of all discharges in Fiscal Year 1994. The age distribution of large state facility discharges was similar to the age distribution of the general large state facility population; about 9.6% of the persons discharged were 21 years or younger as compared with 8.7% of the general population. Persons between the ages of 22 and 39 years made up 46.1% of discharges and 47.1% of the general large state facility population. Persons 63 years and older made up essentially the same proportion of persons in the general large state facility population (7.1%) as among people being discharged (7.2%).

**Table 1.19 Readmissions to Large State Facilities by Age and Level of Mental Retardation in the Year Ending June 30, 1994**

Level of Retardation	Chronological Age								Total(%)
	0-4	5-9	10-14	15-21	22-39	40-54	55-62	63+	
Mild or No MR	0	0	2	25	145	58	8	7	245 (34.3%)
Moderate	0	0	1	30	82	32	3	4	152 (21.3%)
Severe	4	2	5	16	68	34	10	5	140 (19.6%)
Profound	0	2	16	14	81	47	11	7	178 (24.9%)
Total	4	4	24	85	376	171	32	23	715
%	0.6%	0.6%	3.4%	11.9%	52.6%	23.9%	4.5%	4.5%	100.0%

*Note.* Readmissions in the above Table 1.19 are persons readmitted to the particular large state facilities surveyed. In contrast the "readmission" statistics in Table 1.5 (Chapter 1) of this report reflect the number of persons who were readmitted to any large state facility in the state during Fiscal Year 1994. As reflected in comparison of the two tables, there are more persons in the latter category than in the former. Statistics in Table 1.19 represent 715 (77.3%) of the 944 readmissions to individual large state facilities in Fiscal Year 1994.

**Table 1.20 Discharges from Large State Facilities  
by Age and Level of Mental Retardation, Year Ending June 30, 1994**

Level of Retardation	Chronological Age								Total(%)
	0-4	5-9	10-14	15-21	22-39	40-54	55-62	63+	
Mild or No MR	2	3	10	99	398	184	35	30	761 (18.7%)
Moderate	3	2	7	71	336	183	39	32	673 (16.5%)
Severe	7	8	6	43	353	265	66	83	831 (20.4%)
Profound	2	21	37	71	793	580	160	150	1,841 (44.5%)
Total	14	34	60	284	1,880	1,212	300	295	4,079
%	0.3%	0.8%	1.5%	7.0%	46.1%	29.7%	7.4%	7.2%	100.0%

*Note.* Statistics in this table represent large state facilities with 73.6% of an estimated 5,542 discharges in Fiscal Year 1994.

In contrast, people discharged tended to have levels of cognitive impairment that fell in a range between that of persons being admitted to large state facilities in Fiscal Year 1994 and the general population of these same large state facilities. Persons with profound mental retardation made up 44.5% of discharges and 31.5% of combined new admissions and readmissions, as compared with 65.5% of the general large state facility population. Persons with mild or no mental retardation made up 18.7% of discharges and 29.7% of combined new admissions and readmissions, as compared with 7.0% of the general state institution population. Discharges outnumbered admissions for persons of all levels of mental retardation. It was notable, however, that the smallest relative difference between discharges and admissions was among persons with mild or no mental retardation, for whom estimated discharges (1,034) were only 11.5% more than estimated admissions (915). For persons with profound mental retardation estimated discharges (2,465) were more than double the estimated 974 admissions.

***Persons in Movement in 1987, 1989, 1991 and 1994***

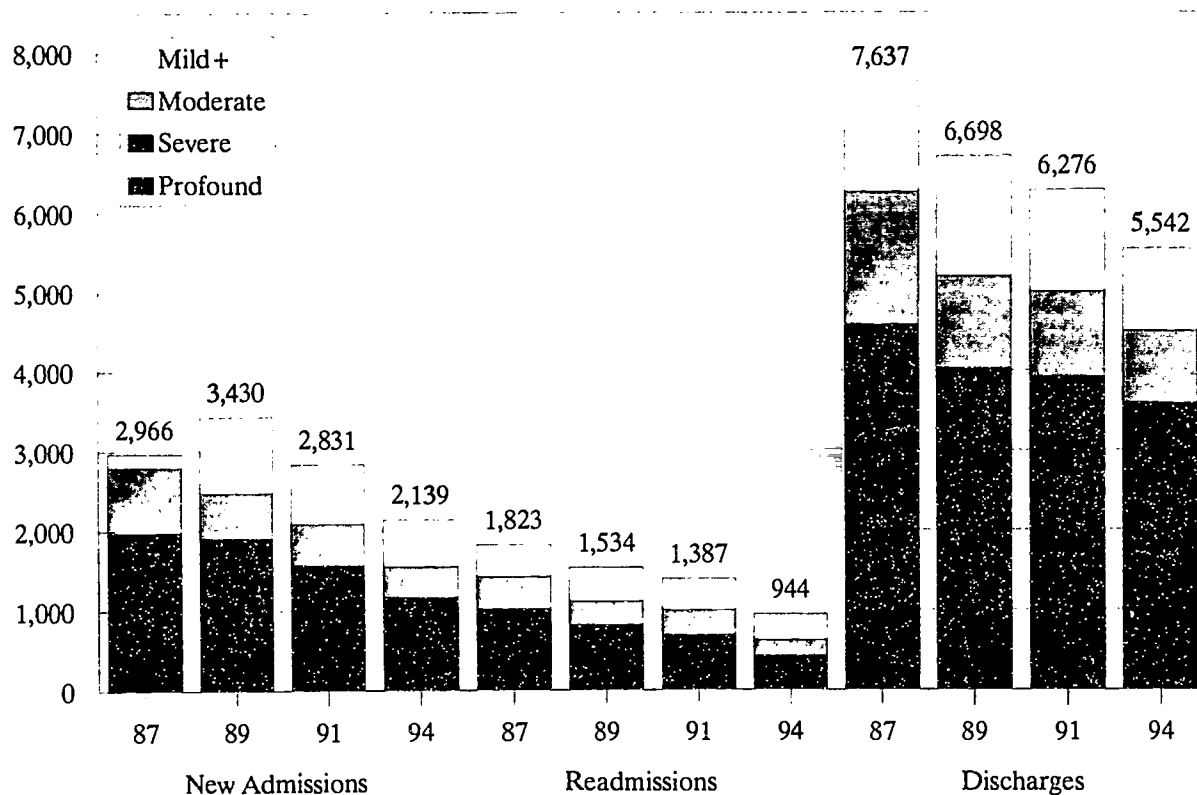
Figure 1.7 compares the number and distribution by level of mental retardation of newly admitted, readmitted and released residents of individual large state facilities in Fiscal Years 1987, 1989, 1991, and 1994. Admission patterns were generally similar in 1987, 1989, 1991, and 1994, although there were steadily fewer persons in each

of these categories, in large part because the June 30, 1994 population of large state facilities was 31% less than the 1987 population. In 1994 total admissions (new admissions and readmissions) were 39.9% fewer than in 1989. Discharges were 17.3% fewer in 1994 than in 1989. This general pattern of decreasing movement into and out of large state facilities has been evident for many years. Figure 1.7 also shows the level of mental retardation of persons in movement to be quite consistent across movement categories (i.e., new admissions, readmissions and discharges) as well as between years (1987, 1989, 1991, and 1994).

***Previous Placement of Admissions***

Table 1.21 summarizes the previous place of residence of persons admitted to specific large state facilities for the first time and of people returning to specific large state facilities after a previous discharge. Statistics are provided for Fiscal Years 1985, 1987, 1989, 1991, and 1994. As was evident in each of years shown, a very frequent place of immediate prior residence for new admissions to one large state facility was another large state MR/DD facility (23.1% of 1994 new admissions). In 1994 combined new admissions from large state MR/DD facilities and psychiatric facilities made up 39% of all new admissions. Since 1987 this proportion has remained in the range of 35% to 41% of all new admissions. A primary factor in the high number

**Figure 1.7**  
**Distribution of Admissions and Discharges for Large State**  
**Facilities by Level of Mental Retardation in Fiscal Years 1987, 1989, 1991 and 1994**



of persons moving into large facilities from other large facilities in recent years has been the large number of facility closures in progress or recently completed in the United States. In 1994 the proportion of new admissions coming directly from the family home continued to decrease, from 39.2% of new admissions in 1985 to 19.1% of new admissions in 1994. A primary factor in this reduction is the rapid decrease in placements of children and youth in the large state facilities. Unfortunately, however, there was a continuing increase in the proportion of new admissions who had previously been living in community foster homes, group homes, or semi-independent or supported independent living settings. In 1985, 8.0% of new admissions came from such settings, increasing to 14.9% in 1989 and to 19.1% in 1994. It should be noted, however, that the actual

numbers of people admitted from these community residential arrangements decreased between 1989 and 1994.

Persons readmitted to large state facilities in 1994 most frequently came from community residential settings, including group homes with 15 or fewer residents (30.1%) and foster homes (5.4%). A notable trend between 1985 and 1991 had been the decrease in persons readmitted from their family home or the home of a relative (36.8% in 1985, 29.1% in 1987, 19.6% in 1989, 14.1% in 1991). In 1994 there was a substantial reversal of this trend with 26.7% of readmissions coming from the homes of parents or relatives. It is not clear why this occurred, although it should be noted that this proportional change represented an increase of only 56 people nationwide.

**Table 1.21 Previous Placement of Persons Admitted or Readmitted to Large State Facilities, Fiscal Years 1985, 1987, 1989, 1991, and 1994**

Previous Placement	New Admissions					Readmissions				
	1985	1987	1989	1991	1994	1985	1987	1989	1991	1994
Parents/relatives	39.2%	29.0%	28.5%	24.2%	19.1%	36.8%	29.1%	19.6%	14.1%	26.7%
Foster home	3.5	3.4	5.2	2.9	2.9	7.1	7.5	9.3	10.1	5.4
Group home (15 or fewer res.)	5.6	7.0	8.4	9.6	14.1	19.7	17.9	22.9	26.1	30.1
Group facility (16-63 res.)	3.5	4.2	4.0	3.0	3.1	4.1	3.9	2.4	4.6	5.1
Nonstate facility (64+ res.)	1.8	2.6	3.3	3.0	5.4	2.5	3.8	2.9	6.6	1.8
State facility (64+ res.)	20.6	27.9	18.5	25.7	23.1	7.4	14.6	13.5	12.1	8.7
Boarding home/board and care	0.5	0.7	1.7	3.1	0.6	1.2	0.4	0.9	2.5	0.6
Nursing facility	1.6	2.4	2.7	2.3	2.1	2.0	2.4	3.1	2.4	1.8
Semi-ind/independent living	1.0	0.8	1.3	1.7	2.1	0.6	0.9	1.3	2.9	2.5
Mental health facility	13.6	10.0	16.3	14.9	15.9	8.5	8.4	12.8	9.5	8.1
Correctional facility	2.3	2.7	3.0	4.2	4.3	1.7	1.5	0.9	2.1	3.1
Unknown/other	6.7	9.3	7.2	5.6	7.3	7.9	8.9	10.4	7.2	9.4
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

Note. Statistics on previous placements for new admissions and readmissions in Fiscal Year 1994 are based on the reports of large state facilities reporting 80.4% of all new admissions and readmissions (1,643 of 2,139 new admissions and 827 of 944 readmissions).

**New residence of discharged residents**

Table 1.22 shows the new place of residence of people leaving large state facilities in Fiscal Year 1994, and, for comparative purposes, in Fiscal Years 1985, 1987, 1989, and 1991 as well. In 1994 well over half (58.4%) of all persons released from large state facilities whose subsequent placement was reported (i.e., excluding unknown/other) went to live in group homes of 15 or fewer residents. Another 17.8% of released residents whose placement was known went to natural, adoptive or foster homes. There was a slight increase in 1994 in the percentage of released residents moving to their parents' or relatives' homes (from 7.2% in 1991 to 9.2% in 1994), but the proportion was still considerably below the 17.1% in 1985 and 12.4%

in 1989. Post discharge placement patterns were generally quite stable between 1985 and 1994. The most notable change was the proportional increase in group home placements (from 40.4% in 1985 to 48.8% in 1989 to 53.2% in 1991 to 55.6% in 1994 in statistics unadjusted for "unknown/other."), although in actual numbers, discharges to community group homes decreased from an estimated 3,269 in 1989 to 3,081 in 1994. Nursing home placements (2.6% of discharges in 1994) were substantially less than the 4.4% of all discharges in 1987, the year in which the OBRA nursing home reforms were enacted (see Part III for a description). But the 1994 proportion of discharges was a slight increase from the 2.0% rate reported in 1989 and 1991.

**Table 1.22 New Place of Residence of Persons Discharged from Large State Facilities, Fiscal Years 1985, 1987, 1989, 1991 and 1994**

New Place of Residence	Fiscal Year				
	1985	1987	1989	1991	1994
Home of parents or relative	17.1%	11.3%	12.4%	7.2%	9.2%
Foster home	7.1	7.0	7.4	6.5	8.6
Group home (15 or fewer res.)	40.4	46.6	48.8	53.2	55.6
Group facility (16-63 res.)	7.4	6.7	5.3	7.5	4.3
Nonstate facility (64+ res.)	3.8	3.6	2.6	4.0	2.4
State facility (64+ res.)	10.1	12.2	10.2	9.3	8.8
Boarding home/Board and care	3.2	0.9	2.3	3.6	1.4
Nursing facility	4.1	4.4	2.0	2.0	2.6
Semi-Ind./Ind.Supported living	1.4	4.9	1.9	1.6	4.6
Mental health facility	1.4	1.2	1.4	1.9	0.9
Correctional facility	0.2	0.5	1.3	1.0	0.4
Unknown/Other	3.7	0.7	4.3	2.3	5.8
<b>Total</b>	<b>100.0%</b>	<b>100.0%</b>	<b>100.0%</b>	<b>100.0%</b>	<b>100.0%</b>

Note. Statistics on new place of residence are for persons leaving a specific large state facility and, therefore, include transfers between large state facilities. These statistics include subsequent residence of 4,098 (73.9%) of 5,542 persons discharged from individual large state facilities in Fiscal Year 1994.

**CHAPTER 4**  
**LARGE STATE MR/DD FACILITY CLOSURES, 1960-1998**

**Robert W. Prouty**  
**Stacey J. Moore**  
**K. Charlie Lakin**

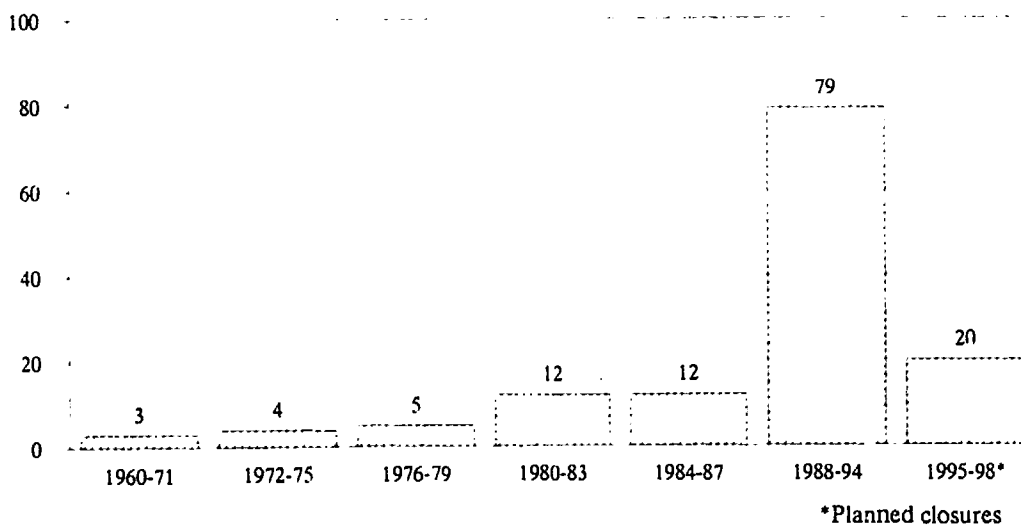
This chapter summarizes information gathered from each of the states on large state MR/DD facilities and special MR/DD units in psychiatric facilities that have operated since 1960 and their present and projected operational status. Responses were obtained from all states.

*Total Large State MR/DD Facility Closures*

Figure 1.8 shows the number of large state MR/DD facilities and MR/DD units in large state facilities primarily serving other populations that have closed since 1960, including planned closures for the period 1996 to 1998. As shown between 1960 and 1971 only three large state MR/DD facilities were closed in the United States, an average of 0.25 per year. In Fiscal Years 1972-1975 there were a total of four closures, an average of 1 per year. In every subsequent 4-year period facility closures occurred at an increasing annual rate. There were 5 in the period Fiscal Years 1976-1979 (an average of 1.25 per year). There were 12 in the period Fiscal Years 1980-1983 and 12 in the period Fiscal Years 1984-1987 (annual

averages of 3.0). In the period Fiscal Years 1988-1991, closures increased rapidly to 34 (an average of 8.5 per year). In the Fiscal Years 1992-1994, closures averaged 15 per year to a total of 45. In the Fiscal Years 1995, 1996, 1997, and 1998 states current project closure of a total of 20 large state MR/DD facilities and MR/DD units in other large state facilities (an average of 5.0 per year). This would represent a substantial decline in the rate of closures established between 1988 and 1995. Four states (District of Columbia, New Hampshire, Rhode Island, and Vermont) no longer have large state-operated MR/DD residential facilities. A number of states are currently developing plans for total or very significant reductions in the number of large state operated MR/DD residential facilities. For example, Michigan, which was still operating 3 large state facilities in 1995, and Hawaii operates one, which still anticipates operating no state institutions by the end of the century. New York which was still operating 12 large state facilities, and Minnesota which was still operating 6 large state MR/DD residential facilities at the end of Fiscal Year 1994.

**Figure 1.8**  
**Numbers of Large State MR/DD Facilities and Units Closed and Planned for Closure, 1960-1998**



### Closures and Projected Closures by States

Table 1.23 presents a state-by-state breakdown of the total number of large state facilities and MR/DD units operated since 1960, the number closed between 1960 and 1994, and the number planned for closure by 1998. As shown, the majority of states (33) have either closed a large state MR/DD facility or are planning to do so by the end of 1998. In the 35 year period from 1960 through 1994, 32 states closed one or more facilities. Thirteen states plan to close at least one large state MR/DD facility between 1995 and 1998. Only one of the states planning large facility closures between 1995 and 1998 has not previously closed a large state MR/DD facility or unit. Overall, 20 of 225 (8.9%) large state-operated MR/DD residential facilities have closed or are planned for closure in Fiscal Years 1995, 1996, 1997, or 1998.

#### Large State MR/DD Residential Facilities Operating and Closing, 1960-1998

Table 1.24 presents a list of all the large state MR/DD facilities and units that have operated in each state since 1960. It provides the year of opening of each facility and the last year of operation of facilities and units that have closed. For large state facilities that are still in operation it is indicated whether there are currently plans for the facility to be closed by the end of 1998. Of course, the stability of such plans, either for closure and increasingly about remaining in operation, are by no means guaranteed.

Table 1.23 Summary of Large State MR/DD Facilities and Units Since 1960, including Closures and Planned Closures Between 1960 and 1998

State	Large State MR/DD Facilities Operating Between 1960 and 1994	Total Closed 1960-1994	Actual/Planned Closures 1995-1998
Alabama	5	0	0
Alaska	1	0	0
Arizona	4	2	0
Arkansas	6	0	0
California	11	4	1
Colorado	3	1	1
Connecticut	15	4	2
Delaware	1	0	0
District of Columbia	3	3	0
Florida	10	3	0
Georgia	8	0	0
Hawaii	2	1	1
Idaho	1	0	0
Illinois	17	6	1
Indiana	11	1	2
Iowa	2	0	0
Kansas	4	1	0
Kentucky	5	2	0
Louisiana	9	0	0
Maine	3	1	1
Maryland	9	4	0
Massachusetts	9	4	1
Michigan	13	10	0
Minnesota	9	3	0
Mississippi	5	0	0
Missouri	16	10	0
Montana	2	0	0
Nebraska	1	0	0
Nevada	2	0	0
New Hampshire	2	2	0
New Jersey	11	3	0
New Mexico	3	1	2
New York	23*	12	4
North Carolina	6	1	0
North Dakota	2	1	0
Ohio	22	11	0
Oklahoma	4	1	0
Oregon	3	1	0
Pennsylvania	23	11	1
Rhode Island	3	3	0
South Carolina	5	0	0
South Dakota	2	0	0
Tennessee	5	0	0
Texas	16	0	2
Utah	1	0	0
Vermont	1	1	0
Virginia	8	3	0
Washington	6	1	0
West Virginia	4	3	1
Wisconsin	3	0	0
Wyoming	1	0	0
Total U.S.	340	115	20

\* Includes only the Developmental Centers operated by the New York State Office of Mental Retardation and Developmental Disabilities.



**Table 1.24 Large State MR/DD Facilities or Units Operating  
Between 1960 and 1994 with Dates and Projections of Closures Through 1998**

State	Large State MR/DD Facilities or Units Operating 1960-1994	City	Year MR/DD Facility Opened	Year Closed or Projected Closure Between 1995-1998
AL	Albert P. Brewer Developmental Center	Mobile	1973	NO
	Glen Ireland II Developmental Center	Tarrant City	1986	NO
	Wm. D. Partlow Developmental Center	Tuscaloosa	1923	NO
	J.S. Tarwater Developmental Center	Wetumpka	1976	NO
	Lurlene B. Wallace Developmental Center	Decatur	1971	NO
AK	Harborview Developmental Center	Valdez	1967	NO
AZ	Arizona Training Program	Phoenix	1973	1988
	Arizona Training Program	Tucson	1970	NO
	Arizona Training Program	Coolidge	1952	NO
	Arizona State Hospital	Phoenix	1978e	1994
AR	Alexander Human Development Center	Alexander	1968	NO
	Conway Human Development Center	Conway	1959	NO
	Arkadelphia Human Development Center	Arkadelphia	1968	NO
	Booneville Human Development Center	Booneville	1973	NO
	Jonesboro Human Development Center	Jonesboro	1970	NO
	Southeast Arkansas Human Dev. Center	Warren	1978	NO
CA	Agnews Developmental Center	San Jose	1966	NO
	Camarillo Developmental Center	Camarillo	1968	NO
	DeWitt State Hospital	Auburn	1946	1972
	Fairview Developmental Center	Costa Mesa	1959	NO
	Lanternman Developmental Center	Pomona	1927	NO
	Modesto State Hospital	Modesto	1947	1962
	Napa State Hospital	Imola	1969	1987
	Patton State Hospital	Patton	1963	1982
	Porterville Developmental Center	Porterville	1953	NO
	Sonoma Developmental Center	Eldrige	1891	NO
Stockton Developmental Center	Stockton	1972	1995	
CO	Grand Junction Regional Center	Grand Junction	1919	NO
	Pueblo State Regional Center	Pueblo	1935	1988
	Wheat Ridge Regional Center	Wheatridge	1912	YES
CT	Bridgeport Center	Bridgeport	1965	1981
	Central Connecticut Center	Meriden	1979	NO
	Clifford Street Group Home	Hartford	1982	YES

State	Large State MR/DD Facilities or Units Operating 1960-1994	City	Year MR/DD Facility Opened	Year Closed or Projected Closure Between 1995-1998
CT cont	John Dempsey Center	Putnam	1964	NO
	Ella Grasso Center	Stratford	1981	NO
	Hartford Center	Newington	1965	NO
	Lower Fairfield County Center	Norwalk	1976	NO
	Mansfield Training School	Mansfield	1917	1993
	Martin House Group Home	Norwalk	1971	NO
	Mystic Center	Groton	1979	NO
	New Haven Center	New Haven	1962	1994
	Northwest Center	Torrington	1984	NO
	Seaside Center	Waterford	1961	YES
	Southbury Training School	Southbury	1940	NO
Waterbury Center	Cheshire	1971	1989	
DE	Stockley Center	Georgetown	1921	NO
DC	Bureau of Forest Haven	Laurel, MD	1925	1990
	St. Elizabeth's Hospital	Washington, DC	1987	1994
	D.C. Village	Washington, DC	1975	1994
FL	FL State Hosp: 1) MR Defendant Program; 2) Unit 27 (Dually Diagnosed)	Chattahoochee	1) 1977 2) 1976	1) NO 2) NO
	Gulf Coast Center	Fort Meyers	1960	NO
	Landmark Learning Center	Opa-Locka	1966	NO
	N.E. Florida State Hospital	MacClenny	1981	NO
	Seguin Unit-Alachua Retarded Defendent Center	Gainesville	1989	NO
	Sunland at Marianna	Marianna	1961	1994
	Sunland Training Center	Orlando	1960	1984
	Sunland Training Center	Tallahassee	1968	1983
Tacachale (Formerly Sunland at Gainesville)	Gainesville	1921	NO	
GA	Brook Run	Atlanta	1969	NO
	Central State Hospital	Milledgeville	1965	NO
	Georgia Regional Hospital at Atlanta	Decatur	1968	NO
	Gracewood State School and Hospital	Gracewood	1921	NO
	Northwest Regional Hospital	Rome	1971	NO
	River's Crossing	Athens	DNF	NO
	Southwestern Developmental Center	Bainbridge	1967	NO
Southwestern State Hospital	Thomasville	1966	NO	

State	Large State MR/DD Facilities or Units Operating 1960-1994	City	Year MR/DD Facility Opened	Year Closed or Projected Closure Between 1995-1998
HI	Waimano Training School and Hospital	Pearl City	1921	1998
	Kula Hospital	Kula	1984	1994
ID	Idaho State School and Hospital	Nampa	1918	NO
IL	Alton Mental Health & Dev Center	Alton	1914	1994
	Bowen Developmental Center	Harrisburg	1966	1982
	Choate Mental Health and Dev. Center	Anna	1873	NO
	Dixon Developmental Center	Dixon	1918	1987
	Elgin Mental Health & Dev. Center	Elgin	1872	1994
	Fox Developmental Center	Dwight	1965	NO
	Galesburg Developmental Center	Galesburg	1959	1985
	Howe Developmental Center	Tinley Park	1973	NO
	Jacksonville Developmental Center	Jacksonville	1851	NO
	Kiley Developmental Center	Waukegan	1975	YES
	Lincoln Developmental Center	Lincoln	1866	NO
	Ludeman Developmental Center	Park Forest	1972	NO
	Mabley Developmental Center	Dixon	1987	NO
	Meyer Mental Health Centex <sup>1</sup>	Decatur	1967	1993
	Murray Developmental Center	Centralia	1964	NO
	Shapiro Developmental Center	Kankakee	1879	NO
Singer Mental Health & Dev Center	Rockford	1966	NO	
IN	Central State Hospital	Indianapolis	1848	1995
	Evansville State Hospital	Evansville	1890	NO
	Fort Wayne Developmental Center	Fort Wayne	1890	NO
	Logansport State Hospital	Logansport	1888	NO
	Madison State Hospital	Madison	1910	NO
	Muscatatuck Developmental Center	Butlerville	1920	NO
	New Castle Developmental Center	New Castle	1907	NO
	Norman Beatty Memorial Hospital	Westville	1951	1979
	Northern Indiana Developmental Center	South Bend	1961	NO
	Richmond State Hospital	Richmond	1890	NO
	Silvercrest State Hospital	New Albany	1974	1995
IA	Glenwood State Hospital and School	Glenwood	1917	NO
	Woodward State Hospital and School	Woodward	1876	NO
KS	Kansas Neurological Institute	Topeka	1960	NO
	Norton State Hospital	Norton	1963	1988
	Parsons State Hospital and Training Center	Parsons	1952	NO

State	Large State MR/DD Facilities or Units Operating 1960-1994	City	Year MR/DD Facility Opened	Year Closed or Projected Closure Between 1995-1998
KS cont	Winfield State Hospital	Winfield	1884	NO
KY	Central State Hospital ICF/MR	Louisville	1873	NO
	Frankfort State Hospital and School	Frankfort	1860	1973
	Hazelwood Center	Louisville	1971	NO
	Oakwood ICF/MR	Somerset	1972	NO
	Outwood ICF/MR <sup>2</sup>	Dawson Springs	1962	1994
LA	Columbia Developmental Center	Columbia	1970	NO
	Hammond Developmental Center	Hammond	1964	NO
	Leesville Developmental Center	Leesville	1964	NO
	Metropolitan Developmental Center	Belle Chase	1967	NO
	Northwest Louisiana Developmental Center	Bossier City	1973	NO
	Peltier-Lawless Developmental Center	Thibodaux	1982	NO
	Pinecrest Developmental Center	Pineville	1918	NO
	Ruston Developmental Center	Ruston	1959	NO
Southwest Louisiana Developmental Center	Iota	1972	NO	
ME	Aroostook Residential Center	Presque Isle	1972	1994
	Elizabeth Levinson Center	Bangor	1971	NO
	Pineland Center	Pownal	1908	1995
MD	Joseph Brandenburg Center	Cumberland	1978	NO
	Victor Cullen Center	Sabillasville	1974	1992
	Great Oaks Center	Silver Spring	1970	NO
	Henryton Center	Henryton	1962	1985
	Highland Health Facility	Baltimore	1972	1989
	Holly Center	Salisbury	1975	NO
	Potomac Center	Hagerstown	1978	NO
	Rosewood Center	Owings Mills	1887	NO
	Walter P. Carter Center	Baltimore	1978	1990
MA	Belchertown State School	Belchertown	1922	1992
	Paul A. Dever State School	Taunton	1946	1995
	Walter E. Fernald State School	Waltham	1848	NO
	Glavin Regional Center	Shrewsbury	1974	NO
	Hogan/Berry Regional Center	Hathorne	1967	1994
	Medfield State Hospital	Medfield	DNF	1994
	Mons on Developmental Center	Palmer	1898	NO
Worcester State Hospital	Worcester	DNF	1994	

State	Large State MR/DD Facilities or Units Operating 1960-1994	City	Year MR/DD Facility Opened	Year Closed or Projected Closure Between 1995-1998
MA cont	Wrentham State School	Wrentham	1907	NO
MI	Alpine Regional Center for DD	Gaylord	1960	1981
	Caro Regional Mental Health Center	Caro	1914	NO
	Coldwater Regional Center for DD	Coldwater	1935	1987
	Fort Custer State Home	Augusta	1956	1972
	Hillcrest Regional Center for DD	Howell	1959	1982
	Macomb-Oakland Regional Center for DD	Mt. Clemens	1967	1989
	Mount Pleasant Regional Center for DD	Mount Pleasant	1937	2000
	Muskegon Regional Center for DD	Muskegon	1969	1992
	Newberry Regional Mental Health Center	Newberry	1895	1992
	Northville Residential Training Center	Northville	1972	1983
	Oakdale Regional Center for DD	Lapeer	1895	1992
	Plymouth Center for Human Development	Northville	1960	1984
Southgate Regional Center	Southgate	1977	NO	
MN	Brainerd Regional Human Services Center	Brainerd	1958	NO
	Cambridge Regional Human Services Center	Cambridge	1925	NO
	Fairbault Regional Center	Fairbault	1879	1998
	Fergus Falls Regional Treatment Center	Fergus Falls	1969	NO
	Moose Lake Regional Treatment Center	Moose Lake	1970	1994
	Owatonna State School	Owatonna	1945	1972
	Rochester State Hospital	Rochester	1968	1982
	St. Peter Regional Treatment Center	St. Peter	1968	NO
	Willmar Regional Treatment Center	Willmar	1973	NO
MS	Boswell Regional Center	Sanatorium	1976	NO
	Ellisville State School	Ellisville	1920	NO
	Hudspeth Regional Center	Whitfield	1974	NO
	North Mississippi Regional Center	Oxford	1973	NO
	South Mississippi Regional Center	Long Beach	1978	NO
MO	Albany Regional Center	Albany	1967	1991
	Bellefontaine Habilitation Center	St. Louis	1924	NO
	Hannibal Regional Center	Hannibal	1967	1989
	Higginsville Habilitation Center	Higginsville	1956	NO
	Joplin Regional Center	Joplin	1967	1992
	Kansas City Regional Center	Kansas City	1970	1993
Kirkville Regional Center	Kirkville	1968	1988	

State	Large State MR/DD Facilities or Units Operating 1960-1994	City	Year MR/DD Facility Opened	Year Closed or Projected Closure Between 1995-1998
MO cont	Marshall Habilitation Center	Marshall	1901	NO
	Marshall Regional Center	Marshall	1975	1982
	Nevada Habilitation Center	Nevada	1973	NO
	Poplar Bluff Regional Center	Poplar Bluff	1968	1992
	Rolla Regional Center	Rolla	1968	1984
	Sikeston Regional Center	Sikeston	1969	1992
	Southeast Missouri Residential Services <sup>3</sup>	Poplar Bluff Sikeston	1992	NO
	Springfield Regional Center	Springfield	1967	1990
	St. Louis DD Treatment Center	St. Louis	1974	NO
MT	Montana Developmental Center	Boulder	1905	NO
	Eastmont Human Services Center	Glendive	1969	NO
NE	Beatrice State Developmental Center	Beatrice	1875	NO
NV	Desert Developmental Center	Las Vegas	1975	NO
	Sierra Developmental Center	Reno	1977	NO
NH	Laconia State School and Training Center	Laconia	1903	1991
	New Hampshire Hospital, Brown Building	Concord	1842	1990
NJ	Developmental Center at Ancora	Hammonton	DNF	1992
	Edison Habilitation Center	Princeton	1975	1988
	E.R. Johnstone Training & Research Ctr	Bordentown	1955	1992
	Green Brook Regional Center	Green Brock	1981	NO
	Hunterdon Developmental Center	Clinton	1969	NO
	New Lisbon Developmental Center	New Lisbon	1914	2000
	North Jersey Developmental Center	Totowa	1928	NO
	North Princeton Developmental Center	Princeton	1975	NO
	Vineland Developmental Center	Vineland	1888	NO
	Woodbine Developmental Center	Woodbine	1921	NO
NM	Woodbridge Developmental Center	Woodbridge	1965	NO
	Fort Stanton Hospital and Training Center	Fort Stanton	1964	YES
	Los Lunas Hospital and Training Center	Los Lunas	1929	1995
	Villa Solano-Hagerman Residential School	Roswell	1964	1982
NY	J.N. Adams DDSO	Perryshurg	1960	1993
	Bronx DDSO	Bronx	1971	1992
	Brooklyn DDSO	Brooklyn	1972	NO
	Broome DDSO	Binghamton	1970	NO
	Bernard M. Fineson DDSO	Corona	1970	NO

State	Large State MR/DD Facilities or Units Operating 1960-1994	City	Year MR/DD Facility Opened	Year Closed or Projected Closure Between 1995-1998
NY cont	Craig DDSO	Sonyea	1935	1988
	Gouverneur	New York	1962	1978
	Oswald D. Heck DDSO	Schenectady	1973	NO
	Letchworth Village DDSO	Thielis	1911	1996
	Long Island DDSO	Melville	1965	1992
	Manhattan Developmental Center	New York	1972	1992
	Monroe DDSO	Rochester	1969	NO
	Newark Developmental Center	Newark	1878	1991
	Rome Developmental Center	Rome	1894	1989
	Sampson State School	Willard	1961	1971
	Staten Island DDSO	Staten Island	1947	1988
	Sunmount DDSO	Tupper Lake	1965	NO
	Syracuse DDSO	Syracuse	1851	1995
	Valatie	Valatie	1971	1974
	Wassaic DDSO	Wassaic	1930	1998
	Westchester Developmental Center	Tarrytown	1979	1988
	West Seneca DDSO	West Seneca	1962	2000
Wilton DDSO	Wilton	1960	1995	
NC	Black Mountain Center	Black Mountain	1982	NO
	Broughton Center	Morganton	1883	1994
	Caswell Center	Kinston	1914	NO
	Murdoch Center	Butner	1957	NO
	O'Berry Center	Goldsboro	1957	NO
	Western Carolina Center	Morganton	1963	NO
ND	Grafton Developmental Center	Grafton	1904	NO
	San Haven State Hospital	Dunseith	1973	1987
OH	Apple Creek Developmental Center	Apple Creek	1931	NO
	Athens Mental Health & Dev. Center	Athens	1975	1994
	Broadview Developmental Center	Broadview Hgts.	1967	1992
	Cambridge Developmental Center	Cambridge	1965	NO
	Cambridge Mental Health Center	Cambridge	1978	1990
	Central Ohio Psychiatric Hospital	Columbus	1978e	1994
	Cleveland Developmental Center	Cleveland	1976	1988
	Columbus Developmental Center	Columbus	1857	NO
	Dayton Developmental Center	Dayton	1979	1983
Dayton Mental Health Center	Dayton	1978e	1994	

State	Large State MR/DD Facilities or Units Operating 1960-1994	City	Year MR/DD Facility Opened	Year Closed or Projected Closure Between 1995-1998
OH cont	Gallipolis Developmental Center	Gallipolis	1893	NO
	Massillon State Hospital	Massillon	1978e	1994
	Montgomery Developmental Center	Huber Heights	1977	NO
	Mount Vernon Developmental Center	Mount Vernon	1948	NO
	Northwest Ohio Developmental Center	Toledo	1977	NO
	Orient Developmental Center	Orient	1898	1984
	Southwest Ohio Developmental Center	Batavia	1981	NO
	Tiffin Developmental Center	Tiffin	1975	NO
	Toledo Mental Health Center	Toledo	1978e	1994
	Warrensville Developmental Center	Warrensville Heights	1975	NO
	Western Reserve Psychiatric Hab Center	Northfield	1978	1990
	Youngstown Developmental Center	Youngstown	1980	NO
OK	Northern Oklahoma Resource Center	Enid	1909	NO
	Robert M. Greer Memorial Center <sup>4</sup>	Enid	1992	NO
	Hisson Memorial Center	Sand Springs	1964	1994
	Southern Oklahoma Resource Center	Pauls Valley	1952	NO
OR	Columbia Park Hospital & Training Center	The Dalles	1963	1977
	Easterl Oregon Training Center	Pendleton	1964	NO
	Fairview Training Center	Salem	1908	NO
PA	Allentown Mental Retardation Unit	Allentown	1974	1988
	Altoona Center <sup>5</sup>	Altoona	1982	NO
	Clarks Summit Mental Retardation Unit	Clarks Summit	1974	1992
	Cresson Center	Cresson	1964	1982
	Embreeville Center	Coatesville	1972	1997
	Ebensburg Center	Ebensburg	1957	NO
	Hamburg Center	Hamburg	1960	NO
	Harrisburg Mental Retardation Unit	Harrisburg	1972	1982
	Hollidaysburg Mental Retardation Center	Hollidaysburg	1974	1976
	Laurelton Center	Laurelton	1920	NO
	Marcy Center	Pittsburgh	1975	1982
	Mayview Mental Retardation Unit	Mayview	1974	NO
	Pennhurst Center	Pennhurst	1908	1988
	Philadelphia Mental Retardation Unit	Philadelphia	1983	1989
Polk Center	Polk	1897	NO	
Selinsgrove Center	Selinsgrove	1929	NO	



State	Large State MR/DD Facilities or Units Operating 1960-1994	City	Year MR/DD Facility Opened	Year Closed or Projected Closure Between 1995-1998
PA cont	Somerset Mental Retardation Unit	Somerset	1974	NO
	Torrance Mental Retardation Unit	Torrance	1974	NO
	Warren Mental Retardation Unit	Warren	1975	1976
	Wernersville Mental Retardation Unit	Wernersville	1974	1987
	Western Center	Canonsburg	1962	NO
	White Haven Center	White Haven	1956	NO
	Woodhaven Center <sup>b</sup>	Philadelphia	1974	1985
RI	Dorothea Dix Unit	Cranston	1982	1989
	Dr. Joseph H. Ladd Center	N. Kingstown	1908	1994
	Zaborano Memorial Hospital	Wallum Lake	1967	1989
SC	Midlands Center	Columbia	1956	NO
	Pee Dee Center	Florence	1971	NO
	Thad E. Saleeby Center	Hartsville	DNF	NO
	Coastal Center	Ladson	1968	NO
	Whitten Center	Clinton	1920	NO
SD	Custer State Developmental Center	Custer	1964	NO
	Redfield State Developmental Center	Redfield	1903	NO
TN	Arlington Developmental Center	Arlington	1969	NO
	Clover Bottom Developmental Center	Donelson	1923	NO
	Greene Valley Developmental Center	Greeneville	1960	NO
	Harold Jordan Habilitation Center	Nashville	1979	NO
	Winston Developmental Center	Bolivar	1979	NO
TX	Abilene State School	Abilene	1957	NO
	Austin State School	Austin	1917	NO
	Brenham State School	Brenham	1974	NO
	Corpus Christi State School	Corpus Christi	1970	NO
	Denton State School	Denton	1960	NO
	El Paso State School	El Paso	1973	NO
	Ft. Worth State School	Ft. Worth	1976	YES
	Laredo State School	Laredo	1979	NO
	Lubbock State School	Lubbock	1969	NO
	Lufkin State School	Lufkin	1962	NO
	Mexia State School	Mexia	1946	NO
	Richmond State School	Richmond	1968	NO
	Rio Grande State School	Harlingen	1973	NO
San Angelo State School	Carlsbad	1969	NO	

State	Large State MR/DD Facilities or Units Operating 1960-1994	City	Year MR/DD Facility Opened	Year Closed or Projected Closure Between 1995-1998
TX cont	San Antonio State School	San Antonio	1978	NO
	Travis State School	Austin	1961	YES
UT	Utah State Training School	American Fork	1931	NO
VT	Brandon Training School	Brandon	1915	1993
VA	Eastern State Hospital	Williamsburg		1990
	Central Virginia Training Center	Lynchburg	1911	NO
	Northern Virginia Training Center	Fairfax	1973	NO
	Southeastern Virginia Training Center	Chesapeake	1975	NO
	Southside Virginia Training Center	Petersburg	1939	NO
	Southwestern State Hospital	Marion	1887	1988
	Southwestern Virginia Training Center	Hillsville	1976	NO
	Western State Hospital <sup>7</sup>	Stanton	1828	1990
WA	Fircrest School	Seattle	1959	NO
	Interlake School	Medical Lake	1967	1994
	Lakeland Village School	Medical Lake	1915	NO
	Frances Haddon Morgan Center	Bremerton	1972	NO
	Rainer School	Buckley	1939	NO
	Yakima Valley School	Selah	1958	NO
WV	Colin Anderson Center	St. Mary's	1932	1996
	Greenbrier Center <sup>8</sup>	Lewisburg	1974	1990
	Spencer State Hospital	Spencer	1893	1989
	Weston State Hospital	Weston	1985	1988
WI	Central Wisconsin Center	Madison	1959	NO
	Northern Wisconsin Center	Chippewa Falls	1895	NO
	Southern Wisconsin Center	Union Grove	1919	NO
WY	Wyoming State Training School	Lander	1912	NO

Notes:

<sup>1</sup> Closed for persons with developmental disabilities, now called the Meyer Mental Health Center.

<sup>2</sup> Outwood was state-owned but contracted to Res-Care, Inc. for management and operation.

<sup>3</sup> Merger of Poplar Bluff and Sikeston Regional Centers.

<sup>4</sup> Administrative change. The center is still located on the grounds of the Enid State School.

<sup>5</sup> Altoona Center began as a unit of Cresson Center. It became independent upon the closing of Cresson Center in 1982.

<sup>6</sup> The state owns the building, but since 1985 it has been run by Temple University, paid for with non-state ICF-MR funding.

<sup>7</sup> Western State Hospital no longer has an identifiable MR Unit.

<sup>8</sup> Became private in 1990. Closed March 15, 1994.

## **SECTION II**

# **STATUS AND CHANGES IN TOTAL STATE RESIDENTIAL SERVICE SYSTEMS**

**CHAPTER 5**  
**SERVICES PROVIDED BY STATE AND NONSTATE AGENCIES IN 1994**

**Troy Mangan**  
**Robert Prouty**  
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**K. Charlie Lakin**

This chapter provides statistics on all residential services that were directly provided or licensed by states for persons with mental retardation and related developmental disabilities (MR/DD). These statistics are reported by state, operator (state or nonstate agency) and residential setting size as of June 30, 1994. Residential services data for 1994 are compared with similar statistics from 1977, 1982, 1987, and 1992. The statistics in this chapter do not include psychiatric facilities or nursing homes, but do include services financed under the federal Medicaid program, most notably the Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) and Home and Community Based Services (HCBS) programs. Statistics on psychiatric facility residents with MR/DD are reported in Chapter 1 and statistics on nursing home residents with MR/DD are reported in Chapter 3. They are excluded here because of this chapter's focus on services provided with the designated MR/DD service systems of each state.

*Number of Residential Settings*

Table 2.1 presents statistics by state, operator, and size on the number of individual residential settings in which people received state licensed or state provided residential services for persons with MR/DD on June 30, 1994. It excludes services provided to people living with their natural or adoptive families.

