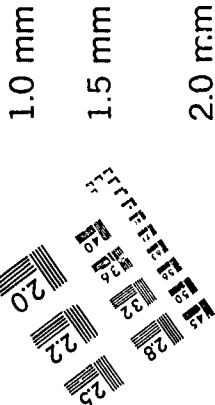
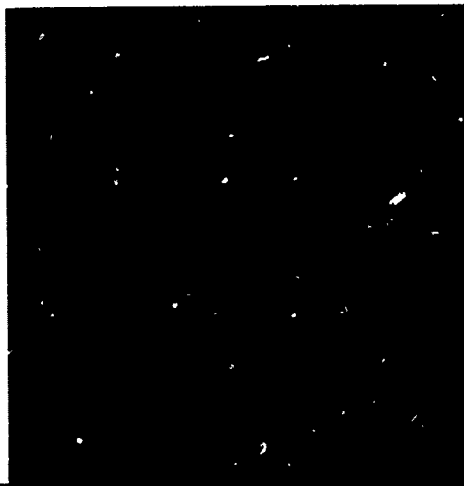
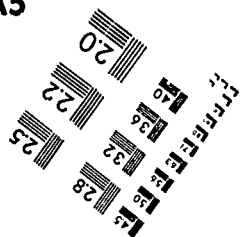


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ABSTRACT

This report presents annual basic descriptive and longitudinal population statistics on people with mental retardation and related conditions in state-operated residential facilities in the United States. Part I presents data on numbers of persons with mental retardation and related conditions, including first admissions, readmissions, releases, deaths, and cost of care. Part II presents statistics on characteristics of persons living in public residential facilities in 1987, such as resident movement, level of retardation, age distribution, medical conditions, activities of daily living, instrumental activities of daily living, and employment status. Part III puts 1988 statistics in the longitudinal context of data gathered since 1950 on state institution populations, resident movement, and costs of care. Facilities are categorized by size and whether or not persons with disabilities other than mental retardation reside there as well. An executive summary analyzes trends in the data. Includes 37 references. (PB)

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Persons With Mental Retardation and Related Conditions in State-Operated Residential Facilities: Year Ending June 30, 1988

Project Report 30
December 1989

Center for Residential and Community Services
Institute on Community Integration
University of Minnesota

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**Persons With Mental Retardation and Related Conditions
in State-Operated Residential Facilities: Year Ending
June 30, 1988 With Longitudinal Trends from 1950 to 1988**

Report #30

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December 1989

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EXECUTIVE SUMMARY

This report presents basic descriptive and longitudinal statistics on persons with mental retardation and related conditions in state-operated residential facilities. Presented in this report are data from recurring surveys conducted by the Center for Residential and Community Services at the University of Minnesota since 1978, and comparative statistics from a variety of other studies of state-operated facilities since 1950. Data on public residential facilities for persons with mental retardation gathered in the 1987 National Medical Expenditure survey are also presented and compared with all (public and private) mental retardation facilities as a whole. The following represent primary statistical trends in state-operated residential facilities.

- In Fiscal Year 1988, there was an increase in the number of state-operated residential facilities. This growth occurred almost exclusively in smaller programs serving 15 or fewer persons (a 17% or 110 facility increase in this category from June 30, 1987 to June 30, 1988). On June 30, 1988 there were reported to be 11 more state mental retardation institutions than a year earlier; however the primary factor in this change was the "reclassification" to PRF/MR of facilities that were previously classified as PRF/Other. In all the number of reported PRF/Other with residents with mental retardation decreased by 22 between 1987 and 1988.
- During FY 1988, states had an average daily population of 99,095 persons with mental retardation and related conditions in all state-operated residential facilities. This included 91,582 residents of state institutions for persons with mental retardation, an "institution" being defined as having 16 or more residents. It also included 5,580 persons in state-operated group homes for 15 or fewer residents and 1,933 persons with mental retardation in other state-operated institutions, almost exclusively psychiatric facilities. The number of persons with mental retardation in large mental retardation or other state institutions decreased by 4,018 persons (or about 4.3%) between June 30, 1987 and June 30, 1988 to 93,515. This is the lowest number of such persons residing in such facilities since 1934.
- There has been a steady decline in the number of persons served in state-operated residential facilities. Between FY 1967 and FY 1988 the daily population of persons with mental retardation in all state-operated institutions decreased by about 59% from 228,500 persons to 93,515. These reductions were paralleled by declines in the "placement rates" (residents with mental retardation per 100,000 of the general U.S. population) in state-operated institutions. These rates peaked in FY 1965 at 115.8 per 100,000 of the general population, were 115.7 in 1967, and had declined to a rate of 38.0 in FY 1988. The FY 1988 placement rate for state-operated mental retardation facilities (37.3) was less than the rate of 39.3 in FY 1922.
- During the past 20 years, there has been a substantial increase in the severity and number of disabilities among persons served by large publicly operated residential facilities. In the mid-1960s about 40 percent of residents were considered mildly or moderately retarded compared to a rate of about 20 percent today.
- Based on the national sample of facilities and residents in the National Medical Expenditure Survey, it is estimated, it appears that nearly 3,000 persons are listed on the waiting lists for placement in public residential programs. This number, while large, represents only a small portion of the number of persons indicated to be on private facility waiting lists (14,000). Neither can the total public and private facility waiting lists be assumed to adequately estimate the number of families in need of support and services, in that it does not include lists maintained by government and private agencies other than residential facilities.

- A relatively large proportion of persons in public residential facilities have conditions other than mental retardation. Approximately 39% are estimated to have epilepsy, 12% cerebral palsy, 2% autism and 10% severe sensory disorders in addition to mental retardation. An estimated 10% have circulatory system conditions, including 32% of residents 55 years or older. Frequent constipation is a reported problem for an estimated 31% of public facility residents.
- Data on the functional characteristics and activities of residents in large public facilities indicate a wide range of disabilities and abilities. For example, about 24% are estimated to bathe or shower independently, 30% to dress independently, 54% to use the toilet independently, 70% to get into and out of bed independently, 66% to feed themselves, and 67% to walk across a room independently without assistance. Independence in four activities of instrumental living was considerably lower: 10% could use the telephone, 6% could manage money, and 7% could shop for some personal items, and 7% could get around the community without assistance through the use of personal or public transportation. While these data portray a high prevalence of functional limitations, they also suggest considerable existing potential among public institution residents for participation in community life.
- The average cost in state institutions for persons with mental retardation in FY 1988 was \$156.77. This represents an annual increase of 5.0% from the previous year, the smallest annual increase since FY 1981 (following a 15% increase from FY 1986 to FY 1987). But the cost of care provided in state-operated residential facilities for persons with mental retardation has increased dramatically since 1950, from an annual expenditure of \$750 per person to an average of \$57,200 per year in FY 1988. Controlling for changes in the Consumer Price Index, costs per resident in FY 1988 were 15 times the 1950 cost. These increased costs were associated with a number of factors, including increased regulatory requirements under Medicaid's ICF-MR program, increasing severity of populations, increasing staff-to-resident ratios, and increased pay for professional and direct service personnel. Court decisions and settlements in a majority of states requiring substantial improvements in state institution programs have also had a significant impact on costs.
- Large public facilities averaged 1.51 full-time equivalent (FTE) direct care staff members per resident in 1987. This compared with 0.97 FTE direct care staff per resident in small public facilities and 1.06 in all public and private facilities. In 1974 large public facilities averaged 0.56 FTE direct care staff members per resident and in 1981 large public facilities averaged 1.25 FTE direct care staff members per resident.
- Only an estimated 25% of large public facility residents do any work for pay. Only 5% work for pay off the grounds of the residential facility. In contrast 49% of small public facility residents work for pay and 47% work for pay away from the residential facility.
- There has been a great reduction in both in and out movement of residents of large public facilities in recent years. Both the relative rates (i.e., proportion of total population) and the total number of admissions, discharges and deaths among large public facilities residents in 1988 were all at or near their lowest points since 1950. The 5,431 admissions in 1988 were only 30% as many as the high of 18,075 reported in 1974. The 6,323 discharges were only about 37% as many as the 16,980 reported in 1979. The 1,333 deaths reported in 1988 were only 37% as many as the 3,635 reported in 1967.