There were 63,654 distinct residential settings for persons with MR/DD who were receiving residential services on June 30, 1994. Of the total 63,654 residential settings, 61,904 (97.3%) were operated by nonstate agencies or individuals and 1,750 (2.7%) were state-operated. In all, 55,784 (87.7%) settings had 6 or fewer residents, 6,500

(10.2%) had 7 to 15 residents and 1,370 (2.1%) had 16 or more residents. Virtually all residential settings with 6 or fewer residents were operated by nonstate agencies (99.0%), as were most of those with 7 to 15 persons (86.3%) and with 16 or more residents (79.1%).

*Number of Persons Receiving Residential Services*

Table 2.2 presents statistics by state, operator, and setting size on the number of people with MR/DD receiving residential services on June 30, 1994. Of the 310,911 persons receiving residential services on June 30, 1994, 234,844 (75.5%) were served by nonstate agencies. Virtually all persons in settings with 6 or fewer residents (98.5%) and an overwhelming majority of those in settings with 7 to 15 residents (85.7%) received services from nonstate agencies. In contrast, over three-fifths (61.1%) of all persons in facilities with 16 or more residents were served by state agencies, even though 79.1% of facilities with 16 or more residents were operated by nonstate agencies. California and New York had by far the largest numbers of persons receiving residential services (42,701 and 30,938, respectively). Illinois and California had the largest number of persons living in facilities of 16 or more residents (11,551 and 10,234, respectively). Illinois had the largest number of persons living in large nonstate facilities (6,468 or 15.4% of the national total). California and New York had the largest number of persons living in residential settings of 15 or fewer persons (31,150 and 25,481 respectively). California, Michigan, and Pennsylvania had the largest number of persons living in residential settings of 6 or fewer persons (27,822, 8,719, and 8,040, respectively).

Table 2.1 Residential Settings for Persons with Mental Retardation and Related Developmental Disabilities Served by State and Nonstate Agencies on June 30, 1994

State	Nonstate Residential Settings by Size					State Residential Settings by Size					State and Nonstate Residential Settings				
	1-6	7-15	1-15	16+	Total	1-6	7-15	1-15	16+	Total	1-6	7-15	1-15	16+	Total
AL	122**	83**	205**	2**	207**	0	0	0	5	5	122	83	205	7	212
AK	295	7	302	0	302	0	0	0	1	1	295	7	302	1	303
AZ	1,444e	18	1,462e	1	1,463e	23	10	33	7	40	1,467e	28	1,495e	8	1,503e
AR	308e	30	338e	4	342e	0	0	0	6	6	308e	30	338e	10	348e
CA	6,726e	348	7,074*	151	7,225*	0	0	0	7	7	6,726*	348*	7,074*	158*	7,232*
CO	1,365*	64*	1,429*	4	1,433*	3	36	39	2	41	1,368*	100*	1,468*	6	1,474*
CT	1,502	28	1,530	0	1,530	118	38	156	12	168	1,620	66	1,686	12	1,698
DE	198	0	198	0	198	0	0	0	1	1	198	0	198	1	199
DC	183	44	227	0	227	0	0	0	0	0	183	44	227	0	227
FL	846	199	1,045	74	1,119	0	0	0	24	24	846	199	1,045	98	1,143
GA	721	0	721	1	722	0	0	0	12	12	721	0	721	13	734
HI	814	1	815	13	828	0	0	0	2	2	814	1	815	15	830
ID	390	90e	480	24e	504	0	0	0	1	1	390	90	480	25	505
IL	393	504	897	133	1,030	0	0	0	12	12	393	504	897	145	1,042
IN	1,322	343	1,665	13	1,678	0	0	0	11	11	1,322	343	1,665	24	1,689
IA	1,379*	136	1,515*	27	1,542*	0	0	0	2	2	1,379*	136	1,515*	29	1,544*
KS	110	109	219	11	230	0	0	0	3	3	110	109	219	14	223
KY	989	37	1,026	36	1,062	0*	0*	0*	2*	2*	989	37	1,026	38	1,064
LA	895	74	969	14	983	11	0	11	9	20	906	74	980	23	1,003
ME	442	30	472	6	478	0	1	1	2	3	442	31	473	8	481
MD	1,213	0	1,213	5	1,218	0	0	0	5	5	1,213	0	1,213	10	1,223
MA	1,665	116	1,781	0	1,781	37	61	98	8	106	1,702	177	1,879	8	1,887
MI	2,244e	0	2,244e	0	2,244e	0	0	0	3	3	2,244e	0	2,244e	3	2,247e
MN	2,346e*	170*	2,516e*	35	2,551e*	34	0	34	6	40	2,380e*	170*	2,550e*	41	2,591e*
MS	100	6	106	5	111	91	24	115	5	120	191	30	221	10	231
MO	854	169	1,023	87	1,110	0	0	0	6	6	854	169	1,023	93	1,116
MT	620	68	688	0	688	0	0	0	2	2	620	68	688	2	690
NE	293	27	320	2	322	0	0	0	1	1	293	27	320	3	323
NV	230	0	230	4	234	4	0	4	2	6	234	0	234	6	240
NH	2,095e	29e	2,124e	2e	2,126e	11	0	11	0	11	2,106e	29e	2,135e	2e	2,137e
NJ	1,257	0	1,257	41	1,298	0	0	0	8	8	1,257	0	1,257	49	1,306
NM	171*	36*	207*	1*	208*	0	0	0	2	2	171*	36*	207*	3	210*
NY	3,987*	1,137*	5,124*	51*	5,175*	196*	704*	900*	25*	925*	4,183*	1,841*	6,024*	76*	6,100*
NC	671	65	736	14	750	0	0	0	6	6	671	65	736	20	756
ND	528	61	589	4	593	0	1	1	1	2	528	62	590	5	595
OH	1,835	315	2,150	95	2,245	0	0	0	12	12	1,835	315	2,150	107	2,257
OK	756	23	779	29	808	0	0	0	3	3	756	23	779	32	811
OR	909	65	974	8	892	7	0	7	2	9	916	65	981	10	991
PA	4,021	116	4,137	70	4,207	0	0	0	12	12	4,021	116	4,137	82	4,219
RI	248	25	273	2	275	36	13	49	0	49	284	38	322	?	324
SC	573	315	888	5	893	0	0	0	5	5	573	315	888	10	898
SD	431e	67	498e	0	498e	0	0	0	2	2	431e	67	498e	2	500e
TN	328	202	530	3	533	0	0	0	5	5	328	202	530	8	538
TX	1,079*	78	1,157	30	1,187	1	3	4	16	20	1,080	81	1,161	46	1,027
UT	479	45	524	9	533	0	0	0	1	1	479	45	524	10	534
VT	566	0	566	0	566	0	0	0	0	0	566	0	566	0	566
VA	74	55	129	11	140	0	0	0	15	15	74	55	129	26	155
WA	1,620	88	1,708	11	1,719	0	0	0	7	7	1,620	88	1,708	18	1,726
WV	347*	53*	400*	4*	404*	0*	0*	0*	1*	1*	347*	53*	400*	5*	405*
WI	2,898	124	3,022	41	3,063	0	0	0	3	3	2,898	124	3,022	44	3,066
WY	330	9	339	0	339	0	0	0	2	2	330	9	339	2	341
U.S. Total	55,212	5,609	60,821	1,083	61,904	572	891	1,463	287	1,750	55,784	6,509	62,284	1,370	63,654

\* indicates 1993 data \*\* indicates 1992 data

e indicates estimates

Table 2.2 Persons with Mental Retardation and Related Developmental Disabilities Served by State and Nonstate Agencies on June 30, 1994

	Residents of Nonstate Settings by Size					Residents of State Settings by					Total Residents of All Settings 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
AL	361**	679**	1,040**	29**	1,069**	0	0	0	1,113	1,113	361**	679**	1,040**	1,142	2,182
AK	468	70	538	0	538	0	0	0	38	38	468	70	538	38	576
AZ	4,624	160	4,784	45	4,829	106	171	277	123	400	4,730	331	5,061	168	5,229
AR	429e	300	729e	185	914e	0	0	0	1,258	1,258	429	300	729	1,443	2,172
CA	27,822	3,328	31,150	5,208	36,358	0	0	0	6,343	6,343	27,822	3,328	31,150	11,551	42,701
CO	2,806	378	3,184	172	3,356	8	264	272	248	520	2,814	642	3,456	420	3,876
CT	3,261	238	3,499	0	3,499	428	302	730	1,342	2,072	3,689	540	4,229	1,342	5,571
DE	385	0	385	0	385	0	0	0	320	320	385	0	385	320	705
DC	721	363	1,084	0	1,084	0	0	0	0	0	721	363	1,084	0	1,084
FL	3,292	1,834	5,126	2,446	7,572	0	0	0	1,535	1,535	3,292	1,834	5,126	3,981	9,107
GA	1,538	0	1,538	110	1,648	0	0	0	1,991	1,991	1,538	0	1,538	2,101	3,639
HI	1,015	7	1,022	12	1,034	0	0	0	84	84	1,015	7	1,022	96	1,118
ID	824	505e	1,329	193e	1,522	0	0	0	143	143	824	505	1,329	336	1,665
IL	738	4,836	5,574	6,468	12,042	0	0	0	3,726	3,726	738	4,836	5,574	10,194	15,768
IN	2,506	2,791	5,297	945	6,242	0	0	0	1,384	1,384	2,506	2,791	5,297	2,329	7,626
IA	2,006*	1,884	3,890*	1,197	5,087	0	0	0	752	752	2,006*	1,884	3,890*	1,949	5,839
KS	584	941	1,525	671	2,196	0	0	0	806	806	584	941	1,525	1,477	3,002
KY	1,353	189	1,542	543	2,085	0*	0*	0*	620*	620*	1,353	189	1,542	1,163	2,705
LA	3,002e	682e	3,684e	2,085e	5,769e	58	0	58	2,126	2,184	3,060e	682e	3,742e	4,211	7,953*
ME	979	292	1,271	130	1,401	0	15	15	137	152	979	307	1,286	267	1,553
MD	3,470	0	3,470	191	3,661	0	0	0	822	822	3,470	0	3,470	1,013	4,483
MA	5,187	386	5,573	0	5,573	144	488	632	2,119	2,751	5,331	874	6,205	2,119	8,324
MI	8,719	0	8,719	0	8,719	0	0	0	411	411	8,719	0	8,719	411	9,130
MN	6,012e*	1,911	7,923e*	1,412e	9,335e*	170	0	170	751	921	6,182e*	1,911	8,093e*	2,163*	10,256e*
MS	167	68	235	685e	920	242	235	477	1,439	1,916	409	303	712	2,124	2,836
MO	2,384	1,463	3,847	871	4,718	0	0	0	1,500	1,500	2,384	1,463	3,847	2,371	6,218
MT	778	531	1,309	0	1,309	0	0	0	163	163	778	531	1,309	163	1,472
NE	800	208	1,008	247	1,255	0	0	0	439	439	800	208	1,008	686	1,694
NV	434	0	434	5	439	24	0	24	145	169	458	0	458	150	608
NH	3,027e	242e	3,269e	53e	3,322e	26	0	26	0	26	3,053e	242e	3,295e	53e	3,348e
NJ	4,440	0	4,440	1,127	5,567	0	0	0	4,363	4,363	4,440	0	4,440	5,490	9,930
NM	493*	272*	765*	16*	781*	0	0	0	349	349	493*	272*	765*	365	1,130*
NY	7,075*	11,151*	18,226*	1,524*	19,750*	701*	6,554*	7,255*	3,933*	11,188*	7,776*	17,705*	25,481	5,457*	30,938*
NC	3,245	711	3,956	559	4,515	0	0	0	2,378	2,378	3,245	711	3,956	2,937	6,893
ND	1,093	523	1,616	80	1,696	0	12	12	146	158	1,093	535	1,628	226	1,854
OH	4,546	2,714	7,260	3,873	11,133	0	0	0	2,179	2,179	4,546	2,714	7,260	6,052	13,312
OK	1,333	249	1,582	1,598	3,180	0	0	0	658	658	1,333	249	1,582	2,256	3,838
OR	2,585	555	3,140	139	3,279	35	0	35	489	524	2,620	555	3,175	628	3,803
PA	8,040	834	8,874	2,561	11,435	0	0	0	3,563	3,563	8,040	834	8,874	6,124	14,998
RI	726	213	939	43	982	206	102	308	0	308	932	315	1,247	43	1,290
SC	1,246	1,443	2,689	112	2,801	0	0	0	1,885	1,885	1,246	1,443	2,689	1,997	4,686
SD	729	689	1,418	0	1,418	0	0	0	351	351	729	689	1,418	351	1,769
TN	723	1,597	2,320	144	2,464	0	0	0	1,784	1,784	723	1,597	2,320	1,928	4,248
TX	4,017	943	4,960	2,617	7,577	6	35	41	6,124	6,165	4,023	978	5,001	8,741	13,742
UT	939e	312e	1,251e	55e	1,801	0	0	0	362	362	939	312	1,251	912	2,163
VT	770	0	770	0	770	0	0	0	0	0	770	0	770	0	770
VA	223**	386**	609**	300e*	909**	0	0	0	2,298	2,298	223**	386**	609**	2,598	3,207
WA	4,266	773	5,039	290	5,329	0	0	0	1,346	1,346	4,266	773	5,039	1,636	6,675
WV	531*	424*	955*	150*	1,105*	0*	0*	0*	109*	109*	531*	424*	955*	259*	1,214*
WI	6,567	996	7,563	2,301	9,864	0	0	0	1,384	1,384	6,567	996	7,563	3,685	11,248
WY	543	64	607	0	607	0	0	0	156	156	543	64	607	156	763
U.S. total	143,822	49,135	192,957	41,887	234,844	2,154	8,178	10,332	65,735	76,067	145,976	57,313	203,289	107,622	310,911

e indicates estimate

\* indicates 1993 data

\*\* indicates 1992 data

### Relative Size of Residential Settings

Table 2.3 presents statistics summarizing the relative size of the residential settings for persons with MR/DD across the states. It shows the extreme variability among states on three measures of relative size of residential settings.

**Average residential settings size.** On June 30, 1994 an average of 4.9 persons with MR/DD lived in each setting in which residential services were provided in the United States. The average number of persons with MR/DD per residential setting ranged from more than 10 in six states to less than 3 in nine states. Twenty states were at or over the national average. Figure 2.1 shows changes in average number of residents with MR/DD per residential setting between 1977 and 1994. It indicates that the average number of residents per setting continues to decrease steadily, although not at the more dramatic rates that were evident from 1977 through 1987.

### Percentage living in small residential settings.

Table 2.3 shows the percentage of all persons receiving residential services in each state on June 30, 1994 who were living in residential settings with 15 or fewer residents and with 6 or fewer residents. Nationally, 65.4% of residents lived in settings with 15 or fewer residents. In over half of the states (30), 60% or more of all residential service recipients lived in places with 15 or fewer residents, while in three states less than 35% of residential service recipients lived in places with 15 or fewer residents. Nationally, on June 30, 1994 47.0% of residents lived in settings with 6 or fewer residents. In 19 states more than 60% of all persons receiving residential services lived in settings with 6 or fewer residents, while in 10 states less than one-third of all residential service recipients lived in settings of 6 or fewer residents. (Figure 2.2 shows these variations on a state-by-state basis).

**Figure 2.1**  
Average Number of Persons with Mental Retardation and Related Developmental Disabilities per Residential Setting on June 30, 1977, 1982, 1987, 1992, and 1994

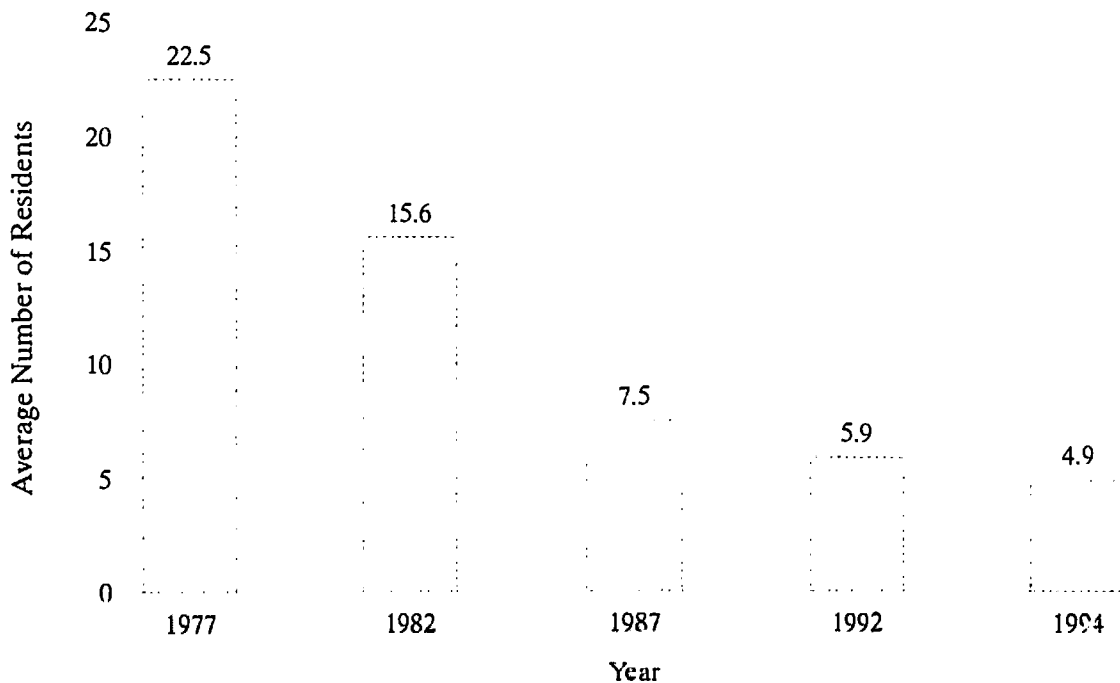


Table 2.3 Summary Statistics on the Size of Residential Settings on June 30, 1994

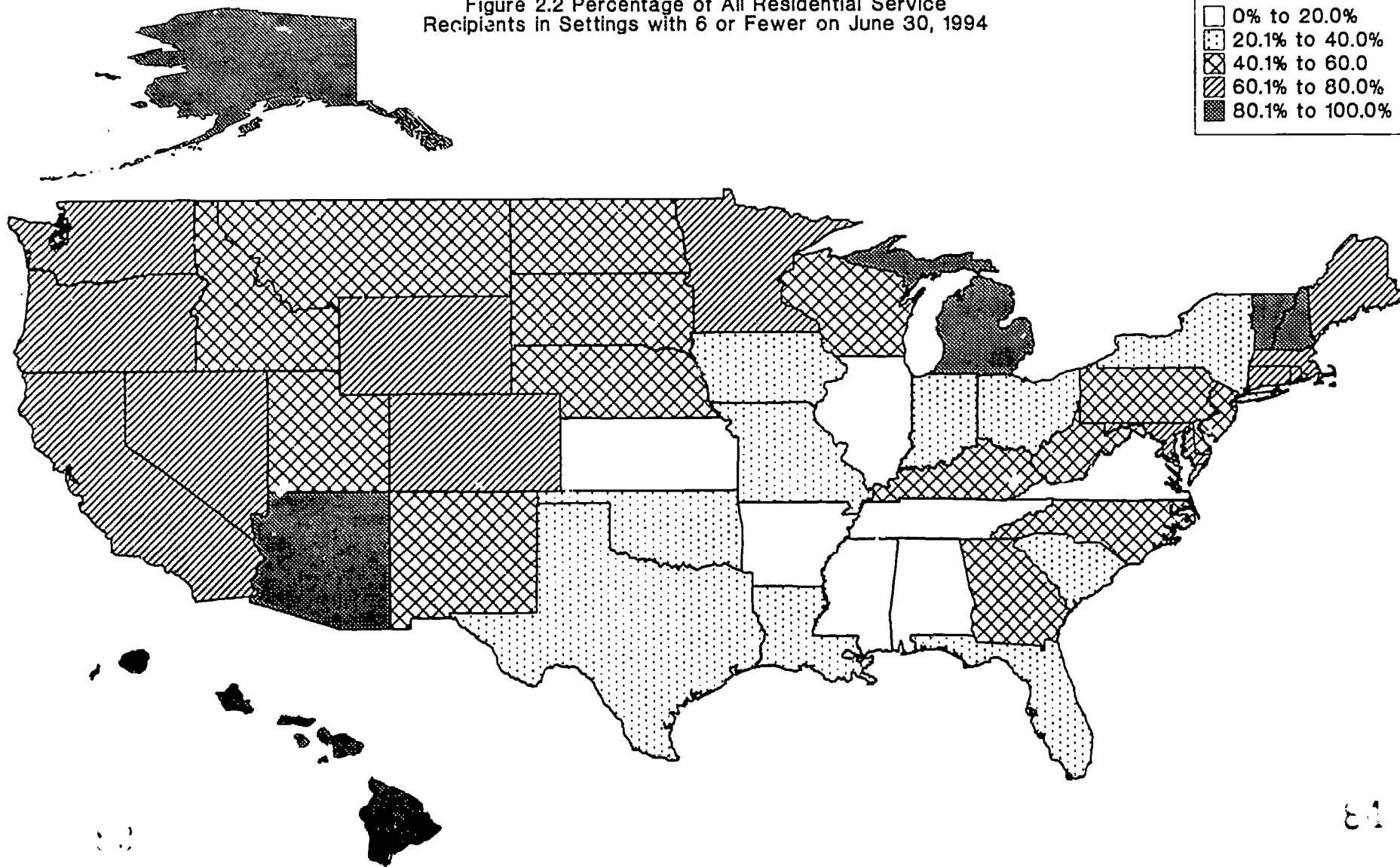
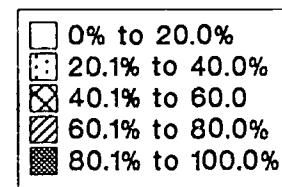
	Total Settings	Total Residents	Average Residents/Setting	Percent in Settings with 1-15 Res.	Percent in Settings with 1-6 Res.
AL	212	2,182	10.3	47.7%	16.5%
AK	303	576	1.9	93.4%	81.3%
AZ	1,503e	5,229	3.5	96.8%	90.5%
AR	348e	2,172	6.2	33.6%	19.8%
CA	7,232*	42,701	5.9	72.9%	65.2%
CO	1,474*	3,876	2.6	89.2%	72.6%
CT	1,698	5,571	3.3	75.9%	66.2%
DE	199	705	3.5	54.6%	54.6%
DC	227	1,084	4.8	100.0%	66.5%
FL	1,143	9,107	8.0	56.3%	36.1%
GA	734	3,639	5.0	42.3%	42.3%
HI	830	1,118	1.3	91.4%	90.8%
ID	505	1,665	3.3	79.8%	49.5%
IL	1,042	15,768	15.1	35.4%	4.7%
IN	1,689	7,626	4.5	69.5%	32.9%
IA	1,544*	5,839	3.8	66.6%	34.4%
KS	233	3,002	12.9	50.8%	19.5%
KY	1,064	2,705	2.5	57.0%	50.0%
LA	1,003	7,953*	7.9	47.1%	38.5%
ME	481	1,553	3.2	82.8%	63.0%
MD	1,223	4,483	3.7	77.4%	77.4%
MA	1,887	8,324	4.4	74.5%	64.0%
MI	2,247e	9,130	4.1	95.5%	95.5%
MN	2,591e*	10,256e*	4.0	78.9%	60.3%
MS	231	2,836	12.3	25.1%	14.4%
MO	1,116	6,218	5.6	61.9%	38.3%
MT	690	1,472	2.1	88.9%	52.9%
NE	323	1,694	5.2	59.5%	47.2%
NV	240	608	2.5	75.3%	75.3%
NH	2,137e	3,348e	1.6	98.4%	91.2%
NJ	1,306	9,930	7.6	44.7%	44.7%
NM	210*	1,130*	5.4	67.7%	43.6%
NY	6,100*	30,938*	5.1	82.4%	25.1%
NC	756	6,893	9.1	57.4%	47.1%
ND	595	1,854	3.1	87.8%	59.0%
OH	2,257	13,312	5.9	54.5%	34.1%
OK	811	3,838	4.7	41.2%	34.7%
OR	991	3,803	3.8	83.5%	68.9%
PA	4,219	14,998	3.6	59.2%	53.6%
RI	324	1,290	4.0	96.7%	72.2%
SC	898	4,686	5.2	57.4%	26.6%
SD	500c	1,769	3.5	80.2%	41.2%
TN	538	4,248	7.9	54.6%	17.0%
TX	1,207	13,742	11.4	36.4%	29.3%
UT	534	2,163	4.1	57.8%	43.4%
VT	566	770	1.4	100.0%	100.0%
VA	155	3,207	20.7	19.0%	7.0%
WA	1,726	6,675	3.9	75.5%	63.9%
WV	405*	1,214*	3.0	78.7%	43.7%
WI	3,066	11,248	3.7	67.2%	58.4%
WY	341	763	2.2	79.6%	71.2%
U.S. total	63,654	310,911	4.9	65.4%	47.0%

e indicates estimate

\* indicates 1993 data



Figure 2.2 Percentage of All Residential Service Recipients in Settings with 6 or Fewer on June 30, 1994



National Average = 47.0%

*Number of Residential Service Recipients  
Per 100,000 General Population*

Figure 2.3 and Table 2.4 present statistics on the number of persons with MR/DD receiving residential services per 100,000 of each state's general population on June 30, 1994. On June 30, 1994 there were 120.6 persons with MR/DD receiving residential services per 100,000 of the U.S. population. Nevada had the lowest overall residential placement rate per 100,000 state citizens (43.8). New Hampshire had the highest overall placement rate with 297.6 persons receiving residential services per 100,000 of the state population. In all, 25 states reported placement rates below the national average, with four states (Alabama, Georgia, Nevada, and Virginia) reporting rates less than 50% of the national average. Of the 26 states above the national average, eight (District of Columbia, Iowa, Louisiana, Minnesota, New Hampshire, North Dakota, South Dakota, and Wisconsin) were more than 150% of the national average. While states varied substantially in the number of persons with MR/DD receiving residential services per 100,000 of the state's population, most states fell within the range of the national average plus or minus one-third.

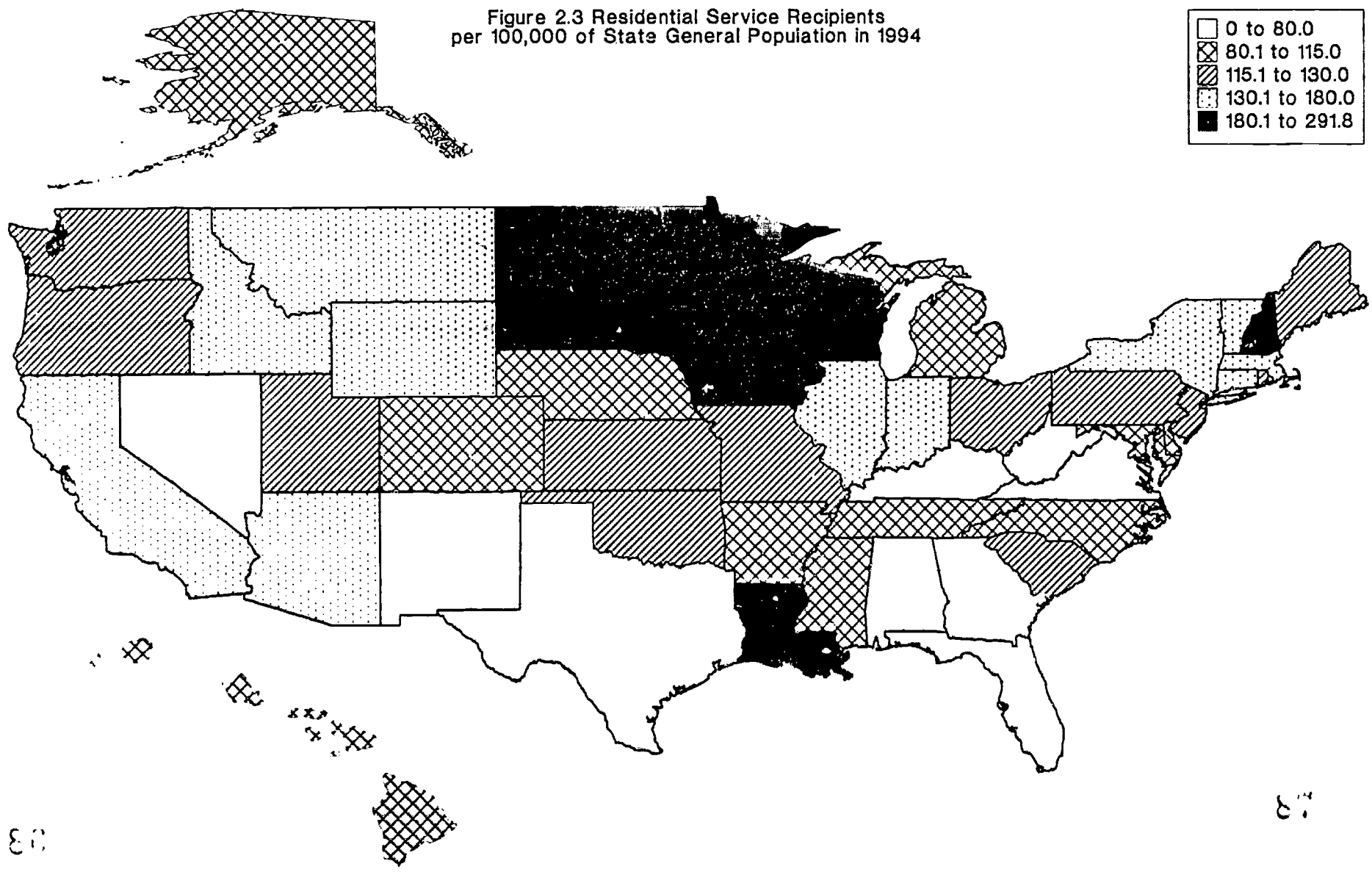
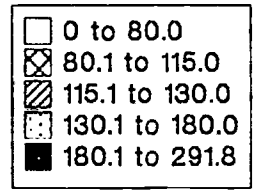
On June 30, 1994 there were 78.8 persons receiving residential services in settings with 15 or fewer residents per 100,000 of the U.S. population. A total of 15 states had placement rates that were more than 150% of this national average. Five states reported rates more than twice the national average (District of Columbia, Minnesota, New Hampshire, North Dakota, and South Dakota). The national average placement rate for settings with 6 or fewer residents was 56.6 residents per 100,000 of the general population. Eight states reported rates more than twice the national average (Arizona, District of Columbia, Minnesota, New Hampshire, North Dakota, Vermont, Wisconsin, and Wyoming). The national placement rate for facilities of 16 or more residents was 41.7 residents per 100,000 of the national population. Two states (Louisiana and Illinois)

reported rates more than twice the national average. Figure 2.3 shows the geographic variation among states in their number of persons receiving residential services per 100,000 of the general population.

*Persons Presently Not Receiving Residential Services  
on Waiting Lists for Residential Services*

Table 2.5 summarizes statistics reported by states on the actual or estimated number of people with mental retardation and related conditions not receiving residential services who are on waiting lists for such services on June 30, 1993. These statistics are presented as raw numbers and as percentages of the total number of all persons receiving and waiting for services. As shown, 33 states provided statistics on the number of persons waiting for residential services on June 30, 1993. Statistics from the June 30, 1991 state survey were available for an additional 14 states, for a total of 47 states. Among these states a total of 49,481 persons were reported to be waiting for residential services. An estimation was made for the national total of persons waiting for services by assuming the same ratio of persons waiting for residential services to persons receiving residential services in non-reporting states as in reporting states. (Two of the six states with the largest residential service programs were not able to report waiting list data.) On June 30, 1993, an estimated national total of 56,300 persons with mental retardation and related conditions were waiting for residential services. This was 18.2% of the total number of persons receiving and waiting for services, a slight decrease over the 19.3% reported for June 30, 1991. (The total number of people receiving residential services increased by 19,600 persons or 6.8% over that same period.) While five states (California, Idaho, Maryland, North Dakota, and Rhode Island) reported having no persons with mental retardation and related conditions waiting for residential services, 13 states reported waiting lists of such length that their residential services programs would need to be expanded by more than one-quarter to accommodate presently identified needs.

Figure 2.3 Residential Service Recipients  
per 100,000 of State General Population in 1994



National Average = 120.6

Table 2.4 Persons with Mental Retardation and Related Developmental Disabilities Receiving Residential Services per 100,000 of State General Population by Size of Residential Setting, June 30, 1994

	State Population (100,000)	Number of Residents in Residential Setting				Total
		1-6	7-15	1-15	16+	
AL	41.87	8.6**	16.2**	24.8**	27.3	52.1
AK	5.99	78.1	11.7	89.8	6.3	96.2
AZ	39.36	120.2	8.4	128.6	4.3	132.9
AR	24.24	17.7	12.4	30.1	59.5	89.6
CA	312.11	89.1	10.7	99.8	37.0	136.8
CO	35.66	78.9	18.0	96.9	11.8	108.7
CT	32.77	112.6	16.5	129.1	41.0	170.0
DE	7.00	55.0	0.0	55.0	45.7	100.7
DC	5.78	124.7	62.8	187.5	0.0	187.5
FL	136.79	24.1	13.4	37.5	29.1	66.6
GA	69.17	22.2	0.0	22.2	30.4	52.6
HI	11.72	86.6	0.6	87.2	8.2	95.4
ID	10.99	75.0	46.0	120.9	30.6	151.5
IL	116.97	6.3	41.3	47.7	87.2	134.8
IN	57.13	43.9	48.9	92.7	40.8	133.5
LA	28.14	71.3*	67.0*	138.2*	69.3	207.5
KS	25.31	23.1	37.2	60.3	58.4	118.6
KY	37.89	35.7	5.0	40.7	30.7	71.4
LA	42.95	71.2e	15.9e	87.1e	98.0	185.2*
ME	12.39	79.0	24.8	103.8	21.5	125.3
MD	49.65	69.9	0.0	69.9	20.4	90.3
MA	60.12	88.7	14.5	103.2	35.2	138.5
MI	94.78	92.0	0.0	92.0	4.3	96.3
MN	45.17	136.9e*	42.3	179.2e*	47.9*	227.1e*
MS	26.43	15.5	11.5	26.9	80.4	107.3
MO	52.34	45.5	28.0	73.5	45.3	118.8
MT	8.39	92.7	63.3	156.0	19.4	175.4
NE	16.07	49.8	12.9	62.7	42.7	105.4
NV	13.89	33.0	0.0	33.0	10.8	43.8
NH	11.25	271.4e	21.5e	292.9e	4.7e	297.6e
NJ	78.79	56.4	0.0	56.4	69.7	126.0
NM	16.16	30.5*	16.8*	47.3*	22.6	69.9*
NY	181.97	42.7*	97.3*	140.0*	30.0*	170.0*
NC	69.45	46.7	10.2	57.0	42.3	99.3
ND	6.35	172.1	84.3	256.4	35.6	292.0
OH	110.91	41.0	24.5	65.5	54.6	120.0
OK	32.31	41.3	7.7	49.0	69.8	118.8
OR	30.32	86.4	18.3	104.7	20.7	125.4
PA	120.48	66.7	6.9	73.7	50.8	124.5
RI	10.00	93.2	31.5	124.7	4.3	129.0
SC	36.43	34.2	39.6	73.8	54.8	128.6
SD	7.15	102.0	96.4	198.3	49.1	247.4
TN	50.99	14.2	31.3	45.5	37.8	83.3
TX	180.31	22.3	5.4	27.7	48.5	76.2
UT	18.60	50.5	16.8	67.3	49.0	116.3
VT	5.76	133.7	0.0	133.7	0.0	133.7
VA	64.91	3.4**	5.9**	9.4**	40.0	49.4
WA	52.55	81.2	14.7	95.9	31.1	127.0
WV	18.20	29.2*	23.3*	52.5*	14.2*	66.7*
WI	50.38	130.3	19.8	150.1	73.1	223.3
WY	4.70	115.5	13.6	129.1	3.2	162.3
U.S. total	2,579.04	56.6	22.2	78.8	41.7	120.6

e indicates estimate

\* indicates 1993 data

\*\* indicates 1992 data

**Table 2.5 Persons with Mental Retardation and Related Conditions Not Presently Receiving Residential Services Who Are on Waiting Lists for Residential Services on June 30, 1993**

State	Total Number of Persons on Waiting List	Total Number of Residential Service Recipients	% Growth Needed Match to Needs
AL	1,061*	2,303	31.5%
AK	127*	368	25.7%
AZ	557e	4,671	10.7%
AR	190	3,564	5.1%
CA	0	37,790	0.0%
CO	1,338	3,701	26.6%
CT	1,307	5,531	19.1%
DE	305	701	30.3%
DC	150*	1,166	11.4%
FL	1,784*	10,362	14.7%
GA	735*	3,642	16.8%
HI	5	1,026	0.5%
ID	0	1,234	0.0%
IL	DNF	16,201	NA
IN	1,583	7,611	17.2%
IA	DNF	5,877	NA
KS	1,187*	3,607	24.8%
KY	1,073	2,393	31.0%
LA	305*	7,953**	3.7%
ME	DNF	2,152**	NA
MD	0	4,875	0.0%
MA	1,468*	8,952**	14.1%
MI	2,066*	8,958	18.7%
MN	374*	11,000	3.3%
MS	319*	2,764	10.3%
MO	673	6,318	9.6%
MT	467	1,500	23.7%
NE	738	1,831	28.7%
NV	245	600	29.0%
NH	139	2,858	4.6%
NJ	3,350	9,590	25.9%
NM	385	1,226	23.9%
NY	4,897	30,938	15.8%
NC	3,500*	6,820	33.9%
ND	0	1,876	0.0%
OH	4,647	13,761	25.2%
OK	525e	3,822	12.1%
OR	2,446	3,739	39.5%
PA	3,995*	15,094	20.9%
RI	0	1,395	0.0%
SC	1,142	4,625	19.8%
SD	31e	1,737	1.8%
TN	738	4,189	15.0%
TX	DNF	13,111	NA
UT	769	2,316	24.9%
VT	99e	732	11.9%
VA	1,332*	3,322**	28.6%
WA	879	6,550	11.8%
WV	500e	1,214	29.2%
WI	2,150	10,603	16.9%
WY	50	815	5.8%
<b>U.S. est. total</b>	<b>16,300</b>	<b>308,984</b>	<b>18.2%</b>

DNF indicates Data Not Furnished

e indicates estimate

\*\* indicates 1991 data

CHAPTER 6  
NUMBER OF RESIDENTIAL SETTINGS AND RESIDENTS  
BY TYPE OF LIVING ARRANGEMENT

Troy Mangan  
Robert Prouty  
Barbara Polister  
K. Charlie Lakin

This chapter describes residential settings for persons with mental retardation and related developmental disabilities (MR/DD) by setting type. Three separate types of residential settings have been developed on the basis of conformity to state MR/DD reporting systems. These include:

**"Congregate Care":** A residence owned, rented, or managed by the residential services provider, or the provider's agent, to provide housing for persons with MR/DD in which staff provide care, instruction, supervision, and other support for residents with MR/DD (includes ICF-MR certified facilities).

**"Family Foster Care":** A home owned or rented by an individual or family in which they live and provide care for one or more unrelated persons with MR/DD.

**"Own Home":** A home owned or rented by one or more persons with MR/DD as the person(s)' own home in which personal assistance, instruction, supervision, and other support is provided as needed.

*"Congregate Care" Settings and Residents*

Table 2.6 presents statistics on congregate care residential settings and persons with MR/DD living in these settings on June 30, 1994, by size and state, for the 42 states that were able to supply complete breakdowns of the number of residences meeting the definition of congregate care and the number of residents living in them.

Of the total 23,153 congregate care residential settings in the 42 reporting states, 22,054 (95.3%) had 15 or fewer residents and 16,418 (70.9%) had six or fewer residents. New York (3,525) and Pennsylvania (2,436) accounted for over one-fourth (25.7%) of the total congregate care residences across the 42 reporting states, while six states reported fewer than 100 congregate care residences.

Of the 188,763 residents of congregate care settings in the 42 reporting states, 109,469 (58.0%) lived in settings with 15 or fewer residents and 59,443 (31.5%) lived in settings with six or fewer residents. Of the 42 reporting states, New York (26,797), Illinois (15,569), and Pennsylvania (12,688) accounted for almost one-third (29.1%) of the total residents of congregate care residences in the reporting states, and 23.3% of the estimated national total of 236,386 residents of congregate care residences.

*"Family Foster Care" Settings and Residents*

Table 2.7 presents statistics on family foster care settings and persons with MR/DD living in such settings on June 30, 1994, by size and state, for the 46 states that were able to supply complete breakdowns of the number of family foster care settings.

Of the total 14,047 family foster care settings in the 46 reporting states, virtually all (99.9%) had six or fewer residents. New York (2,575) accounted for 18.3% of the total family foster care settings across the 46 states, while 15 of the 46 reporting states reported less than 100 family foster care settings.

Of the 22,104 persons with MR/DD in family foster care settings in the 46 reporting states, virtually all (99.7%) lived in settings with six or fewer residents. Of the 46 reporting states, six states (Michigan, Minnesota, New Jersey, New York, Washington, and Wisconsin) accounted for 36.2% of the estimated national total of 31,929 recipients of family foster care. Eleven of the 46 reporting states reported less than 100 persons in family foster care settings. Estimates for non-reporting states based on the statistics of the reporting states suggested that nationally on June 30, 1994 there were about 31,929 persons with mental retardation and related developmental

disabilities living in 16,464 family foster care settings.

*"Own Home" Settings and Residents*

Table 2.8 presents statistics on the number of homes owned or leased by persons with MR/DD who were receiving residential services and the number of persons with MR/DD living in their own homes on June 30, 1994 by size and state. Forty states reported information on the number of homes and 48 states were able to report information on the number of persons living in their own homes. These statistics were used to compute estimates for the non-reporting states.

The greatest number of homes owned or leased by persons with MR/DD were reported by California (4,162), Wisconsin (1,776), Iowa (1,211), and Pennsylvania (1,109). These states accounted for 45.7% of the estimated national total of 18,290 homes owned or leased by persons with MR/DD receiving residential services and supports. Four states reported less than 20 places in which persons with MR/DD received services in those homes.

All people living in homes that they leased or owned lived with five or fewer other people. California (8,325), Wisconsin (3,551), and Washington (2,354) reported 40.4% of the estimated national total of 35,189 people living in their own homes. Three states reported less than 50 persons living in their own homes.