INTRODUCTION

This is the eighth publication since fiscal year 1978, in a series of Center for Residential and Community Services (CRCS) reports providing statistics on persons with mental retardation and related conditions in state-operated residential facilities in the United States. Part I of this report presents population statistics for Fiscal Year 1988. These statistics were compiled within state agencies, with the exception of a few states for which individual facility data were collected. The data collection in Part I represents a somewhat expanded continuation of a statistical program originated in the Office of Mental Retardation (now the Administration on Developmental Disabilities) in 1968 and continued through 1972. The current survey has been expanded over the years to include population and cost statistics on "small" state-operated mental retardation facilities (those with 15 or fewer residents) and facilities designated primary for populations other than persons with mental retardation and related conditions, as well as the larger state mental retardation facilities. The addition of "other" state-operated facilities was begun for Fiscal Year 1978, and the small state-operated facilities were added in Fiscal Year 1986.

Part II presents statistics on the characteristics of persons living in public residential facilities in 1987. It also presents certain resident movement and facility administrative statistics on public facilities with comparative statistics on all (public and private) facilities. The data in Part II were gathered as part of the Institutional Population Component of the 1987 National Medical Expenditure Survey. In addition to these basic findings a description is provided of the origin and methods of this survey. The authors are grateful to the Office of the Assistant Secretary for Planning and Evaluation (especially John Drabek, Mary Harahan and Bob Clark) and the National Center for Health Services Research (especially Dan Walden) for assistance in acquiring and understanding this important data base.

Part III of this report places Fiscal Year 1988 statistics described in Part I within the longitudinal context of data gathered on state institution populations, resident movement, and costs of care since 1950. A brief historical review of these and other preceding surveys since 1950 can be found in Lakin,

Hill, Street, and Bruininks (1986). For a more detailed review, including surveys and statistics since 1880, see Lakin (1979).

As noted, this report distinguishes among facilities by size, notably those with 15 or fewer residents (1-15) and those with 16 or more residents (16+). It also distinguishes between two general classes of state-operated facility:

Public Residential Facilities/Mental Retardation (PRF/MR) are state-operated (public, in a slightly restricted sense) residential facilities managed and operated by state employees, which as a whole or as distinct administrative units are designated to be primarily or exclusively for persons with mental retardation and related conditions.

Other Public Residential Facilities (PRF/Other) are state-operated (public) residential facilities managed and operated by state employees, which as a whole are designated for persons with disabilities other than mental retardation (in the vast majority of cases, mental health facilities), but in which reside one or more persons with a primary diagnosis of mental retardation or a formal dual diagnosis including mental retardation.

For the purposes of this report, persons with "mental retardation" are those who have been so designated by their respective state governments as part of the process of placing them in the state residential care system. The formal and currently accepted definition of mental retardation is "significant subaverage general intellectual functioning (generally an I.Q. of 69 or below) existing concurrently with deficits in adaptive behavior, and manifested during the developmental period" (Grossman, 1977, p. 11). "Related conditions" refer to conditions closely associated with mental retardation that cause or substantially contribute to developmental disabilities.

Persons designated as multiply handicapped (mentally retarded/mentally ill) living in "PRF/Other" present some states with reporting problems, though the problems have become considerably fewer as procedures and data management have improved and the "PRF/Other" population of persons with mental retardation has decreased. Nevertheless, the actual number of persons residing in PRF/Other who have mental retardation may be slightly higher than the number reported in some states.

**PART I: PERSONS WITH MENTAL RETARDATION AND RELATED CONDITIONS
IN STATE-OPERATED RESIDENTIAL FACILITIES: YEAR ENDING JUNE 30, 1988**

Methodology

The survey questionnaire for State-Operated Residential Facilities, Fiscal Year 1988, was mailed with a cover letter to each state's mental retardation/developmental disabilities program director or the state's designated "data supplier" on March 3, 1989. The questionnaire on state-operated facilities was Part I of a three-part survey which also included sections on nonstate facilities and ICF-MR certified facilities. This questionnaire and its cover letter are included in Appendix A. Telephone follow-up began two weeks later to determine which individual(s) within each state agency had been given responsibility for compiling the requested statistics and to clarify questions respondents may have about the data requested. A second mailing to 22 states was necessary.

Additional follow-up telephone calls to promote initial response and to clarify and edit the statistics on returned questionnaires continued until August 1989, when draft tables of the data prepared from the state questionnaires were sent to all states for verification. Corrections and special notes on state data were completed by December 1989. Compiling statistics from states on the three-part survey took an average of five telephone conversations generally involving one to four different people in each state. In nine states contacts were made with both mental retardation and mental health agencies to gather the required statistics for public residential facilities for persons with mental retardation or related conditions (PRF/MR) and public residential facilities for persons with other primary conditions—almost exclusively psychiatric conditions (PRF/Other). In two states data on PRF/MR were obtained from individual state-operated residential facilities. New data collection systems in a few states resulted in some delay in reporting the requested statistics for Fiscal Year 1988. State agencies in Arizona and Massachusetts were unable to provide the requested data for this period but agreed to estimation procedures that are detailed in the *State Notes* in Appendix B.

Response rates for each of the items on the questionnaire are shown in Table 1. For PRF/MR, item response rates ranged from 80% to 98% with generally higher rates for the larger traditional

institutions than for the 15 or fewer resident facilities. Item response rates for PRF/Other ranged from 74% to 98%. Data elements of the state agency survey covered the number of facilities and residents, resident movement, and the costs of care. The specific elements and the corresponding definitions for the state agency survey can be found in the survey instrument attached as Appendix A.