Table 2.6 Number of "Congregate Care" Residential Settings and Persons with Mental Retardation and Related Developmental Disabilities Living in Them on June 30, 1994 by State

State	Number of Residential Settings					Number of Residents				
	1-6	7-15	1-15	16+	Total	1-6	7-15	1-15	16+	Total
AL	80**	82*	162**	7	169**	225**	665**	890**	1,142	2,032
AK	58	7	65	1	66	212	70	282	38	320
AZ	1,044	28	1,072	8	1,080	3,795	331	4,126	168	4,294
AR	15e	30	45	10	55	38e	300	338	1,443	1,781
CA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CO	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
CT	585	66	651	12	663	2,455	540	2,995	1,342	4,337
DE	51	0	51	1	52	238	0	238	320	558
DC	131	44	175	0	175	636	363	999	0	999
FL	437	199	636	98	734	1,977	1,834	3,811	3,981	7,792
GA	185	0	182	13	198	754	0	754	2,101	2,855
HI	48	1	49	15	64	184	7	191	96	287
ID	25	90	115	5	120	95e	505e	600e	336	936e
IL	194e	504e	698e	145e	843e	539e	4,836	5,375	10,194	15,569
IN	181	343	524	24	548	960	2,791	3,751	2,329	6,080
IA	103	136	239	29	268	692	1,884	2,576	1,949	4,525
KS	110	109	219	14	233	584	941	1,525	1,477	3,002
KY	113	37	150	38	188	254	189	443	1,163*	1,606*
LA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MA	1,284	177	1,461	8	1,469	4,803	874	5,677	2,119	7,796
ME	61	31	92	8	100	366	307	673	267	940
MD	1,075	0	1,075	10	1,085	3,015	0	3,015	1,013	4,028
MI	1,064e	0	1,064e	3	1,067e	6,364	0	6,364	411	6,775
MN	1,510e*	170	1,680e*	41	1,721e*	5,132e*	1,911	7,043e*	2,163e	9,206e*
MS	112	31	142	10	152	320	303	623	2,124	2,747
MT	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
MO	169	169	338	93	431	719	1,463	2,182	2,371	4,553
NE	293e	27e	320e	3	323e	800e	208e	1,008e	686	1,694e
NH	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NM	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
NV	31	0	31	6	37	182	0	182	150	332
NJ	453	0	453	49	502	2,539	0	2,539	5,490	8,029
NY	1,613*	1,836*	3,449*	76*	3,525*	3,670*	17,670*	21,340*	5,457*	26,797*
NC	525	65	590	20	610	2,911	711	3,622	2,937	6,559
ND	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
OH	918	313	1,231	107	1,338	2,554	2,679	5,233	6,052	11,285
OK	79	23	102	32	134	462	249	711	2,256	2,967
OR	323	65	388	10	398	1,417	555	1,972	628	2,600
PA	2,238	116	2,354	82	2,436	5,730	834	6,564	6,124	12,688
RI	151	38	189	2	191	756	360	1,116	43	1,159
SC	129	315e	444	10	454	400	1,803	2,203	1,997	4,200
SD	186	67	253	2	255	518	669	1,007	351	1,358
TN	65	202	267	8	275	273	1,597	1,870	1,928	3,798
TX	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
UT	227	42	269	10	279	696e	300e	996e	912	1,908
VA	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF	DNF
VT	46	0	46	0	46	188	0	188	0	188
WA	42	88	130	18	148	229	773	1,002	1,636	2,638
WV	55*	53*	108*	5*	113*	208*	424*	632*	259*	891*
WI	328	124	452	44	496	1,459	996	2,455	3,685	6,140
WY	81	9	90	22	112	294	64	358	156	514
Reported Total	16,418	5,636	22,054	1,090	23,153	59,443	50,026	109,469	79,294	188,763
Est. U.S. Total	17,189	6,491	23,680	1,370	25,050	71,564	57,200	128,764	107,622	236,386

DNF indicates Data Not Furnished

e indicates estimate

\* indicates 1993 data

\*\* indicates 1992 data



Table 2.7 Number of Family Foster Care Settings and Persons with Mental Retardation and Related Conditions Living in Them on June 30, 1994 by State

	Number of Residential Settings			Number of Residents		
	1-6	7-15	Total	1-6	7-15	Total
AL	26**	1**	27**	65**	8**	73**
AK	98	0	98	108	0	108
AZ	406e	0	406e	832e	0	832e
AR	18e	0	18e	38e	0	38e
CO	304e*	0	304e*	428e*	0	428e*
CT	304	0	304	503	0	503
DE	147	0	147	147	0	147
DC	52	0	52	85	0	85
FL	121	0	121	162	0	162
GA	210	0	210	351	0	351
HI	688	0	688	747	0	747
ID	333	0	333	363	0	363
IL	23	0	23	23	0	23
IN	382	0	382	434	0	434
IA	65	0	65	103	0	103
KY	163	0	163	318	0	318
LA	91	0	91	147	0	147
ME	232	0	232	464e	0	464e
MD	138	0	138	206e	0	206
MA	418	0	418	528	0	528
MI	780e	0	780e	1,557	0	1,557
MN	870e*	0	870e*	1,050e*	0	1,050e*
MS	0	0	0	0	0	0
MO	101	0	101	206	0	206
MT	150e	0	150e	167	0	167
NV	31	0	31	71	0	71
NH	367	0	367	514	0	514
NJ	804	0	804	1,578	0	1,578
NM	20*	0*	20*	30*	0*	30*
NY	2,570*	5*	2,575*	4,106*	35*	4,141*
NC	98	0	98	113	0	113
ND	35	0	35	38	0	38
OH	232	2	234	349	35	384
OK	142	0	142	188	0	188
OR	320	0	320	629	0	629
PA	674	0	674	741	0	741
RI	53	0	53	66	0	66
SC	102e	0	102e	160	0	160
SD	24e	0	24	33	0	33
TN	100	0	100	201	0	201
UT	17	0	17	17	0	17
VT	390	0	390	440	0	440
WA	673e	0	673	1,683	0	1,683
WV	244*	0	244*	251*	0	251*
WI	794	0	794	1,557	0	1,557
WY	229	0	229	229	0	229
Reported Total	14,039	8	14,047	22,026	78	22,104
Estimated U.S. Total	16,455	9	16,464	31,816	113	31,929

DNF indicates Data Not Furnished

e indicates estimate

\* indicates 1993 data

\*\* indicates 1992 data

**Table 2.8 Number of Homes Owned or Leased By Persons with Mental Retardation and Related Developmental Disabilities and the Number of People Living in Them on June 30, 1994 by State**

State	Total Residences	Residents	All Residents	% In Own Home
AL	16**	71**	2,182	3.25%
AK	139	148	576	25.69%
AZ	17	103	5,229	1.97%
AR	275e	353e	2,172	16.25%
CA	4,162e	8,325	42,701	19.50%
CO	DNF	503	3,876	12.98%
CT (a)	851	851	5,571	15.28%
DE	0	0	705	0.00%
DC	0*	0*	1,084	0.00%
FL	DNF	1,153	9,107	12.66%
GA	326	433	3,639	11.90%
HI	78	84	1,118	7.51%
ID	56e*	56e*	1,665	3.36%
IL	176	176	15,808	1.11%
IN	759	1,112	7,626	14.58%
IA	1,211*	1,211*	5,839	20.74%
KS	DNF	689**	3,002	22.95%
KY	59	66	2,705	2.44%
LA	DNF	307e	7,953	3.86%
ME	149	149	1,553	9.59%
MD	DNF	249	4,483	5.55%
MA	804	804	8,324	9.66%
MI	400c	798	9,130	8.74%
MN	550e*	550e*	11,000	5.00%
MS	79	89	2,836	3.14%
MO	584e	1,459	6,218	23.46%
MT	437	437	1,472	29.69%
NE	DNF	DNF	1,694	0.00%
NV	172	205	608	33.72%
NH	230	243	3,348	7.26%
NJ	DNF	323	9,305	3.47%
NM	135*	388*	1,029	37.71%
NY	336*	504*	30,938	1.63%
NC	48	221	6,877	3.21%
ND	460e	860e	1,854	46.39%
OH	DNF	1,643	13,312	12.34%
OK	535	683	3,838	17.80%
OR	273e	574	3,803	15.09%
PA	1,109	1,569	14,998	10.46%
RI	80	110	1,290	8.53%
SC	342e	686	4,686	14.64%
SD	221e	378	1,769	21.37%
TN	163e	249	4,248	5.86%
TX	DNF	DNF	13,742	0.00%
UT	238	238	2,163	11.00%
VT	130	142	770	18.44%
VA	DNF	DNF	3,207	0.00%
WA	905e	2,354	6,379	36.90%
WV	48e*	72e*	1,214	5.93%
WI	1,776	3,551	11,248	31.57%
WY	20	20	763	2.62%
Total Reported	18,290	35,189	310,911	13.0%
Estimated U.S.	22,140	42,596		

DNF indicates Data Not Furnished

e indicates estimate

\* indicates 1993 data

\*\* indicates 1992 data

a includes 416 people in DMR (state-operated) supported living

CHAPTER 7  
CHANGING PATTERNS IN RESIDENTIAL SERVICE SYSTEMS: 1977-1994

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*Changing Patterns in Residential Settings*

Table 2.9 presents summary statistics on the number of residential settings in which services by state agencies or by nonstate agencies licensed by the state were provided to persons with mental retardation and related developmental disabilities (MR/DD) on June 30th of 1977, 1982, 1987, 1992, and 1994. Totals are reported by type of operator (state or nonstate) and size of residential setting (6 or fewer residents, 7-15 residents, and 16 or more residents).

Between 1977 and 1994 the total number of residential settings in which services to persons with MR/DD were provided increased from 11,008 to 63,654 (478%). All of this growth occurred in small settings with 15 or fewer residents, with settings of 7-15 residents increasing by 170% and settings with 6 or fewer residents increasing by 709%, or nearly 49,000 residential settings. Of the increase of 52,981 in small residential settings between 1977 and 1994, 51,656 (97.5%) occurred in nonstate settings.

The total number of large residential settings decreased by 335 between 1977 and 1994, with the number of large nonstate facilities declining by 295 (-21.4%). The net increase in all nonstate residential settings (51,361) accounted for 97.6% of the overall increase in all residential settings. There was a decrease of 40 large state residential settings (-12.2%), but there was an increase of 1,325 small state residential settings during the same period (859%).

The highest annual growth in number of small nonstate residential settings occurred between 1992 and 1994, averaging 7,109 additional settings per year. During the period 1982 to 1992 small state facilities grew at an average rate of 63 settings per year. Between 1992 and 1994 that rate increased to 115 new small state facilities per year.

Between 1977 and 1994 there was considerable stability in the proportions of residential settings operated by state and nonstate agencies. Between 1977 and 1994 the nonstate share of all small

residential settings decreased slightly from 98.5% to 97.7% while during the same period the nonstate share of all large residential facilities decreased slightly from 80.8% to 79.1%. On June 30, 1977, 98.5% of all residential settings were nonstate operated; on June 30, 1994, 97.3% were nonstate operated. So, while the total number of all residential settings for persons with MR/DD increased by almost 500% between 1977 and 1994, large nonstate and large state residential settings for persons with MR/DD declined in number (-21.4% for nonstate settings; and -12.2% for state settings; -19.6% for all large settings). The total number of small nonstate and state operated residential settings increased dramatically (564% for small nonstate settings; 960% for small state settings; 570% for all small settings). During the most recent two year period, 1992-1994, these trends continued very much as in the previous 15 years.

*Changes in Number of Residential  
Service Recipients*

Table 2.10 presents summary statistics on the number of residents with MR/DD in residential settings served by state or nonstate agencies on June 30th of 1977, 1982, 1987, 1992, and 1994. Totals are reported by type of operator (state or nonstate) and size of residential setting ("small" settings with 1-6 or 7-15 residents; and "large" facilities with 16 or more residents).

Between 1977 and 1994 the total number of residents of state and nonstate settings in which residential services were provided to persons with MR/DD increased from 247,780 to 310,911, an increase of 63,131 (20.3%) residents over the 18 year period. All of this growth occurred in small settings with 15 or fewer residents. Of the 162,865 person increase in small residential settings between 1977 and 1994, 153,699 (94.4%) occurred in nonstate settings, and 125,576 (77.1%) occurred in settings with 6 or fewer residents. The number of residents of large nonstate residential settings

decreased by 10,831 (-20.5%) between 1977 and 1994, but there was a net increase in residents of all nonstate residential settings (142,868) as small nonstate settings residents increased by 153,699, residents (123,638 in places with 6 or fewer residents). There was, of course, a dramatic decrease in the number of people receiving residential services directly from state agencies, with a large decrease of 88,903 (-57%) in the population of large state residential facilities and an increase of 9,166 residents of small state residential settings.

The largest average annual increase in total population of small nonstate residential settings occurred between 1992 and 1994, averaging 14,315 additional residents per year. The population of small state residential settings showed the greatest average annual increase during the period 1987 to 1992, averaging 928 additional residents per year.

The total population of large nonstate residential settings decreased from 52,718 to 41,887 between 1977 and 1994 (20.5%). Over the period, the population of large nonstate residential settings varied considerably, increasing by 4,678 from 1977 to 1982, followed by a decrease of 15,315 from 1982 to 1987. Between 1987 and 1992 there was an increase of 5,920 large nonstate residential facility residents as the OBRA 1987 nursing home legislation (described in Chapter 3) caused many large private settings once operated outside the MR/DD system as nursing homes to be converted to ICFs-MR within the MR/DD system. Between 1992 and 1994 the decrease of large nonstate facility residents was again evident with 3,918 fewer residents in 1994 than in 1992. Between 1977 and

1994 the nonstate share of the total population of all large residential facilities increased from 25.4% to 38.9%.

In summary, while the total population of all residential facilities for persons with MR/DD increased by over 25% between 1977 and 1994, the number of residents of large nonstate and large state residential settings declined significantly (20.5% in nonstate settings; -57.5% in state settings; -48.1% in all settings). The total population of small state and nonstate residential settings increased dramatically (392% in nonstate settings; 786% in state settings; 403% in all settings). Places with 6 or fewer residents were most prominent in these increases. Residents of such settings increased by 616% (about 125,600, individuals) between 1977 and 1994. During the most recent 2 year period reported, 1992-1994, these trends continued.

Figure 2.4 depicts graphically the residential service trends from 1977 to 1994 summarized in Table 2.10, with one change. In Figure 2.4 the categories of residents of small state residential settings and small nonstate residential settings are combined in two additional categories, all residential settings with 1-6 residents and all residential settings with 7-15 residents. This breakdown shows that the rapid growth from June 30, 1977 to June 30, 1994 in the number of people living in small residential settings came primarily from growth in number of persons in residential settings with 1-6 residents. This breakdown also clearly shows the significant decrease in the total population of large state residential facilities.

*Selected Data Points for Figure 2.4: Persons with Mental Retardation and Related Developmental Disabilities in State and Nonstate Residential Settings on June 30, of 1977, 1982, 1987, 1992, and 1994.*

Year	State, 16+ Residents	Nonstate, 16+ Residents	All, 1-6 Residents	All, 7-15 Residents
1977	154,638	52,718	20,409	20,026
1982	122,750	57,396	33,188	30,515
1987	95,022	42,081	66,933	48,637
1992	74,538	45,805	119,675	54,008
1994	65,735	41,887	145,976	57,313

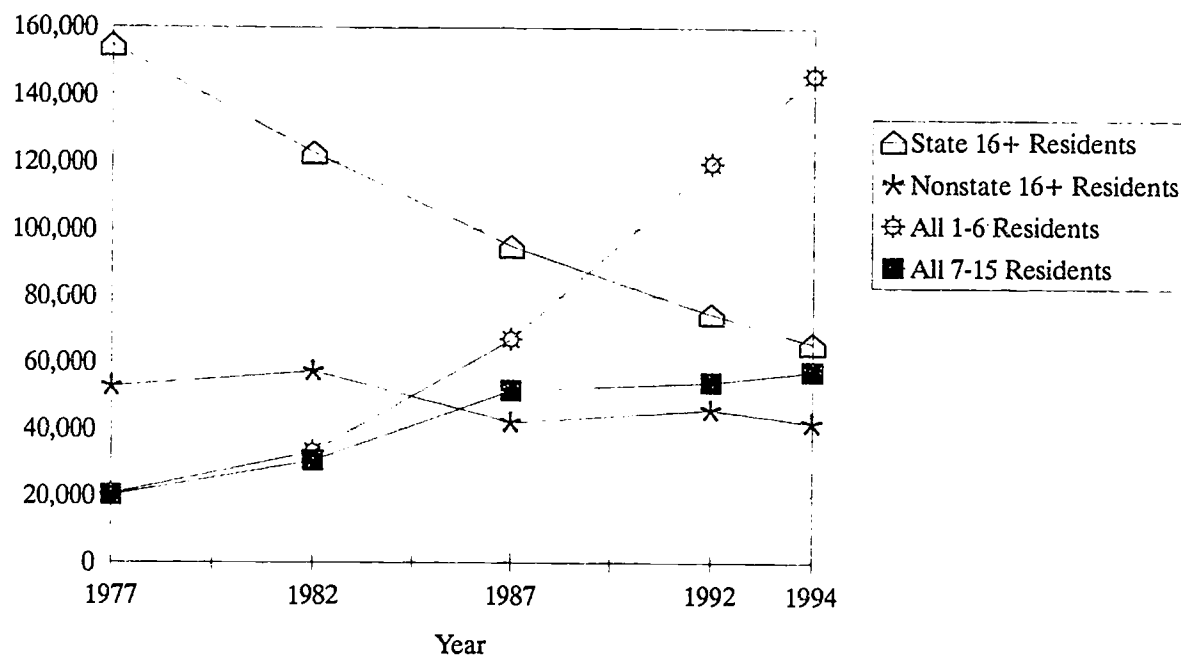
**Table 2.9 State and Nonstate Residential Settings for Persons with MR/DD on June 30 of 1977, 1982, 1987, 1992 and 1994**

Year	Residential Settings											
	Nonstate				State				Total			
	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total
1977	6,855	2,310	1,378	10,543	43	95	327	465	6,898	2,405	1,705	11,008
1982	10,073	3,181	1,370	14,624	182	426	349	957	10,255	3,607	1,719	15,581
1987	26,475	4,713	1,370	32,558	189	443	287	919	26,664	5,156	1,657	33,477
1992	41,444	5,158	1,320	47,922	382	852	323	1,557	41,826	6,010	1,643	49,479
1994	55,212	5,609	1,083	61,904	572	891	287	62,284	55,784	6,500	1,370	63,654

**Table 2.10 Persons with MR/DD Receiving State and Nonstate Residential Services on June 30 of 1977, 1982, 1987, 1992 and 1994**

Year	Residents											
	Nonstate Settings				State Settings				All Settings			
	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total
1977	20,184	19,074	52,718	91,976	216	950	154,638	155,804	20,400	20,024	207,356	247,780
1982	32,335	28,810	57,396	118,541	853	1,705	122,750	125,308	33,188	30,515	180,146	243,849
1987	68,631	45,223	42,081	155,935	1,302	3,414	95,022	99,738	69,933	48,637	137,103	255,673
1992	118,304	46,023	45,805	210,132	1,371	7,985	74,538	83,894	119,675	54,008	120,343	294,026
1994	143,822	49,135	41,887	234,844	2,154	8,178	65,735	76,067	145,976	57,313	107,662	310,911

**Figure 2.4**  
**Persons with Mental Retardation and Related Developmental Disabilities in State and Nonstate Residential Settings on June 30 of 1977, 1982, 1987, 1992, and 1994**



**SECTION III**

**STATUS AND CHANGES  
IN MEDICAID FUNDED RESIDENTIAL  
AND RELATED SERVICES**

## CHAPTER 8 BACKGROUND AND SUMMARY OF MEDICAID LONG-TERM CARE PROGRAMS<sup>1</sup>

This chapter provides a brief overview of the development of Medicaid programs for persons with mental retardation and related developmental disabilities.

### *Federal Involvement Prior to ICFs-MR*

Before 1965 there was no federal participation in long-term care for persons with mental retardation and related developmental disabilities. In 1965, Medicaid was enacted as Medical Assistance, Title XIX of the Social Security Act. It provided federal matching funds of from 50% to 82%, depending on each state's per capita income, for medical assistance provided to people in the categories of blind, disabled, and their dependent children and their families as well as to elderly people. Otherwise eligible persons who resided in public institutions except "medical institutions" were excluded. Persons in public MR/DD institutions were still excluded from coverage, although otherwise eligible adult residents of private nursing homes became qualified for Medicaid participation if the homes met established standards. Also eligible for federally cost-shared long-term care were persons 65 years or older residing in public mental hospitals meeting federal standards. Because on June 30, 1964 public mental institutions held 144,000 residents age 65 years or older (about three-quarters as many people as were in large state MR/DD facilities) most states had considerable incentives to invest available state funds in bringing their public mental institutions up to federal standards (Lakin, 1979; National Institute on Mental Health, 1975).

Title XIX also created for states 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, financing long-term care for 37,821 people with MR/DD in state institution units at a total

cost of 168 million dollars in Fiscal Year 1969 (Boggs, Lakin, & Clauser, 1985). Thus, Title XIX in its early form brought a number of incentives that were not necessarily beneficial to persons with MR/DD in long-term care settings. And yet today most long-term care service expenditures for persons with MR/DD are financed through Medicaid and most persons with MR/DD receiving long-term care services received Medicaid financed services. 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 in 1965 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. 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. 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 in facilities specifically for people with mental retardation.

Three primary outcomes of the ICF-MR legislation appear to have been intended by Congress: 1) to provide substantial federal incentives for upgrading the physical environment and the quality of care and habilitation being provided in public MR/DD

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<sup>1</sup> Adapted and updated from E. Boggs, K.C. Lakin, and S. Clauser (1985)



institutions; 2) to neutralize the above mentioned incentives for states to place persons with MR/DD in nonstate nursing homes and/or to certify their state institutions as SNFs; and 3) to provide a program for care and habilitation ("active treatment") specifically focused on the needs of persons with MR/DD rather than upon medical care. Many proponents of the new ICF-MR program also saw it as a way to enlist the federal government in assisting states with their rapidly increasing state institution costs, which were averaging real dollar increases of 14% per year in the five years prior to the passage of the ICF-MR legislation (Greenberg, Lakin, Hill, Bruininks, & Hauber, 1985).

The ICF-MR program was initiated in a period of rapid change in residential care for persons with MR/DD. By Fiscal Year 1973 state institution populations had already decreased to 173,775 from their high of 194,650 in Fiscal Year 1967 (Lakin, 1979). Nevertheless, states overwhelmingly opted to participate in the ICF-MR program, with two notable outcomes: 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. Forty 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, primarily to meet ICF-MR standards (Gettings & Mitchell, 1980).

In the context of growing support for community 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 in state institutions by providing federal contributions for 50% to 80% of the costs of those institutions; 2) had diverted funds that could otherwise have been spent on community program development into institution renovations solely to obtain FFP; 3) had promoted the development of private ICF-MR institutions for people leaving state institutions through available FFP (11,943 people were living in ICF-MR units in private institutions by June 1977); and 4) had promoted organizational inefficiency and individual dependency by promoting a single uniform

standard for care and oversight of ICF-MR residents irrespective of the nature and degree of their 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 ICFs-MR 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 Community ICF-MR Group Homes*

Expansion of ICF-MR services to privately-operated programs in the late 1970's and the 1980's was a major development in the evolution of the program. Private residential facilities were not an issue at the time of original ICF-MR enactment in 1971, probably because: 1) most private facilities were 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 large state MR/DD facility population of 190,000 (Lakin, Bruininks, Doth, Hill, & Hauber, 1982).

Although Congressional debate about the ICF-MR programs had focused on public institutions, the statute did not specifically limit ICF-MR coverage either to public facilities, or to "institutions" in the common meaning of the term. The definition of "institution" which served as the basis for participation in the ICF-MR program is the one that also covered the general ICF institution: "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" facility, 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. ICF-MR regulations, first published in January 1974, also supported the option of developing

relatively small facilities, delineating two categories of ICFs-MR, those housing 16 or more people ("large") and those housing 15 or fewer people ("small") and providing several specifications that allowed greater flexibility in meeting ICF-MR standards in the smaller facilities.

Despite the regulatory recognition of small ICFs-MR, the numbers of such ICFs-MR actually developed varied enormously among states and regions. In some DHHS regions (e.g., Region V) hundreds of small ICFs-MR were developed while other regions (e.g., II and X) had none. By mid-1977 three-quarters (74.5%) of the 188 small ICFs-MR were located in just two states (Minnesota and Texas), and by mid-1982 nearly half (46.4%) of the 1,202 small ICFs-MR were located in Minnesota and New York and nearly two-thirds (65.1%) were located in Minnesota, New York, Michigan and Texas. These variations reflected what some states and national organizations considered a failure of the Health Care Financing Administration (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.

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 ICFs-MR. These guidelines did not change the existing standards for the ICF-MR program, but clarified how the existing standards could be applied to delivering the ICF-MR level of care in small facilities with 4 to 15 residents. The publication of the 1981 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 opportunity and flexibility to states to use Medicaid funding for community services, the Medicaid Home and Community Based Services waiver authority (Section 2176 of P.L. 97-35).

#### *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, granted the Secretary of Health and Human Services the authority to waive certain existing Medicaid requirements and allow states to finance certain "non-institutional" services for Medicaid-eligible individuals. The HCBS program was designed to provide home and community based services for people who are aged, blind, disabled, or who have MR/DD and who, in the absence of alternative non-institutional services, would remain in or would be at a risk of being placed in a Medicaid facility (i.e., a Nursing Facility or an ICF-MR). Final regulations were published in March 1985 and since then a number of new regulations and interpretations have been developed, although none have changed the fundamental premise of the program, that of using home- and community-based services and supports to reduce the need for institutional services.

Non-institutional services that can be provided under the HCBS 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 MR/DD do provide residential support services under the categories of personal care, habilitation, and homemaker services, using cash assistance from other Social Security Act programs to fund people's room and board costs. In 1994 about 76% of HCBS recipients received services in settings other than the home of natural or adoptive family members. Given both its flexibility and its potential for promoting individualization of services, the HCBS program is recognized in all states as a significant resource in the provision of community services as an alternative to institutional care. Recently, requirements that prevailed in the HCBS program's first 10 years that states demonstrate reductions in projected ICF-MR residents and expenditures roughly equal to the increases in HCFA participants and expenditures have been

considerably relaxed. As a result there has been recent dramatic growth in the number of HCBS participants, even as the number of ICF-MR participants has remained stable. All states now provide HCBS.

#### *Community Supported Living Arrangements Programs*

Although Medicaid HCBS programs now exist in all states to provide services to persons who would otherwise be at risk of ICF-MR or nursing home care, states have desired continued expansion of Medicaid community service benefits. Of particular interest has been increasing the number of people who can be served in the community with Medicaid funding beyond the total number of authorized HCBS recipients. States have also had an interest in being able to serve persons who would not necessarily be ICF-MR eligible, especially with respect to their need for "active treatment."

In 1990 Congress enacted Section 1930 to the Social Security Act to allow up to eight states to provide Community Supported Living Arrangements (CSLA) to Medicaid-eligible persons with MR/DD. Separate from, but in many ways similar to, the Medicaid HCBS program, CSLA provides greater flexibility in service provision, permits specific targeting of services to eligible groups and geographic areas within a state, does not require demonstration of ICF-MR or nursing home level-of-care need for eligibility and allows each state to develop its own quality assurance plan within defined federal standards. Total cost of the CSLA program is capped on an annual basis in each of the program's first five years and at a five year total of 100 million dollars, evenly divided among the eight states permitted to add CSLA to their state Medicaid program.

Programs vary among the eight CSLA states (California, Colorado, Florida, Illinois, Maryland, Michigan, Rhode Island, and Wisconsin) with respect to target populations, numbers of recipients, services provided, cost per recipient, and in other ways. They share common goal statements related to enhancing quality of services through increased consumer choice and control over services and providers, person-

centered planning, and other programmatic elements identified by consumers, advocates, providers, and other professionals to be essential to allowing people to live life as they wish to live. Although early program development proceeded more slowly than was initially projected, by June 1994 nearly 2,000 persons with MR/DD in the eight participating states were receiving CSLA services.

#### *Medicaid Nursing Facilities*

As noted earlier, almost from the inception of Medicaid, states noted incentives for placing persons with MR/DD in Medicaid certified nursing facilities. Almost as soon as this began to happen there was a sense among the advocacy community that many more people with MR/DD were living in nursing homes than were appropriately served in them (National Association for Retarded Citizens, 1975). As concern grew supportive documentation was sought through evaluation studies. The largest such study, involving 2,700 Illinois nursing home residents with MR/DD (Davis, Silverstein, Uehara, & Sadden, 1987), concluded that only 10% of the residents clearly needed services that warranted 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 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 were required to assure that each person's needs for "active treatment" are met. Despite these requirements the number of people with MR/DD in Medicaid-certified nursing facilities in 1994 was about 95% of the number in 1970 (38,000) when the ICF-MR program was first conceived, in part, to halt the disturbing growth in the number of people with MR/DD who were being placed in nursing homes.

**CHAPTER 9**  
**UTILIZATION OF AND EXPENDITURES FOR MEDICAID INSTITUTIONAL**  
**AND HOME AND COMMUNITY BASED SERVICES**

This chapter provides statistics on the utilization of the three primary Medicaid long-term care programs for persons with mental retardation and related developmental disabilities: Intermediate Care Facilities for (persons with) Mental Retardation (ICF-MR), Home and Community-Based Services (HCBS), and Nursing Facilities (NF). These statistics are reported on a state by state basis because of the substantial variability among states in program utilization.

*ICF-MR Program Utilization on June 30, 1994*

*Number of facilities.* Table 3.1 presents state-by-state statistics on the number of ICFs-MR in the United States by size and state/nonstate operation on June 30, 1994. The total of 7,151 ICFs-MR compares with 574 ICFs-MR reported on June 30, 1977; 1,889 on June 30, 1982; 3,913 on June 30, 1987; and 6,512 on June 30, 1992. The increase in total ICFs-MR between 1987 and 1994 was significant, not only in amount (3,238 facilities) and percent (82.7%) of increase, but also because the average annual increase of 463 facilities exceeded the average annual increase of 334 facilities in the preceding ten-year period. But the period between June 1993 and June 1994 provided the first ever decrease in ICFs-MR. It was a substantial reduction of 460 from the 1993 total of 7,611. The major contribution to this reduction was New York which was operating 526 fewer ICFs-MR in 1994 than 1993, primarily because of conversions to Medicaid Home and Community Based Services (HCBS) financing.

Over four-fifths (86.8%) of the 7,151 ICFs-MR on June 30, 1994 were in the 14 states with 100 or more ICFs-MR each. Of these, 47.7%

were concentrated in four states (California, Indiana, New York, and Texas) with more than 500 ICFs-MR each. Despite its substantial reduction in ICFs-MR in Fiscal Year 1004, almost one-fifth (19.1%) of the national total was still in New York on June 30, 1994. In contrast, 14 states had fewer than 10 ICFs-MR and their combined total of 74 was only slightly more than 1% of all ICFs-MR.

The vast majority of all ICFs-MR (88.6%) on June 30, 1994 were small (15 or fewer residents), of which 47.9% had six or fewer residents. Most (86.7%) of all ICFs-MR with six or fewer residents were in nine states (California, Indiana, Louisiana, Michigan, Minnesota, New York, North Carolina, Pennsylvania, and Texas). Eighteen states reported no ICFs-MR with six or fewer residents and eight states (Colorado, Georgia, Kentucky, Maryland, Massachusetts, New Jersey, Oregon, and Wyoming) reported no small ICFs-MR of any size.

All but two states (District of Columbia and Vermont) report having one or more large ICFs-MR on June 30, 1994. Twenty-one states reported having five or fewer large ICFs-MR. Over one-third (36.3%) of all large ICFs-MR were located in four states with more than 50 large ICFs-MR each (Florida, Illinois, New York, Ohio) and almost three-fourths (71.7%) in the twelve states with 24 or more large ICFs-MR each. Large ICFs-MR were also predominantly (68.3%) nonstate operated. Most (97.5%) ICFs-MR with six or fewer residents were nonstate operated, as were most (80.7%) ICFs-MR of 7 to 15 residents. Of the total 7,151 ICFs-MR reported on June 30, 1994, 6,245 (87.3%) were nonstate operated.

Table 3.1 ICF-MR Certified Facilities on June 30, 1994 by State and Size

State	State-Operated Facilities					Nonstate-Operated Facilities					All Facilities				
	1-6	7-15	1-15	16+	Total	1-6	7-15	1-15	16+	Total	1-6	7-15	1-15	16+	Total
AL	0	0	0	5	5	0**	3**	3**	0**	3**	0	3**	3**	5	8
AK	0	0	0	1	1	4	2	6	0	6	4	2	6	1	7
AZ	0	10	10	7	17	0	0	0	1	1	0	10	10	8	18
AR	0	0	0	6	6	0	30	30	4	34	0	30	30	10	40
CA	0	0	0	7	7	608	51	659	32	691	608	51	659	39	698
CO	0	0	0	2	2	0	0	0	4	4	0	0	0	6	6
CT	9	32	41	10	51	64	4	68	0	68	73	36	109	10	119
DE	0	0	0	1	1	5	0	5	0	5	5	0	5	1	6
DC	0	0	0	0	0	74	42	116	0	116	74	42	116	0	116
FL	0	0	0	18	18	28	0	28	51	79	28	0	28	69	97
GA	0	0	0	8	8	0	0	0	1	1	0	0	0	9	9
HI	0	0	0	1	1	13	1	14	0	14	13	1	14	1	15
ID	0	0	0	1	1	10	35	45	2	47	10	35	45	3	48
IL	0	0	0	12	12	38	190	228	42	270	38	190	228	54	282
IN	0	0	0	11	11	179	344	523	13	536	179	344	523	24	547
IA	0	0	0	2	2	0	22	22	22	44	0	22	22	24	46
KS	0	0	0	3	3	12	22	34	11	45	12	22	34	14	48
KY	0*	0*	0*	2*	2*	0	0	0	6	6	0	0	0	8	8
LA	11	0	11	9	20	313	74	387	14	401	324	74	398	23	421
ME	0	1	1	2	3	21	15	36	5	41	21	16	37	7	44
MD	0	0	0	5	5	0	0	0	0	0	0	0	0	5	5
MA	0	0	0	8	8	0	0	0	0	0	0	0	0	8	8
MI	0	0	0	3	3	494	0	494	0	494	494	0	494	3	497
MN	17	0	17	6	23	139	150	289	35	324	156	150	306	41	347
MS	0	16	16	5	21	0	0	0	5*	5*	0	16	16	10	26
MO	0	0	0	6	6	3	15	18	2	20	3	15	18	8	26
MT	0	0	0	2	2	0	1	1	0	1	0	1	1	2	3
NE	0	0	0	1	1	0	1	1	2	3	0	1	1	3	4
NV	4	0	4	2	6	6	0	6	0	6	10	0	10	2	12
NH	1	0	1	0	1	1	4	5	1	6	2	4	6	1	7
NJ	0	0	0	8	8	0	0	0	3	3	0	0	0	11	11
NM	0	0	0	2	2	3*	29*	32*	1*	33*	3*	29*	32*	3	35
NY	43e	498e	541e	24	565e	135e	618e	753e	47	800	178e	1,116e	1,294e	71	1,365e
NC	0	0	0	5	5	238	33	271	11	282	238	33	271	16	287
ND	0	0	0	1	1	27	30	57	0	57	27	30	57	1	58
OH	0	0	0	12	12	29	194	223	89	312	29	194	223	101	324
OK	0	0	0	3	3	2	0	2	29	31	2	0	2	32	34
OR	0	0	0	1	1	0	0	0	0	0	0	0	0	1	1
PA	0	0	0	12	12	121	94	215	26	241	121	94	215	38	253
RI	0	3	3	0	3	50	4	54	2	56	50	7	57	2	59
SC	0	0	0	5	5	10	131	141	5	146	10	131	141	10	151
SD	0	0	0	2	2	0	13	13	0	13	0	13	13	2	15
TN	0	0	0	5	5	8	49	57	3	60	8	49	57	8	65
TX	1	3	4	16	20	671	78	749	30	779	672	81	753	46	799
UT	0	0	0	1	1	0	3	3	9	12	0	3	3	10	13
VT	0	0	0	0	0	7	0	7	0	7	7	0	7	0	7
VA	0	0	0	5	5	2	14	16	0	16	2	14	16	5	21
WA	0	0	0	4	4	12	5	17	4	21	12	5	17	8	25
WV	0*	0*	0*	1*	1*	11*	45*	56*	3*	59*	11*	45*	56*	4*	60
WI	0	0	0	3	3	0	5	5	41	46	0	5	5	44	49
WY	0	0	0	1	1	0	0	0	0	0	0	0	0	1	1
U.S. total	86	563	649	257	906	3,338	2,351	5,689	556	6,245	3,424	2,914	6,338	813	7,151
% of all															
ICFs-MR	1.2%	7.9%	9.1%	3.6%	12.7%	46.7%	32.9%	79.6%	7.8%	87.3%	47.9%	40.7%	88.6%	11.4%	100.0%

e indicates estimates

\* indicates 1993 data

\*\* indicates 1992 data

*Number of residents.* Table 3.2 presents state-by-state statistics on the number of people residing in ICFs-MR of different sizes and state/nonstate operation on June 30, 1994. There were a total of 142,118 ICF-MR residents in June 30, 1994. This represented a substantial decrease of 5,611 from the 147,729 ICF-MR residents in June 1993. In fact, this was the first notable decrease in ICF-MR populations since the program began in 1971. As with ICF-MR facilities, New York was the major contributor to the decrease, reducing ICF-MR populations by 5,767 in Fiscal Year 1994. Still in June 1994 the greatest number of ICF-MR residents was still in New York (16,083). California, Illinois, New York, and Texas all had over 10,000 ICF-MR residents, while Alaska, New Hampshire and Vermont each had fewer than 100.

#### *Nonstate ICF-MR Utilization*

Throughout the period from 1977 to 1994 there was a steady and substantial shift toward nonstate operation of ICFs-MR, although significantly less than the shift toward nonstate residential services generally. 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 1987, the 53,052 nonstate ICF-MR residents were 36.8% of all ICF-MR residents. On June 30, 1994, a slight majority (73,742 or 51.9%) of all ICF-MR residents were in nonstate ICFs-MR.

*Large nonstate ICFs-MR.* Since 1977 there has been a strong trend toward greater "privatization" of all residential services, including those provided in ICFs-MR. This has happened primarily as people with mental retardation and related developmental disabilities have moved from large state facilities to relatively small, overwhelmingly nonstate operated residential settings. Most of the growth in the number of residents in large nonstate ICFs-MR took place in the decade between program inception and 1982. There were 23,686 ICF-MR residents on June 30, 1982, 11,728 more than on June 30, 1977. The ICF-MR certification of large nonstate facilities continued at a generally high rate until 1987, when there were 32,398 residents. Since then there has actually been a net decrease in number of large nonstate ICF-MR residents. From June 30, 1977 to June 30, 1982 states were on the average increasing large nonstate ICF-MR facility populations by 2,340 per year; whereas in the seven years between 1987 and 1994, the large nonstate ICF-MR population decreased by 1,218 residents.

It should be noted that the net national increase of 7,494 residents in large nonstate ICFs-MR between 1982 and 1994 was primarily the result of a few states certifying existing large, nonstate MR/DD and nursing facilities as ICFs-MR as described above. The average number of people living in large nonstate ICFs-MR decreased from 76 to 56 residents between 1977 and 1994.

Table 3.2 Persons with Mental Retardation and Related Developmental Disabilities in ICF-MR Certified Facilities on June 30, 1994 by State and Size

State	Residents in State-Operated ICFs-MR					Residents in Nonstate-Operated ICFs-MR					Residents in All ICFs-MR				
	1-6	7-15	1-15	16+	Total	1-6	7-15	1-15	16+	Total	1-6	7-15	1-15	16+	Total
AL	0	0	0	1,113	1,113	0**	32**	32**	0**	32**	0	32**	32**	1,113	1,145
AK	0	0	0	38	38	20	20	40	0	40	20	20	40	38	78
AZ	0	171	171	123	294	0	0	0	45	45	0	171	171	168	339
AR	0	0	0	1,258	1,258	0	300	300	185	485	0	300	300	1,443	1,743
CA	0	0	0	6,343	6,343	3,648	765	4,413	2,025	6,438	3,648	765	4,413	8,368	12,781
CO	0	0	0	248	248	0	0	0	172e	172	0	0	0	420	420
CT	52	241	293	614	907	333	36	369	0	369	385	277	662	614	1,276
DE	0	0	0	320	320	36	0	36	0	36	36	0	36	320	356
DC	0	0	0	0	0	388	334	722	0	722	388	334	722	0	722
FL	0	0	0	1,333	1,333	168	0	168	1,906	2,074	168	0	168	3,239	3,407
GA	0	0	0	1,787	1,787	0	0	0	110	110	0	0	0	1,897	1,897
HI	0	0	0	80	80	55	7	62	0	62	55	7	62	80	142
ID	0	0	0	143	143	46	29J	326	58	384	46	280	326	201	527
IL	0	0	0	3,726	3,726	184	2,684	2,868	4,385	7,253	184	2,684	2,868	8,111	10,979
IN	0	0	0	1,384	1,384	974	2,921	3,895	945	4,840	974	2,921	3,895	2,329	6,224
IA	0	0	0	752	752	0	200	200	866	1,066	0	200	200	1,618	1,818
KS	0	0	0	806	806	72	218	290	671	961	72	218	290	1,477	1,767
KY	0*	0*	0*	620*	620*	0	0	0	513e	513	0	0	0	1,133	1,133
LA	58	0	58	2,126	2,184	1,871	591	2,462	1,383	3,845	1,929	591	2,520	3,509	6,029
ME	0	15	15	137	152	126	155	281	109	390	126	170	296	246	542
MD	0	0	0	822	822	0	0	0	0	0	0	0	0	822	822
MA	0	0	0	2,119	2,119	0	0	0	0	0	0	0	0	2,119	2,119
MI	0	0	0	411	411	2,955	0	2,955	0	2,955	2,955	0	2,955	411	3,366
MN	102	0	102	751	853	812	1,761	2,573	1,412e	3,985	914	1,761	2,675	2,163e	4,838
MS	0	155	155	1,237	1,392	0	0	0	685e	685e	0	155	155	1,922	2,077
MO	0	0	0	1,500	1,500	16	127	143	66	209	16	127	143	1,566	1,709
MT	0	0	0	163	163	0	8	8	0	8	0	8	8	163	171
NE	0	0	0	439	439	0	8	8	247e	255	0	8	8	686	694
NV	24	0	24	145	169	36	0	36	0	36	60	0	60	145	205
NH	6	0	6	0	6	6	38	44	23	67	12	38	50	23	73
NJ	0	0	0	3,738	3,738	0	0	0	237	237	0	0	0	3,975	3,975
NM	0	0	0	349	349	15*	205*	220*	16*	236*	15*	205*	220*	365	585
NY	181	4,686	4,867	3,146	8,013	586	6,136	6,722	1,348	8,070	767	10,822	11,589	4,494	16,083
NC	0	0	0	2,362	2,362	1,420	470	1,890	480	2,370	1,420	470	1,890	2,842	4,732
ND	0	0	0	146	146	161	244	405	0	405	161	244	405	146	551
OH	0	0	0	2,179	2,179	157	1,788	1,945	3,697	5,642	157	1,788	1,945	5,876	7,821
OK	0	0	0	658	658	12	0	12	1,598	1,610	12	0	12	2,256	2,268
OR	0	0	0	417	417	0	0	0	0	0	0	0	0	417	417
PA	0	0	0	3,563	3,563	646	756	1,402	1,985	3,387	646	756	1,402	5,548	6,950
RI	0	45	45	0	45	234	31	265	43	308	234	76	310	43	353
SC	0	0	0	1,885	1,885	40	1,074	1,114	112	1,226	40	1,074	1,114	1,997	3,111
SD	0	0	0	351	351	0	151	151	0	151	0	151	151	351	502
TN	0	0	0	1,784	1,784	48	374	422	144	566	48	374	422	1,928	2,350
TX	6	35	41	6,124	6,165	4,017	943	4,960	2,617	7,577	4,023	978	5,001	8,741	13,742
UT	0	0	0	362	362	0	12	12	550	562	0	12	12	912	924
VT	0	0	0	0	0	42	0	42	0	42	42	0	42	0	42
VA	0	0	0	2,298	2,298	10	158	168	0	168	10	158	168	2,298	2,466
WA	0	0	0	1,050	1,050	71	42	113	139	252	71	42	113	1,189	1,302
WV	0*	0*	0*	109*	109*	64*	360*	424*	107*	531*	64*	360*	424*	216*	640*
WI	0	0	0	1,384	1,384	0	64	64	2,301	2,365	0	64	64	3,685	3,749
WY	0	0	0	156	156	0	0	0	0	0	0	0	0	156	156
U.S. Total	429	5,348	5,777	62,599	68,376	19,269	23,293	42,562	31,180	73,742	19,698	28,641	48,339	93,779	142,118
% of all in ICF-MR	3%	3.8%	4.1%	44.0%	48.1%	13.6%	16.4%	29.9%	21.9%	51.9%	13.9%	20.2%	34.0%	66.0%	100.0%

e indicates estimates

\* indicates 1993 data

\*\* indicates 1992 data

*Small nonstate ICFs-MR.* On June 30, 1994 small (15 or fewer residents) nonstate ICFs-MR made up 79.6% of all ICFs-MR, although only 29.9% of all ICF-MR residents lived in them. These numbers compare with 26% of facilities and 1.3% of residents in 1977, 56% of facilities and 6.0% of residents in 1982, and 70.3% of facilities and 14.3% of residents in 1987. From 1982 to 1994, small nonstate ICFs-MR grew by 38,710 residents as compared with 7,494 residents in large nonstate ICFs-MR.

Further broken down, on June 30, 1994 of the 42,562 people living in small nonstate ICFs-MR, 45.3% (19,269) were living in ICFs-MR of six or fewer residents. In comparison, on June 30, 1977 of the 1,354 small ICF-MR residents, 18.6% (252) lived in ICFs-MR of six or fewer residents, and on June 30, 1982, of the 8,358 small nonstate ICF-MR residents, 28% (2,364) were living in ICFs-MR of six or fewer residents. As a consequence of the increasing development of ICFs-MR with six or fewer residents, the average size of small ICFs-MR dropped from 9.2 residents in 1982 to 7.5 residents in 1994.

On June 30, 1994 the eight states with the greatest number of small nonstate ICF-MR residents (California, Indiana, Illinois, Louisiana, Michigan, Minnesota, New York, and Texas) had 72.5% of all small nonstate ICF-MR residents. New York (with 7% of the U.S. population) had 15.8% of the total population of small nonstate ICFs-MR in 1994. As noted, however, this represents a significant reduction from 1993 when New York had 26.6% of all small nonstate ICFs-MR. In contrast, of the 41 states utilizing small nonstate ICFs-MR, the two-thirds (26) with the lowest utilization rate had a total of only 8.8% of all residents on June 30, 1994.

#### *State ICF-MR Utilization*

The proportion of ICF-MR residents living in state facilities has been decreasing steadily since 1982. But Fiscal Year 1994 was just the second year since the beginning of the ICF-MR program that fewer ICF-MR residents lived in state facilities than in nonstate facilities; 48.1% of all ICF-MR residents on June 30, 1994. Even though there has been growth in small state-operated ICFs-MR in recent years, from 2,874 residents on June 30, 1987 to 5,777 residents on June 30, 1994, only 8.4% of the residents of state

ICFs-MR on June 30, 1994 were living in facilities of 15 or fewer residents. Tables 3.1, 3.2, and 3.3 present the current status of ICF-MR utilization described below.

*Large state ICFs-MR.* Nationally on June 30, 1994, the population of large state MR/DD facilities with ICF-MR certification was 62,599 (out of a total large state MR/DD facility population of 65,735). Although the percentage of large state MR/DD facility residents living in ICF-MR certified units increased from 88% to 95.3% between 1982 and 1994, there was an overall reduction in the population of large state ICFs-MR. From June 30, 1982 to June 30, 1994 there was a national net decrease of about 44,500 residents of large state ICFs-MR, as compared with a net increase of about 15,000 residents between June 30, 1977 and June 30, 1982. This trend toward lower numbers of residents in large state ICFs-MR was evident in the vast majority of states.

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 1994. Between June 30, 1977 and June 30, 1982 states were increasing the proportion of their large state MR/DD facility capacity certified to participate in the ICF-MR program from about 60% of the national total to about 88%. Therefore, although states were decreasing large state MR/DD facility 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 units. However, by 1982, with nearly 90% of large state MR/DD facility residents already living in units with ICF-MR certification, the ongoing depopulation of these facilities caused substantial decreases in the number of residents in ICF-MR units. The decreasing populations in large state MR/DD facilities continues to reduce the extent to which the ICF-MR program is essentially a large state MR/DD facility-centered program. In 1992, for the first time, fewer than half (48.7%) of all ICF-MR residents lived in large state MR/DD facilities. In 1994 44.0% of ICF-MR residents lived in large state MR/DD facilities. This compares with 87.1% in 1977; 76.3% in 1982, and 61.3% in 1987.



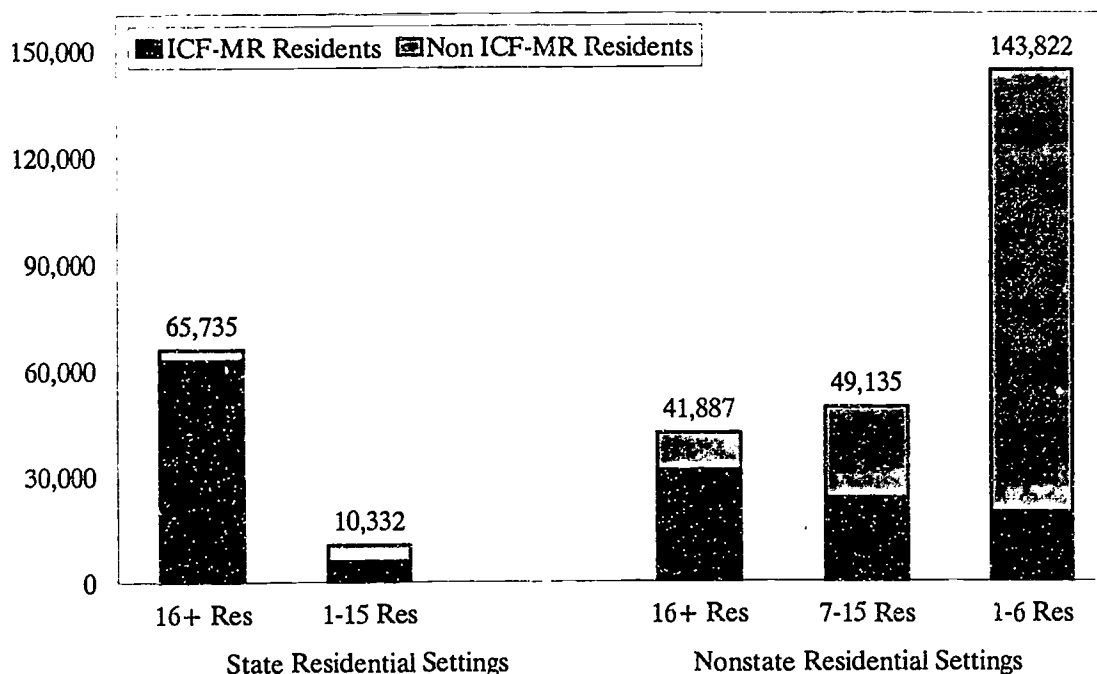
**Small state ICFs-MR.** On June 30, 1994 there was a total of 649 small state-operated ICFs-MR operating in the United States. In all, only 5,777 (4.1%) of all ICF-MR residents lived in these facilities. Of the total 649 small state ICFs-MR, 541 (83.4%) were in New York; Connecticut had 41 (6.3%), Michigan had 17 (2.6%), and Minnesota had 16 (2.5%), for a combined total of 94.8% of all small state-operated ICFs-MR. In general, small state ICFs-MR are larger than small nonstate ICFs-MR, with the average size of 8.9 residents as compared with about 7.5 residents in small nonstate ICFs-MR.

Figure 3.1 shows ICF-MR residents as a proportion of all persons receiving residential services in state and nonstate facilities of different sizes on June 30, 1994. As shown, 95.3% of large state MR/DD facility residents

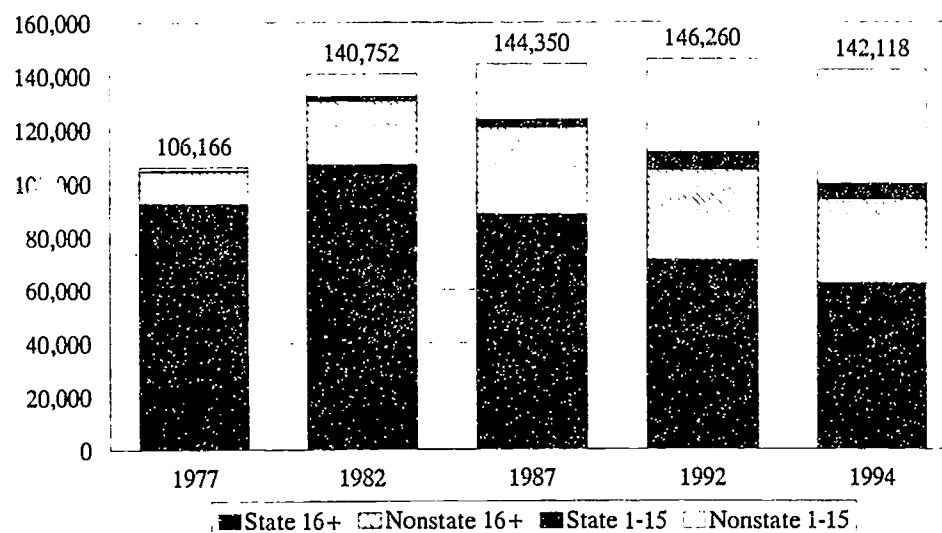
lived in ICF-MR units, as did 74.4% of large nonstate facility residents and 55.9% of small state-operated facility residents. Nationally, 44.5% of the people living in nonstate settings of 7 to 15 residents, but only 13.3% of the people living in nonstate settings of six or fewer residents resided in ICFs-MR.

Figure 3.2 shows the proportion of all ICF-MR residents living in each of the four types of ICFs-MR described above from 1977 to 1994. It shows the substantial growth in the number of residents in ICFs-MR other than large state residential facilities, but also, that large state residential facilities remain the most frequently used setting for ICF-MR services. It also shows that there has been considerable stability in the number of ICF-MR residents since 1982.

**Figure 3.1**  
**ICF-MR Residents as a Proportion of All Residents**  
**of State and Nonstate Settings by Size on June 30, 1994**



**Figure 3.2**  
**Residents of ICF-MR Certified Facilities by Size and State/Nonstate Operation**  
**on June 30, 1977, 1982, 1987, 1992, and 1994**



*Large and Small Certified Facilities*

Table 3.3 reports the total number of persons with MR/DD who a) live in large and small ICFs-MR, b) live in all large and small residential settings licensed or operated by the various states for persons with mental retardation and related developmental disabilities (irrespective of ICF-MR certification), and c) the percentages of all residents of large and small residential settings who were residing in places with ICF-MR certification on June 30, 1994.

A total of 48,339 persons were reported living in small ICFs-MR nationwide on June 30, 1994. These persons made up 34.0% of all ICF-MR residents on that day. However, states varied greatly in their particular use of large and small ICFs-MR. Use of small ICFs-MR on June 30, 1994 was dominated by seven states (California, Indiana, Illinois, Louisiana, Michigan, Minnesota, New York, and Texas), each having 2,500 or more residents in small ICFs-MR, and together serving 74.1% of all small ICF-MR residents. Fifteen states had at least 50% of their total ICF-MR population in small facilities, while eight other states participating in the ICF-MR program had no

residents in small ICFs-MR. Figure 3.3 shows these variations on a state-by-state basis.

The "Total Residents" columns of Table 3.3 present statistics on combined ICF-MR and non-ICF-MR (state and nonstate) residential services in the various states. It shows that nationally on June 30, 1994, 65.8% of persons in all state and nonstate MR/DD residential programs were in residential settings with 15 or fewer residents. The "Percentage in ICF-MR" indicates the percentage of all MR/DD residential service recipients, by size of residential facility, who were living in facilities with ICF-MR certification. It shows that 45.1% of all MR/DD residential service recipients nationally were in ICFs-MR, but that only 23.3% of all people living in residential settings with 15 or fewer residents were living in ICFs-MR. In contrast, 87.1% of residents of large residential facilities lived in ICF-MR certified units. Figure 3.4 shows variations in utilization of ICF-MR services on a state-by-state basis. A total of nine states reported more than 60% of their total residential populations living in ICFs-MR on June 30, 1994. Ten states reported less than 20% of their residents in ICF-MR certified settings.

Table 3.3 Number and Percentage of Residents in ICF-MR Facilities on June 30, 1994 by State and Size

State	ICF-MR Residents						Total Residents						% of All Residents in ICF-MR				
	1-6	7-15	1-15	16+	Total	% in 1-15	1-6	7-15	1-15	16+	Total	% in 1-15	1-6	7-15	1-15	16+	Total
AL	0	32**	32**	1,113	1,145	2.8%	361**	679**	1,040**	1,142	2,182	47.7%	0.0%	4.7%	3.1%	97.5%	52.5%
AK	20	20	40	38	78	51.3%	468	70	538	38	576	93.4%	4.3%	28.6%	7.4%	100.0%	13.5%
AZ	0	171	171	168	339	50.4%	4,730	331	5,061	168	5,229	96.8%	0.0%	51.7%	3.4%	100.0%	6.5%
AR	0	300	300	1,443	1,743	17.2%	429	300	729	1,443	2,172	33.6%	0.0%	100.0%	41.2%	100.0%	80.2%
CA	3,648	765	4,413	8,368	12,781	34.5%	27,822	3,328	31,150	11,551	42,701	72.9%	13.1%	23.0%	14.2%	72.4%	29.9%
CO	0	0	0	420	420	0.0%	2,814	642	3,456	420	3,876	89.2%	0.0%	0.0%	0.0%	100.0%	10.8%
CT	385	277	662	614	1,276	51.9%	3,689	540	4,229	1,342	5,571	75.9%	10.4%	51.3%	15.7%	45.8%	22.9%
DE	36	0	36	320	356	10.1%	385	0	385	320	705	54.6%	9.4%	0.0%	9.4%	100.0%	50.5%
DC	388	334	722	0	722	100.0%	721	363	1,084	0	1,084	100.0%	53.8%	92.0%	66.6%	0.0%	66.6%
FL	168	0	168	3,239	3,407	4.9%	3,292	1,834	5,126	3,981	9,107	56.3%	5.1%	0.0%	3.3%	81.4%	37.4%
GA	0	0	0	1,897	1,897	0.0%	1,538	0	1,538	2,101	3,639	42.3%	0.0%	0.0%	0.0%	90.3%	52.1%
HI	55	7	62	80	142	43.7%	1,015	7	1,022	96	1,118	91.4%	5.4%	100.0%	6.1%	83.3%	12.7%
ID	46	280	326	201	527	61.9%	824	505	1,329	336	1,665	79.8%	5.6%	55.4%	24.5%	59.8%	31.7%
IL	184	2,684	2,868	8,111	10,979	26.1%	738	4,836	5,574	10,194	15,768	35.4%	24.9%	55.5%	51.5%	79.6%	69.6%
IN	974	2,921	3,895	2,329	6,224	62.3%	3,480	5,712	9,192	2,329	11,521	79.8%	28.0%	51.1%	42.4%	100.0%	54.0%
IA	0	200	200	1,618	1,818	11.0%	2,006*	1,884	3,890*	1,949	5,839	66.5%	0.0%	10.6%	5.1%	83.0%	31.1%
KS	72	218	290	1,477	1,767	16.4%	584	941	1,525	1,477	3,002	50.8%	12.3%	23.2%	19.0%	100.0%	58.9%
KY	0	0	0	1,133	1,133	0.0%	1,353	189	1,542	1,163	2,705	57.0%	0.0%	0.0%	0.0%	97.4%	41.9%
LA	1,929	591	2,520	3,509	6,029	41.8%	3,060e	682e	3,742e	4,211	7,953*	47.1%	63.0%	86.7%	67.3%	83.3%	75.8%
ME	126	170	296	246	542	54.6%	979	307	1,286	267	1,553	82.8%	12.9%	55.4%	23.0%	92.1%	34.9%
MD	0	0	0	822	822	0.0%	3,470	0	3,470	1,013	4,483	77.4%	0.0%	0.0%	0.0%	81.1%	18.3%
MA	0	0	0	2,119	2,119	0.0%	5,331	874	6,205	2,119	8,324	74.5%	0.0%	0.0%	0.0%	100.0%	25.5%
MI	2,955	0	2,955	411	3,366	87.8%	8,719	0	8,719	411	9,130	95.5%	33.9%	0.0%	33.9%	100.0%	36.9%
MN	914	1,761	2,675	2,163e	4,838	55.3%	6,182e*	1,911	8,093e*	2,163*	10,256e*	78.9%	14.8%	92.2%	33.1%	100.0%	47.2%
MS	0	155	155	1,922	2,077	7.5%	409	303	712	2,124	2,836	25.1%	0.0%	51.2%	21.8%	90.5%	73.2%
MO	16	127	143	1,566	1,709	8.4%	2,384	1,463	3,847	2,371	6,218	61.9%	0.7%	8.7%	3.7%	66.0%	27.5%
MT	0	8	8	163	171	4.7%	778	531	1,309	163	1,472	88.9%	0.0%	1.5%	0.6%	100.0%	11.6%
NE	0	8	8	686	694	1.2%	800	208	1,008	686	1,694	59.5%	0.0%	3.8%	0.8%	100.0%	41.0%
NV	60	0	60	145	205	29.3%	458	0	458	150	608	75.3%	13.1%	0.0%	13.1%	96.7%	33.7%
NH	12	38	50	23	73	68.5%	3,053e	242e	3,295e	53e	3,348e	98.4%	0.4%	15.7%	1.5%	43.4%	2.2%
NJ	0	0	0	3,975	3,975	0.0%	4,440	0	4,440	5,490	9,930	44.7%	0.0%	0.0%	0.0%	72.4%	40.0%
NM	15*	205*	220*	365	585	37.6%	493*	272*	765*	365	1,130	67.7%	3.0%	75.4%	28.8%	100.0%	51.8%
NY	767	10,822	11,89	4,494	16,083	72.1%	7,776*	17,705*	25,481*	5,457*	30,938*	82.4%	9.9%	61.1%	45.5%	82.4%	52.0%
NC	1,420	470	1,890	2,842	4,732	39.9%	3,245	711	3,956	2,937	6,893	57.4%	43.8%	66.1%	47.8%	96.8%	68.6%
ND	161	244	405	146	551	73.5%	1,093	535	1,628	226	1,854	87.8%	14.7%	45.6%	24.9%	64.6%	29.7%
OH	157	1,788	1,945	5,876	7,821	24.9%	4,546	2,714	7,260	6,052	13,312	54.5%	3.5%	65.9%	26.8%	97.1%	58.8%
OK	12	0	12	2,256	2,268	0.5%	1,333	249	1,582	2,256	3,838	41.2%	0.9%	0.0%	0.8%	100.0%	59.1%
OR	0	0	0	417	417	0.0%	2,620	555	3,175	628	3,803	83.5%	0.0%	0.0%	0.0%	66.4%	11.0%
PA	646	756	1,402	5,548	6,950	20.2%	8,040	834	8,874	6,124	14,998	59.2%	8.0%	90.6%	15.8%	90.6%	46.3%
RI	234	76	310	43	353	87.8%	932	315	1,247	43	1,290	96.7%	25.1%	24.1%	24.9%	100.0%	27.4%
SC	40	1,074	1,114	1,997	3,111	35.8%	1,246	1,443	2,689	1,997	4,686	57.4%	3.2%	74.4%	41.4%	100.0%	66.4%
SD	0	151	151	351	502	30.1%	729	689	1,418	351	1,769	80.2%	0.0%	21.9%	10.6%	100.0%	28.4%
TN	48	374	422	1,928	2,350	18.0%	723	1,597	2,320	1,928	4,248	54.6%	6.6%	23.4%	18.2%	100.0%	55.3%
TX	4,023	978	5,001	8,741	13,742	36.4%	4,023	978	5,001	8,741	13,742	36.4%	100.0%	100.0%	100.0%	100.0%	100.0%
UT	0	12	12	912	924	1.3%	939	312	1,251	912	2,163	57.8%	0.0%	3.8%	1.0%	100.0%	42.7%
VT	42	0	42	0	42	100.0%	770	0	770	0	770	100.0%	5.5%	0.0%	5.5%	0.0%	5.5%
VA	10	58	168	2,298	2,466	6.8%	223a	386a	609a	2,598	3,207	19.0%	4.5%	40.9%	27.6%	88.5%	76.9%
WA	71	42	113	1,189	1,302	8.7%	4,266	773	5,039	1,636	6,675	75.5%	1.7%	5.4%	2.2%	72.7%	19.5%
WV	64*	360*	424*	216*	640*	66.3%	531*	424*	955*	259*	1,214*	78.7%	12.1%	84.9%	44.4%	83.4%	52.7%
WI	0	64	64	3,685	3,749	1.7%	6,567	996	7,563	3,685	11,248	67.2%	0.0%	6.4%	0.8%	100.0%	33.3%
WY	0	0	0	156	156	0.0%	543	64	607	156	763	79.6%	0.0%	0.0%	0.0%	100.0%	20.4%
U.S.																	
Total	19,698	28,641	48,339	93,779	142,118	34.0%	146,950	60,234	207,184	107,622	314,806	65.8%	13.4%	47.5%	23.3%	87.1%	45.1%

e indicates estimates

\* indicates 1993 data

\*\* indicates 1992 data

Figure 3.3 Percentage of ICF-MR Residential Service Recipients  
in Settings with 15 or Fewer Residents on June 30, 1994

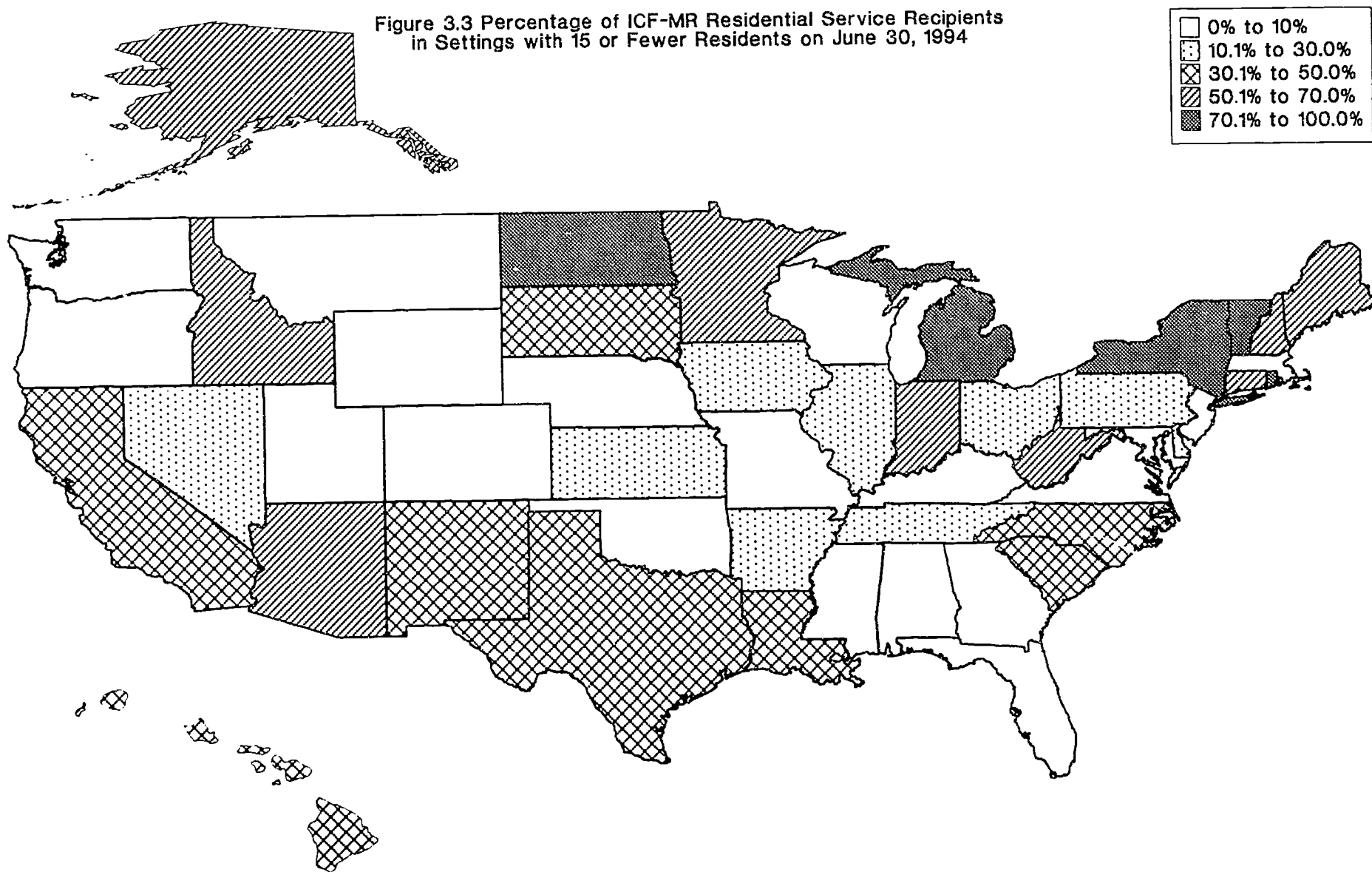
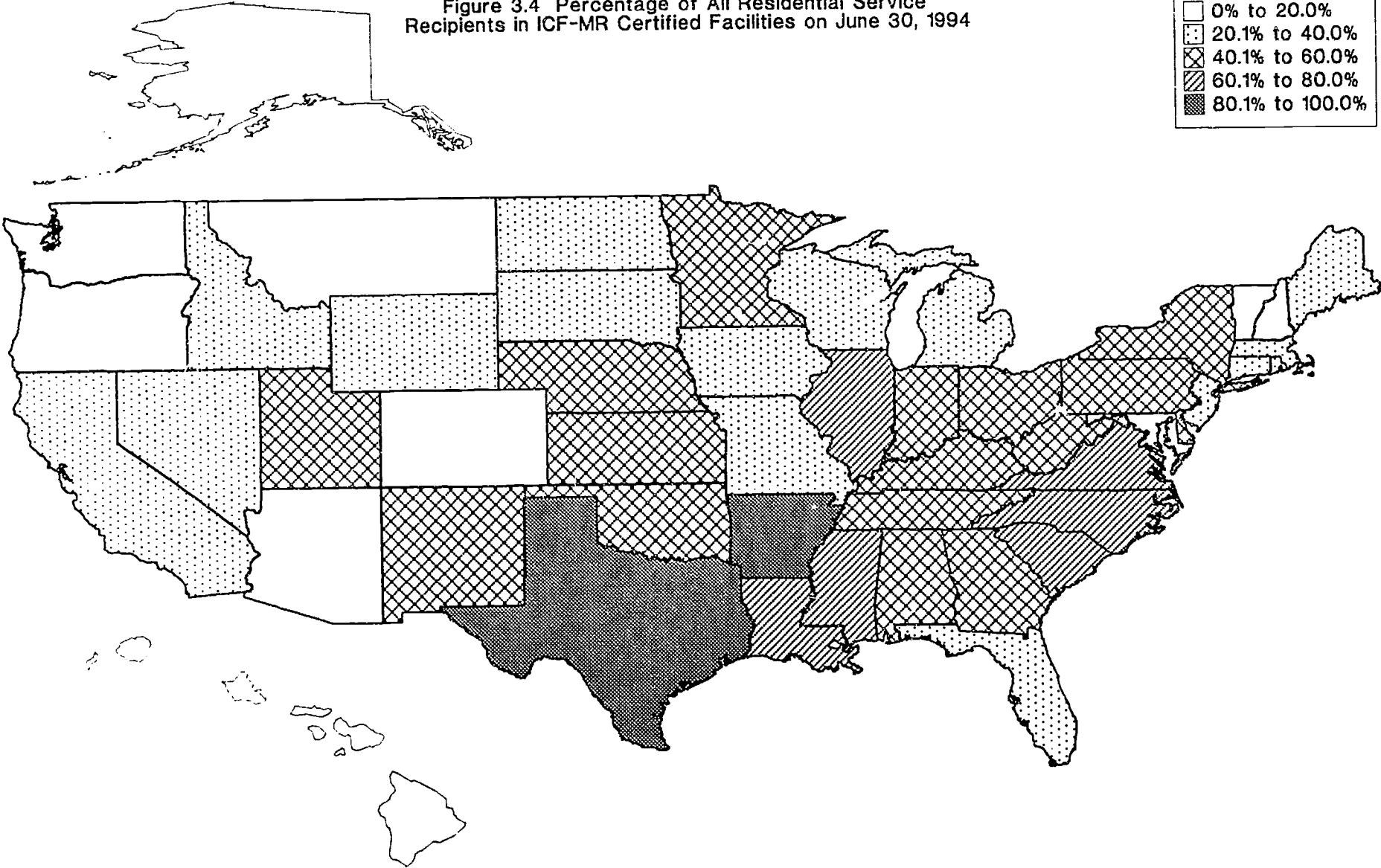
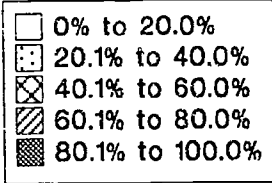


Figure 3.4 Percentage of All Residential Service Recipients in ICF-MR Certified Facilities on June 30, 1994



National Average = 45.1%

Figure 3.5 shows the number of people living in ICF-MR and non-ICF-MR residential settings of 1-15 and 16 or more total residents in June 30, 1977, 1982, 1987, 1992, and 1994. This figure shows the decreasing role of ICFs-MR in residential services and the overall growth in the number of people living in smaller residential settings among both the ICFs-MR and non-ICF-MR residential settings. It also shows that while the ICF-MR program continues to be primarily concentrated in large facilities, there has been a gradual shift over time toward greater total and proportional use 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 settings were in ICFs-MR. By 1987, 19.8% (23,528) of 118,570 residents in smaller residential settings were in ICFs-MR and by 1994, 23.3% (48,339) of 207,184 persons in small residential settings were in ICFs-MR. It is also notable that while in 1977 barely half (50.5%) of the people living in all state and nonstate facilities of 16 or more residents lived in ICFs-MR, by 1994, 87% of the people living in large facilities lived in ICFs-MR.

One notable change in ICF-MR utilization that is obvious in Figure 3.5 is the rapid growth in the non-ICF-MR component of residential services. In 1994, persons receiving residential services in settings without ICF-MR certification were more numerous than they were in 1977 when the efforts of states to maximize their ICF-MR participation were still in process. Persons residing in settings without ICF-MR certification fell rapidly between 1977 and 1982 (from 141,600 to 103,000 people) as states made substantial efforts to increase federal financial participation in residential services through ICF-MR certification. Beginning in 1982 there has been a trend which has grown more rapid since 1987 for states to increase the number of persons with MR/DD living in settings without ICF-MR certification. From the 103,000 persons in residential settings without ICF-MR certification in 1982, persons living in non-certified settings grew to 111,353 in 1987 and 172,688 in 1994.

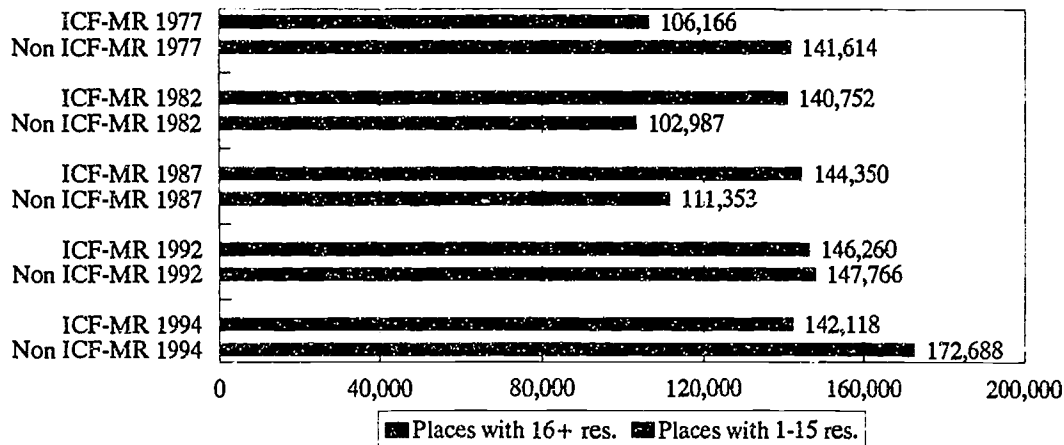
The primary factor promoting such change in state policy has been the Medicaid Home and Community Based Services (HCBS) waiver

option. It has permitted states to provide residential services to persons living in community living arrangements and to receive Medicaid federal cost sharing of the residential services provided to them without accepting adherence to the ICF-MR standards for residential facilities. On June 30, 1994 an estimated 92,950 individuals with MR/DD were receiving HCBS financed residential services outside their natural or adoptive family home (see Table 3.11). In other words, although the number of people receiving residential services that were not financed through the ICF-MR program increased from 103,000 to 172,688, the number of people receiving services financed by neither the ICF-MR program or its HCBS alternative has actually decreased by over 20,000 to an estimated 79,738 persons.

#### *Expenditures for ICF-MR Services*

Table 3.4 shows national totals and interstate variations on ICF-MR program recipients and expenditures for Fiscal Year 1994. Fiscal Year 1994 was the first year since the ICF-MR program developed that ICF-MR expenditures did not increase. Previously total ICF-MR expenditures had continued to increase steadily each year. Between Fiscal Year 1971 when there were no ICF-MR expenditures and Fiscal Year 1977 ICF-MR expenditures grew to 1.1 billion dollars. Between 1977 and 1982 ICF-MR expenditures grew from 1.1 billion dollars to 3.6 billion dollars. Although the rate of growth in ICF-MR expenditures slowed notably from Fiscal Year 1982 to Fiscal Year 1993, expenditures still increased 5.6 billion dollars, from 3.6 billion dollars to 9.2 billion dollars over the period. In Fiscal Year 1994 ICF-MR expenditures remained at 9.2 billion dollars. In the four years between June 30, 1989 and June 30, 1994 ICF-MR recipients remained almost unchanged (147,148 and 142,118 respectively), but ICF-MR expenditures grew from 6.6 billion to 9.2 billion (39%). By the end of Fiscal Year 1994 total ICF-MR residents had decreased by 6.4% allowing total expenditures to remain stable even with small increases in per recipient expenditures.

**Figure 3.5**  
**Number of Residents in ICF-MR and Non ICF-MR Residential Settings with**  
**1-15 and 16 or more Total Residents, 1977 to 1994**



Before 1982 the ICF-MR program expenditures were pushed upward by both increased number of recipients and increased expenditures per recipient. Between 1982 and 1994 growing expenditures per recipient have been by far the most significant factor in the increasing expenditures for 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 only about 1% between June 30, 1982 and June 30, 1993. Because this single factor (increasing costs per recipient) has been responsible for expenditure increases in the past decade, cost analysis has become much more straightforward. It has also calmed concerns about the annual 25% increases in ICF-MR expenditures evident between 1972 and 1982, as a stable number of recipients has led to a considerably lower rate of growth between 1982 and 1994 (even though the average annual increase of about 470 million dollars between 1982 and 1994 was actually greater than the average annual dollar increase from 1973 to 1982). It is perhaps too early to suggest that the Fiscal Year 1994 decreases in ICF-MR residents will become an established pattern, particularly given one state's (New York) major contribution to the national decrease. On the other hand given the large scale disenchantment with the ICF-MR model as the most appropriate and

efficient way of providing community services, and the increasing flexibility in utilizing Medicaid HCBS for community residential services, it is difficult to imagine a reason why ICF-MR utilization will not continue to decrease.

In addition to the changing utilization patterns, there has also been a substantial reduction in the past decade in the per resident rate of increase in expenditures for ICF-MR care. While per recipient expenditures between 1975 and 1982 increased from \$5,530 to \$25,590 per year, or at an average annual rate of about 29%, from 1982 to 1994 those increases were from \$25,590 to \$63,931, or about 8% annually. With cost inflation of the ICFs-MR substantially below the increases of other Medicaid services, for the most part attention now given to the program by federal and state policy makers is directed toward issues of the quality, equity, and system-wide effects of the program rather than what was perceived as runaway expenditures a decade ago. However at the state level cost management in ICF-MR services remains a major concern and opportunities to reallocate ICF-MR expenditures to more flexible and less costly HCBS and similar services have been of growing interest to states. Between 1992 and 1994 that interest was expressed in an explosive growth in HCBS enrollments (95.4% increase).

Table 3.4 Summary Statistics on ICF-MR Expenditures by State for Fiscal Year 1994

State	ICF-MR Expenditures	Federal cost share	Total Federal ICF-MR Payments	Persons with MR/DD in ICF-MR Facilities	ICF-MR Expenditures per Recipient	State Population (100,000)	ICF-MR Expenditure per state resident	State % of Federal ICF-MR
AL	\$79,259,148	0.71	\$56,448,365	1,145	\$69,222	41.87	\$18.93	1.07%
AK	\$11,589,274	0.50	\$5,794,637	78	\$148,580	5.99	\$19.35	0.11%
AZ	\$16,911,180e	0.66	\$11,161,379	339	\$49,885	39.36	\$4.30	0.21%
AR	\$94,186,907	0.74	\$70,131,571	1,743	\$54,037	24.24	\$38.86	1.33%
CA	\$365,970,455	0.50	\$182,985,228	12,781	\$28,634	312.11	\$11.73	3.47%
CO	\$38,872,894	0.54	\$21,107,981	420	\$92,555	35.66	\$10.90	0.40%
CT	\$179,704,129	0.50	\$89,852,065	1,276	\$140,834	32.77	\$54.84	1.70%
DE	\$27,269,884	0.50	\$13,634,542	356	\$76,601	7.00	\$38.96	0.26%
DC	\$64,030,193	0.50	\$32,015,097	722	\$88,684	5.78	\$110.78	0.61%
FL	\$212,266,722	0.55	\$116,279,710	3,407	\$62,303	136.79	\$15.52	2.20%
GA	\$119,694,232	0.62	\$74,772,987	1,897	\$63,097	69.17	\$17.30	1.42%
HI	\$10,540,552	0.50	\$5,270,276	142	\$74,229	11.72	\$8.99	0.10%
ID	\$40,364,385	0.71	\$28,626,422	527	\$76,593	10.99	\$36.73	0.54%
IL	\$489,074,612	0.50	\$244,537,306	10,979	\$44,546	116.97	\$41.81	4.63%
IN	\$309,133,359	0.63	\$196,268,770	6,224	\$49,668	57.13	\$54.11	3.72%
IA	\$161,161,376	0.63	\$102,063,499	1,818	\$88,648	28.14	\$57.27	1.93%
KS	\$105,435,798	0.60	\$62,755,387	1,767	\$59,669	25.31	\$41.66	1.19%
KY	\$71,528,596	0.71	\$50,720,927	1,133	\$63,132	37.89	\$18.88	0.96%
LA	\$299,378,672	0.73	\$220,380,836	6,029	\$ 9,739	42.95	\$69.82	4.18%
ME	\$54,806,503	0.62	\$33,958,109	542	\$101,119	12.39	\$44.23	0.64%
MD	\$59,588,868	0.50	\$29,794,434	822	\$72,493	49.65	\$12.00	0.56%
MA	\$295,029,013	0.50	\$147,514,507	2,119	\$139,230	60.12	\$49.07	2.80%
MI	\$157,233,505	0.56	\$88,632,527	3,366	46,712	94.78	\$16.59	1.68%
MN	\$245,807,000	0.55	\$134,333,526	4,838	\$50,808	45.17	\$54.42	2.55%
MS	\$84,960,608	0.79	\$66,991,439	2,077	\$40,905	26.43	\$32.15	1.27%
MO	\$144,138,825	0.61	\$87,405,783	1,709	\$84,341	52.34	\$27.54	1.66%
MT	\$14,221,768	0.71	\$10,104,566	171	\$83,168	8.39	\$16.95	0.19%
NE	\$34,234,126	0.62	\$21,218,311	694	\$49,329	16.07	\$21.30	0.40%
NV	\$20,334,863	0.50	\$10,230,470	205	\$99,194	13.89	\$14.64	0.19%
NH	\$5,979,764	0.50	\$2,989,882	73	\$81,915	11.25	\$5.32	0.06%
NJ	\$357,321,411	0.50	\$178,660,706	3,975	\$89,892	78.79	\$45.35	3.39%
NM	\$38,311,007	0.74	\$28,415,274	585	\$65,489	16.16	\$23.71	0.54%
NY	\$2,011,018,234	0.50	\$1,005,509,117	16,083	\$125,040	181.97	\$110.51	19.05%
NC	\$331,537,743	0.65	\$215,963,686	4,732	\$70,063	69.45	\$47.74	4.09%
ND	38,746,760	0.71	\$27,560,570	551	\$70,321	6.35	\$61.02	0.52%
OH	\$453,032,866	0.61	\$275,579,892	7,821	\$57,925	110.91	\$40.85	5.22%
OK	\$91,297,595	0.70	\$64,264,377	2,268	\$40,255	32.31	\$28.26	1.22%
OR	\$78,885,481	0.62	\$49,003,661	417	\$189,174	30.32	\$26.02	0.93%
PA	\$501,094,381	0.55	\$273,647,641	6,950	\$72,100	120.48	\$41.59	5.19%
RI	\$42,164,534	0.54	\$22,714,034	353	\$119,446	10.00	42.16	0.43%
SC	\$172,312,260	0.71	\$122,479,554	3,111	\$55,388	36.43	\$47.30	2.32%
SD	\$31,815,475	0.70	\$22,111,755	502	\$63,377	7.15	\$44.50	0.42%
TN	\$135,559,639	0.67	\$91,028,298	2,350	\$57,685	50.99	\$26.59	1.72%
TX	\$552,768,743	0.64	\$354,766,979	13,742	\$40,225	180.31	\$30.66	6.72%
UT	\$38,094,684	0.74	\$28,323,398	924	\$41,228	18.60	\$20.48	0.54%
VT	\$5,525,346	0.60	\$3,290,344	42	\$131,556	5.76	\$9.59	0.06%
VA	\$153,543,506	0.50	\$76,771,753	2,466	\$62,264	64.91	\$23.65	1.45%
WA	\$166,587,723	0.54	\$90,357,181	1,302	\$127,948	52.55	\$31.70	1.71%
WV	\$14,288,181	0.76	\$10,819,011	640*	\$22,325	18.20	\$7.85	0.20%
WI	\$188,315,604	0.60	\$113,874,446	3,749	\$50,231	50.38	\$37.38	2.16%
WY	\$6,829,072	0.66	\$4,481,920	156	\$43,776	4.70	\$14.53	0.08%
U.S.								
Total	\$9,222,257,456		\$5,277,604,535	142,118	\$64,891	2,579.04	\$35.76	100.0%

\* indicates 1993 data



### *Interstate Variations in ICF-MR Expenditures*

Earlier in this chapter statistics were provided on the substantial interstate variations in the utilization of the ICF-MR option. Not surprisingly, there were also major variations in state expenditures for ICF-MR services. 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 residents or state size. Table 3.4 presents Fiscal Year 1994 statistics for ICF-MR expenditures across the states with respect to total expenditures, federal expenditures, per recipient average annual expenditures, per capita annual ICF-MR expenditures (ICF-MR expenditures per resident of the state), and each state's proportion of the total federal ICF-MR expenditures.

*Per capita cost variations.* 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 3.4 shows the great variation in these expenditures among the states. While nationally in Fiscal Year 1994 the average daily expenditure for ICF-MR services was \$35.76 per U.S. citizen, the average varied from over twice the national average in the District of Columbia and New York to less than half the national average in 14 states (Arizona, California, Colorado, Florida, Georgia, Hawaii, Maryland, Michigan, Montana, Nevada, New Hampshire, Vermont, West Virginia, Wyoming). 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.

*Variations due to disproportionate placements.* Variations in ICF-MR utilization rates across states have an important direct effect on interstate differences in total expenditures and federal contributions to the total costs of residential programs in the various states. As an example of the variability, on June 30, 1994, nine states housed more than 60% of their total residential care population in ICF-MR certified facilities, and ten states housed 20% 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 expenditures.* 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 3.4 also shows the enormous variations among states in the average per resident expenditures for ICF-MR services. The national average expenditures for ICF-MR services per recipient in Fiscal Year 1994 (total ICF-MR expenditures in the year divided by total recipients on June 30, 1994) was \$64,891 per year. Among the states with the highest per recipient expenditures in 1994 were, Oregon (\$189,174), Alaska (\$148,580), Connecticut (\$140,843), and Massachusetts (\$139,230). Among the states with the lowest per recipient expenditures were West Virginia (\$22,325), and California (\$28,634). The effects of relatively high per resident expenditures are straightforward. Alaska, Connecticut, Massachusetts, and Oregon had 3.5% of all ICF-MR residents on June 30, 1994, but accounted for 6.1% of total Fiscal Year 1994 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 7.0% of the total U.S. population and 11.3% of the ICF-MR population on June 30, 1994, it accounted for 21.8% of all ICF-MR expenditures.

### *Medicaid HCBS Recipients*

The Medicaid Home and Community Based Services (HCBS) program is associated with the ICF-MR program through its dedication to persons who but for the services available through the Medicaid HCBS program would be at risk of placement in an ICF-MR. In the decade between enactment of the Medicaid HCBS program in 1981 to June 30, 1994 49 states chose to provide Home and Community Based Services as an alternative to ICF-MR services. This growth in state participation is

shown in Table 3.5. As shown, the number of HCBS program participants on June 30, 1982 was estimated to be 1,381. By June 30, 1987 there were 22,689 HCBS recipients. On June 30, 1994 there were 122,075 persons with mental retardation and related developmental disabilities receiving Medicaid Home and Community Based Services. Between June 30, 1989 and June 30,

1994, states had a combined increase of 86,998 HCBS recipients. States with the greatest increase in total recipients over the five-year period were New York (18,877), California (9,911), Arizona (6,773) and Massachusetts (3,920). Between June 1992 and June 1994, HCBS recipients nearly doubled from 62,462 to 122,075.