Table 1
Response Rates by Survey Item and Facility Type, Fiscal Year 1988

<u>Survey Items</u>	<u>% of PRF/MR</u>		<u>% of PRF/Other</u>
	<u>1-15 res.</u>	<u>16+ res.</u>	
1. Number of Facilities	96	100	96
2. Residents Beginning of Year (July 1, 1987)	96	96	96
3. Average Daily Residents (Fiscal Year)	96	96	96
4. Residents End of Year (June 30, 1988)	96	96	96
5. First Admissions During Year	88	92	76
6. Readmissions During Year	86	80	74
7. Live Releases During Year	88	92	80
8. Deaths During Year	90	94	78
9. Per Diem Cost	90	98	98

In recent years every state has increased efforts to place residents of large state facilities into smaller residential facilities. To assist in the effort several states have established state-operated, community based group homes and/or apartment programs. For the third year, in addition to collecting data on state institution and state hospital populations, this survey also collected data from each state specifically on residents of state-operated facilities with 15 or fewer residents, frequently referred to as "small" in this report. A further breakdown of data on small facilities into sizes 1-6 and 7-15 was requested for the first time in these surveys. All states except Arizona and Massachusetts provided these data on the number of facilities and residents.

Limitations are encountered when gathering statistics at the state level. Most notable among these are the variations in the types of statistics maintained by the various states, in other instances in the specific operational definitions governing certain data elements. For example, several states indicated that they were unable to provide data on first admissions, readmissions, and releases according to the specific survey definitions, while in others, transfers between state-operated facilities,

and respite care placements could not be separated from other movement as the survey instructions requested. General problems in the collection of the data are presented in the discussion accompanying each table in the body of the report. Specific state idiosyncracies are reported in the State Notes in Appendix B. Although these variations are noted, it is not likely that they have a substantial effect on national or state totals or on the longitudinal trends presented in this report.

Findings and Discussion

The following eleven tables and accompanying discussion summarize the statistics reported on state-operated residential facilities for the year ending June 30, 1988. The report is organized so that the discussion and accompanying tables are presented side by side. Definitions for each data element as well as the variations and problems in definitions as employed in the various states are noted in the discussion. Each table is also accompanied by a short summary of highlights of the state and national statistics presented.

In the discussion of these statistics, the descriptor "small" and the abbreviation "1-15 res." are used for state-operated facilities with 15 or fewer residents. Data on these small facilities are further reported as facilities of 1-6 residents and 7-15 residents where those statistics were available from the states. The descriptor "large" and the abbreviation "16+ res." are used in this report for state-operated facilities with 16 or more residents. No distinction is made for "large" or "small" PRF/Other, as all are assumed to be large, that is to have 16 or more residents.

In the tables of this report a common set of symbols is used for estimated or unavailable statistics. These symbols are:

- DNF** "Data Not Furnished" is used where states were unable to report the specific type of data requested. It is assumed that this number is larger than zero, but it is unknown.
- (e)** "Estimated" data have been provided where exact statistics were not available. It is assumed that these state estimates represent the best available information under existing circumstances.
- N/A** "Not Applicable" is used where no data are reported in a particular cell of the table because a specific category of facility is not used in a state. It is the equivalent of "0," but is used where the value "0" would have distorted averaged U.S. statistics.

Number of State-Operated Residential Facilities

Table 2 presents statistics by state on the number of state-operated residential facilities serving persons with mental retardation and related conditions in the United States on June 30, 1988. Separate counts are provided for facilities serving persons with mental retardation and related conditions in PRF/MR with 15 or fewer residents (1-15), further summarized by sizes 1-6 residents and 7-15 residents; PRF/MR with 16 or more residents; PRF/Other; and total state-operated facilities.

On June 30, 1988, states reported a total of 1,177 state-operated residential facilities serving persons with mental retardation and related conditions. Of these 1,055 were PRF/MR and 122 were PRF/Other. Of the 1,055 PRF/MR, 759 had 15 or fewer residents; 296 had 16 or more residents. All states operated at least one large PRF/MR on June 30, 1988; 16 states operated at least one small PRF/MR. Twenty-two states reported at least one PRF/Other housing persons with mental retardation in units not specifically for persons with mental retardation. The total of 759 small state-operated facilities on June 30, 1988, represented an increase of about 17% (110 facilities) between June 30, 1987 and June 30, 1988, although some of the change reflects improved reporting. It is projected that the development of state-operated residential programs will continue, at least for the near future (see Lakin, Jaskulski, Hill, Bruininks, Menke, White, & Wright, 1989). The greatest number of small PRF/MR were operated by New York (469 facilities) and Texas (103 facilities), which together had 76% of all small state-operated facilities on June 30, 1988.

The number of large state-operated facilities has remained relatively stable during the past several years. Between June 30, 1987 and June 30, 1988 the number of large PRF/MR increased by 10 and the reported number of PRF/Other decreased by 22. Part of this change was the result of reclassification of PRF/Other with distinct mental retardation units into the category of PRF/MR in Ohio, Hawaii, and New Hampshire. In addition some states have recently opened relatively small, but still more than 15 resident PRF/MR. New Jersey, North Dakota, and Pennsylvania reported fewer large PRF/MR than in Fiscal Year 1987.

Table 2

Number of State-Operated Residential Facilities Serving
Persons with Mental Retardation and Related Conditions on June 30, 1988 by State

State	Small PRF/MR			Large PRF			Total State-Operated Facilities
	1-6 res.	7-15 res.	1-15 Total	PRF/MR 16+ res.	PRF/Other	Large Total	
ALABAMA	0	0	0	5	0	5	5
ALASKA	0	0	0	1	1	2	2
ARIZONA	14e	0e	14e	3e	0e	3e	17e
ARKANSAS	0	1	1	6	0	6	7
CALIFORNIA	0	0	0	7	0	7	7
COLORADO	0	36	36	3	0	3	39
CONNECTICUT	29	36	65	13	6	21	86
DELAWARE	0	0	0	1	0	1	1
D.C.	0	0	0	1	1	2	2
FLORIDA	0	0	0	6	4	10	10
GEORGIA	0	0	0	6	4	12	12
HAWAII	0	0	0	2	0	2	2
IDAHO	0	0	0	1	0	1	1
ILLINOIS	0	0	0	13	6	19	19
INDIANA	0	0	0	9	0	9	9
IOWA	0	0	0	2	0	2	2
KANSAS	0	0	0	4	0	4	4
KENTUCKY	0	0	0	4	5	9	9
LOUISIANA	5	0	5	9	0	9	14
MAINE	0	2	2	2	2	4	6
MARYLAND	0	1	1	7	8e	15	16
MASSACHUSETTS	0e	3e	3e	7e	17e	24e	27e
MICHIGAN	0	0	0	8	0	8	8
MINNESOTA	7	0	7	7	2	9	16
MISSISSIPPI	26	2	28	5	0	5	33
MISSOURI	0	2	2	10	10	20	22
MONTANA	0	0	0	2	0	2	2
NEBRASKA	0	0	0	1	0	1	1
NEVADA	0	0	0	2	0	2	2
NEW HAMPSHIRE	0	0	0	2	0	2	2
NEW JERSEY	0	0	0	9	6	15	15
NEW MEXICO	0	0	0	2	0	2	2
NEW YORK	127	342	469	37	30	67	536
NORTH CAROLINA	0	0	0	6	0	6	6
NORTH DAKOTA	0	1	1	1	1	2	3
OHIO	0	0	0	20	0	20	20
OKLAHOMA	0	0	0	3	0	3	3
OREGON	0	0	0	2	0	2	2
PENNSYLVANIA	0	0	0	14	0	14	14
RHODE ISLAND	11	10	21	2	1	3	24
SOUTH CAROLINA	0	1	1	5	0	5	6
SOUTH DAKOTA	0	0	0	2	1	3	3
TENNESSEE	0	0	0	5	5	10	10
TEXAS	59	44	103	17	0	17	120
UTAH	0	0	0	1	0	1	1
VERMONT	0	0	0	1	0	1	1
VIRGINIA	0	0	0	5	4	9	9
WASHINGTON	0	0	0	6	2	8	8
WEST VIRGINIA	0	0	0	3	2	5	5
WISCONSIN	0	0	0	3	2	5	5
WYOMING	0	0	0	1	0	1	1
U.S. TOTAL	278	491	759	296	122	418	1,177

Average Daily Population of Persons With Mental Retardation and Related Conditions in State-Operated Residential Facilities

Table 3 presents state reported statistics on the average daily number of persons with mental retardation and related conditions living in large and small PRF/MR and PRF/Other in Fiscal Year 1988. For five states unable to furnish average daily resident data for a particular facility size category, the year end on roll population in that category was used as the best estimate.

During FY 1988 states had an average daily population of 99,095 persons with mental retardation and related conditions in all state-operated residential facilities. This included 5,580 in small PRF/MR, 91,582 in large PRF/MR, and 1,933 in PRF/Other categories. In FY 1987 the average daily population of people with mental retardation and related conditions in all PRF/MR and PRF/Other was 102,075, including 97,533 residents of large PRF/MR and PRF/Other and 4,542 residents in small PRF/MR. Between June 30, 1987 and June 30, 1988 the total number of persons with mental retardation and related conditions in large state-operated facilities (both PRF/MR and PRF/Other) decreased by 4,018 persons (or about 4.1%). During the same period the average daily population of persons with mental retardation and related conditions in small PRF/MR increased by nearly 23%. New York showed the largest increase in small PRF/MR residents (695). However, some of the computed national increase was also due in part to improved reporting by states. Thirty-five states did not operate small residential programs, although large numbers of smaller facilities are found in many of these states managed as private nonprofit or proprietary programs.

As has been the case each year for the past 20 years, there was a decrease in average daily population of persons with mental retardation and related conditions in large state-operated facilities between Fiscal Year 1987 and Fiscal Year 1988. Decreases were again evident in nearly every state. Only 5 states reported the same or increasing total populations in large PRF/MR and PRF/Other combined, with the greatest increase being 27 in Missouri. Over one third (34,190) of the total U.S. daily average number of persons in state-operated facilities in this study resided in the states of California, New Jersey, New York, and Texas. In addition to having 67.3% of small PRF/MR residents, New York had 11.0% of all residents of large PRF/MR and PRF/Other residential programs.

Table 3

Average Daily Population of Persons with Mental Retardation and Related
Conditions in State-Operated Residential Facilities in Fiscal Year 1988 by State

State	Small PRF/MR			Large PRF			Total in State- Operated Facilities
	1-6 res.	7-15 res.	1-15 Total	PRF/MR 16+ res.	PRF/Other	Large Total	
ALABAMA	0	0	0	1,315	0	1,315	1,315
ALASKA	0	0	0	58	2e	60	60
ARIZONA	78e	0e	78e	368e	0	466	544
ARKANSAS	0	12	12	1,303	0	1,315	1,327
CALIFORNIA	0	0	0	6,725	0	6,725	6,725
COLORADO	0	274e	274e	590	0	854	1,128
CONNECTICUT	117	272	389	2,163	45	2,597	2,966
DELAWARE	0	0	0	370	0	370	370
D.C.	0	0	0	263e	100e	363	363
FLORIDA	0	0	0	1,999	135e	2,134	2,134
GEORGIA	0	0	0	2,058	78	2,136	2,136
HAWAII	0	0	0	232	0	232	232
IDAHO	0	0	0	259	0	259	259
ILLINOIS	0	0	0	4,469	37	4,506	4,506
INDIANA	0	0	0	1,930e	0	1,930	1,930
IOWA	0	0	0	1,062	0	1,062	1,062
KANSAS	0	0	0	1,149	0	1,149	1,149
KENTUCKY	0	0	0	749	18	767	767
LOUISIANA	30	0	30	2,785	0	2,815	2,845
MAINE	0	26	26	281	11e	318	344
MARYLAND	0	11	11	1,430	94e	1,535	1,546
MASSACHUSETTS	0	24e	24e	3,401e	318e	3,743	3,767
MICHIGAN	0	0	0	1,547e	0	1,547	1,547
MINNESOTA	28	0	28	1,559	77e	1,664	1,692
MISSISSIPPI	169	15	184	1,507	0	1,691	1,875
MISSOURI	0	15	15	1,865	65e	1,945	1,960
MONTANA	0	0	0	249	0	249	249
NEBRASKA	0	0	0	470	0	470	470
NEVADA	0	0	0	171	0	171	171
NEW HAMPSHIRE	0	0	0	162	0	162	162
NEW JERSEY	0	0	0	5,278	94	5,372	5,372
NEW MEXICO	0	0	0	498	0	498	498
NEW YORK	408e	3,351e	3,757e	9,866	568	14,021	17,778
NORTH CAROLINA	0	0	0	2,835	0	2,835	2,835
NORTH DAKOTA	0	11	11	312	19	342	353
OHIO	0	0	0	2,993	0	2,993	2,993
OKLAHOMA	0	0	0	1,170	0	1,170	1,170
OREGON	0	0	0	1,131	0	1,131	1,131
PENNSYLVANIA	0	0	0	4,426	0	4,426	4,426
RHODE ISLAND	64	102	166	263	26	475	641
SOUTH CAROLINA	0	9	9	2,467	0	2,476	2,485
SOUTH DAKOTA	0	0	0	440	15e	455	455
TENNESSEE	0	0	0	2,011	64	2,075	2,075
TEXAS	190e	376e	566e	7,506	0	8,072	8,631
UTAH	0	0	0	536	0	536	536
VERMONT	0	0	0	190	0	190	190
VIRGINIA	0	0	0	2,828	57	2,885	2,885
WASHINGTON	0	0	0	1,800	22e	1,822	1,822
WEST VIRGINIA	0	0	0	478	26	504	504
WISCONSIN	0	0	0	1,866	32e	1,866	1,866
WYOMING	0	0	0	399	0	399	399
U.S. Total	1,062	4,496	5,580	91,562	1,933	99,095	104,675

**Average Daily Population of Persons With Mental Retardation and Related Conditions
in State-Operated Residential Facilities per 100,000 of the General Population**

Table 4 presents the average daily population of persons with mental retardation and related conditions in state-operated residential facilities for Fiscal Year 1988 per 100,000 of state and national populations on July 1, 1988. This statistic is referred to here as the "placement rate."