Table 3.5 Persons Receiving Medicaid Home and Community Based Services on June 30, 1982 to June 30, 1994 by State

State	HCBS Recipients												Net Change 1989/1994	
	1982	1983	1984	1985	1986	1987	1988	1989	1990	1991	1992	1993		1994
AL	0	808	1,564	1,524	1,568	1,570	1,730	1,830	1,839	2,021	2,184	2,184**	2,900e	1,070
AK	0	0	0	0	0	0	0	0	0	0	0	0	32	32
AZ	0	0	0	0	0	0	0	0	0	3,794	4,832c	6,071	6,773	6,773
AR	0	0	0	0	0	0	0	0	91	196	415	453	429	429
CA	0	433	619	2,500	2,962	3,027	2,493	3,355	3,628	3,360	3,360	11,085	13,266	9,911
CO	0	0	600	920	1,280	1,389	1,621	1,679	1,841	1,993	2,204	2,407	2,684	1,005
CT	0	0	0	0	0	0	644	1,127	1,555	1,655	1,693	2,069	2,361	1,234
DE	0	0	0	50	78	81	144	100	196	245	290	290	310	210
DC	0	0	0	0	0	0	0	0	0	0	33	0	0	0
FL	0	0	7,003	7,003	1,003	2,631	2,631	2,542	2,615	2,631	2,637	6,009	6,430	3,888
GA	0	0	0	0	0	0	0	25	160	353	359e	359e	556	531
HI	0	0	10	24	44	56	78	70	123	189	452	450	513	443
ID	0	0	18	51	25	55	201	270	346	165	225	174	333	63
IL	0	0	40	543	543	664	637	680	724	1,338	2,006	2,850	4,590	3,910
IN	0	0	0	0	0	0	0	0	0	0	0	447	529	529
IA	0	0	0	0	0	4	12	14	5	19	137	170	879	865
KS	0	0	23	186	173	135	185	314	361	497	555e	1,066	1,339	1,025
KY	0	0	475	516	516	609	652	728	743	762	819e	855e	887e	159
LA	0	2,006	2,046	2,087	0	0	0	0	0	56	939	1,134	1,543	1,543
ME	0	0	75	165	353	400	450	453	454	509	509e**	742	289	289
MD	0	0	28	356	464	685	716	813	858	1,082	1,972	2,437	2,787	1,974
MA	0	0	0	235	525	593	593	1,210	1,539	1,700	3,288	3,288**	5,130	3,920
MI	0	0	0	0	2	3	580	1,292	1,658	2,122	2,741e	2,885	3,367	2,075
MN	0	0	0	239	570	1,423	1,896	2,068	2,184	2,551	2,890	3,408	4,385	2,317
MS	0	0	0	0	0	0	0	0	0	0	0	0	0	0
MO	0	0	0	0	0	0	0	338	989	1,452	2,241	2,622	3,057	2,719
MT	21	44	69	78	192	210	286	274	276	355	444	504	546	272
NE	0	0	0	0	0	0	553	540	658	683	710e	991	1,257	717
NV	0	34	80	90	108	129	117	136	133	135	136	186	172	36
NH	0	0	303	409	504	541	634	762	822	955	1,059	1,032	1,303	541
NJ	0	0	1,317	2,025	1,993	2,596	2,873	3,170	3,270	3,655	3,971	4,191	4,729	1,559
NM	0	0	0	53	244	220	134	135	160	160	334	612	402	267
NY	0	0	0	0	0	0	0	0	0	0	379	3,398	18,877	18,877
NC	0	0	17	120	331	328	405	553	731	780	939e	1,190	1,318	765
ND	0	0	68	439	463	724	824	1,063	1,055	1,163	1,334	1,362	1,509e	446
OH	0	0	56	62	86	100	134	240	245	2	397	1,120	2,399	2,159
OK	0	0	0	0	36	70	178	500	621	844	949	1,287	1,693	1,193
OR	1,360	1,886	1,992	973	572	832	968	1,218	1,282	2,177	1,458	2,023	2,136	918
PA	0	0	141	269	542	1,203	1,759	1,930	2,221	2,333	2,705	3,795	4,303	2,373
RI	0	0	11	25	117	136	250	449	277	793	993	1,192	1,333	884
SC	0	0	0	0	0	0	0	0	0	0	471	586	966	966
SD	0	382	457	523	498	596	610	683	721	788	852e	923	1,004	321
TN	0	0	0	0	0	213	351	474	581	579	704e	587	964	490
TX	0	0	0	0	70	70	412	417	485	973	968	968**	1,564	1,147
UT	0	0	0	0	0	0	1,022	1,124	1,200	1,234	1,367e	1,476	1,590	466
VT	0	11	74	116	234	196	248	280	323	485	413e	598	722	442
VA	0	0	0	0	0	0	0	0	0	326	537*	537e	715	715
WA	0	0	844	998	905	886	946	1,084	1,250	1,736	1,918e	1,711	3,068	1,984
WV	0	0	22	55	55	124	124	224	316	413	513	637	803	579
WI	0	0	20	56	124	190	598	913	1,302	1,643	1,812	2,017	2,315	1,402
WY	0	0	0	0	0	0	0	0	0	125	318	459	565	565
U.S. total	1,381	5,604	17,972	22,690	17,180	22,689	28,689	35,077	39,838	51,027	62,462	86,604	122,075	86,998
Number of states with HCBS	2	8	27	31	32	35	38	40	42	45	48	48	49	

Note: Data Source for 1982-85 are from Smith &amp; Gettings, 1992.

### *Expenditures for HCBS Recipients*

Table 3.6 shows national totals and interstate variations on HCBS recipients and expenditures for Fiscal Year 1994. On June 30, 1994, HCBS expenditures were 2.97 billion dollars for 122,075 recipients. Fiscal Year 1994 expenditures divided by end of year HCBS recipients yielded an "average" cost per recipient of \$24,343. In reality, however, when large number of persons are being added to the program during the fiscal year, this substantially underestimates the annualized average cost. Assuming persons were added to the at an even rate all through the Fiscal Year, the annualized average HCBS expenditure would be computed best from the estimated number of HCBS participants at the mid-point of the fiscal year (about 104,339). This estimated number of HCBS participants would yield an annualized average expenditure of \$28,480. The unadjusted "average" expenditure of \$24,343 per recipient represents a 14.6% increase over June 30, 1990, when HCBS expenditures were 846 million dollars for 39,838 recipients (\$21,246 per recipient). In addition to the substantial interstate variations in HCBS utilization noted earlier there were also major variations in state expenditures for HCBS participants. Table 3.6 presents Fiscal Year 1994 statistics for HCBS expenditures across states with respect to total expenditures, federal expenditures, per participant average annual expenditures, per capita annual HCBS expenditures (HCBS expenditures per resident of

the state), and each state's proportion of the federal HCBS expenditures.

*Per capita cost variations.* One indicator of the variation among states in HCBS expenditures is the average expenditure for HCBS per citizen of the state. Table 3.6 shows the great variation in these expenditures among the states. While nationally in Fiscal Year 1994 the average daily expenditure for HCBS was \$11.52, the average varied from over three times the national average in six states (Connecticut, New Hampshire, North Dakota, Rhode Island, Vermont, and Wyoming) to less than one-third the national average in nine states (Alaska, Georgia, Idaho, Indiana, Iowa, Nevada, North Carolina, Tennessee, and Texas). The variability in total and per citizen expenditures among states is affected by both the extent to which persons received HCBS and the amount of money spent per recipient.

*Variations due to disproportionate placements.* Variations in HCBS utilization rates across states have an important direct effect on interstate differences in total and per capita expenditures. Nationally, on June 30, 1994, HCBS recipients were 46.2% of the total HCBS and ICF-MR recipient population. In five states HCBS recipients were less than 20% of the total HCBS and ICF-MR recipient population, while in five states HCBS recipients were over 80% of the total HCBS and ICF-MR recipient population.

Table 3.6 Summary statistics on HCBS Expenditures by State for Fiscal Year 1994

State	HCBS Expenditures	Federal Cost Share	Federal HCBS Expenditures	Total HCBS Recipients	HCBS Expenditures per Recipient	State Population (100,000)	HCBS Expenditure per state resident	State % of Federal HCBS
AL	\$30,500,000e	0.71	\$21,722,100	2,900e	\$10,517	41.87	\$7.28	1.30%
AK	\$666,594	0.50	\$333,297	32	\$20,831	5.99	\$1.11*	0.02%
AZ	\$109,357,800	0.66	\$72,066,790	6,773	\$16,146	39.36	\$27.78	4.33%
AR	\$14,057,101	0.74	\$10,466,917	429	\$32,767	24.24	\$5.80	0.63%
CA	\$133,839,149	0.50	\$66,919,575	13,266	\$10,089	312.11	\$4.29*	4.02%
CO	\$77,602,279	0.54	\$42,138,037	2,684	\$28,913	35.66	\$21.76	2.53%
CT	\$135,134,012	0.50	\$67,567,006	2,361	\$57,236	32.77	\$41.24	4.06%
DE	\$9,074,353	0.50	\$4,537,177	310	\$29,272	7.00	\$12.96	0.27%
DC	\$0	0.50	\$0	0	\$0	5.78	\$0.00	0.00%
FL	\$67,760,413	0.55	\$37,119,154	6,430	\$10,538	136.79	\$4.95	2.23%
GA	\$17,300,000	0.62	\$10,807,310	556	\$31,115	69.17	\$2.50*	0.65%
HI	\$12,000,000e	0.50	\$6,000,000	513	\$23,392	11.72	\$10.24*	0.36%
ID	\$2,035,028	0.71	\$1,443,242	333	\$6,111	10.99	\$1.85	0.09%
IL	\$57,553,816	0.50	\$28,776,908	4,590	\$12,539	116.97	\$4.92	1.73%
IN	\$4,016,174	0.63	\$2,549,869	529	\$7,592	57.13	\$0.70	0.15%
LA	\$4,025,328	0.63	\$2,549,240	879	\$4,579	28.14	\$1.43	0.15%
KS	\$32,031,858	0.60	\$19,065,362	1,339	\$23,922	25.31	\$12.66	1.14%
KY	\$25,165,278	0.71	\$17,844,699	887e	\$28,371	37.89	\$6.64	1.67%
LA	\$25,000,000e	0.73	\$18,372,500	1,543	\$16,202	42.95	\$5.82	1.10%
ME	\$23,738,025	0.62	\$14,708,080	742	\$31,992	12.39	\$19.16	0.88%
MD	\$119,236,508	0.50	\$59,618,254	2,787	\$42,783	49.65	\$24.02	3.58%
MA	\$204,300,000	0.50	\$102,150,000	5,130	\$39,825	60.12	\$33.98	6.13%
MI	\$90,300,000	0.56	\$50,902,110	3,367	\$26,819	94.78	\$9.53	3.06%
MN	\$127,711,222	0.55	\$69,794,183	4,385	\$29,125	45.17	\$28.27	4.19%
MS	\$0	0.79	\$0	0	\$0	26.43	\$0.00	0.00%
MO	\$80,547,488	0.61	\$48,843,997	3,057	\$26,349	52.34	\$15.39	2.93%
MT	\$15,564,370	0.71	\$11,058,485	546	\$28,506	8.39	\$18.55	0.66%
NE	\$32,271,390	0.62	\$20,001,808	1,257	\$25,673	16.07	\$20.08	1.20%
NV	\$2,060,407	0.50	\$1,036,591	172	\$11,979	13.89	\$1.48*	0.06%
NH	\$64,005,401	0.50	\$32,002,701	1,303	\$49,122	11.25	\$56.89	1.92%
NJ	\$130,063,493	0.50	\$65,031,747	4,729	\$27,503	78.79	\$16.51	3.90%
NM	\$10,178,666	0.74	\$7,549,517	402	\$25,320	16.16	\$6.30	0.45%
NY	\$403,370,865	0.50	\$201,685,433	18,877	\$21,368	181.97	\$22.17	12.11%
NC	\$19,846,196	0.65	\$12,927,812	1,318	\$15,058	69.45	\$2.86	0.78%
ND	\$23,269,934	0.71	\$16,551,904	1,509e	\$15,421	6.35	\$36.65	0.99%
OH	\$49,739,511	0.61	\$30,256,545	2,399	\$20,733	110.91	\$4.48	1.82%
OK	\$57,848,596	0.70	\$40,719,627	1,693	\$34,169	32.31	\$17.90	2.45%
OR	\$78,199,623	0.62	\$48,577,606	2,136	\$36,610	30.32	\$25.79	2.92%
PA	\$247,511,000	0.55	\$135,165,757	4,303	\$57,521	120.48	\$20.54	8.12%
RI	\$58,725,000	0.54	\$31,635,158	1,333	\$44,055	10.00	\$58.73	1.90%
SC	\$18,000,000e	0.71	\$12,794,400	966	\$18,634	36.43	\$4.94	0.77%
SD	\$22,526,640	0.70	\$15,656,015	1,004	\$22,437	7.15	\$31.51	0.94%
TN	\$16,031,049	0.67	\$10,764,849	964	\$16,630	50.99	\$3.14	0.65%
TX	\$47,384,302	0.64	\$30,411,245	1,564	\$30,297	180.31	\$2.63	1.83%
UT	\$31,114,289	0.74	\$23,133,474	1,590	\$19,569	18.60	\$16.73	1.39%
VT	\$33,139,589	0.60	\$19,734,625	722	\$45,900	5.76	\$57.53	1.18%
VA	\$26,129,717	0.50	\$13,064,859	715	\$36,545	64.91	\$4.03	0.78%
WA	\$77,223,317	0.54	\$41,885,927	3,068	\$25,171	52.55	\$14.70	2.52%
WV	\$19,923,405	0.76	\$15,086,002	803	\$24,811	18.20	\$10.95*	0.91%
WI	\$60,559,064	0.60	\$36,620,066	2,315	\$26,159	50.38	\$12.02	2.20%
WY	\$23,986,815	0.66	\$15,742,547	565	\$42,455	4.70	\$51.04	0.95%
U.S.								
Total	\$2,971,625,064		\$1,665,390,502	122,075	\$24,343	2,579.04	\$11.52	100.0%

e indicates estimates

*Variations due to differences in per recipient expenditures.* The average number of dollars expended per HCBS participant is also a key factor in interstate differences in HCBS expenditures. Table 3.6 shows the enormous variations among the states in the average per participant expenditures for HCBS. The national average expenditures for HCBS per recipient for Fiscal Year 1994 (total HCBS expenditures in the year divided by total recipients on June 30, 1994) was \$24,343 per year. Among the states with the highest per recipient expenditures in 1994 were Pennsylvania (\$57,521), Connecticut (\$57,236), New Hampshire (\$49,122), and Vermont (\$45,900). Among the states with the lowest per recipient expenditures were Iowa (\$4,579), Idaho (\$6,111), and Indiana (\$7,592).

The effects of relatively high per resident expenditures are straightforward. Pennsylvania, Connecticut, New Hampshire, and Vermont accounted for 7.1% of all HCBS recipients on June 30, 1994, but accounted for 16.1% of total Fiscal Year 1994 HCBS expenditures.

#### *HCBS Recipients and Residents of Small ICFs-MR*

Medicaid long-term care services for persons with mental retardation and related developmental disabilities have long been criticized for their primarily institutional orientation. Clearly the utilization of the HCBS program and the development of ICF-MR services in homes of 15 or fewer residents, and increasingly 6 or fewer residents, is reducing the

statistical substantiation for such criticisms, although "institutional" is obviously not exclusively dictated by facility size. Table 3.7 presents statistics on states' use of the Medicaid HCBS option on June 30, 1994 and summarizes the combined use of the Medicaid HCBS and small ICF-MR options to provide community services as well as the total use of ICF-MR and waiver services by the individual states.

Table 3.7 shows that on June 30, 1994 there were 122,075 people receiving Medicaid HCBS services and 48,339 persons living in small ICFs-MR. This combined total of community Medicaid service recipients (170,414) was 65.4% of the 264,193 total of all Title XIX recipients (HCBS and all sizes of ICF-MR). Combining HCBS and small ICF-MR service recipients also shows 39 states to be serving the majority of their recipients of Title XIX services for persons with MR/DD in community programs. Twenty states were serving three-quarters or more of their Title XIX service recipients in community settings. Figure 3.6 shows this variation on a state-by-state basis.

Figure 3.7 shows the total large (16 or more residents) state and nonstate ICF-MR residents and small state and nonstate ICF-MR residents and HCBS recipients for 1977, 1982, 1987, 1992, and 1994. It shows the dramatic increase in community Title XIX service recipients from 1977 to 1994, from 1,710 to 170,414. It also shows the substantial decrease of the population of large ICFs-MR from 1982 to 1994, from 130,767 to 93,779.

Table 3.7 ICF-MR Residents and Medicaid Home and Community Based Service (HCBS)  
Recipients with Mental Retardation and Related Developmental Disabilities on June 30, 1994 by State

State	Total HCBS Recipients	Total Residents of Small ICFs-MR	Total Recipients of Small ICFs-MR and HCBS	Total Residents of ICFs-MR	Total Recipients of ICF-MR & HCBS	Small ICF-MR & HCBS Recipient as % of All ICF-MR & HCBS Recipient
AL	2,900e	32**	2,932e	1,145	4,045e	72.5%
AK	32	40	72	78	110	65.5%
AZ	6,773	171	6,944	339	7,112	97.6%
AR	429	300	729	1,743	2,172	33.6%
CA	13,266	4,413	17,679	12,781	26,047	67.9%
CO	2,684	0	2,684	420	3,104	86.5%
CT	2,361	662	3,023	1,276	3,637	83.1%
DE	310	36	346	356	666	52.0%
DC	0	722	722	722	722	100.0%
FL	6,430	168	6,598	3,407	9,837	67.1%
GA	556	0	556	1,897	2,453	22.7%
HI	513	62	575	142	655	87.8%
ID	333	326	659	527	860	76.6%
IL	4,590	2,868	7,458	10,979	15,569	47.9%
IN	529	3,895	4,424	6,224	6,753	65.5%
IA	879	200	1,079	1,818	2,697	40.0%
KS	1,339	290	1,629	1,767	3,106	52.4%
KY	887e	0	887e	1,133	2,020e	43.9%
LA	1,543	2,520	4,063	6,029	7,572	53.7%
ME	742	296	1,038	542	1,284	80.8%
MD	2,787	0	2,787	822	3,609	77.2%
MA	5,130	0	5,130	2,119	7,249	70.8%
MI	3,367	2,955	6,322	3,366	6,733	93.9%
MN	4,385	2,675	7,060	4,838	9,223	76.5%
MS	0	155	155	2,077	2,077	7.5%
MO	3,057	143	3,200	1,709	4,766	67.1%
MT	546	8	554	171	717	77.3%
NE	1,257	8	1,265	694	1,951	64.8%
NV	172	60	232	205	377	61.5%
NH	1,303	50	1,353	73	1,376	98.3%
NJ	4,729	0	4,729	3,975	8,704	54.3%
NM	402	220*	622	585	987	63.0%
NY	18,877	11,589	30,466	16,083	34,960	87.1%
NC	1,318	1,890	3,208	4,732	6,050	53.0%
ND	1,509e	405	1,914	551	2,060	92.9%
OH	2,399	1,945	4,344	7,821	10,220	42.5%
OK	1,693	12	1,705	2,268	3,961	43.0%
OR	2,136	0	2,136	417	2,553	83.7%
PA	4,303	1,402	5,705	6,950	11,253	50.7%
RI	1,333	310	1,643	353	1,686	97.4%
SC	966	1,114	2,080	3,111	4,077	51.0%
SD	1,004	151	1,155	502	1,506	76.7%
TN	964	422	1,386	2,350	3,314	41.8%
TX	1,564	5,001	6,565	13,742	15,306	42.9%
UT	1,590	12	1,602	924	2,514	63.7%
VT	722	42	764	42	764	100.0%
VA	715	168	883	2,466	3,181	27.8%
WA	3,068	113	3,181	1,302	4,370	72.8%
WV	803	424*	1,227	640*	1,443	85.0%
WI	2,315	64	2,379	3,749	6,064	39.2%
WY	565	0	565	156	721	78.4%
U.S.Total	122,075	48,339	170,414	142,118	264,193	64.5%

e indicates estimates

\* indicates 1993 data

\*\* indicates 1993 data

### *ICF-MR and HCBS Recipients and Expenditures*

Medicaid Intermediate Care Facilities for the Mentally Retarded (ICF-MR) and Medicaid Waiver Home and Community Based Services (HCBS) share common eligibility criteria and should serve the same general population. Yet, as reported in Table 3.8, expenditures for ICF-MR and HCBS services disproportionately favor the former. Nationally, HCBS recipients were 46.2% of the total HCBS and ICF-MR recipient population but were beneficiaries of only 24.4% of total HCBS and ICF-MR expenditures.

HCBS and ICF-MR recipients and expenditures varied among individual states but in all but two states (Arizona and West Virginia) the ICF-MR share of total expenditures was disproportionately high when measured against the ICF-MR share of total recipient population. In 16 states, (Alabama, Alaska, Arkansas, Florida, Idaho, Illinois, Indiana, Iowa, Louisiana, Nevada, New York, North Carolina, Ohio, South Carolina, and Washington), HCBS recipients as a percentage of all recipients exceeded HCBS expenditures as a percentage of all expenditures by a factor of 2 or greater; in nine of those states (Alaska, Idaho, Indiana, Iowa, Nevada and North Carolina) by a factor of 3 or greater.

In some states, disproportionately higher expenditures for ICF-MR recipients may be

explained by artificially inflated institutional costs resulting from deinstitutionalization. The consistent pattern of relatively lower expenditures for HCBS recipients in some states, is an intended and controlled consequence of an effort to achieve cost containment in Medicaid spending. In such states HCBS expenditures are limited in reference to ICF-MR expenditures. In almost all states some HCBS recipients live in their family homes which reduces long-term care costs by the relative value of the supports provided in the home and community by family members and other non-paid support providers. Somewhat related children and youth are more likely to be served under HCBS than ICF-MR and as a result "day program" costs are more likely to be covered by educational agencies. Finally, although federal regulations require that both HCBS and ICF-MR recipients meet the same eligibility criteria and supervision (24 hour) and treatment ("active") standards it is reasonable to consider whether, in actual practice, HCBS has become defined as a less intensive service than ICF-MR in a "continuum" of Medicaid long term care services, with large institutions seen as most restrictive and smaller community ICFs-MR at intermediate points of intensity. As a result HCBS may be, almost by definition, less costly than ICF-MR.



Table 3.8 ICF-MR Residents and HCBS Recipients and ICF-MR and HCBS Expenditures on June 30, 1994 by State

State	Total	ICF-MR & HCBS Expenditures	% of recipients		% of expenditures	
	Recipients of ICF-MR & HCBS		HCBS	ICF-MR	HCBS	ICF-MR
AL	4,045e	\$109,759,148	71.7%	28.3%	27.8%	72.2%
AK	110	\$12,255,868	29.1%	70.9%	5.4%	94.6%
AZ	7,112	\$109,466,249	95.2%	4.8%	99.9%	0.1%
AR	2,172	\$125,155,188	19.8%	80.2%	0.0%	100.0%
CA	26,047	\$499,809,604	50.9%	49.1%	26.8%	73.2%
CO	3,104	\$116,475,173	86.5%	13.5%	66.6%	33.4%
CT	3,637	\$314,838,141	64.9%	35.1%	42.9%	57.1%
DE	666	\$36,344,237	46.5%	53.5%	25.0%	75.0%
DC	722	\$64,030,193	0.0%	100.0%	0.0%	100.0%
FL	9,837	\$280,027,135	65.4%	34.6%	24.2%	75.8%
GA	2,453	\$136,994,232	22.7%	77.3%	12.6%	87.4%
HI	655	\$22,540,552	78.3%	21.7%	53.2%	46.8%
ID	860	\$42,399,413	38.7%	61.3%	4.8%	95.2%
IL	15,569	\$546,628,428	29.5%	70.5%	10.5%	89.5%
IN	6,753	\$313,149,533	7.8%	92.2%	1.3%	98.7%
IA	2,697	\$165,186,704	32.6%	67.4%	2.4%	97.6%
KS	3,106	\$137,467,656	43.1%	56.9%	23.3%	76.7%
KY	2,020e	\$96,693,874	43.9%	56.1%	26.0%	74.0%
LA	7,572	\$324,878,672	20.4%	79.6%	7.7%	92.3%
ME	1,284	\$78,544,528	57.8%	42.2%	30.2%	69.8%
MD	3,609	\$178,825,376	77.2%	22.8%	66.7%	33.3%
MA	7,249	\$499,329,013	70.8%	29.2%	40.9%	59.1%
MI	6,733	\$247,533,505	50.0%	50.0%	36.5%	63.5%
MN	9,223	\$373,518,222	47.5%	52.5%	34.2%	65.8%
MS	2,077	\$84,960,608	0.0%	100.0%	0.0%	100.0%
MO	4,766	\$224,686,313	64.1%	35.9%	35.8%	64.2%
MT	717	\$29,786,138	76.2%	23.8%	52.3%	47.7%
NE	1,951	\$66,505,516	64.4%	35.6%	48.5%	51.5%
NV	377	\$22,395,270	45.6%	54.4%	9.2%	90.8%
NH	1,376	\$69,985,165	94.7%	5.3%	91.5%	8.5%
NJ	8,704	\$487,384,904	54.3%	45.7%	26.7%	73.3%
NM	987	\$48,489,673	40.7%	59.3%	21.0%	79.0%
NY	34,960	\$2,414,389,099	46.4%	53.6%	16.7%	83.3%
NC	6,050	\$351,383,939	21.8%	78.2%	5.6%	94.4%
ND	2,060	\$62,016,694	73.3%	26.7%	37.5%	62.5%
OH	10,220	\$502,772,377	23.5%	76.5%	9.9%	90.1%
OK	3,961	\$149,146,191	42.7%	57.3%	38.8%	61.2%
OR	2,553	\$157,085,104	83.7%	16.3%	49.8%	50.2%
PA	11,253	\$748,605,381	38.2%	61.8%	33.1%	66.9%
RI	1,686	\$100,889,534	79.1%	20.9%	58.2%	41.8%
SC	4,077	\$190,312,260	23.7%	76.3%	9.5%	90.5%
SD	1,506	\$54,342,115	66.7%	33.3%	41.5%	58.5%
TN	3,314	\$151,590,688	29.1%	70.9%	10.6%	89.4%
TX	15,306	\$600,153,045	10.2%	89.8%	7.9%	92.1%
UT	2,514	\$69,208,973	63.2%	36.8%	45.0%	55.0%
VT	764	\$38,664,935	94.5%	5.5%	85.7%	14.3%
VA	3,181	\$179,673,223	22.5%	77.5%	14.5%	85.5%
WA	4,370	\$243,811,040	70.2%	29.8%	31.7%	68.3%
WV	1,443	\$34,211,586	55.6%	44.4%	58.2%	41.8%
WI	6,064	\$248,874,668	38.2%	61.8%	24.3%	75.7%
WY	721	\$30,815,887	78.4%	21.6%	77.8%	22.2%
U.S.Total	264,193	\$12,193,990,970	46.2%	53.8%	24.4%	75.6%

e indicates estimates  
\* indicates 1993 data

*Variations in State Financial Benefit for  
Combined ICF-MR and HCBS Programs*

The federal government shares the costs of the ICF-MR and HCBS programs with the states as a function of the state per capita income relative to national per capita income. Relatively rich states share total expenditures on an equal basis with the federal government; relatively poor states may have federal involvement in financing Medicaid services up to 83% (Mississippi's 79.0% was the highest federal share in 1994). It is often presumed, therefore, that the extent to which states benefit from ICF-MR and HCBS program participation should be related to their general need for assistance as reflected in the federal Medicaid cost share ratio. However, because states vary considerably in their combined ICF-MR and HCBS utilization rates, in the proportions of ICF-MR and HCBS recipients, and in their expenditures per recipient, some deviation is expected between total benefit in federal dollars from the combined ICF-MR and HCBS program and the proportion of total ICF-MR and HCBS expenditures reimbursed by the federal government. This concept of relative benefit has become of increasing interest recently as discussions of Medicaid "block grants" take place. Questions arise as to whether block grant allocations should be based on present Medicaid expenditures, including relative "benefit" disparities to be noted, or whether they should be based on separate criteria (e.g., total persons served, percentage of state population in poverty), or if the former whether some adjustment would be needed over time to close the gap between states that presently receive relatively more or less federal Medicaid reimbursements.

To demonstrate the differences that exist among states in their relative "return" on current contributions to Medicaid, a "state benefit ratio" was computed. The state Medicaid benefit ratio in Table 3.9 represents a ratio of combined federal

ICF-MR and HCBS 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), a major factor in the block grant discussions. Despite the oversimplifications, such an index is one way of assessing the balance between state contributions to the federal government for the combined ICF-MR and HCBS programs and federal reimbursements back to the states for ICF-MR and HCBS programs.

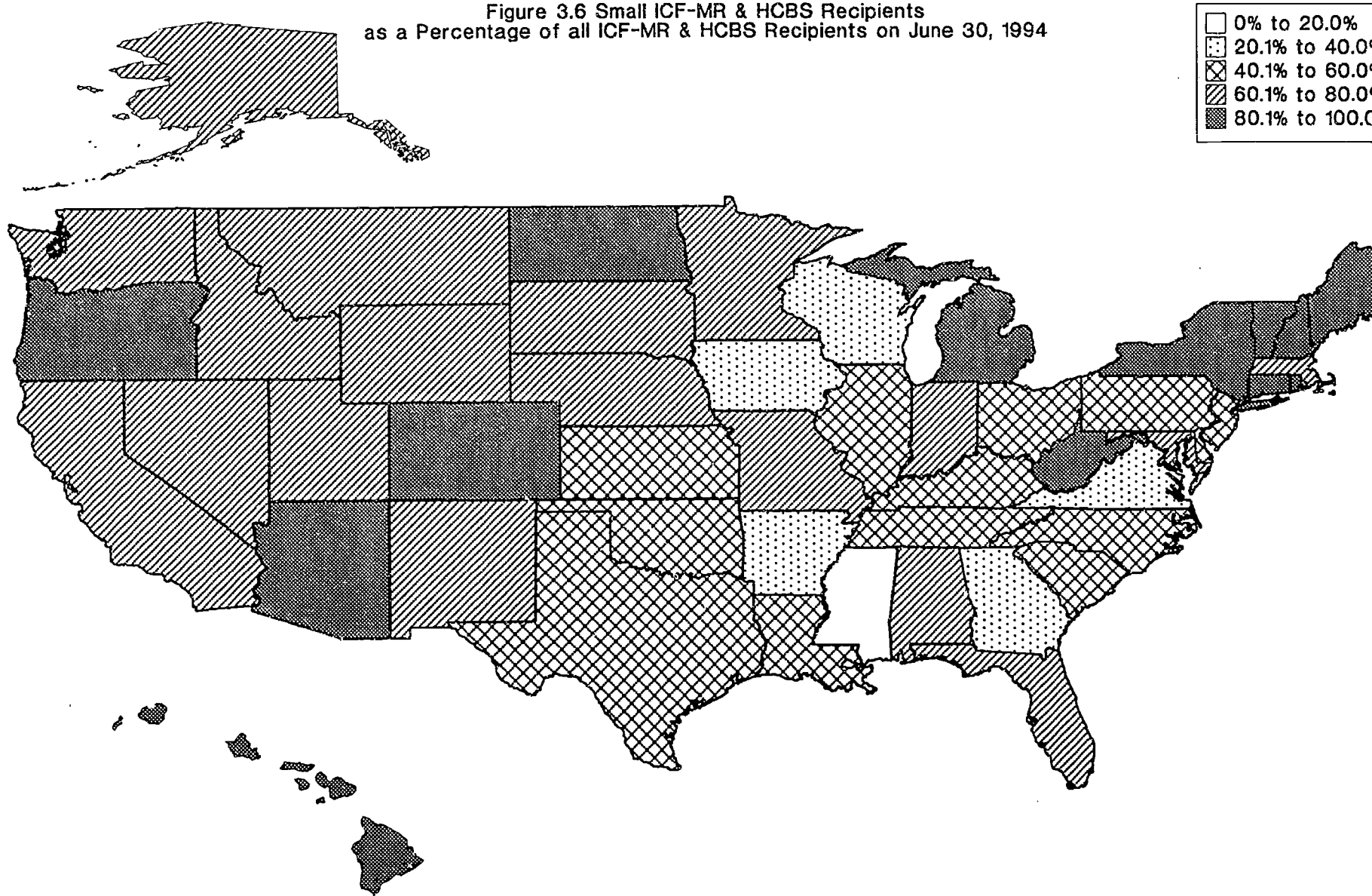
Table 3.9 shows that in Fiscal Year 1994, 4 states got back over two dollars in federal reimbursements for every dollar contributed. In contrast 6 states got back \$.50 or less in reimbursements for every dollar contributed. Of the 31 states showing a favorable "State Benefit Ratio" (state's % of total Federal ICF-MR reimbursements divided by state's % of total Federal income tax payments being greater than 1.00), 13 of the 14 poorest states (with federal Medicaid matching rates of 70% or greater) were included. Only 5 of the fourteen richest states with federal Medicaid matching rates of 50.0% had a favorable "state benefit ratio." Therefore, while differential ICF-MR and HCBS utilization and average costs may cause a poor state such as Alabama to subsidize combined ICF-MR and HCBS services in a number of states with lower rates of Federal cost-sharing (e.g., Connecticut, the District of Columbia, Massachusetts, New Hampshire, New York), 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 combined ICF-MR and HCBS reimbursements than they contribute to them.

Table 3.9 Summary of Combined ICF-MR and HCBS Contributions and State Benefit Ratios by State for Fiscal Year 1994

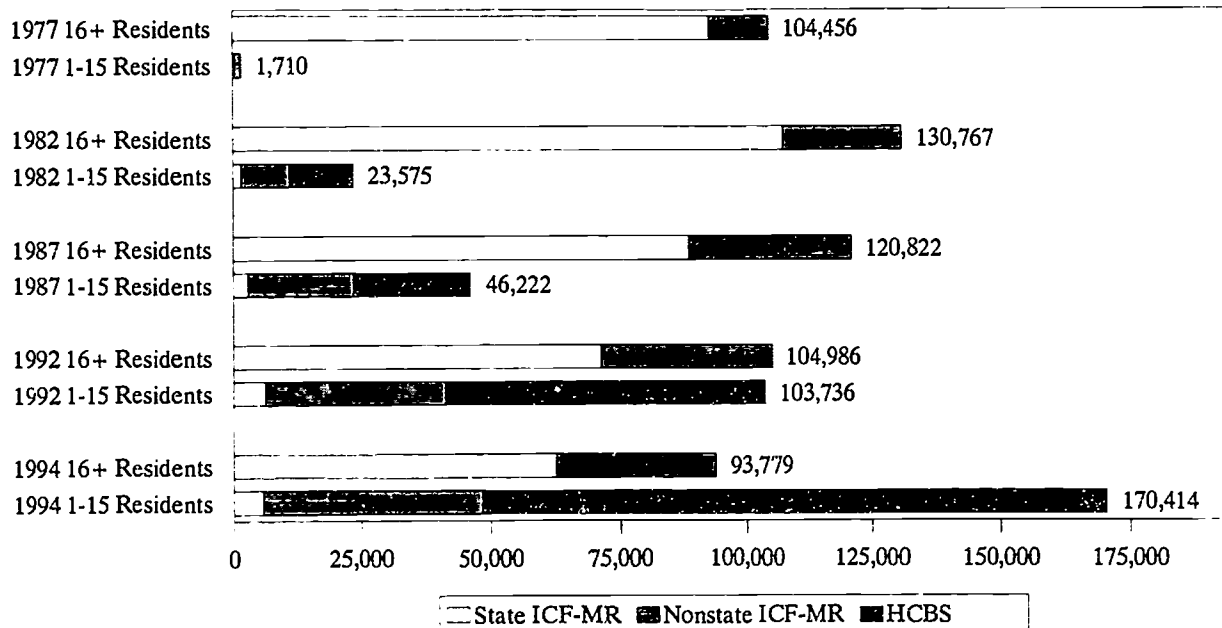
State	Federal ICF-MR Expenditures	Federal HCBS Expenditures	State % of Federal ICF-MR + HCBS	Federal Income Tax in Millions**	State % of Total Income Tax	State Medicaid Benefit Ratio
AL	\$56,448,365	\$21,722,100	1.13%	\$5,682	1.21	0.93
AK	\$5,794,637	\$333,297	0.09%	\$1,427	0.30	0.29
AZ	\$11,161,379	\$72,066,790	1.20%	\$5,680	1.21	0.99
AR	\$70,131,571	\$10,466,917	1.16%	\$2,791	0.60	1.95
CA	\$182,985,228	\$66,919,575	3.61%	\$62,650	13.16	0.27
CO	\$21,107,981	\$42,138,037	0.91%	\$6,657	1.42	0.64
CT	\$89,852,065	\$67,567,006	2.27%	\$10,037	2.14	1.06
DE	\$13,634,942	\$4,537,177	0.26%	\$1,451	0.31	0.85
DC	\$32,015,097	\$0	0.46%	\$1,500	0.32	1.44
FL	\$116,279,710	\$37,119,154	2.21%	\$25,504	5.45	0.41
GA	\$74,772,987	\$10,807,310	1.23%	\$10,933	2.33	0.53
HI	\$5,270,276	\$6,000,000	0.16%	\$2,416	0.52	0.32
ID	\$28,626,422	\$1,443,242	0.43%	\$1,402	0.30	1.45
IL	\$244,537,306	\$28,776,908	3.94%	\$25,118	5.36	0.74
IN	\$196,268,770	\$2,549,869	2.87%	\$9,384	2.00	1.43
IA	\$102,063,499	\$2,549,240	1.51%	\$4,294	0.92	1.65
KS	\$62,755,387	\$19,065,362	1.18%	\$4,321	0.92	1.28
KY	\$50,720,927	\$17,844,699	0.99%	\$4,933	1.05	0.94
LA	\$220,380,836	\$18,372,500	3.44%	\$5,743	1.23	2.81
ME	\$33,958,109	\$14,708,080	0.70%	\$1,766	0.38	1.86
MD	\$29,794,434	\$59,618,254	1.29%	\$11,044	2.36	0.55
MA	\$147,514,507	\$102,150,000	3.60%	\$13,698	2.92	1.23
MI	\$88,632,527	\$50,902,110	2.01%	\$16,974	3.62	0.56
MN	\$134,333,526	\$69,794,183	2.94%	\$8,255	1.76	1.67
MS	\$66,991,439	\$0	0.97%	\$2,645	0.56	1.71
MO	\$87,405,783	\$48,843,997	1.97%	\$8,473	1.81	1.09
MT	\$10,104,566	\$11,058,485	0.31%	\$1,073	0.23	1.33
NE	\$21,218,311	\$20,001,808	0.59%	\$2,536	0.54	1.10
NV	\$10,230,470	\$1,036,591	0.16%	\$3,016	0.64	0.25
NH	\$2,989,882	\$32,002,701	0.50%	\$2,345	0.50	1.01
NJ	\$178,660,706	\$65,031,747	3.52%	\$20,650	4.41	0.80
NM	\$28,415,274	\$7,549,517	0.52%	\$1,994	0.43	1.22
NY	\$1,005,509,117	\$201,685,433	17.42%	\$40,339	8.61	2.02
NC	\$215,963,686	\$12,927,812	3.30%	\$10,191	2.18	1.52
ND	\$27,560,570	\$16,551,904	0.64%	\$911	0.19	3.27
OH	\$275,579,892	\$30,256,545	4.41%	\$18,692	3.99	1.11
OK	\$64,264,377	\$40,719,627	1.51%	\$4,382	0.94	1.62
OR	\$49,003,661	\$48,577,606	1.41%	\$4,801	1.03	1.37
PA	\$273,647,641	\$135,165,757	5.90%	\$22,062	4.71	1.25
RI	\$22,714,034	\$31,635,158	0.78%	\$1,821	0.39	2.02
SC	\$122,479,554	\$12,794,400	1.95%	\$4,703	1.00	1.94
SD	\$22,111,755	\$15,656,015	0.54%	\$1,016	0.22	2.51
TN	\$91,028,298	\$10,764,849	1.47%	\$7,784	1.66	0.88
TX	\$354,766,979	\$30,411,245	5.56%	\$30,739	6.56	0.85
UT	\$28,323,398	\$23,133,474	0.74%	\$2,340	0.50	1.49
VT	\$3,290,344	\$19,734,625	0.33%	\$903	0.19	1.72
VA	\$76,771,753	\$13,064,859	1.30%	\$12,516	2.67	0.48
WA	\$90,357,181	\$41,885,927	1.19%	\$10,898	2.33	0.82
WV	\$10,819,011	\$15,086,002	0.37%	\$2,166	0.46	0.81
WI	\$113,874,446	\$36,620,066	2.17%	\$8,355	1.78	1.22
WY	\$4,481,920	\$15,742,547	0.29%	\$835	0.18	1.64
U.S. Total	\$5,277,604,535	\$1,665,390,502	100.0%	\$470,846	100.00	1.00

e indicates estimate  
 \* indicates 1993 data  
 \*\* indicates 1992 data

Figure 3.6 Small ICF-MR & HCBS Recipients  
as a Percentage of all ICF-MR & HCBS Recipients on June 30, 1994



**Figure 3.7**  
**Residents of Settings with 15 or Fewer and 16 or More Residents Among Medicaid ICF-MR**  
**and HCBS Recipients on June 30, 1977, 1982, 1987, 1992, and 1994**



*Indexed Utilization Rates*

Table 3.10 presents the number of ICF-MR residents and HCBS recipients in each state per 100,000 of that state's population, along with national totals. On June 30, 1994 there were 55.1 ICF-MR residents per 100,000 of the national population. That included 18.7 persons per 100,000 in small ICFs-MR (7.6 in places with 6 or fewer residents and 11.1 in places with 7-15 residents) and 36.4 persons per 100,000 in large ICFs-MR. There was rather remarkable variation in utilization among the states. Louisiana had the highest utilization rate nationally, with 140.4 ICF-MR residents per 100,000 population, followed by District of Columbia with 124.9 residents per 100,000 population. Seven states had more than 150% of the national rate. In contrast, 12 states were less than 50% of the national rate. Figure 3.8 shows this variation on a state-by-state basis.

States with the highest utilization rates for large ICFs-MR included Louisiana (81.7), Wisconsin (73.1 per 100,000), and Mississippi (72.7 per 100,000). Seventeen states reported large ICF-

MR utilization rates below 20 per 100,000. But by far the greatest interstate variability was evident among the small ICFs-MR. Utilization rates for ICFs-MR with 15 or fewer residents were more than 50 per 100,000 in the District of Columbia (124.9), Indiana (68.2) Louisiana (58.7), Minnesota (59.2), New York (63.7), and North Dakota (63.8). Eight states had no small ICFs-MR and utilization rates were less than 3.0 in ten additional states. There were 33 states with ICFs-MR of 6 or fewer residents, and the states with the highest utilization rates for this size facility were the District of Columbia (67.1) and Louisiana (44.9).

Total ICF-MR and HCBS utilization for persons with mental retardation and related developmental disabilities also shows high interstate variability. Nationally on June 30, 1994 there were 102.4 ICF-MR and HCBS recipients per 100,000 of the nation's population. Three states had rates more than double the national utilization rate: Minnesota, North Dakota, and South Dakota, while Alaska, Georgia, Indiana, Nevada, and Virginia had total Medicaid utilization rates that were less than half the national rate.

Utilization rates for Medicaid community services (both HCBS and small ICF-MR) also showed great variation around the national average utilization rate of 66.1 per 100,000. Four states provided Medicaid community services to fewer than 15 persons with MR/DD per 100,000 of the states' total population. Six states had Medicaid community service utilization rates that were more than twice the national average: Arizona (176.4), Minnesota (156.3), New York (167.4), North Dakota (301.4), Rhode Island (164.3), and South Dakota (161.5). Figure 3.9 shows this variation on a state-by-state basis.

In noting the extreme variability among states in the utilization of Medicaid 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, 1994 states had an average total utilization rate for all residential services (both ICF-MR and non-ICF-MR) of 122.1 per 100,000. States varied from 43.8 residential service recipient per 100,000 in Nevada to 297.6 in New Hampshire and 292.0 in North Dakota. While states vary markedly in their total utilization of residential placements for persons with MR/DD, state policy decisions create even greater variability in their relative utilization of Medicaid ICF-MR and HCBS programs to finance those services.