For Fiscal Year 1988 the national placement rate for all state-operated facilities was 40.4 compared to 42.0 one year earlier. Contributing to the decrease in the placement rate for all state-operated facilities was the decrease in the national placement rate for all large facilities (from 40.1 in 1987 to 38.1 in 1988). This included decreases for both large PRF/MR (from 38.9 in 1987 to 37.3 in 1988) and for PRF/Other (from 1.2 in 1987 to 0.8 in 1988). During the same year the national placement rate for small PRF/MR increased from 1.9 to 2.3 in the same period.

The national decrease in placement rate between Fiscal Years 1987 and 1988 in large state-operated facilities was evident in almost all states. Small increases in the placement rate occurred in New Mexico (32.0 to 33.1) and in Wyoming (81.2 to 83.3), partly due to decreases in the population of those two states. Rates in Alabama, Alaska, Illinois, Mississippi, Missouri, Oklahoma, and Utah remained essentially the same. North Dakota showed the largest decrease in large facility placement rate (from 65.7 in 1987 to 49.6 in 1988) continuing its dramatic decline from the highest rate nationally in earlier years of this study. Other states that experienced a decrease of 5 or more per 100,000 population were Connecticut, District of Columbia, New Hampshire, Pennsylvania, and South Dakota.

In addition to Wyoming, the only other states showing placement rates of 70 or more per 100,000 in large state facilities were South Carolina (71) and New Jersey (70). The states with the lowest placement in large state-operated facilities in 1988 were Alaska, Arizona, Colorado, Nevada, New Hampshire, Florida, and Michigan, all below 20 per 100,000. The highest placement rates in small state-operated facilities were in New York (21.0), Rhode Island (16.7), and Connecticut (12.0).

Table 4

Average Daily Population of Persons with Mental Retardation and Related Conditions
in State-Operated Residential Facilities per 100,000 of the General Population in Fiscal Year 1988

State	7/1/88 State Pop.	Average Daily Residents					Placements per 100,000					
		Small PRF/MR			Large PRF		Small PRF/MR			Large PRF		
		1-6 res.	7-15 res.	1-15 Total	PRF/MR 16+ res.	PRF/ Other	1-6 res.	7-15 res.	1-15 Total	PRF/MR 16+ res.	PRF/ Other	Large Total
AL	41.02	0	0	0	1,315	0	.0	.0	.0	32.1	.0	32.1
AK	5.24	0	0	0	58	2e	.0	.0	.0	11.1	.4	11.5
AZ	34.89	78e	DNF	78e	388e	0	2.2	.0	2.2	11.1	.0	11.1
AR	23.95	0	12	12	1,303	0	.0	.5	.5	54.4	.0	54.4
CA	283.14	0	0	0	6,725	0	.0	.0	.0	23.8	.0	23.8
CO	33.01	0	274e	274e	580	0	.0	8.3	8.3	17.6	.0	17.6
CT	32.33	117	272	389	2,163	45	3.6	8.4	12.0	66.9	1.4	68.3
DE	6.60	0	0	0	370	0	.0	.0	.0	56.1	.0	56.1
DC	6.17	0	0	0	263e	100e	.0	.0	.0	42.6	16.2	58.8
FL	123.35	0	0	0	1,999	135e	.0	.0	.0	16.2	1.1	17.3
GA	63.42	0	0	0	2,058	78	.0	.0	.0	32.5	1.2	33.7
HI	10.98	0	0	0	232	0	.0	.0	.0	21.1	.0	21.1
ID	10.03	0	0	0	259	0	.0	.0	.0	25.8	.0	25.8
IL	116.14	0	0	0	4,469	37	.0	.0	.0	36.5	.3	36.8
IN	55.56	0	0	0	1,930e	0	.0	.0	.0	34.7	.0	34.7
IA	28.34	0	0	0	1,062	0	.0	.0	.0	37.5	.0	37.5
KS	24.95	0	0	0	1,149	0	.0	.0	.0	46.1	.0	46.1
KY	37.27	0	0	0	749	18	.0	.0	.0	20.1	.5	20.6
LA	44.08	30	0	30	2,785	0	.7	.0	.7	63.2	.0	63.2
ME	12.05	0	26	26	281	11e	.0	2.2	2.2	23.3	.9	24.2
MD	48.22	0	11	11	1,430	94e	.0	.2	.2	30.9	2.0	33.0
MA	58.89	0e	24e	24e	3,401e	318e	.0	.4	.4	57.8	5.4	63.2
MI	92.40	0	0	0	1,547e	0	.0	.0	.0	16.7	.0	16.7
MN	43.07	28	0	28	1,559	77e	.7	.0	.7	36.2	1.3	38.0
MS	26.20	189	15	184	1,507	0	6.5	.6	7.0	57.5	.0	57.5
MO	51.41	0	15	15	1,865	65e	.0	.3	.3	36.3	1.3	37.5
MT	8.05	0	0	0	249	0	.0	.0	.0	30.9	.0	30.9
NE	16.02	0	0	0	470	0	.0	.0	.0	29.3	.0	29.3
NV	10.54	0	0	0	171	0	.0	.0	.0	16.2	.0	16.2
NH	10.85	0	0	0	162	0	.0	.0	.0	14.9	.0	14.9
NJ	77.21	0	0	0	5,278	94	.0	.0	.0	68.4	1.2	69.6
NM	15.07	0	0	0	498	0	.0	.0	.0	33.0	.0	33.0
NY	179.09	406e	3,351e	3,757e	9,886	598	2.3	18.7	21.0	54.0	3.3	57.3
NC	64.89	0	0	0	2,835	0	.0	.0	.0	43.7	.0	43.7
ND	6.67	0	11	11	312	19	.0	1.6	1.6	46.8	2.8	49.6
OH	108.55	0	0	0	2,993	0	.0	.0	.0	27.6	.0	27.6
OK	32.42	0	0	0	1,170	0	.0	.0	.0	36.1	.0	36.1
OR	27.87	0	0	0	1,131	0	.0	.0	.0	40.9	.0	40.9
PA	120.01	0	0	0	4,428	0	.0	.0	.0	36.9	.0	36.9
RI	9.93	64	102	166	283	26	6.4	10.3	16.7	28.5	2.6	31.1
SC	34.70	0	9	9	2,467	0	.0	.3	.3	71.1	.0	71.1
SD	7.13	0	0	0	440	15e	.0	.0	.0	61.7	2.1	63.8
TN	48.95	0	0	0	2,011	64	.0	.0	.0	41.1	1.3	42.4
TX	188.41	190e	376e	566e	7,508	0	1.1	2.2	3.4	44.6	.0	44.6
UT	16.90	0	0	0	536	0	.0	.0	.0	31.7	.0	31.7
VT	5.57	0	0	0	190	0	.0	.0	.0	34.1	.0	34.1
VA	60.15	0	0	0	2,828	57	.0	.0	.0	47.0	.9	48.0
WA	46.48	0	0	0	1,000	22e	.0	.0	.0	36.7	.5	39.2
WV	18.76	0	0	0	478	26	.0	.0	.0	25.5	1.4	26.9
WI	48.55	0	0	0	1,836	32e	.0	.0	.0	37.8	.7	38.5
WY	4.79	0	0	0	399	0	.0	.0	.0	83.3	.0	83.3
U.S.	2,459.07	1,082	4,498	5,580	91,582	1,933	.4	1.8	2.3	37.3	.8	38.0

***Persons With Mental Retardation and Related Conditions on the Rolls
of State-Operated Facilities at the Beginning and End of the Year***

Tables 5, 6 and 7 present statistics on the number of persons with mental retardation and related conditions on the rolls of state-operated facilities on the first and last days of Fiscal Year 1988. Table 5 presents statistics on the number of persons with mental retardation and related conditions in small PRF/MR (15 or fewer residents), large PRF/MR (16 or more residents), and PRF/Other on July 1, 1987. The small facilities are further classified into 1-6 residents and 7-15 residents where data were available. Table 6 presents the same statistics for the same categories of state-operated facilities on June 30, 1988. Table 7 presents statistics on the net change in the number of residents with mental retardation and related conditions in large and small PRF/MR and PRF/Other from July 1, 1987 to June 30, 1988.

As shown most clearly in Table 7, there was a consistent tendency for states to reduce the number of persons with mental retardation and related conditions on the rolls of large state-operated facilities in Fiscal Year 1988. Overall, nationally there was a decrease of 3.9% in the on-rolls population of those facilities from the beginning to the end of Fiscal Year 1988. Four states showed a net increase in large state facility populations over that period, reporting a total increase of 68 residents or .6% over the year. New Mexico reported the largest relative increase of 1.4% although the overall numerical increase was quite small (7 residents).

Nine states reported a net reduction of more than 10% in the number of persons with mental retardation and related conditions in their large state-operated facilities between July 1, 1987 and June 30, 1988. The largest decreases were in Hawaii (21%), New Hampshire (20%), and Colorado (16%). The number of residents in small PRF/MR increased by about 14% during Fiscal Year 1988 due primarily to growth in this category in New York and Texas. The number of PRF/Other residents with mental retardation was indicated to have declined about 12% nationally during the year, but some of this change can be attributed to the reclassification of some PRF/Other to PRF/MR, as distinct units for persons with mental retardation have been formed in facilities that were formerly in the PRF/Other classification.

Table 5

Persons with Mental Retardation and Related Conditions on Rols of State-Operated Residential Facilities at the Beginning of Fiscal Year 1988 by State

State	Small PRF/MR			Large PRF			Total in State-Operated Facilities
	1-6 res.	7-15 res.	1-15 Total	PRF/MR 16+ res.	PRF/Other	Large Total	
ALABAMA	0	0	0	1,341	0	1,341	1,341
ALASKA	0	0	0	60	2e	62	62
ARIZONA	DNF	DNF	134e	423e	0e	423	557
ARKANSAS	0	12	12	1,322	0	1,322	1,334
CALIFORNIA	0	0	0	6,820	0	6,820	6,820
COLORADO	0	273	273	630	0	630	903
CONNECTICUT	72	311	383	2,298	71	2,369	2,752
DELAWARE	0	0	0	383	0	383	383
D.C.	0	0	0	271	100e	371	371
FLORIDA	0	0	0	2,065	136e	2,201	2,201
GEORGIA	0	0	0	2,055	62	2,117	2,117
HAWAII	0	0	0	267	0	267	267
IDAHO	0	0	0	273	0	273	273
ILLINOIS	0	0	0	4,436	23	4,459	4,459
INDIANA	0	0	0	2,279	0	2,279	2,279
IOWA	0	0	0	1,057	0	1,057	1,057
KANSAS	0	0	0	1,298	0	1,298	1,298
KENTUCKY	0	0	0	766	89	855	855
LOUISIANA	30	0	30	2,882	0	2,882	2,912
MAINE	0	26	26	278	33	311	337
MARYLAND	0	12	12	1,452	106e	1,558	1,570
MASSACHUSETTS	0	24e	24e	3,367e	318e	3,685	3,709
MICHIGAN	0	0	0	1,658	0	1,658	1,658
MINNESOTA	28	0	28	1,624	85e	1,709	1,737
MISSISSIPPI	167	15	182	1,512	0	1,512	1,694
MISSOURI	0	16	16	1,873	78	1,951	1,967
MONTANA	0	0	0	255	0	255	255
NEBRASKA	0	0	0	476	0	476	476
NEVADA	0	0	0	172	0	172	172
NEW HAMPSHIRE	0	0	0	180	0	180	180
NEW JERSEY	0	0	0	5,313	134e	5,447	5,447
NEW MEXICO	0	0	0	500	0	500	500
NEW YORK	DNF	DNF	3,218e	9,965	669	10,654	13,872
NORTH CAROLINA	0	0	0	2,984	0	2,984	2,984
NORTH DAKOTA	0	12	12	334	27	361	373
OHIO	0	0	0	3,095	0	3,095	3,095
OKLAHOMA	0	0	0	1,276	0	1,276	1,276
OREGON	0	0	0	1,145	0	1,145	1,145
PENNSYLVANIA	0	0	0	5,307	0	5,307	5,307
RHODE ISLAND	57	102	159	305	27	332	491
SOUTH CAROLINA	0	10	10	2,530	0	2,530	2,540
SOUTH DAKOTA	0	0	0	485	15e	500	500
TENNESSEE	0	0	0	2,068	71	2,139	2,139
TEXAS	DNF	DNF	444e	7,936	0	7,936	8,380
UTAH	0	0	0	548	0	548	548
VERMONT	0	0	0	198	0	198	198
VIRGINIA	0	0	0	2,830	85	2,935	2,935
WASHINGTON	0	0	0	1,808	21	1,829	1,829
WEST VIRGINIA	0	0	0	469	42	511	511
WISCONSIN	0	0	0	1,877	32e	1,909	1,909
WYOMING	0	0	0	437	0	437	437
U.S. Total			4,963	95,201	2,226	97,427	102,390