Table 3.10 Utilization Rates per 100,000 of State Population: ICF-MR Residents, HCBS Recipients with MR/DD, and All Residential Service Recipients on June 30, 1994 by State

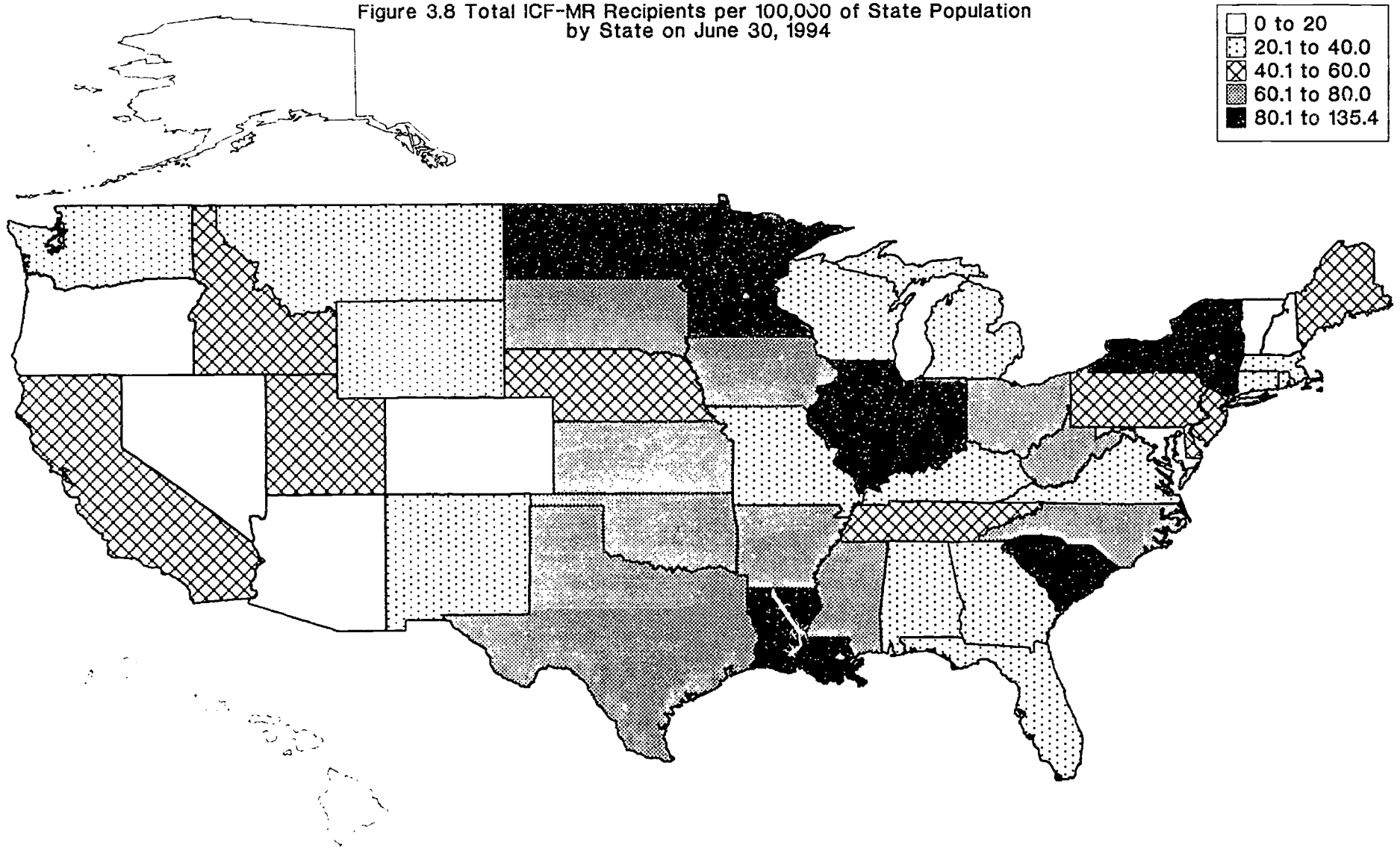
State	State Population (in 100,000's)	ICF-MR Residents/100,000 of State Population					Total Recipients			All Residents (ICF-MR & non-ICF-MR)				
		1-6	7-15	1-15	16+	Total	HCBS & Small		HCBS & ICF-MR	1-6	7-15	1-15	16+	All
							HCBS	ICFs-MR						
AL	41.87	0.0	0.8**	0.8**	26.6	27.3	69.3e	70.0e	96.6e	8.6**	16.2**	24.8**	27.3	52.1
AK	5.99	3.3	3.3	6.7	6.3	13.0	5.3	12.0	18.4	78.1	11.7	89.8	6.3	96.2
AZ	39.36	0.0	4.3	4.3	4.3	8.6	172.1	176.4	180.7	120.2	8.4	128.6	4.3	132.9
AR	24.24	0.0	12.4	12.4	59.5	71.9	17.7	30.1	89.6	17.7	12.4	30.1	59.5	89.6
CA	312.11	11.7	2.5	14.1	26.8	41.0	42.5	56.6	83.5	89.1	10.7	99.8	37.0	136.8
CO	35.66	0.0	0.0	0.0	11.8	11.8	75.3	75.3	87.0	78.9	18.0	96.9	11.8	108.7
CT	32.77	11.7	8.5	20.2	18.7	38.9	72.0	92.2	111.0	112.6	16.5	129.1	41.0	170.0
DE	7.00	5.1	0.0	5.1	45.7	50.9	44.3	49.4	95.1	55.0	0.0	55.0	45.7	100.7
DC	5.78	67.1	57.8	124.9	0.0	124.9	0.0	124.9	124.9	124.7	62.8	187.5	0.0	187.5
FL	136.79	1.2	0.0	1.2	23.7	24.9	47.0	48.2	71.9	24.1	13.4	37.5	29.1	66.6
GA	69.17	0.0	0.0	0.0	27.4	27.4	8.0	8.0	35.5	22.2	0.0	22.2	30.4	52.6
HI	11.72	4.7	0.6	5.3	6.8	12.1	43.8	49.1	55.9	86.6	0.6	87.2	8.2	95.4
ID	10.99	4.2	25.5	29.7	18.3	48.0	30.3	60.0	78.3	75.0	46.0	120.9	30.6	151.5
IL	116.97	1.6	22.9	24.5	69.3	93.9	39.2	63.8	133.1	6.3	41.3	47.7	87.2	134.8
IN	57.13	17.0	51.0	68.2	40.8	108.9	9.3	77.4	118.2	60.9	100.0	160.9	40.8	201.67
IA	28.14	0.0	7.1	7.1	57.5	64.6	31.2	38.3	95.8	71.3*	67.0*	138.2*	69.3	207.5
KS	25.31	2.8	8.6	11.5	58.4	69.8	52.9	64.4	122.7	23.1	37.2	60.3	58.4	118.6
KY	37.89	0.0	0.0	0.0	29.9	29.9	23.4e	23.4e	53.3e	35.7	5.0	40.7	30.7	71.4
LA	42.95	44.9	13.8	58.7	81.7	140.4	35.9	94.6	176.3	71.2e	15.9e	87.1e	98.0	185.2*
ME	12.39	10.2	13.7	23.9	19.9	43.7	59.9	83.8	103.6	79.0	24.8	103.8	21.5	125.3
MD	49.65	0.0	0.0	0.0	16.6	16.6	56.1	56.1	72.7	69.9	0.0	69.9	20.4	90.3
MA	60.12	0.0	0.0	0.0	35.2	35.2	85.3	85.3	120.6	88.7	14.5	103.2	35.2	138.5
MI	94.78	31.2	0.0	31.2	4.3	35.5	35.5	66.7	71.0	92.0	0.0	92.0	4.3	96.3
MN	45.17	20.2	39.0	59.2	47.9e	107.1	97.1	156.3	204.2	136.9e*	42.3	179.2e*	47.9*	227.1e*
MS	26.43	0.0	5.9	5.9	72.7	78.6	0.0	5.9	78.6	15.5	11.5	26.9	80.4	107.3
MO	52.34	0.3	2.4	2.7	29.9	32.7	58.4	61.1	91.1	45.5	28.0	73.5	45.3	118.8
MT	8.39	0.0	1.0	1.0	19.4	20.4	65.1	66.0	85.5	92.7	63.3	156.0	19.4	175.4
NE	16.07	0.0	0.5	0.5	42.7	43.2	78.2	78.7	121.4	49.8	12.9	62.7	42.7	105.4
NV	13.89	4.3	0.0	4.3	10.4	14.8	12.4	16.7	27.1	33.0	0.0	33.0	10.8	43.8
NH	11.25	1.1	3.4	4.4	2.0	6.5	115.8	120.3	122.3	271.4e	21.5e	292.9e	4.7e	297.6e
NJ	78.79	0.0	0.0	0.0	50.5	50.5	60.0	60.0	110.5	56.4	0.0	56.4	69.7	126.0
NM	16.16	0.9*	12.7*	13.6*	22.6	36.2	24.9	38.5	61.1	30.5*	16.8*	47.3*	22.6	69.9*
NY	181.97	4.2	59.5	63.7	24.7	88.4	103.7	167.4	192.1	42.7*	97.3*	140.0*	30.0*	170.0*
NC	69.45	20.4	6.8	27.2	40.9	68.1	19.0	46.2	87.1	46.7	10.2	57.0	42.3	99.3
ND	6.35	25.4	38.4	63.8	23.0	86.8	237.6e	301.4	324.4	172.1	84.3	256.4	35.6	292.0
OH	110.91	1.4	16.1	17.5	53.0	70.5	21.6	39.2	92.1	41.0	24.5	65.5	54.6	120.0
OK	32.31	0.4	0.0	0.4	69.8	70.2	52.4	52.8	122.6	41.3	7.7	49.0	69.8	118.8
OR	30.32	0.0	0.0	0.0	13.8	13.8	70.4	70.4	84.2	86.4	18.3	104.7	20.7	125.4
PA	120.48	5.4	6.3	11.6	46.0	57.7	35.7	47.4	93.4	66.7	6.9	73.7	50.8	124.5
RI	10.00	23.4	7.6	31.0	4.3	35.3	133.3	164.3	168.6	93.2	31.5	124.7	4.3	129.0
SC	36.43	1.1	29.5	30.6	54.8	85.4	26.5	57.1	111.9	34.2	39.6	73.8	54.8	128.6
SD	7.15	0.0	21.1	21.1	49.1	70.2	140.4	161.5	210.6	102.0	96.4	198.3	49.1	247.4
TN	50.99	0.9	7.3	8.3	37.8	46.1	18.9	27.2	65.0	14.2	31.3	45.5	37.8	83.3
TX	180.31	22.3	5.4	27.7	48.5	76.2	8.7	36.4	84.9	22.3	5.4	27.7	48.5	76.2
UT	18.60	0.0	0.6	0.6	49.0	49.7	85.5	86.1	135.2	50.5	16.8	67.3	49.0	116.3
VT	5.76	7.3	0.0	7.3	0.0	7.3	125.3	132.6	132.6	133.7	0.0	133.7	0.0	133.7
VA	64.91	0.2	2.4	2.6	35.4	38.0	11.0	13.6	49.0	3.4	5.9	9.4	40.0	49.4
WA	52.55	1.4	0.8	2.2	22.6	24.8	58.4	60.5	83.2	81.2	14.7	95.9	31.1	127.0
WI	50.38	0.0	1.3	1.3	73.1	74.4	46.0	47.2	120.4	130.3	19.8	150.1	73.1	223.3
WV	18.20	3.5*	19.8*	23.3*	11.9*	35.2*	44.1	67.4	79.3	29.2*	23.3*	52.5*	14.2*	66.7*
WY	4.70	0.0	0.0	0.0	33.2	33.2	120.2	120.2	153.4	115.5	13.6	129.1	33.2	162.3
U.S. Total	2,579.04	7.6	11.1	18.7	36.4	55.1	47.3	66.1	102.4	57.0	23.4	80.3	41.7	122.1

e indicates estimate

\*\* indicates 1992 data

\* indicates 1993 data

Figure 3.8 Total ICF-MR Recipients per 100,000 of State Population by State on June 30, 1994



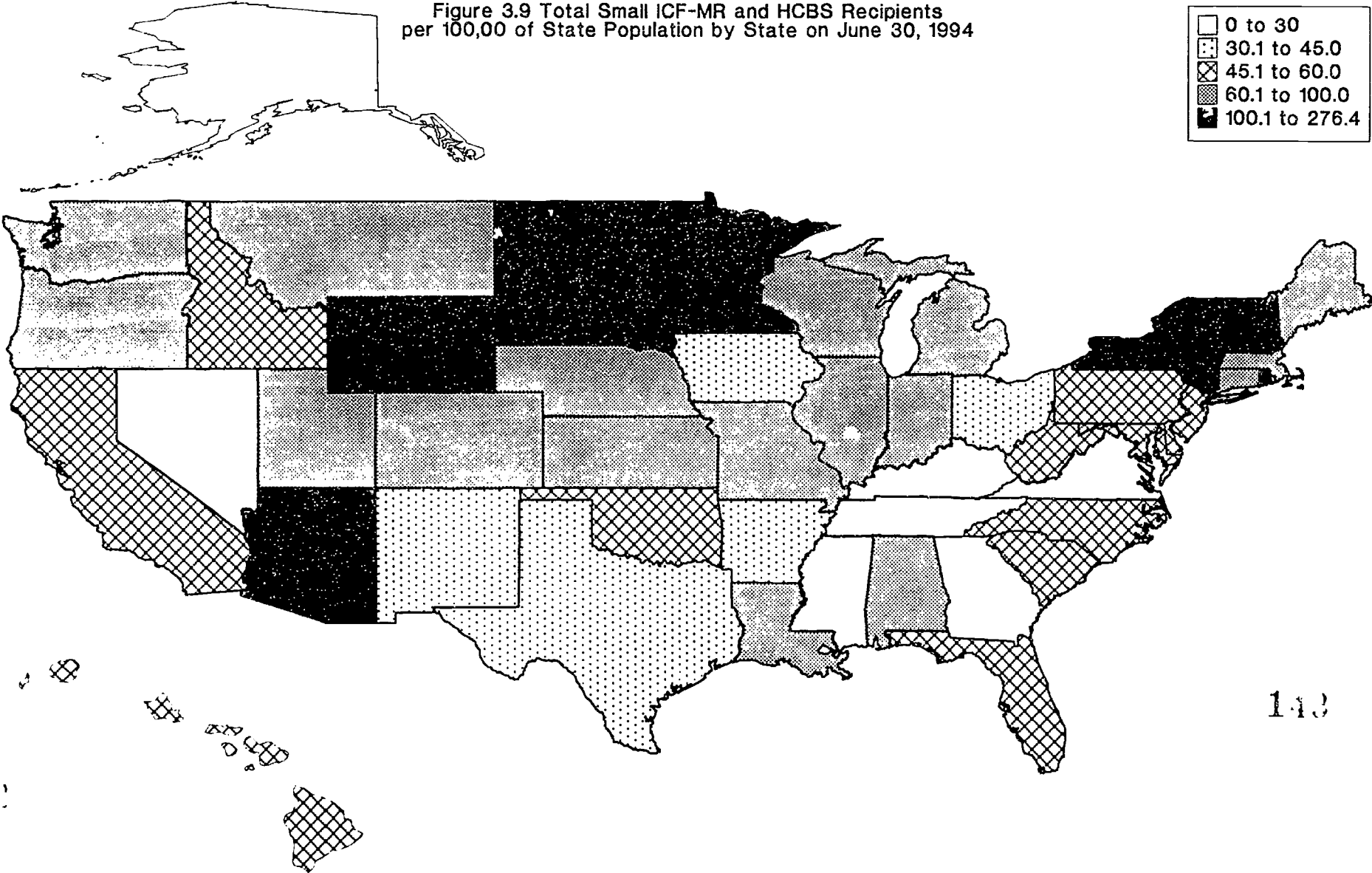
140

National Average = 55.1

141



Figure 3.9 Total Small ICF-MR and HCBS Recipients per 100,00 of State Population by State on June 30, 1994



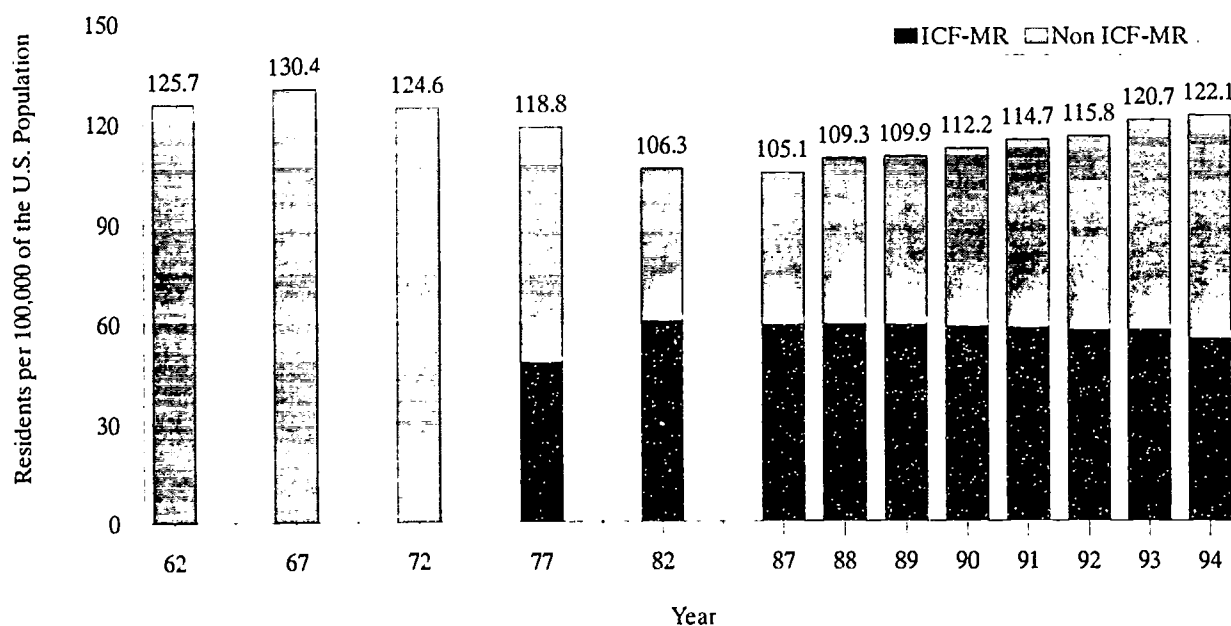
National Average = 66.1

Figure 3.10 shows patterns of overall U.S. residential services and ICF-MR services utilization from 1962 to 1994. It shows the generally stable, but slightly decreasing ICF-MR utilization rates since 1982. It also shows the steadily increasing overall residential services utilization rate since 1987, when residential services utilization reached 105.1 service recipients per 100,00 of the general U.S. population. It is notable that while the residential utilization rate was increasing by 15.5 residents per 100,000 in the U.S. population in the seven years between 1987 and 1994, the ICF-MR utilization rate decreased by 5.7 residents per 100,000 in the general population. The aging of the "baby boom" generation into adulthood has been the primary driving force of increasing overall

placement rates and is contributing to the growing number of people waiting for services.

As shown below, the HCBS program played a major role in funding the residential services of persons not living in ICFs-MR, with an estimated 76.2% of HCBS recipients receiving residential services outside of a home shared with relatives (see Table 3.11). Applying that statistic to all 122,075 HCBS recipients on June 30, 1994 would yield an estimated 93,007 persons receiving residential services outside their family home financed by Medicaid Home and Community Based Services. This means the overall utilization of HCBS to fund community residential services (other than room and board) is now more than double that of the ICF-MR program.

**Figure 3.10**  
**ICF-MR and Non ICF-MR Residential Service Recipients per 100,000**  
**of the U.S. Population, 1962 to 1994**



### *Residential Arrangement of HCBS Recipients*

As part of the 1994 data collection, states were asked to report the most recent available statistics on where their Medicaid Home and Community Based Service recipients lived. The same five categories of residential arrangements were provided as described in Chapter 6. In all, 40 states were able to provide these breakdowns for their HCBS service recipients. These reports are summarized in Table 3.11 by state and residential arrangement. As indicated in the U.S. total, the majority of HCBS recipients (51.5%) received services in a residence owned, rented, or managed by an agency, in which agency staff provide care, instruction, supervision, and support to residents with MR/DD. The estimated national total number of HCBS recipients living in such arrangements was 62,888. The second most

frequently utilized residential arrangement of HCBS recipients was living in a home that was also the home of other family member(s). An estimated 29,068 HCBS recipients (23.8% of the total) lived with other family members. The third most frequent residential arrangement was a "family foster home" (i.e., a home owned or rented by a family or individual in which they live and provide care to an unrelated person(s) with MR/DD. It is estimated that nationally 16,560 HCBS recipients (13.6% of the total) lived in such arrangements. Finally, an estimated total of 13,502 HCBS lived in their own homes (i.e., a home owned by or rented to them to which persons come to provide personal assistance, supervision, and/or other support). A small number of people (about 57) were served in other residential arrangements.

Table 3.11 The Residential Arrangements of Medicaid Home and Community Based Services Recipients in 1994

State	Number of Persons by Type of Residential Arrangement					Total
	Residential Facility	Family Foster Home	Person's Own Home	Family Home	Other	
Alabama	DNF	DNF	DNF	DNF	DNF	DNF
Alaska	15	14	3	0	0	32
Arizona	3,849	832	103	1,989	0	6,773
Arkansas	38	38	353	0	0	429
California <sup>f</sup>	5,385 <sup>f</sup>	2,433 <sup>f</sup>	328 <sup>f</sup>	2,939 <sup>f</sup>	0 <sup>f</sup>	11,085 <sup>f</sup>
Colorado <sup>f</sup>	1,727 <sup>f</sup>	424 <sup>f</sup>	167 <sup>f</sup>	0 <sup>f</sup>	0 <sup>f</sup>	2,318 <sup>f</sup>
Connecticut	1,677	157	0	125	0	1,959
Delaware	167	143	0	0	0	310
D.C.	0	0	0	0	0	0
Florida	3,082	81	158	2,677	0	5,998
Georgia <sup>f</sup>	182 <sup>f</sup>	6 <sup>f</sup>	5 <sup>f</sup>	20 <sup>f</sup>	0 <sup>f</sup>	213 <sup>f</sup>
Hawaii	92	285	0	70	0	447
Idaho	0	298	0	0	0	298
Illinois	DNF	DNF	DNF	DNF	DNF	DNF
Indiana	DNF	DNF	DNF	DNF	DNF	DNF
Iowa	200 <sup>e</sup>	0	350 <sup>e</sup>	320	0	870
Kansas	DNF	DNF	DNF	DNF	DNF	DNF
Kentucky	139	318	0	104	0	561
Louisiana	490 <sup>e</sup>	125	307	621	0	1,543
Maine	DNF	DNF	DNF	DNF	DNF	DNF
Maryland	2,615	134	38	0	0	2,787
Massachusetts	DNF	DNF	DNF	DNF	DNF	DNF
Michigan	DNF	DNF	DNF	DNF	DNF	DNF
Minnesota	1,363 <sup>g</sup>	405 <sup>g</sup>	192 <sup>g</sup>	506 <sup>g</sup>	0 <sup>g</sup>	2,466 <sup>g</sup>
Mississippi	0	0	0	0	0	0
Missouri	1,841	0	1,200	0	0	3,941
Montana	315	20	62	123	0	520
Nebraska	DNF	DNF	DNF	DNF	DNF	DNF
Nevada	82	50 <sup>e</sup>	40 <sup>e</sup>	0	0	172
New Hampshire	602	492	0	209	0	1,303
New Jersey	2,176	927	0	1,626	0	4,729
New Mexico <sup>f</sup>	80 <sup>e,f</sup>	20 <sup>e,f</sup>	50 <sup>e,f</sup>	420 <sup>e,f</sup>	0 <sup>f</sup>	570 <sup>f</sup>
New York <sup>f</sup>	524 <sup>f</sup>	263 <sup>f</sup>	0 <sup>f</sup>	2,611 <sup>f</sup>	0 <sup>f</sup>	3,398 <sup>f</sup>
North Carolina	DNF	DNF	DNF	DNF	DNF	DNF
North Dakota	327	20 <sup>e</sup>	687	157	0	1,191
Ohio	651	121	637	631	0	2,040
Oklahoma	223	186	622	662	0	1,693
Oregon	2,063	0	73	0	0	2,136
Pennsylvania	3,245	692	95	271	0	4,303
Rhode Island	498	66	60	108	0	732
South Carolina	359	84	367	0	0	810
South Dakota	696	21	129	42	24	912
Tennessee	595	45	2 <sup>e</sup>	233	0	875
Texas	DNF	DNF	DNF	DNF	DNF	DNF
Utah	934	16	144	205	0	1,299
Vermont	119	440	11	72	0	642
Virginia	DNF	DNF	DNF	DNF	DNF	DNF
Washington	644	130	1,633	537	11	2,955
West Virginia <sup>f</sup>	143 <sup>f</sup>	81 <sup>f</sup>	12 <sup>f</sup>	401 <sup>f</sup>	0 <sup>f</sup>	637 <sup>f</sup>
Wisconsin	1,082	558	436	139	0	2,215
Wyoming	340	229	15	5	0	589
<b>Reported Total</b>	<b>38,560</b>	<b>10,154</b>	<b>8,279</b>	<b>17,823</b>	<b>35</b>	<b>74,851</b>
<b>% of Recipients by category</b>	<b>51.5%</b>	<b>13.6%</b>	<b>11.1%</b>	<b>23.8%</b>	<b>0.0%</b>	<b>100.0%</b>
<b>Estimated U.S. Recipients (June 1994)</b>	<b>62,888</b>	<b>16,560</b>	<b>13,502</b>	<b>29,068</b>	<b>57</b>	<b>122,075</b>

NOTES:

- a Residential Facility: A place of residence owned, rented or managed by an agency, in which staff provide care, instruction, supervision and support to residents with MR/DD
- b Family Foster Home: A home owned or rented by families or individuals in which they live and provide care to unrelated persons with MR/DD
- c Persons Own Home: A home owned or rented by person(s) with MR/DD into which persons come to provide personal assistance, instruction, monitoring and/or other support
- d Family Home: The home of persons with MR/DD which is also the primary residence of parents or other relatives
- e Reports are based on those HCBS recipients whose residential situation was known. A state's report may exclude persons receiving HCBS, but whose situation was unknown. Statistics do not necessarily reflect the June 30 effective date used throughout this report. Unless otherwise noted statistics are from Fiscal Year 1994.
- f Indicates Fiscal Year 1993 report
- g Indicates Fiscal Year 1992 report
- DNF Indicates that "Data Not Furnished"

*Persons with Mental Retardation and Related  
Developmental Disabilities in  
Generic Medicaid Nursing Homes*

Table 3.12 presents the number of people with mental retardation and related developmental disabilities reported by states to be in Medicaid nursing facilities, other than ones specifically licensed for persons with mental retardation and related developmental disabilities. The ability of states to report an actual or estimated count of Medicaid nursing facility residents was established primarily in response to the requirement under the Omnibus Budget Reconciliation Act of 1987 (OBRA-87) that states screen nursing home residents with mental retardation and related developmental disabilities for the appropriateness of their placement. States were required to submit an "Alternative Disposition Plan" to the U.S. Department of Health and Human Services regarding the findings of those screenings.

On June 30, 1994, 36,197 persons with MR/DD were in nursing homes. This statistic compares with a report of 37,817 on June 30, 1991, 38,564 for June 30, 1992, and 38,177 on June 30, 1993. Nationwide, the total reported number of persons with mental retardation and related developmental disabilities in nursing homes was 12.2% of the total number receiving ICF-MR, Medicaid HCBS and Medicaid (generic) nursing home services, and the reported number of nursing home residents with mental retardation and related developmental disabilities equaled 10.3% of the nation's total population of persons in all types of MR/DD residential settings and in nursing homes. In 1994, seven states (Alabama, Arkansas, Georgia, Mississippi, Nebraska, Oklahoma, and Virginia) reported persons with mental retardation and related developmental disabilities in nursing homes as more than one-fourth of the total of their MR/DD program residents and nursing home residents.

Table 3.12 Persons with Mental Retardation and Related Developmental Disabilities in Nursing Facilities on June 30, 1994 by State

State	Persons with MR/DD in Non-Specialized Nursing Homes	Total MR/DD Recipients of ICF-MR and HCBS	Persons with MR/DD in Nursing Homes, ICFs-MR, or Receiving HCBS	Persons with MR/DD in Nursing Homes, as % of Persons with MR/DD in Nursing Homes, ICFs-MR, or Receiving HCBS	Total Residents in MR/DD Residential Settings	Total Residents in MR/DD Residential Settings and Nursing Homes	Persons with MR/DD in Nursing Homes, as % of All Residents in MR/DD Residences and Nursing Homes
AL	1,300e**	4,045e	5,345	24.3%	2,182	3,482	37.3%
AK	35	110	145	24.1%	576	611	5.7%
AZ	83	7,112	7,195	1.2%	5,229	5,312	1.6%
AR	1,290	2,172	3,462	37.3%	2,172	3,462	37.3%
CA	0	26,047	26,047	0.0%	42,701	42,701	0.0%
CO	339e	3,104	3,443	9.8%	3,876	4,215	8.0%
CT	419	3,637	4,056	10.3%	5,571	5,990	7.0%
DE	0	666	666	0.0%	705	705	0.0%
DC	0	722	722	0.0%	1,084	1,084	0.0%
FL	212*	9,837	10,049	2.1%	9,107	9,319	2.3%
GA	2,200e	2,453	4,653	47.3%	3,639	5,839	37.7%
HI	95	655	750	12.7%	1,118	1,213	7.8%
ID	113	860	973	11.6%	1,665	1,778	6.4%
IL	1,750	15,569	17,319	10.1%	15,768	17,518	10.0%
IN	2,047	6,753	8,800	23.3%	11,521	13,568	15.1%
IA	1,562*	2,697	4,259	36.7%	5,839	7,401	21.1%
KS	0*	3,106	3,106	0.0%	3,002	3,002	0.0%
KY	0	2,020e	2,020	0.0%	2,705	2,705	0.0%
LA	1,243	7,572	8,815	14.1%	7,953*	9,196	13.5%
ME	354	1,284	1,638	21.6%	1,553	1,907	18.6%
MD	738	3,609	4,347	17.0%	4,483	5,221	14.1%
MA	937	7,249	8,186	11.4%	8,324	9,261	10.1%
MI	1,550e**	6,733	8,283	18.7%	9,130	10,680	14.5%
MN	750e	9,223	9,973	7.5%	10,256e*	11,006	6.8%
MS	975	2,077	3,052	31.9%	2,836	3,811	25.6%
MO	1,267	4,766	6,033	21.0%	6,218	7,485	16.9%
MT	158	717	875	18.1%	1,472	1,630	9.7%
NE	649**	1,951	2,600	25.0%	1,694	2,343	27.7%
NV	7	377	384	1.8%	608	615	1.1%
NH	108**	1,376	1,484	7.3%	3,348e	3,456	3.1%
NJ	371	8,704	9,075	4.1%	9,930	10,301	3.6%
NM	121*	987	1,108	10.9%	1,130*	1,251	9.7%
NY	1,454*	34,960	36,414	4.0%	30,938*	32,392	4.5%
NC	300	6,050	6,350	4.7%	6,893	7,193	4.2%
ND	167	2,060	2,227	7.5%	1,854	2,021	8.3%
OH	2,382	10,220	12,602	18.9%	13,312	15,694	15.2%
OK	1,285	3,961	5,246	24.5%	3,838	5,123	25.1%
OR	0	2,553	2,553	0.0%	3,803	3,803	0.0%
PA	1,544e*	11,253	12,797	12.1%	14,998	16,542	9.3%
RI	0	1,686	1,686	0.0%	1,290	1,290	0.0%
SC	199	4,077	4,276	4.7%	4,686	4,885	4.1%
SD	144	1,506	1,650	8.7%	1,769	1,913	7.5%
TN	1,603e	3,314	4,317	23.2%	4,248	5,251	19.1%
TX	3,258***	15,306	18,564	17.6%	13,742	17,000	19.2%
UT	241	2,514	2,755	8.7%	2,163	2,404	10.0%
VT	81	764	845	9.6%	770	851	9.5%
VA	1,933***	3,101	5,114	37.8%	3,207	5,140	37.6%
WA	516	4,370	4,886	10.6%	6,675	7,191	7.2%
WV	211*	1,443	1,654	12.8%	1,214*	1,425	14.8%
WI	798	6,064	6,862	11.6%	11,248	12,046	6.6%
WY	8	721	729	1.1%	763	771	1.0%
U.S.							
Total	36,197	264,193	300,390	12.1%	314,806	351,003	10.3%

e indicates estimate  
 \* indicates 1993 data  
 \*\* indicates 1992 data  
 \*\*\* indicates 1991 data

CHAPTER 10  
STATUS AND CHANGES IN ICFs-MR AND RESIDENTS

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This section provides descriptive and program statistics on Intermediate Care Facilities [for Persons with] Mental Retardation (ICFs-MR) from the most recent ICF-MR surveys available on the Online Survey Certification and Reporting (OSCAR) System in January 1994. As described in the methodology section, the effective date of the statistics is considered June 1992. Small and large ICFs-MR are compared on a range of topics, including facility and resident characteristics, the use of various behavioral, medical, and legal interventions, and staffing characteristics. State-by-state breakdowns are provided on the number of residents and direct service staff members in public, private non-profit, and private for-profit ICFs-MR; and ICFs-MR in 1992 are compared with those in 1982. The methodologies associated with these data are briefly described in the methods section of this report and more comprehensively in Larson and Lakin (1995).<sup>2</sup>

*Residents and Facilities in 1992*

Table 3.13 provides summary statistics on ICFs-MR and residents. In 1992, 143,625 people lived in 6,389 ICFs-MR nationwide. Of those, 15,507 people lived in 2,913 ICFs-MR with six or fewer residents, 24,491 people lived in 2,522 ICFs-MR with 7 to 15 residents, and 103,627 people lived in 954 ICFs-MR with 16 or more residents. While the vast majority of ICF-MR residents lived in large facilities (16 or more residents) these facilities made up only a small portion of the total number of ICFs-MR. Size made a difference in people's lives; over 85% of the residents of small ICFs-MR participated in day program activities away from their residential setting. In contrast only 26.9% of

the residents of large ICFs-MR participated in day activities away from the institution.

*Basic Demographics*

Overall, 1.5% of ICF-MR residents were reported to have no mental retardation, 25.2% to have mild or moderate mental retardation, and 73.4% to have severe or profound mental retardation. Level of mental retardation varied considerably depending on facility size. Large facilities were much more likely to serve persons with severe or profound mental retardation.

Overall, 11.0% of ICF-MR residents were 21 years old or younger, 83.6% were between 22 and 64, and 5.5% were 65 or older. The ages of residents varied by the size of the ICF-MR in which they lived. The proportion of children and youth was highest in ICFs-MR with six or fewer residents. The proportion of persons ages 65 and older was highest in large ICFs-MR. ICFs-MR with six or fewer residents had a much smaller proportion of residents ages 65 and older (2.8%) than large ICFs-MR (5.9%).

*Functional Limitations and Secondary Conditions*

The prevalence of selected functional limitations and secondary conditions among ICF-MR residents varied with the size of the facility. Overall, 61.0% of the residents had speech or language impairments, with rates highest among residents of large ICFs-MR (64.5%). In addition, 47.8% were unable to move from place to place or required devices such as walkers, crutches, or wheelchairs to do so. There was relatively little variability by facility size in the proportion of residents with mobility limitations. Of all ICF-MR residents, 38.4% had epilepsy, including 41.1% of residents in large facilities, and 18.8% had cerebral palsy, including 20.3% of the residents of large ICFs-MR. Only 4.8% of ICF-MR residents were reported to have autism, with the highest prevalence (6.7%) among residents of ICFs-MR with 6 or fewer residents.

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<sup>2</sup>Larson, S.A. & Lakin, K.C. (1995). *Status and changes in Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) program: Results from Analysis of the Online Survey Certification and Reporting System*. Minneapolis: University of Minnesota, Center on Residential Services and Community Living/Institute on Community Integration.

**Table 3.13 Characteristics of Small and Large ICFs-MR and the People Who Lived in Them in 1992**

Characteristic	6-	7-15	16+	Total
Number of residents	15,507	24,491	103,627	143,625
Number of facilities	2,913	2,522	954	6,389
Residents per facility	5.3	9.7	108.6	22.5
% Attending off-campus day programs	87.2	85.2	26.9	2.1
% without mental retardation	1.7	2.4	1.2	1.5
% with mild or moderate mental retardation	37.3	37.9	20.4	25.1
% with severe or profound mental retardation	61.0	59.7	78.4	73.4
% 0-21 years	13.5	8.7	11.1	11.0
% 22-64 years	83.7	85.8	83.0	83.6
% 65 years and older	2.8	5.5	5.9	5.5
% Male	56.7	56.2	58.2	57.7
% Speech/Language Impaired	57.5	48.3	64.5	61.0
% who need mobility assistance	42.7	45.5	49.1	47.8
% with Epilepsy	32.1	29.5	41.4	38.4
% with Cerebral Palsy	15.5	14.5	20.3	18.8
% with Autism	6.7	4.9	4.5	4.8
% Blind	6.4	5.7	8.8	8.0
% Deaf	2.5	2.5	3.1	2.9
% with legal guardian	41.9	31.6	45.6	42.8
% with court ordered admission	4.3	2.5	14.5	11.4
% with medical care plan	15.3	15.7	29.2	25.4
% with drugs to control behavior	26.7	29.8	28.5	28.5
% with physical restraint	4.1	7.8	10.0	9.0
% with time out room intervention	1.2	1.7	1.8	1.7
Medication error rate	0.57	1.00	2.10	1.00
% of FTE employees who are direct service staff	90.8	86.3	64.1	67.7
% of FTE employees who are LPN/LVN	3.1	5.2	6.1	5.4
% of FTE employees who are RNs	2.9	4.0	3.7	3.5
Number of FTE direct service staff per resident	1.33	1.06	0.93	1.00
Number of FTE employees per resident	1.47	1.22	1.45	1.45

Note: Shaded boxes indicate the size ICF-MR that has the highest proportion of people with each characteristic.



Overall, 8.0% of ICF-MR residents were blind ("corrected acuity of 20/200 or less" in better eye or visual field of 20 degrees or less) and 2.9% were deaf, again with the highest rates reported in large facilities.

#### *Legal, Medical and Behavioral Practices*

**Court-Appointed Guardians.** The proportion of ICF-MR residents with court-appointed guardians was estimated by dividing the number of residents 18 years old or older who had court-appointed guardians by the total number of residents. Unfortunately, it was not possible to exclude persons under 18 from this calculation because the ages of all children and young adults were reported in the single aggregated age category of 0-21 years. Therefore, to the extent that children under 18 were living in ICFs-MR (they were about 9% of all ICF-MR residents in 1987), the actual percentage of adults with court-appointed guardians is slightly underestimated. Almost one-half (42.8%) of ICF-MR residents 18 years old or older had a court-appointed legal guardian. Court-appointed guardians were most common for residents of large ICFs-MR (45.6%) and were least common for residents of facilities with 7 to 15 residents (31.6%).

**Court-Ordered Admissions.** Only 11.4% of all persons living in ICFs-MR were admitted under court order. There were substantial differences in the use of court-ordered admissions for ICFs-MR of different sizes. In large ICFs-MR, 14.5% of all residents were admitted under court order compared with 4.3% of residents in ICFs-MR with 6 or fewer residents and 2.5% of residents in ICFs-MR of 7-15 residents.

**Medical care plans.** Medical care plans refer to plans "intended only for those so ill or so at medical risk that 24-hour licensed nursing care is essential... Individuals with chronic, but stable health problems such as controlled epilepsy, diabetes, etc., do not require a medical care plan." In all, 25.4% of ICF-MR residents had a medical care plan. The proportion of persons with medical care plans in the facilities with 6 or fewer residents (15.3%) and facilities with 7 to 15 residents (15.7%) ICFs-MR were only about half the proportion in large ICFs-MR (29.2%).

**Drugs to Control Behaviors.** Drugs to control behavior (i.e., "medications prescribed and administered for the purpose of modifying the "maladaptive behavior") are commonly used in ICFs-MR. Overall, 28.5% of ICF-MR residents (40,933 people) received drugs to control their behavior. The proportion of persons receiving drugs to control behavior was highest in facilities with 7-15 residents (29.8%), but the differences among the facility sizes was small.

**Physical Restraints.** Physical restraint programs (i.e., "any manual method or physical or mechanical device that the individual cannot remove easily, and which restricts the free movement of, normal functioning of, or normal access to a portion or portions of an individual's body") were much less frequently used than medication to control behavior. Only 9% of ICF-MR residents were involved with physical restraint procedures. Large ICFs-MR used physical restraints for 10.0% of all residents, the ICFs-MR with 7 to 15 residents for 7.8% of all residents, and the ICFs-MR with 6 or fewer residents for 4.1% of all residents.

**Time Out Rooms.** The use of time out rooms (i.e., "the use of a room to implement a clinical procedure by which an individual is removed from positive reinforcement contingent upon the exhibition of a maladaptive behavior until appropriate or adaptive behavior is exhibited,") was uncommon in ICFs-MR. The rates were higher among large facilities (1.8%) and those with 7-15 residents (1.7%) ICFs-MR than in ICFs-MR with 6 or fewer residents (1.2%).

**Medication error rate.** The medication error rate is the number of medication errors divided by the number of medication passing opportunities observed by ICF-MR surveyors. Overall, medication errors were made in 1% of observations. Medication error rates varied by size of ICFs-MR, with large ICFs-MR reporting rates of 2.10%, ICFs-MR with 7-15 residents reporting rates of 1.00%, and ICFs-MR with 6 or fewer residents reporting rates of 0.57%.

#### *Staffing Characteristics*

Staffing data were available on 6,311 ICFs-MR employing a total of 141,083 FTE direct service

staff members, 7,362 FTE RNs, and 11,275 FTE LPN/LVNs. There were 208,514 FTE employees in these ICFs-MR. The vast majority of employees (67.7%) were direct service staff members, 3.5% were RNs and 5.4% were LPN/LVNs. Overall, 23.4% of the FTE employees in ICFs-MR worked in other job classifications. The FTE direct service staff to resident ratio in ICFs-MR was 1.00 and the FTE total employee to resident ratio was 1.47.

It is interesting to observe that the percent of employees who were in direct service roles declined dramatically as the number of residents increased. In the ICFs-MR with 6 or fewer residents, 90.8% of all staff were direct service employees while in large ICFs-MR only 64.1% of all staff were direct service employees. The ratio of direct service staff members to residents was highest in ICFs-MR with six or fewer residents (1.33) and lowest in ICFs-MR with 16 or more residents (0.93). The number of direct service staff members per resident also declined as size increased. Overall staff to resident ratios were different from the ratios for direct service staff members. Both the ICFs-MR with 6 or fewer residents and the large ICFs-MR had higher overall staff to resident ratios (1.47 and 1.45 respectively) than ICFs-MR with 7-15 residents (1.22). The percent of FTE RNs was similar across ICF-MR size categories (range from 2.9% to 4.0%). The proportion of LPN/LVNs was highest in the large ICFs-MR (6.1%) and lowest in the ICFs-MR with 6 or fewer residents (3.1%).

#### *State ICF-MR Programs in 1992*

This section examines the 1992 status of each state's ICF-MR program with regard to: number of residents, levels of mental retardation, and staff to resident ratios. Statistics are presented by size and type (i.e., public, private non-profit and private for-profit) of ICF-MR.

#### *Resident Level of Mental Retardation*

Table 3.14 presents the distribution of residents in small and large ICFs-MR by level of mental retardation. In 1992, 11.1% of ICF-MR residents had mild mental retardation, 14.0% had moderate mental retardation, 22.7% had severe mental retardation and 50.7% had profound mental

retardation. There were substantial variations in these percentages by facility size and by state. Large ICFs-MR had substantially greater percentages of residents with profound mental retardation than ICFs-MR with 15 or fewer residents (50.7% vs. 33.3%). ICFs-MR with 15 or fewer residents were more likely than large ICFs-MR to serve individuals with mild, moderate or no mental retardation (39.6% vs. 20.4%).

Among states, the proportion of ICF-MR residents with mild or moderate mental retardation ranged from 3.4% in Alaska to 51.6% in Indiana. In seven states, more than 30% of ICF-MR residents had mild or moderate mental retardation (Illinois, Indiana, Louisiana, Minnesota, Oklahoma, Texas and Wisconsin). In four states, more than 75% of ICF-MR residents had profound mental retardation (Florida, Maryland, Montana, and Wyoming) as compared with fewer than 40% in five states (Alaska, Idaho, Indiana, Minnesota, and Oklahoma). There were no consistent patterns among states in the relative use of large or small ICFs-MR for persons with mild or moderate mental retardation, but in most states the proportion of residents with profound mental retardation was higher in large ICFs-MR.

#### *Number of Residents by Size and Type*

Seven types of ownership or control used in the OSCAR database were condensed into four categories for this report: public, private profit, private non-profit, and other. Facilities listed on the facility cover sheet as private non-profit were coded as private non-profit. Facilities listed as private proprietary were coded as private profit. Facilities listed as ownership or control by state, city, town or county were coded as public. Facilities listed as "other" were contacted to find out which of the three categories they fit into. Of these, 303 were successfully contacted and recoded. The remaining 31 homes were listed as other/type unknown and were excluded from analyses based on facility type.