Table 6

Persons with Mental Retardation and Related Conditions on the Rolls of
State-Operated Residential Facilities at the End of Fiscal Year 1988 by State

State	Small PRF/MR			Large PRF			Total in State- Operated Facilities
	1-6 res.	7-15 res.	1-15 Total	PRF/MR 16+ res.	PRF/Other	Large Total	
ALABAMA	0	0	0	1,333	0	1,333	1,333
ALASKA	0	0	0	57	2 ^e	59	59
ARIZONA	DNF	DNF	78 ^e	388 ^e	0	388	466
ARKANSAS	0	12	12	1,302	0	1,302	1,314
CALIFORNIA	0	0	0	6,826	0	6,826	6,826
COLORADO	0	274	274	529	0	529	803
CONNECTICUT	121	273	394	2,137	38	2,175	2,569
DELAWARE	0	0	0	374	0	374	374
D.C.	0	0	0	356	100 ^e	356	356
FLORIDA	0	0	0	2,019	135 ^e	2,154	2,154
GEORGIA	0	0	0	2,056	59	2,117	2,117
HAWAII	0	0	0	210	0	210	210
IDAHO	0	0	0	236	0	236	236
ILLINOIS	0	0	0	4,482	31	4,513	4,513
INDIANA	0	0	0	2,015	0	2,015	2,015
IOWA	0	0	0	1,056	0	1,056	1,056
KANSAS	0	0	0	1,237	0	1,237	1,237
KENTUCKY	0	0	0	757	89	846	846
LOUISIANA	30	0	30	2,769	0	2,769	2,819
MAINE	0	24	24	290	11	301	325
MARYLAND	0	11	11	1,418	106 ^e	1,524	1,535
MASSACHUSETTS	0	24 ^e	24 ^e	3,367 ^e	318 ^e	3,685	3,709
MICHIGAN	0	0	0	1,436	0	1,436	1,436
MINNESOTA	28	0	28	1,471	75 ^e	1,546	1,574
MISSISSIPPI	169	15	184	1,505	0	1,505	1,689
MISSOURI	0	15	15	1,889	56	1,945	1,960
MONTANA	0	0	0	243	0	243	243
NEBRASKA	0	0	0	472	0	472	472
NEVADA	0	0	0	173	0	173	173
NEW HAMPSHIRE	0	0	0	144	0	144	144
NEW JERSEY	0	0	0	5,234	126	5,360	5,360
NEW MEXICO	0	0	0	507	0	507	507
NEW YORK	406	3,351	3,757	9,507	572	10,079	13,836
NORTH CAROLINA	0	0	0	2,845	0	2,845	2,845
NORTH DAKOTA	0	11	11	316	20	336	347
OHIO	0	0	0	2,888	0	2,888	2,888
OKLAHOMA	0	0	0	1,186	0	1,186	1,186
OREGON	0	0	0	1,098	0	1,098	1,098
PENNSYLVANIA	0	0	0	4,606	0	4,606	4,606
RHODE ISLAND	71	103	174	261	26	287	461
SOUTH CAROLINA	0	9	9	2,437	0	2,437	2,446
SOUTH DAKOTA	0	0	0	434	15 ^e	449	449
TENNESSEE	0	0	0	2,017	58	2,075	2,075
TEXAS	211	418	629	7,833	0	7,833	8,562
UTAH	0	0	0	533	0	533	533
VERMONT	0	0	0	186	0	186	186
VIRGINIA	0	0	0	2,774	72	2,846	2,846
WASHINGTON	0	0	0	1,801	24	1,825	1,825
WEST VIRGINIA	0	0	0	456	5	461	461
WISCONSIN	0	0	0	1,796	32 ^e	1,828	1,828
WYOMING	0	0	0	419	0	419	419
U.S. Total	1,036	4,540	5,654	91,703	1,970	93,673	99,327

Table 7

Net Change in the Number of Persons with Mental Retardation and Related Conditions on the Rolls of State-Operated Residential Facilities on the First and Last Day of Fiscal Year 1988 by State

State	PRF/MR									Total Large (16+)		
	1-15 res.			16+ res.			PRF/Other			PRF/MR and PRF/Other		
	Begin	End	Percent	Begin	End	Percent	Begin	End	Percent	Begin	End	Percent
AL	0	0	--	1,341	1,333	-0.6%	0	0	--	1,341	1,333	-0.6%
AK	0	0	--	60	57	-5.0%	2	2	.0%	62	59	-4.8%
AZ	134	78	-41.8%	423	388	-8.3%	0	0	--	423	388	-8.3%
AR	12	12	.0%	1,322	1,302	-1.5%	0	0	--	1,322	1,302	-1.5%
CA	0	0	--	6,820	6,826	.1%	0	0	--	6,820	6,826	.1%
CO	273	274	.4%	630	529	-16.0%	0	0	--	630	529	-16.0%
CT	363	394	2.9%	2,298	2,137	-7.0%	71	38	-48.5%	2,369	2,175	-8.2%
DE	0	0	--	363	374	2.3%	0	0	--	363	374	2.3%
DC	0	0	--	271	256	-5.5%	100	100	.0%	371	356	-4.0%
FL	0	0	--	2,065	2,019	-2.2%	136	135	-.7%	2,201	2,154	-2.1%
GA	0	0	--	2,055	2,056	.1%	62	59	-4.8%	2,117	2,117	.0%
HI	0	0	--	267	210	-21.3%	0	0	--	267	210	-21.3%
ID	0	0	--	273	236	-13.6%	0	0	--	273	236	-13.6%
IL	0	0	--	4,436	4,482	1.0%	23	31	34.8%	4,459	4,513	1.2%
IN	0	0	--	2,279	2,015	-11.6%	0	0	--	2,279	2,015	-11.6%
IA	0	0	--	1,057	1,056	-.1%	0	0	--	1,057	1,056	-.1%
KS	0	0	--	1,298	1,237	-4.7%	0	0	--	1,298	1,237	-4.7%
KY	0	0	--	766	757	-1.2%	89	89	.0%	855	846	-1.1%
LA	30	30	.0%	2,882	2,789	-3.2%	0	0	--	2,882	2,789	-3.2%
ME	26	24	-7.7%	278	280	4.3%	33	11	-66.7%	311	301	-3.2%
MD	12	11	-8.3%	1,452	1,416	-2.3%	106	106	.0%	1,558	1,524	-2.2%
MA	24	24	N/A	3,367	3,367	N/A	318	318	.0%	3,685	3,685	N/A
MI	0	0	--	1,658	1,436	-13.4%	0	0	--	1,658	1,436	-13.4%
MN	28	28	.0%	1,624	1,471	-9.4%	85	75	-11.8%	1,709	1,546	-9.5%
MS	182	184	1.1%	1,512	1,505	-.5%	0	0	--	1,512	1,505	-.5%
MO	16	15	-6.3%	1,873	1,889	.9%	78	58	-26.2%	1,951	1,945	-.3%
MT	0	0	--	255	243	-4.7%	0	0	--	255	243	-4.7%
NE	0	0	--	478	472	-.8%	0	0	--	478	472	-.8%
NV	0	0	--	172	173	.6%	0	0	--	172	173	.6%
NH	0	0	--	180	144	-20.0%	0	0	--	180	144	-20.0%
NJ	0	0	--	5,313	5,234	-1.5%	134	126	-6.0%	5,447	5,360	-1.6%
NM	0	0	--	500	507	1.4%	0	0	--	500	507	1.4%
NY	3,218	3,757	16.7%	9,985	9,507	-4.8%	689	572	-14.5%	10,654	10,079	-5.4%
NC	0	0	--	2,964	2,845	-4.0%	0	0	--	2,964	2,845	-4.0%
ND	12	11	-8.3%	334	316	-5.4%	27	20	-25.9%	361	336	-6.9%
OH	0	0	--	3,095	2,888	-6.7%	0	0	--	3,095	2,888	-6.7%
OK	0	0	--	1,278	1,186	-7.1%	0	0	--	1,278	1,186	-7.1%
OR	0	0	--	1,145	1,088	-4.1%	0	0	--	1,145	1,088	-4.1%
PA	0	0	--	5,307	4,806	-9.2%	0	0	--	5,307	4,806	-9.2%
RI	159	174	9.4%	305	261	-14.4%	27	26	-3.7%	332	267	-13.6%
SC	10	9	-10.0%	2,530	2,437	-3.7%	0	0	--	2,530	2,437	-3.7%
SD	0	0	--	485	434	-10.5%	15	15	.0%	500	449	-10.2%
TN	0	0	--	2,088	2,017	-2.5%	71	58	-18.3%	2,139	2,075	-3.0%
TX	444	629	41.7%	7,938	7,933	-.0%	0	0	--	7,938	7,933	-.0%
UT	0	0	--	548	533	-2.7%	0	0	--	548	533	-2.7%
VT	0	0	--	196	186	-5.1%	0	0	--	196	186	-5.1%
VA	0	0	--	2,850	2,774	-2.7%	85	72	-15.3%	2,935	2,846	-3.0%
WA	0	0	--	1,808	1,801	-.4%	21	24	14.3%	1,829	1,825	-.2%
WV	0	0	--	469	456	-2.8%	42	5	-88.1%	511	461	-9.8%
WI	0	0	--	1,877	1,796	-4.3%	32	32	.0%	1,909	1,828	-4.2%
WY	0	0	--	437	419	-4.1%	0	0	--	437	419	-4.1%
U.S. Total	4,963	5,654	13.9%	95,201	91,703	-3.7%	2,226	1,970	-11.5%	97,427	93,673	-3.9%