Table 3.15 shows the number of ICF-MR residents in each size and type of ICF-MR in 1992. In 1992, 77,923 people lived in public ICFs-MR. An additional 40,381 ICF-MR residents lived in private non-profit ICFs-MR and 25,321 lived in private profit ICFs-MR. The number of ICF-MR

Table 3.14 Percent of ICF-MR Residents in Small and Large Facilities with Each Level of Mental Retardation in 1992

State	1-15					16+					Total					Total # residents
	Not MR	Mild	Moderate	Severe	Profound	Not MR	Mild	Moderate	Severe	Profound	Not MR	Mild	Moderate	Severe	Profound	
AL	0.0	3.1	15.6	65.6	15.6	0.0	6.4	11.1	24.4	58.1	0.0	6.3	11.2	25.5	57.0	1,261
AK	0.0	0.0	0.0	95.1	4.9	0.0	0.0	6.5	32.6	60.9	0.0	0.0	3.4	62.1	34.5	87
AZ	1.1	1.1	5.4	14.0	78.5	16.4	2.7	11.8	45.5	23.6	9.4	2.0	8.9	31.0	48.8	203
AR	0.7	18.3	25.6	39.1	16.3	0.2	6.3	7.7	21.3	64.4	0.3	8.3	10.7	24.3	56.4	1,728
CA	2.3	13.5	19.9	24.0	40.3	3.9	9.5	9.8	17.4	59.4	4.1	10.4	12.3	18.9	54.3	9,580
CO						0.3	7.0	10.4	25.6	56.7	0.3	7.0	10.4	25.6	56.7	700
CT	8.2	13.4	19.2	26.0	33.2	1.3	3.3	6.5	17.7	71.1	4.9	8.7	13.2	22.1	51.1	1,326
DE	5.8	5.8	10.1	36.2	42.0	3.4	12.4	5.3	17.7	61.1	3.8	11.4	6.0	20.6	58.2	447
DC	0.3	6.4	14.6	21.2	57.5						0.3	6.4	14.6	21.2	57.5	685
FL	3.9	2.0	21.6	39.2	33.3	0.2	4.4	6.6	12.0	76.9	0.3	4.4	6.8	12.4	76.2	3,193
GA						0.5	4.5	11.2	23.6	60.2	0.5	4.5	11.2	23.6	60.2	1,945
HI	6.0	0.0	8.0	34.0	52.0	0.0	7.1	12.9	20.0	60.0	2.2	4.4	11.1	25.2	57.0	135
ID	2.8	11.3	22.9	46.2	16.8	0.0	4.1	9.1	21.5	65.3	1.6	8.4	17.4	36.3	36.3	546
IL	1.3	23.8	37.5	28.9	8.5	0.5	9.4	17.6	24.1	48.3	0.6	10.9	19.7	24.6	44.2	11,640
IN	1.0	41.2	27.3	20.1	10.4	3.5	16.0	11.5	17.6	51.4	2.2	30.8	20.8	19.0	27.1	5,967
IA	1.1	5.4	13.8	34.9	44.9	3.3	9.0	13.6	23.2	51.0	2.9	8.3	13.7	25.2	49.9	2,101
KS	2.2	15.0	18.5	33.4	30.9	0.4	9.9	12.1	24.3	53.3	0.7	10.7	13.1	25.8	49.7	1,945
KY						1.6	10.0	12.8	28.3	47.4	1.6	10.0	12.8	28.3	47.4	1,134
LA	3.7	28.7	25.5	24.2	17.9	0.3	11.8	10.4	20.6	57.0	1.8	18.4	16.3	22.0	41.5	5,960
ME	1.3	7.0	18.1	24.1	49.5	3.5	5.4	4.3	20.2	66.6	2.5	6.1	10.6	22.0	58.7	686
MD						0.0	4.2	6.8	12.2	76.8	0.0	4.2	6.8	12.2	76.8	954
MA	4.0	5.5	14.0	39.5	37.0	3.4	12.2	14.0	23.7	46.6	3.5	11.1	14.0	26.3	45.0	3,222
MI	2.0	5.0	8.3	19.3	65.3	0.0	11.1	11.9	14.3	62.6	1.7	6.1	8.9	18.5	64.8	2,899
MN	0.6	19.1	24.6	30.7	25.1	0.2	16.8	12.4	24.4	46.1	0.4	18.0	18.8	27.7	35.1	5,193
MS						1.8	7.0	11.0	21.6	58.6	1.8	7.0	11.0	21.6	58.6	1,869
MO	11.8	26.8	27.6	28.3	5.5	3.4	11.7	12.6	23.8	48.5	4.0	12.9	13.9	24.2	45.0	1,558
MT	0.0	37.5	62.5	0.0	0.0	0.0	7.4	9.9	3.1	79.6	0.0	8.8	12.4	2.9	75.9	170
NE	0.0	0.0	25.0	37.5	37.5	1.2	8.8	11.2	18.7	60.1	1.1	8.7	11.4	18.9	59.9	703
NV	0.0	13.0	7.4	35.2	44.4	0.0	13.9	13.9	21.4	50.9	0.0	13.7	12.3	24.7	49.3	227
NH	0.0	8.6	6.9	13.8	70.7	0.0	24.0	0.0	4.0	72.0	0.0	13.3	4.8	10.8	71.1	83
NJ						1.6	5.3	8.6	17.9	66.5	1.6	5.3	8.6	17.9	66.5	3,708
NM	7.5	9.3	28.0	46.6	8.7	0.0	7.4	12.5	20.3	59.8	1.6	7.8	15.7	25.8	49.2	771
NY	1.9	9.6	13.9	27.0	47.6	1.7	10.7	10.0	18.8	58.8	1.8	10.1	12.2	23.4	52.5	16,994
NC	0.1	8.9	18.6	33.9	38.5	0.0	2.9	7.2	16.5	73.4	0.2	4.9	11.0	22.3	61.6	4,600
ND	2.5	6.9	13.5	41.4	35.7	0.0	6.8	7.3	9.9	75.9	1.8	6.8	11.6	31.8	47.9	628
OH	0.5	16.2	25.8	25.9	31.5	0.7	9.3	15.2	19.6	55.3	0.8	10.8	17.5	21.0	49.9	7,993
OK	0.0	66.7	13.3	0.0	20.0	1.3	16.2	19.0	27.3	36.2	1.3	16.5	19.0	27.1	36.1	2,632
OR						0.0	6.6	10.4	10.7	72.3	0.0	6.6	10.4	10.7	72.3	797
PA	0.5	16.2	22.3	30.6	30.3	0.5	5.7	8.8	21.3	63.8	0.5	7.7	11.3	23.0	57.6	7,190
RI	2.6	7.6	18.1	36.4	35.3	2.2	6.0	3.3	8.2	80.2	7.8	6.7	11.8	24.0	49.7	525
SC	1.3	16.0	19.8	41.9	21.1	0.7	7.7	8.2	15.5	68.0	0.9	10.0	11.5	23.0	54.7	3,336
SD	1.9	15.7	13.2	28.3	40.9	0.0	8.8	2.6	7.5	81.1	0.5	10.8	5.7	13.6	69.4	546
TN	1.3	5.9	15.9	31.6	45.3	0.2	5.3	8.9	17.7	67.9	0.4	5.4	9.8	19.6	64.8	2,373
TX	0.4	31.8	30.8	22.4	14.6	0.2	6.6	12.2	27.3	53.6	0.6	13.8	17.5	25.8	42.3	13,249
UT	44.4	0.0	3.7	18.5	33.3	1.8	13.0	8.1	20.1	57.0	3.0	12.6	8.0	20.1	56.3	936
VT	0.0	0.0	14.6	35.4	50.0	0.0	2.7	8.0	26.7	62.7	0.0	1.6	10.6	30.1	57.7	123
VA	0.7	10.8	25.2	43.9	19.4	3.1	4.2	9.9	21.2	61.5	3.0	4.5	10.7	22.4	59.3	2,664
WA	0.0	14.3	15.1	37.3	33.3	3.6	5.2	9.3	20.6	61.3	3.3	5.9	9.8	21.9	59.1	1,624
WV	1.9	8.8	12.8	32.0	44.5	0.4	21.4	10.5	14.0	53.7	1.4	13.2	12.0	25.7	47.8	651
WI	3.2	37.6	34.4	20.4	4.3	0.8	13.9	15.2	23.5	46.6	0.9	14.5	15.6	23.4	45.7	4,053
WY						0.0	0.0	4.7	9.4	85.9	0.0	0.0	4.7	9.4	85.9	85
U.S. Total	1.7	17.4	20.5	27.1	33.3	1.2	8.8	11.6	21.0	57.4	1.5	11.1	14.0	22.7	50.7	143,625

Blank cells indicate that a state does not have any ICF's-MR of that size.

1101

Table 3.15 Total Number of ICF-MR Residents in Each Size and Type of ICF-MR in 1992

State	Private Profit				Private Non Profit				Public				Total			Total N
	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	
AL				-			32	32			1,229	1,229		32	1,229	1,261
AK				-	11	30		41			46	46	11	30	46	87
AZ				-			34	34		93	76	169		93	110	203
AR			163	163		289	25	314			1,251	1,251		289	1,439	1,728
CA	1,383	115	1,635	3,133	707	193	642	1,542			4,905	4,905	2,090	308	7,182	9,580
CO			119	119			76	76			505	505			700	700
CT				-	352	46		398	50	251	627	928	402	297	627	1,326
DE				-	6	63	45	114			333	333	6	63	378	447
DC	51	62		113	293	279		572					344	341		685
FL	10		444	454		41	973	1,014			1,725	1,725	10	41	3,142	3,193
GA			110	110				-			1,835	1,835			1,945	1,945
HI	6			6	41			41	3		85	88	50		85	135
ID	3	187	57	247	48	89		137			162	162	51	276	219	546
IL		432	1,624	2,056	6	757	4,466	5,229			4,355	4,355	6	1,189	10,445	11,640
IN	359	1,532	684	2,575	644	995	262	1,901			1,491	1,491	1,003	2,527	2,437	5,967
IA		152	225	377	64	154	585	803			921	921	64	306	1,731	2,101
KS		28	626	654	84	202	16	302			989	989	84	230	1,631	1,945
KY			291	291			139	139			704	704			1,134	1,134
LA	794	273	461	1,528	951	246	755	1,952	81	18	2,381	2,480	1,826	537	3,597	5,960
ME		15	58	73	107	157	75	339		36	238	274	107	208	371	686
MD				-				-			954	954			954	954
MA		8		8	18	312	78	408		189	2,617	2,806	18	509	2,695	3,222
MI	51	7		58	2,136	58		2,194	121	31	495	647	2,308	96	495	2,899
MN	403	957	805	2,165	419	818	641	1,878	65	62	1,023	1,150	887	1,837	2,469	5,193
MS			576	576				-			1,293	1,293			1,869	1,869
MO		55	18	73	23	49	66	138			1,347	1,347	23	104	1,431	1,558
MT				-		8		8			162	162		8	162	170
NE				-		8	256	264			439	439		8	695	703
NV	12			12	11	15		26	16		173	189	39	15	173	227
NH				-	18	40	25	83					18	40	25	83
NJ				-			72	72			3,636	3,636			3,708	3,708
NM		9	25	34	9	143	103	255			482	482	9	152	610	771
NY	16	19	16	51	540	5,712	1,550	7,802	176	3,084	5,881	9,141	732	8,815	7,447	16,994
NC	333	12		345	784	356	561	1,701	57		2,497	2,554	1,174	368	3,058	4,600
ND	18	60		78	117	242		359			191	191	135	302	191	628
OH	25	395	1,563	1,983	121	938	1,737	2,796	10	302	2,902	3,214	156	1,635	6,202	7,993
OK			1,227	1,227		15	538	553			852	852		15	2,617	2,632
OR				-			16	16			781	781			797	797
PA	38	23	112	173	587	682	2,145	3,414			3,603	3,603	625	705	5,860	7,190
RI			23	23	205	107		312	22	9	159	190	227	116	182	525
SC				-		41		41	6	898	2,391	3,295	6	939	2,391	3,336
SD				-		159		159			387	387		159	387	546
TN			39	39	32	288	156	476			1,858	1,858	32	288	2,053	2,373
TX	2,011	469	2,266	4,746	581	172	248	1,001	268	321	6,913	7,502	2,860	962	9,427	13,249
UT		27	461	488			62	62			386	386		27	909	936
VT				-	48			48			75	75	48		75	123
VA				-	4	63	135	202	6	66	2,390	2,462	10	129	2,525	2,664
WA	6	10	142	158	70	40	73	183			1,283	1,283	76	50	1,498	1,624
WV	30	191	52	273	40	161	54	255			123	123	70	352	229	651
WI		78	834	912			695	695		15	2,431	2,446		93	3,960	4,053
WY				-				-			85	85			85	85
U.S. Total	5,549	5,116	14,656	25,321	9,077	14,000	17,304	40,381	881	5,375	71,667	77,923	15,507	24,491	103,627	143,625

Blank cells indicate that a state does not have any ICFs-MR of that type and size combination  
 - in the total column indicates that a state does not have any ICFs-MR of that size or type

residents ranged from 16,994 in New York to 83 in New Hampshire. Two states (District of Columbia and New Hampshire) did not have any public ICFs-MR. Four states (Georgia, Maryland, Mississippi and Wyoming) had no private non-profit ICFs-MR; 16 had no private profit ICFs-MR. In 1992, only the District of Columbia had no large ICFs-MR and 8 states (Colorado, Georgia, Kentucky, Mississippi, Maryland, New Jersey, Oregon, and Wyoming) had no ICFs-MR with 15 or fewer residents.

In most states, public ICFs-MR housed more people than any other type of operation. Exceptions were the District of Columbia, Illinois, Maine, and North Dakota, where the greatest number of residents lived in private non-profit facilities; and Idaho, Indiana, Minnesota, Oklahoma and West Virginia where more residents lived in private profit facilities. In the vast majority of states, most persons living in ICFs-MR lived with 16 or more persons. Exceptions to this were the District of Columbia where all persons in ICFs-MR lived with 15 or fewer people; Idaho, Indiana, North Dakota, New Hampshire, New York, and West Virginia where more residents lived with 7-15 persons; and Michigan and Rhode Island where the largest proportion of persons lived in homes with 6 or fewer residents.

#### *Staffing Characteristics*

Table 3.16 shows that there were 141,082.56 full-time equivalent (FTE) direct service staff members in ICFs-MR in 1992, or 1.00 direct service FTEs per resident nationwide. There was a great deal of variation among states, with Vermont reporting 1.90 direct service FTEs per ICF-MR resident, as compared with California's 0.67. Six states had more than 1.5 FTE direct service staff members per resident, while seven states had fewer than .90. In 25 states, the highest ratios were found in public ICFs-MR. In 19 states, the highest staff to resident ratios were found in private non-profit facilities and in 13 states the highest ratios were found in private non-profit facilities. In 26 states, the staff ratios were the highest in the smallest facilities, while in 22 they were highest in large facilities.

#### *Changes in ICFs-MR Between 1982 and 1992*

A number of notable changes occurred in the ICF-MR program between 1982 and 1992 in the number of facilities, and in the number, ages, and level of mental retardation of residents by facility size and type. However, remarkably little change was evident in the total number of ICF-MR residents nationally (increasing from 140,000 in 1982 to 143,795 in 1992).

#### *Changes in Size and Type, 1982-1992*

Table 3.17 shows that between 1982 and 1992, the number of ICFs-MR increased from 1,853 to 6,420 or about 246%. Although substantial growth was evident in the number of ICFs-MR in all size and type categories, increases were much greater among facilities with 6 or fewer residents. Between 1982 and 1992, the number of ICFs-MR with six or fewer residents increased from 500 to 2,943; by 1992 they made up 46% of all ICFs-MR. Although the total number of large ICFs-MR increased from 651 to 954 between 1982 and 1992, they declined as a proportion of all ICFs-MR from 35% to only 15%. In 1992, as in 1982, the majority of ICFs-MR (54% in both years) were operated by private non-profit agencies. In 1992, 31 facilities listed as other/unknown could not be reached to establish their type of operation.

Between 1982 and 1992, the average number of residents per ICF-MR decreased from 75.9 to 22.5. In 1982, more than three-quarters of all ICF-MR residents lived in large public residential facilities compared with only half of all ICF-MR residents in 1992. While the majority of ICF-MR residents still lived in settings with 16 or more residents in 1992 (72%; as compared with 93% in 1982), the average size of large facilities dropped from 201.2 to 108.6 residents between 1982 and 1992. The number of residents per ICF-MR in large public facilities decreased from 366.4 in 1982 to 207.7 in 1992. Substantial decreases in average size occurred in private profit ICFs-MR, the average size of which decreased from 37.6 to 13.6 persons in the 10 year period. The number of residents per private non-profit facility also declined from 16.8 in 1982 to 11.7 in 1992.

Table 3.16 Number of FTE Direct Service Staff Per Resident in Each Size and Type of ICF-MR in 1992

State	Private Profit				Private Non Profit				Public				Total			Average ratio	Total #FTE dss
	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+	Total	1-6	7-15	16+		
AL				-		0.76		0.76			1.11	1.11	-	0.76	1.13	1.10	1,388.25
AK				-	1.64	1.29		1.38			1.67	1.67	1.64	1.29	1.67	1.54	133.55
AZ				-			1.38	1.38		1.66	1.32	1.51	-	1.66	1.34	1.49	301.50
AR			1.32	1.32		0.90	0.80	0.89			1.01	1.01	-	0.90	1.04	1.02	1,754.52
CA	1.17	0.85	0.62	0.87	1.11	0.94	0.71	0.93			0.46	0.46	1.15	0.91	0.52	0.67	6,316.20
CO			0.66	0.66			0.63	0.63			1.25	1.25	-	-	1.08	1.08	757.55
CT				-	1.65	0.71		1.54	1.42	1.21	1.47	1.40	1.62	1.13	1.47	1.44	1,909.88
DE				-	1.10	1.05	0.53	0.85			1.17	1.17	1.10	1.05	1.10	1.09	487.35
DC	2.03	1.54		1.76	2.01	1.66		1.84					2.01	1.63	-	1.83	1,228.97
FL	1.30		0.85	0.86		0.83	1.06	1.05			1.06	1.06	1.30	0.83	1.03	1.03	3,206.28
GA			1.28	1.28							0.94	0.94	-	-	0.96	0.96	1,860.60
HI	1.33			1.33	1.14			1.14	2.00			2.00	1.22	-	-	1.22	60.75
ID	2.00	1.62	1.16	1.52	1.41	1.53		1.49					1.45	1.59	1.16	1.51	578.28
IL		0.50	0.70	0.66	2.04	0.59	0.65	0.64			0.91	0.91	2.04	0.56	0.76	0.74	8,588.49
IN	0.95	0.87	1.03	0.92	0.97	0.82	0.53	0.83			1.18	1.18	0.96	0.85	1.07	0.96	5,674.00
IA		1.62	1.42	1.50	1.97	1.84	1.55	1.63			1.21	1.21	1.97	1.73	1.35	1.42	2,949.70
KS		1.29	1.01	1.03	1.78	1.11	1.56	1.33			1.31	1.31	1.78	1.14	1.21	1.22	2,297.28
KY			0.83	0.83			1.15	1.15			1.14	1.14	-	-	1.06	1.06	1,201.14
LA	1.05	0.78	0.91	0.96	1.08	0.74	0.92	0.97	1.29	0.93	0.85	0.87	1.08	0.77	0.87	0.93	5,514.98
ME		1.08	0.96	0.99	1.57	1.24	0.99	1.28			1.24	1.27	1.57	1.23	1.17	1.24	837.74
MD				-							1.02	1.02	-	-	1.02	1.02	976.00
MA		1.22		1.22	1.33	1.40	0.69	1.37			1.20	1.25	1.33	1.53	1.20	1.26	3,617.91
MI	1.67	1.36		1.63	1.78	1.08		1.76	1.59	1.41	1.17	1.26	1.77	1.21	1.17	1.65	4,776.75
MN	1.17	0.72	0.68	0.79	1.33	0.85	1.09	1.04	1.42	0.84	0.97	0.99	1.27	0.79	0.90	0.92	4,741.25
MS			0.54	0.54							0.78	0.78	-	-	0.71	0.71	1,324.96
MO		0.83	0.70	0.80	0.85	0.87	0.94	0.90			1.72	1.72	0.85	0.85	1.67	1.61	2,496.00
MT						0.75		0.75			1.30	1.30	-	0.75	1.30	1.27	216.34
NE						1.53	0.86	0.88			0.71	0.71	-	1.53	0.76	0.77	543.90
NV	1.13			1.13	1.05	2.15		1.68	1.66		1.10	1.15	1.32	2.15	1.10	1.21	274.25
NH					1.93	1.55	1.05	1.48					1.93	1.55	1.05	1.48	122.98
NJ							1.04	1.04			0.85	0.85	-	-	0.85	0.85	3,147.89
NM		1.06	1.24	1.19	0.72	0.98	1.08	1.01			1.16	1.16	0.72	0.98	1.15	1.11	839.90
NY	2.23	0.95	1.09	1.40	1.90	1.23	1.18	1.27	1.83	1.18	0.97	1.06	1.89	1.21	1.01	1.15	19,605.50
NC	1.61	1.81		1.62	1.57	1.34	1.31	1.44	1.44		1.05	1.06	1.57	1.36	1.10	1.24	5,706.00
ND	1.24	0.85		0.94	1.38	1.06		1.17			1.51	1.51	1.36	1.02	1.51	1.24	780.25
OH	1.40	0.89	0.75	0.78	1.18	0.96	1.02	1.01	1.60	1.21	0.81	0.85	1.24	0.99	0.85	0.89	7,091.79
OK			0.59	0.59		0.70		0.51			1.58	1.58	-	0.70	0.89	0.89	2,348.85
OR							0.58	0.58			1.49	1.49	-	-	1.47	1.47	1,170.33
PA	1.50	1.35	0.80	1.02	1.19	1.06	0.81	0.93			0.81	0.81	1.21	1.07	0.81	0.87	6,234.27
RI			0.43	0.43	1.61	0.94		1.39	2.18	0.89		1.57	1.65	0.94	0.43	1.32	342.25
SC						0.96		0.96	2.08	0.98	0.92	0.94	2.08	0.98	0.92	0.94	3,114.49
SD						0.71		0.71			0.97	0.97	-	0.71	0.97	0.90	478.00
TN			1.07	1.07	1.84	1.10	0.98	1.11			0.85	0.85	1.84	1.10	0.87	0.91	2,155.50
TX	1.01	0.48	0.52	0.73	0.99	0.56	0.56	0.82	1.07	0.59	1.08	1.06	1.01	0.53	0.94	0.93	12,058.30
UT		0.62	0.67	0.66			0.71	0.71			1.29	1.29	-	0.62	0.95	0.94	843.62
VT					1.90			1.90					1.90	-	-	1.90	91.14
VA					1.88	1.02	0.89	0.95	1.42	0.96	1.06	1.05	1.60	0.99	1.05	1.05	2,786.23
WA	1.71	1.00	0.86	0.90	1.47	1.75	0.72	1.23			1.23	1.23	1.49	1.60	1.17	1.20	1,951.16
WV	1.90	1.55	2.07	1.69	1.97	1.48	2.04	1.67			2.36	2.36	1.94	1.52	2.22	1.81	1,177.25
WI		0.64	0.56	0.57			0.58	0.58		0.57	0.81	0.81	-	0.63	0.71	0.71	2,871.49
WY											1.78	1.78	-	-	1.78	1.78	151.00
U.S. Total	1.13	0.86	0.72	0.84	1.45	1.10	0.88	1.08	1.43	1.14	0.99	1.00	1.33	1.06	0.93	1.00	141,082.56

Blank cells indicate that a state does not have any ICFs-MR of that type and size combination.

- in the total columns indicate that a state does not have any ICFs-MR of that size or type or that the ICFs-MR of that size and type did not report direct service staff information accurately

Table 3.17 Number of People in ICFs-MR of Various Sizes and Types, 1982 and 1992

Facility Type and Size		1982				1992			
		Number of Facilities	Number of Residents	Percent of All Residents	People Per Facility	Number of Facilities	Number of Residents	Percent of All Residents	People Per Facility
Public	1-6	39	208	0.1	5.3	166	881	0.6	5.3
	7-15	119	1,114	0.8	9.6	558	5,375	3.7	9.6
	16+	293	107,356	76.3	366.4	345	71,667	49.8	207.7
	Total	451	108,708	77.3	241.0	1,069	77,923	54.2	72.9
Private Non-Profit	1-6	382	1,902	1.4	5.0	1,685	9,077	6.3	5.4
	7-15	461	4,551	3.2	9.9	1,430	14,000	9.7	9.8
	16+	154	10,271	7.3	66.7	349	17,304	12.0	49.6
	Total	997	16,724	11.9	16.8	3,464	40,381	28.1	11.7
Private Profit	1-6	79	462	.3	5.8	1,062	5,549	3.9	5.2
	7-15	122	1,447	1.0	11.9	534	5,116	3.6	9.6
	16+	205	13,341	9.5	65.1	260	14,656	10.2	56.4
	Total	406	15,250	10.8	37.6	1,856	25,321	17.6	13.6
Type unknown	1-6					30	159	0.1	5.3
	7-15					1	11	0.0	11.0
	16+					0	0	0.0	0.0
	Total					31	170	0.1	5.5
Total	1-6	500	2,572	1.8	5.1	2,943	15,666	10.9	5.3
	7-15	702	7,142	5.1	10.2	2,523	24,502	17.0	9.7
	16+	651	130,968	93.1	201.2	954	103,627	72.1	108.6
	Total	1,853	140,682	100.0	75.9	6,420	143,795	100.0	22.5

*Changes in Resident Ages*

As Table 3.18 shows, there were substantial changes in the ages of ICF-MR residents between 1982 and 1992. The total number of ICF-MR residents ages 0-21 declined by 50% during the 10 year period. The overall decreasing population of persons 21 years old or younger (nationally from

22.7% in 1982 to 11.1% in 1992) was evident in most states. In 1982, in only three states were fewer than 10% of ICF-MR residents under age 22, in 1992 this was true in 24 states. Only three states (Alabama, Indiana, and North Dakota) reported increases in the number of children and youth in ICFs-MR between 1982 and 1992. Two states certified their first ICFs-MR during this

period (Arizona and Wyoming). In the other states, the number of ICF-MR residents ages 0-21 declined by 8.3% to 99.0% between 1982 and 1992. In twelve states the number of ICF-MR residents ages 0-21 decreased by more than 75%.

Significant changes and variations were also evident among states in the proportion of aging residents between 1982 and 1992. Overall, the number of aging ICF-MR residents (ages 63+ in 1982; ages 65+ in 1992) increased 22.5% between 1982 and 1992. State changes ranged from a 100% decrease in the number of aging ICF-MR residents in Nevada (from 1 person in 1982 to none in 1992), to a 5400% increase in the number of aging ICF-MR residents in Oklahoma (from 2 people in 1982 to 110 people in 1992). Nine states experienced an increase of at least 100% during the 10 year period. The number of states with more than 5% of ICF-MR residents 65 years or older increased from 14 in 1982 to 21 in 1992. In both years, the majority of states served a higher proportion of aging residents in large ICFs-MR (88.2% in 1982; 77.5% in 1992). In a few states the number of ICF-MR residents over 65 declined but the proportion of ICF-MR residents in that age group increased (e.g., Colorado).

#### *Changes in Level of Mental Retardation*

Table 3.19 shows that between 1982 and 1992, the proportion of ICF-MR residents with severe or profound mental retardation decreased from 75.0% to 73.4%. While there was little overall change in the number of ICF-MR residents with severe or profound mental retardation, there was a dramatic shift in the number of residents with severe or profound mental retardation in large versus small settings. Overall, large ICFs-MR in 1992 served 19,999 fewer residents with severe or profound mental retardation while small ICFs-MR served 20,121 more people with severe or profound mental retardation. A total of 40 states showed an increase in the number of residents in small ICFs-MR with severe or profound mental retardation between 1982 and 1992, while 39 states showed a decrease in the number of residents in large ICFs-MR with severe or profound mental retardation. The two states that started providing ICF-MR

services during this period both serve a high proportion of residents with severe or profound mental retardation (95.3% in Wyoming, 79.8% in Arizona).

#### *Discussion*

The ICF-MR program changed in many ways between 1982 and 1992. Remarkably, although large public ICFs-MR lost over 30,000 total residents between 1982 and 1992, the total number of ICF-MR residents increased slightly (from 140,682 in 1982 to 143,795 in 1992) as states undertook large scale to certify large private facilities and to develop smaller community group homes. But attempting to project future trends in ICF-MR services based on this 1982 to 1992 period would likely fail. The recent increased flexibility by the Health Care Financing Administration in allowing more rapid growth of Medicaid Home and Community Based Services, compounded by the growing disenchantment with the high standardization and related administrative rigidities and expenses, and the minimal size requirements (at least four people) would suggest that ICF-MR utilization will decrease significantly in the future. Indeed, Part 1 of this chapter provides evidence of the first substantial decrease in ICF-MR recipients and expenditures since the ICF-MR program was established in 1971. Scenarios regarding the elimination of Medicaid could in effect eliminate ICFs-MR altogether. Continued depopulation of larger institutional settings should continue to reduce the number of ICF-MR residents. But questions remain about the continued use of small ICFs-MR. Many of the above cited criticisms of the ICF-MR model have been evident for many years, and yet the small ICF-MR groups home has remained remarkably resilient in terms of utilization by states. A major factor in this resiliency and growing utilization has been their demonstrated capacity to house persons with severe and profound mental retardation in the community. As the Medicaid HCBS program increasingly is used for this purpose it seems likely that small ICFs-MR will no longer grow in number. But when this will finally happen is difficult to determine.



Table 3.18 Changes in ICF-MR Populations By Age and Facility Size, 1982-1992: Percent of Residents in Each Age Group

State	1982						1992						82 to 92 %Change #0-21	82 to 92 %Change #65+
	1-15		16+		Total		1-15		16+		Total			
	%0-21	%63+	%0-21	%63+	%0-21	%65+	%0-21	%65+	%0-21	%65+	%0-21	%65+		
AL	-	-	11.1	5.8	11.1	5.8	3.1	0.0	16.8	5.5	16.4	5.3	28.6	-20.2
AK	100.0	0.0	36.4	0.0	52.5	0.0	51.2	0.0	0.0	0.0	24.1	0.0	-66.1	-
AZ	-	-	-	-	-	-	4.3	0.0	27.3	0.9	16.7	0.5	-	-
AR	-	-	42.0	0.1	42.0	0.1	7.6	0.3	28.4	0.1	24.9	0.2	-27.5	50.0
CA	-	-	24.1	2.7	24.1	2.7	18.6	1.5	15.1	2.8	16.0	2.5	-38.1	-15.1
CO	16.4	2.4	25.9	2.5	24.7	2.4	-	-	5.1	2.9	5.1	2.9	-90.8	-48.7
CT	10.8	1.8	16.7	3.3	16.2	3.2	4.0	3.1	7.5	0.8	5.7	2.0	-86.2	-74.5
DE	-	-	16.4	8.8	16.4	8.8	18.8	1.4	5.6	9.3	7.6	8.1	-61.4	-23.4
DC	0.0	0.0	46.7	0.0	43.8	0.0	1.9	5.5	-	-	1.9	5.5	-53.6	-
FL	64.1	0.0	17.8	1.9	18.9	1.9	3.9	0.0	12.9	1.2	12.7	1.2	-21.8	-26.9
GA	-	-	21.8	2.9	21.8	2.9	-	-	10.8	2.5	10.8	2.5	-55.9	-22.2
HI	87.5	0.0	79.9	2.6	80.1	2.6	4.0	4.0	1.2	2.4	2.2	3.0	-99.0	-60.0
ID	58.2	0.0	29.0	2.3	32.3	2.1	30.3	1.2	20.1	2.7	26.2	1.8	-8.3	0.0
IL	13.8	0.0	18.9	4.0	18.8	3.9	4.5	6.6	9.9	6.0	9.3	6.1	-22.6	141.6
IN	9.9	1.2	20.4	2.4	19.3	2.2	11.9	4.4	7.9	4.8	10.3	4.5	3.2	292.8
IA	-	-	23.4	1.5	23.4	1.5	18.6	1.4	16.3	3.1	16.8	2.8	-14.4	118.5
KS	20.4	0.0	33.7	2.0	33.3	1.9	6.7	0.6	16.8	3.6	15.2	3.1	-55.6	57.9
KY	-	-	31.8	0.1	31.8	0.1	-	-	11.6	0.3	11.6	0.3	-65.8	200.0
LA	34.7	1.6	35.7	3.1	35.7	3.0	15.2	1.0	21.0	2.9	18.7	2.1	-33.7	-9.9
ME	6.0	0.7	25.1	3.5	21.0	2.9	7.9	4.1	8.1	8.1	8.0	6.3	-58.0	138.9
MD	100.0	0.0	22.7	3.4	23.0	3.4	-	-	8.1	3.7	8.1	3.7	-86.3	-57.8
MA	21.6	0.0	9.3	7.3	9.5	7.2	0.8	4.4	0.6	11.9	0.6	10.7	-94.7	20.2
MI	18.8	2.4	16.5	5.1	16.9	4.5	3.2	5.6	5.3	5.7	3.5	5.6	-84.9	-10.5
MN	18.6	3.6	20.8	6.2	20.0	5.3	5.1	5.6	8.4	6.4	6.7	6.0	-74.2	-12.1
MS	-	-	26.6	6.6	26.6	6.6	-	-	16.7	4.7	16.7	4.7	-49.9	-44.2
MO	15.4	3.1	21.2	3.4	21.0	3.3	7.9	0.0	8.9	2.4	8.8	2.2	-66.4	-47.7
MT	41.2	0.0	19.0	2.2	20.3	2.1	0.0	12.5	6.8	3.1	6.5	3.5	-81.4	0.0
NE	35.7	0.0	18.3	2.7	19.1	2.6	100.0	0.0	6.5	3.9	7.5	3.8	-70.9	8.0
NV	86.7	0.0	40.6	0.6	44.6	0.6	44.4	0.0	23.7	0.0	28.6	0.0	-16.7	-100.0
NH	-	-	14.2	6.7	14.2	6.7	1.7	8.6	100.0	0.0	31.3	6.0	-71.4	-88.4
NJ	-	-	14.1	11.9	14.1	11.9	-	-	4.7	12.0	4.7	12.0	-75.7	-26.8
NM	11.9	2.4	32.7	3.2	31.0	3.2	4.3	0.0	13.9	2.8	11.9	2.2	-44.9	0.0
NY	23.4	3.1	18.4	9.7	19.5	8.3	8.5	7.3	8.4	10.7	8.4	8.8	-25.9	80.1
NC	50.0	0.0	26.7	2.7	26.8	2.6	21.7	0.4	14.8	2.8	17.2	2.0	-14.7	0.0
ND	8.3	0.0	0.0	13.7	1.0	12.1	11.7	9.2	13.1	5.2	12.1	8.0	3700.0	100.0
OH	8.9	2.5	20.5	7.0	20.2	6.9	6.0	4.7	11.9	7.3	10.6	6.7	-31.8	27.5
OK	-	-	68.6	0.1	68.6	0.1	6.7	0.0	10.9	4.2	10.8	4.2	-77.2	5400.0
OR	3.6	1.8	26.5	1.1	25.9	1.1	-	-	5.1	1.1	5.1	1.1	-91.7	-57.1
PA	39.6	1.5	12.7	6.2	13.5	6.1	13.6	4.6	9.3	8.3	10.1	7.6	-39.2	1.9
RI	11.3	9.7	7.2	7.4	9.0	8.4	3.8	7.9	10.4	11.5	6.1	9.1	-59.5	-35.1
SC	14.3	3.8	25.3	3.1	24.9	3.2	8.1	3.9	13.0	6.3	11.7	5.6	-55.3	68.5
SD	10.5	1.0	14.2	4.2	13.6	3.7	8.2	4.4	10.1	8.0	9.5	7.0	-45.8	46.2
TN	20.8	0.0	23.8	5.4	23.7	5.2	30.0	2.8	11.1	4.8	13.7	4.5	-42.6	-13.7
TX	24.1	2.0	27.4	4.6	27.2	4.4	16.8	2.4	11.9	5.7	13.3	4.8	-55.5	-2.6
UT	-	-	29.3	2.0	29.3	2.0	0.0	0.0	16.9	5.6	16.5	5.4	-54.2	121.7
VT	60.6	0.0	15.6	5.1	23.9	4.2	8.3	0.0	0.0	16.0	3.3	9.8	-95.7	-25.0
VA	15.4	0.0	21.3	5.8	21.2	5.7	4.3	1.4	10.3	6.1	10.0	5.9	-64.4	-22.0
WA	0.0	3.5	27.6	2.7	27.0	2.8	4.0	0.0	5.7	2.7	5.6	2.5	-86.3	-41.2
WV	100.0	0.0	39.5	0.0	40.0	0.0	5.2	2.4	7.0	1.3	5.8	2.0	-79.9	-
WI	5.1	3.0	23.7	3.4	23.1	3.3	2.2	29.0	5.6	11.2	5.5	11.6	-68.6	358.3
WY	-	-	-	-	-	-	-	-	0.0	0.0	0.0	0.0	-	-
U.S. Total	21.0	2.8	22.8	4.7	22.7	4.6	10.6	4.5	11.1	5.9	11.0	5.5	-50.4	22.5

Blank cells indicate that a state does not have any ICFs-MR of that size in that year

- in the total columns indicate that a state does not have any ICFs-MR of that size in that year

- in the change column indicates that the state did not have any ICFs-MR with residents of that age in 1982

Table 3.19 Changes in ICF-MR Populations By Level of Mental Retardation and Facility Size, 1982-1992: Percent of Residents with Severe or Profound Mental Retardation

State	1982						1992						82 to 92		82 to 92 change			
	1-15		16+		Total		1-15		16+		Total		% change	# sev/prof				
	%sev	%prof	%sev	%prof	%sev	%prof	%sev/prof	%sev	%prof	%sev	%prof	%sev/prof	#sev/prof	1-15	16+	Total		
AI			23.4	62.3	23.4	62.3	85.6	65.6	15.6	24.4	58.1	25.5	57.0	82.5	-16.5	26	(232)	(206)
AK	53.3	33.3	31.0	46.6	38.1	43.2	81.4	95.1	4.9	32.6	60.9	62.1	34.5	96.6	-12.5	15	(27)	(12)
AZ								14.0	78.5	45.5	23.6	31.0	48.8	79.8		86	76	162
AR			24.1	53.5	24.1	53.5	77.6	39.1	16.3	21.3	64.4	24.3	56.4	80.7	27.7	160	142	302
CA			19.0	66.3	19.0	66.3	85.3	24.0	40.3	17.4	59.4	19.0	54.7	73.7	-20.2	1,543	(3,327)	(1,784)
CO	21.3	13.5	20.0	45.7	20.2	42.2	62.4			25.6	56.7	25.6	56.7	82.3	-52.4	(72)	(562)	(634)
CT	11.6	1.8	24.9	45.5	23.8	41.9	65.7	26.0	33.2	17.7	71.1	22.1	51.1	73.2	-55.9	377	(1,608)	(1,231)
DE			18.7	56.0	18.7	56.0	74.6	36.2	42.0	17.7	61.1	20.6	58.2	78.7	-12.0	54	(102)	(48)
DC	0.0	0.0	33.3	20.0	31.3	18.8	50.0	21.2	57.5			21.2	57.5	78.7	1584.4	539	(32)	507
FL	36.5	47.6	23.0	58.2	23.3	57.9	81.2	39.2	33.3	12.0	76.9	12.4	76.2	88.6	27.2	(16)	621	605
GA			25.0	57.3	25.1	57.6	82.7			23.6	60.2	23.6	60.2	83.8	-23.0	(8)	(479)	(487)
HI	0.0	0.0	14.0	76.8	13.7	75.2	88.9	34.0	52.0	20.0	60.0	25.2	57.0	82.2	-67.7	43	(276)	(233)
ID	27.3	30.9	51.5	35.1	48.8	34.6	83.4	46.2	16.8	21.5	65.3	36.3	36.3	72.5	-1.5	174	(180)	(6)
IL	17.2	1.6	23.1	43.7	23.0	43.4	66.4	28.9	8.5	24.1	48.3	24.6	44.2	68.9	50.6	435	2,257	2,692
IN	10.8	2.0	24.8	46.0	23.1	40.9	64.0	20.1	10.4	17.6	51.4	19.1	27.1	46.2	47.4	1,032	(146)	886
IA			18.3	54.9	18.3	54.9	73.2	34.9	44.9	23.2	51.0	25.2	49.9	75.1	23.3	295	3	298
KS	14.8	9.3	20.3	52.2	20.1	51.1	71.2	33.4	30.9	24.3	53.3	25.8	49.7	75.5	3.5	189	(140)	49
KY			26.9	45.4	26.9	43.4	70.3			28.3	47.4	28.3	47.4	75.7	2.3	0	19	19
LA	10.9	8.5	25.1	47.8	24.4	45.8	70.1	24.2	17.9	20.6	57.0	22.1	41.5	63.5	11.9	947	(544)	403
ME	50.0	16.4	26.3	70.5	31.2	59.3	90.5	24.1	49.5	20.2	66.6	22.0	58.7	80.8	-1.1	147	(153)	(6)
MID	20.0	30.0	24.1	60.4	24.1	60.3	84.4			12.2	76.8	12.2	76.8	89.0	-58.7	(5)	(1,204)	(1,209)
MA	36.5	23.0	31.8	45.7	31.9	45.3	77.1	39.5	37.0	23.7	46.6	26.3	45.0	71.4	-25.1	359	(1,130)	(771)
MI	39.2	39.3	19.0	67.7	23.1	62.0	85.0	19.3	65.3	14.3	62.6	18.5	64.8	83.3	-28.6	1,408	(2,375)	(967)
MN	30.8	8.7	27.1	40.8	28.4	29.2	57.6	30.7	25.1	24.4	46.1	27.7	35.1	62.8	-14.3	576	(1,119)	(543)
MS			26.3	37.9	26.3	37.9	64.2			21.6	58.6	21.6	58.6	80.3	0.1	0	2	2
MO	29.2	27.7	29.1	48.0	29.1	47.3	76.4	28.3	5.5	23.8	48.5	24.2	45.0	69.2	-27.3	6	(410)	(404)
MT	0.0	41.2	7.0	75.5	6.6	73.4	80.0	0.0	0.0	3.1	79.6	2.9	75.9	78.8	-42.2	(7)	(91)	(98)
NE	14.3	28.6	24.3	52.1	23.9	51.1	75.0	37.5	37.5	18.7	60.1	18.9	59.9	78.8	-24.2	(12)	(165)	(177)
NV	0.0	93.3	19.4	52.5	17.7	56.0	73.7	35.2	44.4	21.4	50.9	24.7	49.3	74.0	30.2	29	10	39
NH			35.0	38.0	35.0	38.0	73.0	13.8	70.7	4.0	72.0	10.8	71.1	81.9	-85.4	49	(448)	(399)
NJ			31.4	50.6	31.4	50.6	82.0			17.9	66.5	17.9	66.5	84.5	-25.7	0	(1,083)	(1,083)
NM	31.0	0.0	28.0	59.1	28.3	54.5	82.7	46.6	8.7	20.3	59.8	25.8	49.2	75.0	29.9	76	57	133
NY	35.3	27.4	24.9	60.0	27.1	53.1	80.1	27.0	47.6	18.8	58.8	23.4	52.5	75.9	62.7	5,801	(829)	4,972
NC	25.0	45.0	21.1	68.1	21.1	68.0	89.1	33.9	38.5	16.5	73.4	22.3	61.7	84.0	25.7	1,101	(310)	791
ND	8.3	0.0	49.7	50.3	44.9	44.4	89.4	41.4	35.7	9.9	75.9	31.8	47.9	79.8	170.8	335	(19)	316
OH	33.1	14.6	22.8	53.3	23.0	52.4	75.4	25.9	31.5	19.6	55.3	21.0	50.0	71.0	15.7	954	(182)	772
OK			21.3	39.7	21.3	39.7	61.1	0.0	20.0	27.3	36.2	27.1	36.1	63.2	49.8	3	550	553
OR	17.9	7.1	25.2	47.2	25.0	46.0	71.0			10.7	72.4	10.7	72.4	83.1	-51.4	(14)	(685)	(699)
PA	30.5	11.3	28.2	53.0	28.3	51.8	80.0	30.6	30.3	21.3	63.8	23.0	57.6	80.6	-16.3	699	(1,827)	(1,128)
RI	40.8	9.7	33.2	38.6	42.2	31.8	74.0	36.4	35.3	8.2	80.2	26.7	50.9	77.5	-37.5	54	(298)	(244)
SC	11.3	0.0	22.0	54.1	21.6	52.0	73.6	41.9	21.1	15.5	68.0	23.0	54.7	77.7	0.7	580	(562)	18
SD	22.1	4.4	18.9	68.9	19.6	56.1	75.7	28.3	40.9	7.5	81.1	13.6	69.4	83.0	5.6	80	(56)	24
TN	20.8	0.0	18.9	66.4	19.0	64.4	83.4	31.6	45.3	17.7	67.9	19.6	64.8	84.4	0.7	231	(218)	13
TX	0.3	0.1	28.4	42.3	26.8	39.8	66.6	22.4	14.6	27.3	53.6	25.9	42.4	68.3	-7.7	1,410	(2,167)	(757)
UT			26.0	47.2	26.0	47.2	73.2	18.5	33.3	20.1	57.0	20.1	56.3	76.4	-11.9	14	(139)	(125)
VT	46.2	16.9	37.6	35.4	39.1	32.2	71.2	35.4	50.0	26.7	62.7	30.1	57.7	87.3	-60.0	0	(162)	(162)
VA	44.2	0.0	29.9	51.0	30.2	50.0	80.2	43.9	19.4	21.2	61.5	22.4	59.3	81.8	2.3	65	(17)	48
WA	43.9	33.3	20.3	61.9	20.9	61.2	82.1	37.3	33.3	20.6	61.3	21.9	59.1	81.0	-34.8	45	(748)	(703)
WV	0.0	75.0	12.8	82.3	12.7	82.2	94.9	31.0	44.5	14.0	53.7	25.7	47.8	73.4	6.7	320	(290)	30
WI	16.2	9.1	28.7	47.4	28.3	46.2	74.5	20.4	4.3	23.5	46.6	23.4	45.7	69.1	23.0	(2)	525	523
WY										9.4	85.9	9.4	85.9	95.3		0	81	81
U.S. Total	27.6	15.7	24.9	52.4	25.1	49.9	75.0	27.1	33.3	21.0	57.4	22.7	50.7	73.4	-2.5	20,121	(19,999)	122

Blank cells indicate that a state does not have any ICFs-MR of that type and size combination  
 - in the total column indicates that a state does not have any ICFs-MR of that size or type combination  
 in the change column indicates that the state did not have any ICFs-MR in 1982

**CHAPTER 11**  
**MEDICAID COMMUNITY SUPPORTED LIVING ARRANGEMENTS**

**Brian Burwell**  
**Sally Bachman**  
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In October 1990 Congress authorized up to eight states to add a supported living option for persons with developmental disabilities to their Medicaid state plan. This Community Supported Living Arrangements (CSLA) option is described briefly in Part 1 of this chapter. It is noted there that the CSLA program in its present form will be terminated at the end of Fiscal Year 1995. This part provides a description of some of the outcomes and variations among the 8 selected states in their provision of supported living. This information was provided by state CSLA representatives who were asked to respond to a survey requesting information about CSLA program enrollment and expenditures, demographic characteristics of CSLA recipients, disability and functional status of CSLA recipients, and CSLA services and providers in each state.

The CSLA program was implemented in all eight states in 1992, beginning with Rhode Island, which began enrolling CSLA service recipients in February, and ending with Colorado, which initiated enrollment in August, 1992. Surveys were mailed to states in November, 1994. Michigan, Rhode Island, and Wisconsin responded to the survey using data gathered in January, 1995. Illinois used data from October, 1994. Surveys from Colorado, Florida, and Maryland are based

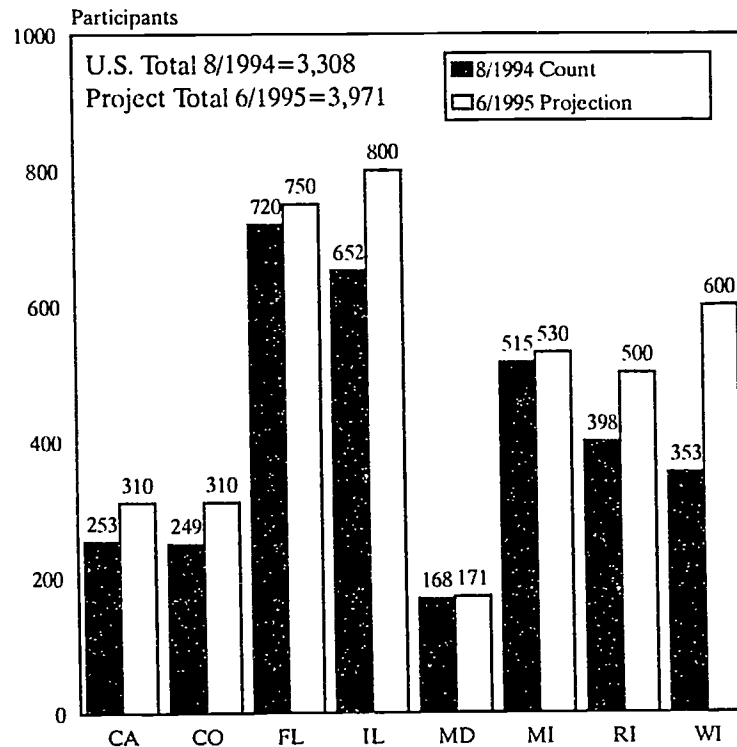
on data from June, 1994. California's last available data had been gathered at the end of December, 1993. The variation in reporting periods may have affected the comparability of the data.

*CSLA Program Enrollment*

As shown in Figure 3.11 there were large variations in the number of CSLA recipients enrolled in each state in 1994, from a low of 168 in Maryland to a high of 720 in Florida. These variations are attributable to multiple explanations, including differences in the way the states implemented CSLA, the total amounts of authorized spending that was actually used, the average costs of serving the enrolled CSLA recipients and so forth. Some of these factors affecting enrollment variations will be discussed later.

There was also variation among the states in the number of CSLA participants projected to be enrolled in CSLA by the end of Fiscal Year (FY) 1995. In FY 1995 California, Colorado, Maryland and Michigan projected modest increases in enrollment over FY 1994, while the remaining states projected enrollment increases of over 100 recipients. Wisconsin projected the largest enrollment increase, from about 350 to about 600.

**Figure 3.11**  
**CSLA Participants by State in August 1994 (+/- 2 mos) and Projected for June 30, 1995**



*Demographic Characteristics of CSLA Recipients*

Demographic characteristics of CSLA participants are summarized in Table 3.20. As shown, the distribution of males and females in the CSLA program was generally similar. Male/female distributions among the states ranged from 55.8% male in Colorado to 52.4% female in Maryland and Rhode Island. Five states served more males and 3 states served more females.

The racial/ethnic background of CSLA participants was primarily white, non-Hispanic. In every state but Maryland, white made up at least three-quarters of all CSLA participants whose racial/ethnic status was known. Black, non-Hispanics made up 12.4% of all CSLA participants, but representation of blacks varied

substantially from state to state (from 25.5% in Maryland to 1.1% in Wisconsin).

CSLA participants were by requirement at least 18 years old. Therefore, relatively small percentages fall into the age range of 21 years or younger. States varied from the 4 states with 5% or less of CSLA participants 21 years or younger, to 12.9% in Colorado. In every state the majority of CSLA participants were in the 22-39 year age range, ranging from 54.7% of CSLA participants in Illinois to 76.3% in California. Only a small percentage (3.3%) of CSLA participants were of retirement age (65 years and older). The inclusion of retirement aged individuals in CSLA programs ranged from 0.1% of CSLA participants in Florida to 6.1% in Illinois.

Table 3.20 CSLA Participants' Demographic Characteristics

	CA	CO	FL	IL <sup>1</sup>	MD	MI	RI	WI
<b>GENDER</b>								
Male	51.8	55.8	50.8	50.9	47.6	54.2	47.6	49.3
Female	48.2	44.2	49.2	49.1	52.4	45.8	52.4	50.7
<b>ETHNICITY</b>								
Whites (non-Hispanic)	81.2	77.3	75.6 <sup>2</sup>	83.4	72.7	86.8 <sup>3</sup>	96.5	96.3 <sup>4</sup>
Asians/Pacific Islanders	2.0	2.0	0.1 <sup>2</sup>	0.2	1.8	0.2 <sup>3</sup>	0.8	0.0 <sup>4</sup>
Hispanics	6.8	16.6	* <sup>2</sup>	2.1	0.0	1.8 <sup>3</sup>	0.5	0.0 <sup>4</sup>
Native Americans	0.4	0.4	* <sup>2</sup>	0.2	0.0	0.4 <sup>3</sup>	0.0	2.6 <sup>4</sup>
Blacks (non-Hispanic)	9.6	3.7	24.3 <sup>2</sup>	14.2	25.5	10.4 <sup>3</sup>	2.3	1.1 <sup>4</sup>
<b>AGE</b>								
18-21	4.0	12.9	6.0	4.1	3.6	5.0	7.8	5.7
22-39	76.3	67.9	69.7	54.7	61.3	66.0	57.0	58.9
40-54	18.6 <sup>5</sup>	13.7	20.0	26.4	23.2	21.7	24.7	25.5
55-64	** <sup>5</sup>	2.4	4.7	8.5	9.5	5.2	6.3	5.9
65+	1.2	3.2	0.1	6.1	2.4	1.9	4.3	3.7

NOTE: All statistics are reported percentages of the total CSLA recipients for each state. Statistics are adjusted for missing data. Notes are provided on the extent of missing data when data are missing on 2% or more of all CSLA participants.

<sup>1</sup> All of Illinois' statistics are based on reports on 84.7% of CSLA participants.

<sup>2</sup> Florida does not distinguish Hispanics or Native Americans in its data. Hispanics are subsumed under "Whites" or "Blacks."

<sup>3</sup> Michigan's statistics on ethnicity are based on reports on 96.9% of CSLA participants.

<sup>4</sup> Wisconsin's statistics on ethnicity are based on reports on 54.7% of CSLA participants.

<sup>5</sup> California combined the 40-54 and 55-64 year age categories in its data base. The 18.6% figure reported for 40-54 years, includes an unknown proportion of 55-64 year olds.

**Primary Disability Conditions of CSLA Participants**

**All Conditions**

Statistics were reported by each of the states on the disabling conditions of CSLA participants. The specific request was for the "primary" disability condition, but a number of difficulties were encountered. For example, California and

Colorado could not distinguish between primary and secondary disabilities; therefore, their totals substantially exceed 100% (194% and 152%, respectively). Florida did not employ some of the categories in Table 3.21 to identify primary disabilities. Illinois had a large percentage (54.1%) of participants for whom the primary disability was unknown. Rhode Island reported one quarter of their 398 participants in the "other" category, but

could not provide greater specificity on which were the disabilities of people in that category. In general, however, as shown in Table 3.21, it is clear

that a significant portion of CSLA participants had mental retardation as a primary condition, followed by cerebral palsy and epilepsy.

Table 3.21 Primary Disability Conditions of CSLA Participants

	CA <sup>1</sup>	CO <sup>1</sup>	FL <sup>2</sup>	IL <sup>3</sup>	MD	MI <sup>4</sup>	RI <sup>5</sup>	WI <sup>6</sup>
PRIMARY DISABILITY								
Mental Retardation	66.4	98.4	93.6	71.9	61.3	72.0	74.5	93.1
Mental Illness	13.4	7.2	0.0 <sup>2</sup>	13.3	0.0	0.0	0.0	0.0
Cerebral Palsy	39.9	21.7	5.6	3.7	12.5	10.5	0.0	2.7
Autism	6.3	1.6	0.8	0.0	3.0	3.5	0.0	1.2
Epilepsy	23.7	21.7	0.0 <sup>2</sup>	11.1	11.9	1.4	0.0	2.1
Traumatic Brain Injury	0.0	1.2	0.0 <sup>2</sup>	0.0	11.3	1.9	0.0	0.9
Other (unspecified)	0.0	0.0	0.0	0.0	0.0	10.7	25.4	0.0
Visual Problems <sup>7</sup>	16.6	--	--	--	--	--	--	--
Hearing Problems <sup>7</sup>	2.4	--	--	--	--	--	--	--
Medical Problems <sup>7</sup>	17.0	--	--	--	--	--	--	--
Technology Dependence <sup>7</sup>	2.8	--	--	--	--	--	--	--
Severe Behavior <sup>7</sup>	5.1	--	--	--	--	--	--	--

<sup>1</sup> Data on California's and Colorado's CSLA participants do not distinguish "primary" and "secondary" disabilities. Therefore, the totals for California and Colorado add up to significantly more than 100% (193.6% and 151.8%, respectively).

<sup>2</sup> Florida's data base would not allow mental illness, epilepsy, or traumatic brain injury to be reported as primary disabilities. It is assumed that few, if any, of Florida's CSLA participants would have been so reported.

<sup>3</sup> Data for Illinois are estimates based on reports including only 45.9% of state CSLA participants.

<sup>4</sup> Data for Michigan are based on reports including 99.6% of state CSLA participants.

<sup>5</sup> Data for Rhode Island are based on reports including 93.0% of state CSLA participants.

<sup>6</sup> Data for Wisconsin are based on reports including 93.8% of state CSLA participants.

<sup>7</sup> These specific conditions were indicated by Florida under the "other" category.

#### *Cognitive impairments among CSLA participants*

Figure 3.12 shows the proportion of CSLA participants in each state who have significant cognitive impairments (mental retardation). As shown, states ranged from less than two-thirds (Maryland, 61.3%; California, 66.4%) to more than 90% (Colorado, 98.4%; Florida, 93.6%; Wisconsin,

93.1%). Figure 3.13 further breaks down the distribution of the CSLA participants with cognitive impairments by level of mental retardation. Maryland was excluded from this figure because data were unavailable, and Illinois' statistics are based on reports of only 40% of CSLA participants reported to have mental retardation. The statistics from all other states are

based on reporting for at least 83% of CSLA participants with cognitive limitations. Figure 3.13 clearly shows that among the CSLA participants with mental retardation a substantial majority had mild mental retardation. Every state reported that

a majority of CSLA participants with mental retardation had mild mental retardation. More notably a slight majority (53.5%) of all CSLA participants, were reported to have mild mental retardation.

**Figure 3.12**  
**Percentage of CSLA Participants with Cognitive Limitations**  
**(among CSLA participants for whom this information was available)**

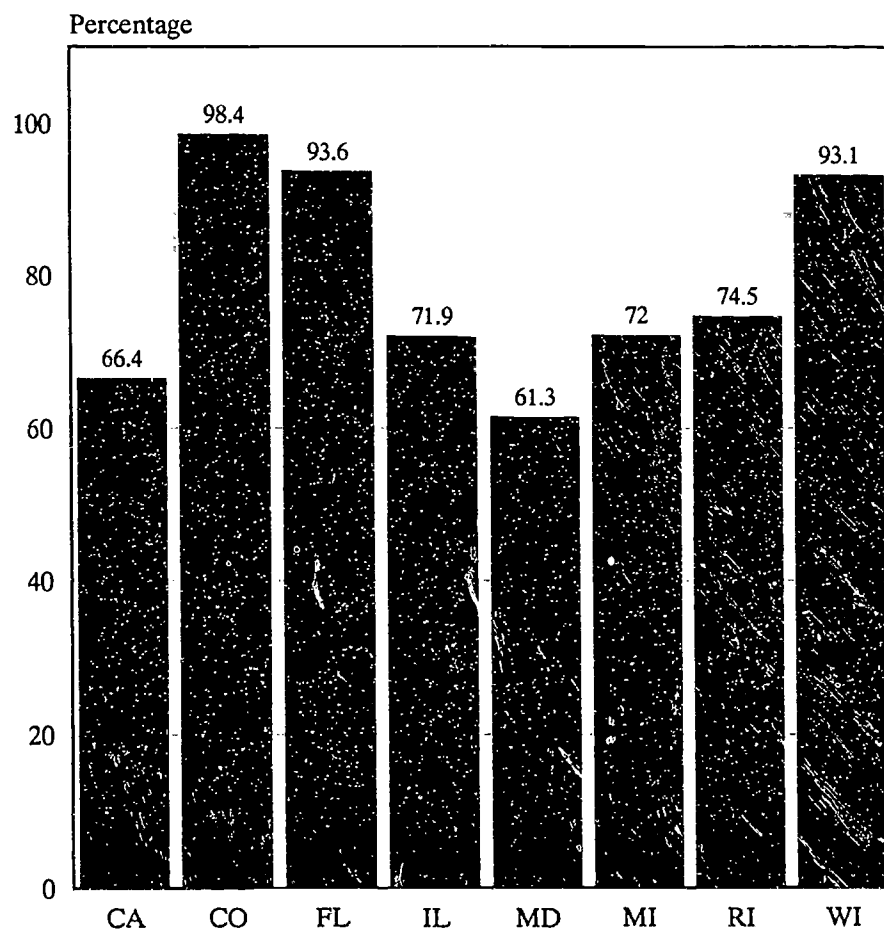
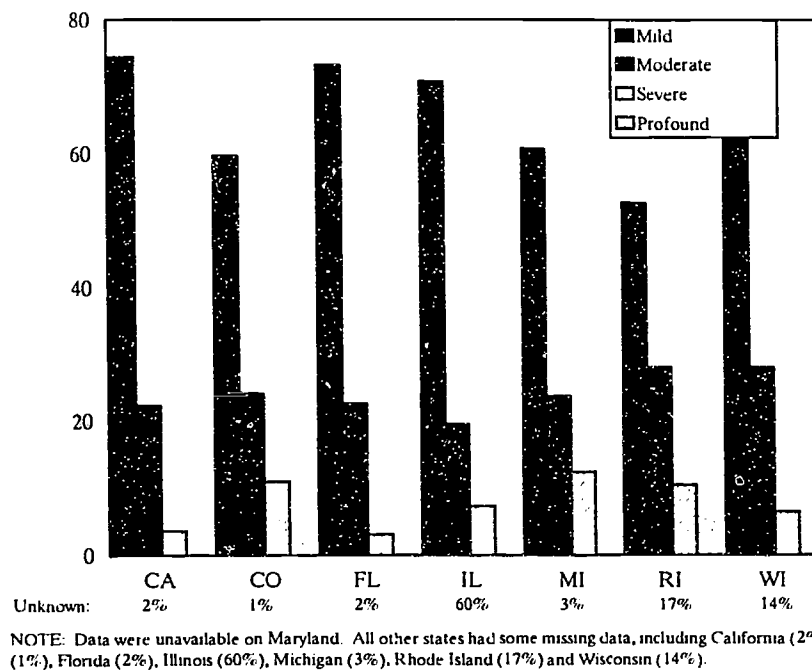


Figure 3.13  
Proportion of CSLA Participants with Cognitive Limitations  
by Level of Mental Retardation



#### Multiple Disability Conditions

States that were able were asked to report the percentage of their CSLA recipients who had more than one disability condition. California and Illinois were unable to report this statistic, but as shown in Figure 3.14, in the other 6 CSLA states between one and two-thirds of CSLA recipients had two or more disability conditions. As would be expected, the frequency of multiple conditions was related to the proportion of persons with physical disabilities or other than mild mental retardation. For example, Maryland reported the highest proportion of CSLA recipients with physical disabilities and no mental retardation (38.7%) and had 56.7% of CSLA participants with multiple conditions. Rhode Island reported 47.4% of CSLA with moderate-to-profound mental retardation and 63.3% of its CSLA participants with multiple conditions. In contrast, Florida and Wisconsin had the highest proportions of their total CSLA population made up of persons with mild mental retardation, 68.5% and 57.8%,

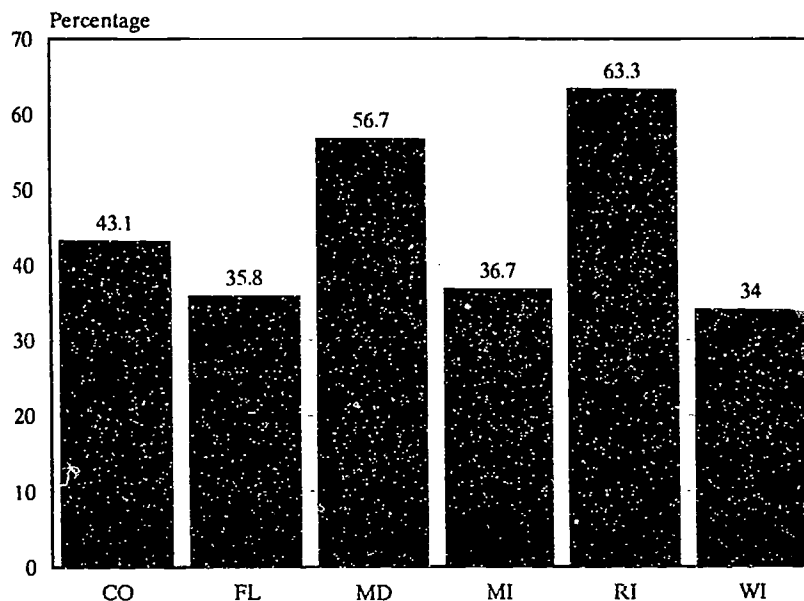
respectively, and the lowest proportions of CSLA participants with multiple conditions (35.8% and 34.0%).

#### Persons using wheelchairs or needing assistance in walking

Only California, Colorado and Florida were able to provide statistics on the proportion of CSLA participants using wheelchairs or needing other forms of assistance in ambulation. These are shown in Figure 3.15. Again California's substantial efforts to enroll persons with developmental disabilities other than mental retardation are reflected in the high proportion of persons who were wheelchair users or needed other forms of assistance in getting from place to place (38.0%). In contrast, Florida's concentration of CSLA services on persons with mild mental retardation are evident in the relatively low (6.9%) proportions of persons needing assistance or equipment for ambulatory activities.

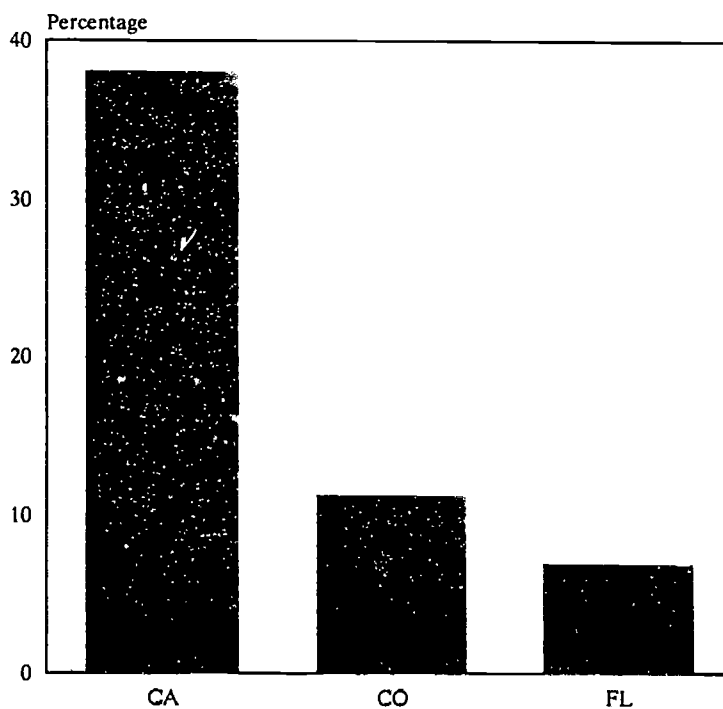


**Figure 3.14**  
**Percentage of CSLA Participants with Two or More Disabilities**



Note: Statistics were not reported by California or Illinois.

**Figure 3.15**  
**Percentage of CSLA Recipients Who Use Wheelchairs or Need Assistance With Ambulation**



Note: These statistics were not reported by Illinois, Maryland, Michigan, Rhode Island, or Wisconsin

### Living Arrangements

Table 3.22 and Figure 3.16 summarize the living arrangements of CSLA participants. Between 74.0% (California) and 100.0% (Florida) of all CSLA recipients live either on their own or with family members. It should be noted that living in group settings reflects California's

authorization of CSLA services to assist persons in locating and preparing to move to a home of their own under CSLA. In total about two-thirds of all CSLA participants live "on their own," either alone or with non-paid roommates. Another 29% live with family members, a proportion that varied tremendously (from more than half in Colorado and Rhode Island to zero in Florida).

Table 3.22 Living Arrangements of CSLA Participants

	CA <sup>1</sup>	CO <sup>2</sup>	FL <sup>3</sup>	IL <sup>4</sup>	MD	MI <sup>5</sup>	RI <sup>6</sup>	WI <sup>7</sup>
<b>ON OWN</b>								
Alone, in own apt./room/house	38.0	30.2	** <sup>3</sup>	25.5	22.6	24.6	13.6	27.6 <sup>7</sup>
With friends/other CSLA	19.0	11.5	** <sup>3</sup>	47.2	33.3	28.5	27.1	29.0 <sup>7</sup>
<b>WITH FAMILY</b>								
With natural parents	10.0	51.2	0.0	22.6	18.5	42.3	** <sup>6</sup>	** <sup>7</sup>
With other relatives	6.0	4.4	0.0	4.9	8.9	4.6	** <sup>6</sup>	** <sup>7</sup>
With foster parents	1.0	0.0	0.0	0.0	0.0	0.0	** <sup>6</sup>	** <sup>7</sup>
<b>Total Family Living</b>	<b>17.0</b>	<b>55.6</b>	<b>0.0</b>	<b>27.4</b>	<b>27.4</b>	<b>47.4</b>	<b>55.1</b>	<b>25.6</b>
<b>STAFFED HOUSING</b>								
Paid roommates/CSLA staff	14.0	2.7	0.0	0.0	16.6	0.0	0.0	6.9
In group living arrangements of four or more	12.0	0.0	0.0	0.0	0.0	0.0	4.1	0.0
<b>Total Staffed Living</b>	<b>26.0</b>	<b>2.7</b>	<b>0.0</b>	<b>0.0</b>	<b>16.6</b>	<b>0.0</b>	<b>4.1</b>	<b>6.9</b>

<sup>1</sup> California's survey reports that these statistics are estimates.

<sup>2</sup> Colorado's statistics on living arrangements of CSLA participants are based on 12/94 figures (where total number of recipients=295).

<sup>3</sup> Florida was unable to distinguish whether CSLA recipients lived alone or with friends; none lived with family or in staffed housing.

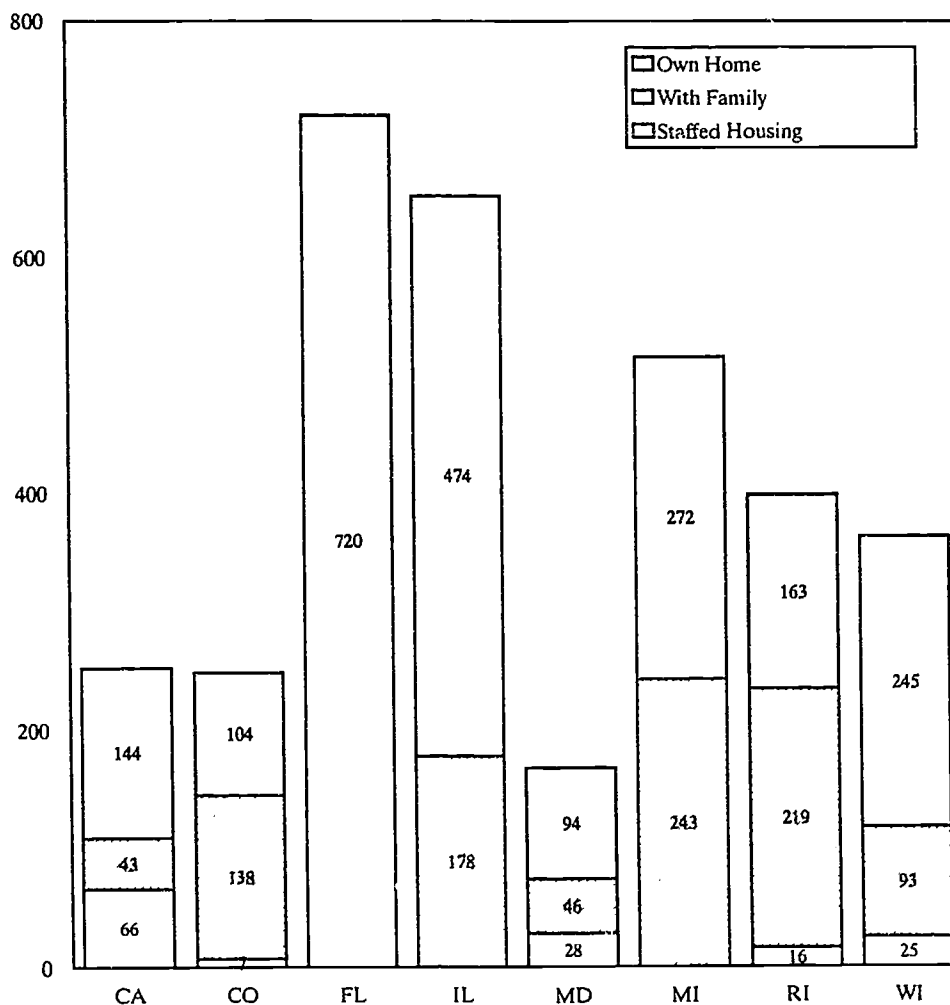
<sup>4</sup> Illinois' statistics are based on reports including 63.8% of CSLA participants.

<sup>5</sup> Michigan's statistics are based on reports including 89.7% of CSLA participants.

<sup>6</sup> Rhode Island's statistics are based on reports including 98.0% of CSLA participants, but could not distinguish among the "types" of family members with whom participants lived.

<sup>7</sup> Wisconsin's statistics are based on reports including 98.6% of CSLA participants. Wisconsin was unable to distinguish the specific status (living alone, living with friends) for 16.2% of persons living "on their own." It was unable to distinguish among the "types" of family members with whom CSLA participants lived.

Figure 3.16  
Type of Residential Arrangement in Which CSLA Participants Live (8/94)



#### Major Day Activities

Table 3.23 provides available statistics on the major day activities of CSLA recipients. Such statistics were not available from California and Maryland. Statistics from the other six states also suffer from considerable missing data (reporting rates are in the notes to the table). The vast majority of CSLA participants on whom there were day activity data were employed. An estimated 35.5% were involved in supported employment,

12.1% in competitive employment and 39.6% in sheltered work programs. Substantial variability was evident among CSLA participants from different states in the major day activity. An estimated 31% of Michigan's CSLA participants worked in competitive work settings without paid supports. Over half of the CSLA participants in Illinois and Rhode Island whose day activities were known attended a sheltered worksite. Relatively few CSLA participants (less than 5%) had no formal work or day program involvement.

Table 3.23 Major Day Activities of CSLA Participants

	CO <sup>1</sup>	FL <sup>2</sup>	IL <sup>3</sup>	MI <sup>4</sup>	RI <sup>5</sup>	WI <sup>6</sup>
WORK STATUS: (percent of all working recipients)						
Competitive employment	0.0	0.0	22.9	30.8	6.8	3.7
Supported employment	74.0	66.3	0.0	40.4	14.6	27.9
Sheltered employment/Workshop	17.3	33.7	53.1	28.8	77.6	15.3
Other day program	8.7	0.0	9.2	0.0	0.0	55.7
No formal day program	0.0	0.0	14.7	0.0	0.0	10.7
Volunteer work	0.0	0.0	0.0	0.0	1.0	0.9
Unknown	44.6	19.2	64.7	14.4	48.5	7.4

NOTE: Statistics on major day activities were not available from California and Maryland.

<sup>1</sup> Colorado's statistics are based on reports including 55.4% of CSLA participants.

<sup>2</sup> Florida's statistics are based on reports including 80.8% of CSLA participants.

<sup>3</sup> Illinois' statistics are based on reports including 35.3% of CSLA participants.

<sup>4</sup> Michigan's statistics are based on reports including 85.6% of CSLA participants.

<sup>5</sup> Rhode Island's statistics are based on reports including 51.5% of CSLA participants.

<sup>6</sup> Wisconsin's statistics are based on reports including 92.6% of CSLA participants; in addition these percentages add up to more than 100.0% because 42 persons are included in more than 1 work status category.

### Services and Providers

#### CSLA services

Table 3.24 shows the types of services offered CSLA participants in each of the states. States provide as few as four CSLA services (Florida) and as many as thirteen (Colorado). Individual support is the only service provided by all eight states. Seven states provide 24-hour emergency services and transportation. Six states provide assistive technology, and five provide behavior management

or counseling services. In contrast, a number of services were identified by states that were unique to a specific state. These include: cash vouchers, acquisition of household goods, best practices assistance, community integration, and personal care services. It should be noted that in most states, CSLA participants were eligible for a range of services not directly funded through CSLA, including Medicaid health and personal care services, vocational rehabilitation services and educational services.

Table 3.24 Services Offered by state CSLA Programs

	CA <sup>2</sup>	CO	FL	IL	MD	MI	RI	WI	Total number of states providing each service
<b>SERVICES</b>									
Paid roommates	X	X			X		X		4
Individual support services	X	X	X	X	X	X	X	X	8
Assistive technology	X	X			X	X	X	X	6
24-hour emergency services	X	X	X	X	X		X	X	7
Cas'l. vouchers							X		1
Transportation	X	X		X	X	X	X	X	7
Case management services	X			X	X				3
Behavioral management services	X	X		X	X			X	6
Counseling services (separate from individual support)	X	X			X		X	X	5
Nursing, home health aide, or other medically oriented services	X	X			X		X		4
Therapeutic services (physical or speech therapy)	X	X					X		3
Household goods (furniture, appliances)				X					1
Best practices <sup>1</sup>		X							1
Training and habilitation <sup>1</sup>		X				X		X	3
Respite care <sup>1</sup>		X				X		X	3
Community integration <sup>1</sup>		X							1
Personal care <sup>1</sup>			X						1
Minor environment modifications (home, auto) <sup>1</sup>		X				X	X	X	4
<b>TOTAL number of CSLA funded services per state</b>	<b>10<sup>2</sup></b>	<b>13</b>	<b>4</b>	<b>6</b>	<b>9</b>	<b>6</b>	<b>10</b>	<b>9</b>	

<sup>1</sup> These services were specified by states under the category "other."

<sup>2</sup> In California only 24-hour emergency services are funded exclusively by the CSLA program; all other services may be financed by CSLA, may have multiple funding sources or may be funded by another source. In general, a commitment is made to use other "generic" funding sources before using CSLA.

### Provider Agencies

CSLA regulations require that a licensed/certified agency be responsible and accountable for providing CSLA services and managing CSLA finances. Responses to this requirement varied substantially from state-to-state, and even within different jurisdictions within the same state. In some areas government agencies (or quasi-governmental agencies) selected private service provider agencies for or with CSLA participants and those agencies assisted the individuals (and/or family) in selecting and managing services and supports. In other areas the "provider agency" was a local governmental (or quasi-governmental) agency which assisted the individuals in recruiting, selecting and managing direct support providers. Variations of these approaches and use of both in the same service jurisdiction were frequent. Because of this the definition and designation of an "agency" licensed to provide CSLA services varies somewhat in definition and regulation in each state. Nevertheless, it is interesting to note the number of licensed agencies participating in the delivery of CSLA services and the average number of CSLA participants in each state. A number of factors affect this average, including the number of diverse services available to people and the different types (and number) of service provider agencies that might serve a single individual, the extent to which mechanisms were established to avoid "licensing" direct support providers who are not part of a larger agency, the extent to which significant numbers of individuals manage their supports without requirement of working through licensed

agencies and so forth. CSLA agencies and average persons served per agency are shown in Table 3.25.

Wisconsin was unable to provide such statistics. Michigan's relatively high average number of persons per agency reflects the role of 21 Community Mental Health Boards as the CSLA managing agency for CSLA services, and the fact that like Colorado and Rhode Island, about half of all CSLA participants lived with their families who played significant roles in purchasing non-agency supports. In general, though, the typical CSLA agency served relatively few CSLA participants.

### CSLA Expenditures

Table 3.26 provides a summary of CSLA expenditures as reported by states for Fiscal Years 1992, 1993 and 1994 and as projected for Fiscal Year 1995. As noted in Part 1 of this chapter, CSLA states were authorized to spend federal funds up to a capped amount in each year, while maintaining the required state Medicaid cost-share. In Fiscal Year 1992 each CSLA state was authorized to spend \$1,250,000 in federal funds, increasing to \$2,500,000 in Fiscal Year 1993, to \$3,750,000 in Fiscal Year 1994 and to \$4,375,000 in Fiscal Year 1995. As shown, only California used its full allocation for CSLA services in Fiscal Year 1994 (\$3,750,000) and only California, Illinois and Michigan projected using effectively all (at least 88%) of their full CSLA allocation for Fiscal Year 1995 (\$4,375,000). The differences among the states are quite notable. In contrast to California, Illinois, and Michigan, Florida and Maryland are projecting the use of less than half of their federal allocation (39.8% and 38.5%, respectively).

Table 3.25 Number of Licensed CSLA Agencies and Average Number of CSLA Participants per State

	CA	CO	FL	IL	MD	MI	RI
Licensed CSLA Agencies	25	13	105	71	34	21	22
Average Number of CSLA Participants	10.1	19.2	6.9	9.2	4.9	24.5	18.1

Wisconsin projected using 76.8%, Rhode Island 62.7% and Colorado 53.7% of the federal funds allocated in Fiscal Year 1995. Returning to Fiscal Year 1994, the last completed Fiscal Year, Figure 3.17 shows the relative used and unused portions of the authorized expenditures of federal Medicaid funds. A major factor affecting the lower use of authorized (and originally projected) expenditures for CSLA services may have been the increased flexibility and permitted expansion of Medicaid HCBS waiver use subsequent to 1991. Between mid-1991 and mid-1994 CSLA states enrolled 3,308 persons into CSLA; during this same period these same states increased Medicaid HCBS enrollments to 21,810 individuals (146%). It does seem that cost factors affected for the more rapid growth of

the HCBS enrollments than CSLA enrollments during the period. Although as shown in Figure 3.18 average per participant CSLA expenditures were less than half of HCBS expenditures, in only California average CSLA expenditures were nearly 3 times greater than HCBS, and still California used its entire CSLA allocation. More realistically, during the period HCBS and CSLA operated largely independently, and the slower than authorized development of CSLA services (and expenditures) reflected the unique challenges and slower development of a new program built around the ideals of supported living. Nationally, CSLA per recipient expenditures in Fiscal Year 1994 average \$9,142 as compared with \$24,343 for HCBS (and \$66,720 for ICF-MR care).

Table 3.26 CSLA Expenditures as Reported by States for Fiscal Years 1992, 1993, 1994, and Projected for 1995

	CA	CO	FL	IL	MD	MI	RI	WI
<b>1992 EXPENDITURES</b>								
Total	1,000,000	n/a	n/a	823,000	n/a	n/a	n/a	422,400
State	500,000	n/a	n/a	411,500	n/a	n/a	n/a	168,960
Federal	500,000	n/a	n/a	411,500	n/a	n/a	n/a	253,440
<b>1993 EXPENDITURES</b>								
Total	3,000,000	225,398	1,569,427	2,913,200	1,771,138	875,200	782,527	1,823,100
State	1,500,000	102,962	706,424	1,456,500	885,569	386,489	362,780	729,240
Federal	1,500,000	122,436	863,185	1,456,500	885,569	488,711	419,747	1,093,860
<b>1994 EXPENDITURES</b>								
Total	7,500,000	1,334,066	2,787,929	4,977,000	3,245,336	4,415,491	2,972,846	3,008,000
State	3,750,000	609,401	1,254,568	2,488,500	1,622,668	1,926,479	1,371,374	1,203,200
Federal	3,750,000	724,665	1,533,361	2,488,500	1,622,668	2,489,012	1,601,472	1,804,800
<b>1995 EXPENDITURES</b>								
Projected Total	8,750,000	4,324,226	3,164,000	8,748,000	3,367,450	7,697,044	5,092,028	5,600,000
State	4,375,000	1,975,305	1,423,800	4,374,000	1,683,725	3,358,220	2,348,953	2,240,000
Federal	4,375,000	2,348,921	1,740,200	4,374,000	1,683,725	4,338,824	2,743,075	3,360,000

Figure 3.17  
 Amount of Federal CSLA Allocation Per State (\$3.75 million)  
 Reported Expended in Fiscal Year 1994

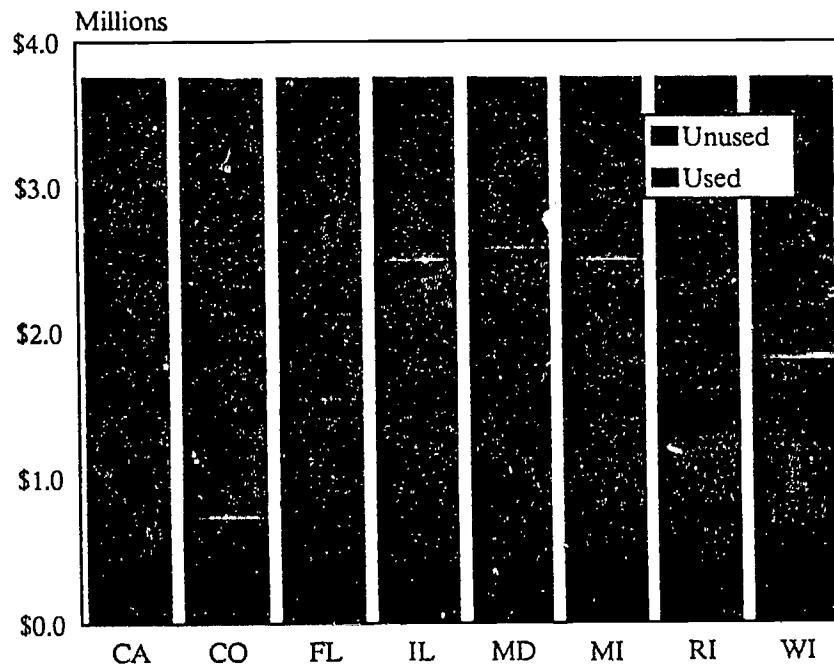
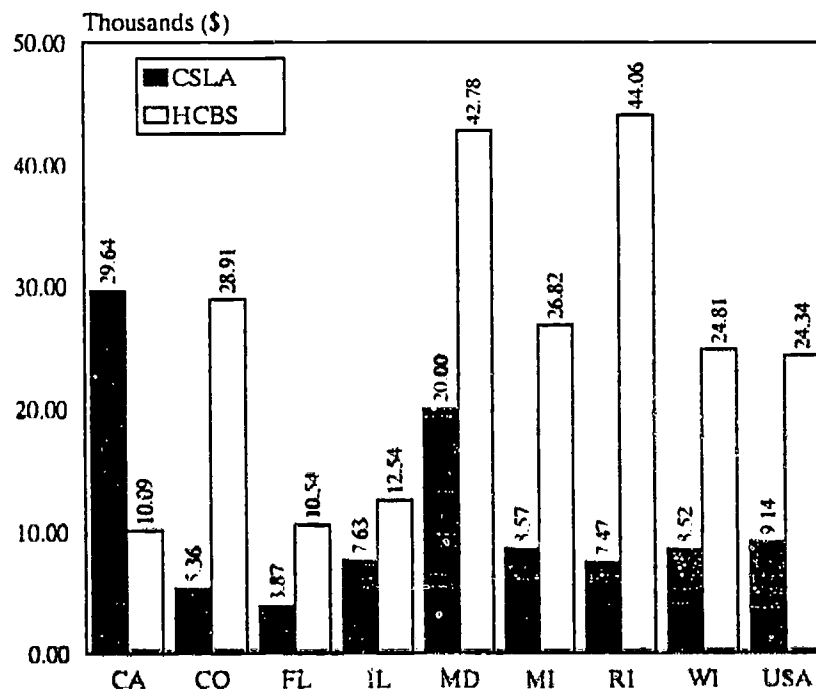


Figure 3.18  
 A Comparison of Average Per Person Medicaid CSLA  
 and HCBS Expenditures in Fiscal Year 1994





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## APPENDIX A: KEY STATE CONTACTS

<b>Alabama</b>	<b>Kentucky</b>	Cecil Greene
Cathy Maddox	Wayne Chester, Jr.	Fred Waddle
Raymond Owens	Pat Russell	<b>North Dakota</b>
Sherry Robertson	<b>Louisiana</b>	Dina Barta
<b>Alaska</b>	Bonnie Callahan	Mike Fisher
Diana Ray	Jerry Westinoreland	Robert Graham
<b>Arizona</b>	<b>Maine</b>	Ohio
Peter Currie	Leda Cunningham	Joan Allen
Ken Curry	Kathy McKinney	Ron Boley
Brian Lensch	<b>Maryland</b>	Melissa Esken
Bonnie Ann Smith	William Wacker	Mary Beth Wickerham
<b>Arkansas</b>	<b>Massachusetts</b>	Donna Wood
Carol Cromer	Mary Cerreto	<b>Oklahoma</b>
Susan Wallace	Theresa LaCroix	David Goodell
<b>California</b>	Ron Sanfield	<b>Oregon</b>
Paul Wiljanen	<b>Michigan</b>	David Baker
<b>Colorado</b>	Stu Hallgren	<b>Pennsylvania</b>
Lynne Struxness	Bill Harrison	Michael Toth
<b>Connecticut</b>	<b>Minnesota</b>	<b>Rhode Island</b>
Lawrence Johnson	Alex Bartolic	Brenda Chamberlain
<b>District of Columbia</b>	James Franczyk	Camille Letourneau
Leola Brooks	<b>Mississippi</b>	<b>South Carolina</b>
Carolyn Nicholas	Vanessa Breckenridge	Al Whiteside
<b>Delaware</b>	Mendal Kemp	Sharon Stokes
Kathleen Wooten	Lisa Romine	<b>South Dakota</b>
Hank Brown	<b>Missouri</b>	Ed Campbell
<b>Florida</b>	John Bright	<b>Tennessee</b>
Julie Griffith	<b>Montana</b>	Jan Coatney
Tom Stankus	Robert Anderson	William Edington
<b>Georgia</b>	Janice Frisch	John Lewis
Greg Brown	<b>Nebraska</b>	<b>Texas</b>
Candy Kidd	Jackie Miller	Rose Rossman
<b>Hawaii</b>	Roger Stortenbecker	<b>Utah</b>
Lois Svenishi	<b>New Hampshire</b>	George Kelner
David Kanno	Diedre Prescott	Cindy Ruckman
<b>Iowa</b>	<b>New Jersey</b>	<b>Vermont</b>
Tim Carroll	Dennis Hemphill	June Bascom
<b>Idaho</b>	Beth Lamanna-Frazier	<b>Virginia</b>
David Crandall	Leon Skowronski	Jim Beck
Lloyd Forbes	<b>New Mexico</b>	Kathi Honeycut
Diane Helton	Michael Martinez	Charleen Whitehead
Richard Jacks	Susan Osborne	<b>Washington</b>
Reed Mulkey	<b>Nevada</b>	Ron Sherman
<b>Illinois</b>	Peter Steinmann	<b>West Virginia</b>
Steve Gappel	<b>New York</b>	Judy Donaldson
Patty Reynolds	Max Chmura	Marc Hanna
<b>Indiana</b>	Mary Edmonds	<b>Wisconsin</b>
Walter Thomas	Christopher Hill	Dennis Harkins
Ann January	Kuie-Lan Lin	<b>Wyoming</b>
<b>Kansas</b>	<b>North Carolina</b>	Jon Fortune
Larry Sheradon	Tara Chandler	Cliff Mikesell