**First Admissions of Persons With Mental Retardation
and Related Conditions to State-Operated Residential Facilities**

Table 8 reports first admissions to state-operated residential facilities in Fiscal Year 1988. In this survey first admissions were defined as persons who had never previously resided in any state-operated residential facility. However, in a number of states this specific statistic was not available, and persons reported as "first admissions" were persons who were new to a particular facility to which they had been admitted. Some of these individuals may have previously resided in another state facility, resulting in some inflation of those states' "first admission" totals. For FY 1988 four states were unable to furnish first admission data on large PRF/MR; twelve were unable to provide those data for PRF/Other; six (including New York and Texas) were unable to provide those data for small PRF/MR.

In Fiscal Year 1988 reporting states indicated a total of 2,618 first admissions to large PRF/MR. Estimations of first admissions to PRF/MR in the four nonreported states based on the proportion of first admissions to average daily population in states reporting first admissions would produce an estimate of 2,857 first admissions in FY 1988, or 3.1% of the June 30, 1988 population of those facilities. Reporting states indicated 273 first admissions to PRF/Other. Again, estimates for states unable to report first admissions to PRF/Other were produced based on the average first admission rate of reporting states. This yielded a national estimate of 551 first admissions to PRF/Other. Therefore, there were an estimated 3,408 first admissions to large state institutions in FY 1988, or 3.4% of the average daily population during Fiscal Year 1988. About 16% of estimated first admissions were to PRF/Other. This is notable considering that only about 2% of the total average daily residents lived in PRF/Other. The large proportion of first admissions to PRF/Other is counterbalanced by similarly high total releases from such facilities (see Table 10). Obviously PRF/Other tend to provide relatively short-term placements for persons with mental retardation, presumably related in most cases to behavioral treatment, crisis intervention, and/or evaluation and assessment.

Alaska and the District of Columbia reported no first admissions to large PRF/MR in Fiscal Year 1988, and Hawaii, Montana, New Hampshire, Rhode Island, and Vermont each reported 4 or fewer first admissions.

Table 8

First Admissions of Persons with Mental Retardation and Related Conditions
to State-Operated Residential Facilities During Fiscal Year 1988 by State

State	PRF/MR		PRF/Other	Large (16+) PRF/MR and PRF/Other
	1-15 res.	16+ res.		
ALABAMA	0	69	0	69
ALASKA	0	0	DNF	0
ARIZONA	DNF	DNF	0	DNF
ARKANSAS	1	25	0	25
CALIFORNIA	0	609	0	609
COLORADO	DNF	45	0	45
CONNECTICUT	DNF	DNF	8	DNF
DELAWARE	0	7	0	7
D.C.	0	0	DNF	0
FLORIDA	0	46	DNF	46
GEORGIA	0	172	70	242
HAWAII	0	2	0	2
IDAHO	0	5	0	5
ILLINOIS	0	70	19	89
INDIANA	0	15	0	15
IOWA	0	59	0	59
KANSAS	0	46	0	46
KENTUCKY	0	19	21	40
LOUISIANA	6	91	0	91
MAINE	8	51	DNF	51
MARYLAND	17	61	DNF	61
MASSACHUSETTS	DNF	DNF	DNF	DNF
MICHIGAN	0	DNF	0	DNF
MINNESOTA	1	109	DNF	109
MISSISSIPPI	55	37	0	37
MISSOURI	0	39	DNF	39
MONTANA	0	4	0	4
NEBRASKA	0	10	0	10
NEVADA	0	29	0	29
NEW HAMPSHIRE	0	2	0	2
NEW JERSEY	0	70	DNF	70
NEW MEXICO	0	23	0	23
NEW YORK	DNF	197	86	283
NORTH CAROLINA	0	24	0	24
NORTH DAKOTA	2	8	9	17
OHIO	0	80	0	80
OKLAHOMA	0	22	0	22
OREGON	0	7	0	7
PENNSYLVANIA	0	69	0	69
RHODE ISLAND	4	3	0	3
SOUTH CAROLINA	5	64	0	64
SOUTH DAKOTA	0	9	0	9
TENNESSEE	0	44	45	89
TEXAS	DNF	161	0	161
UTAH	0	12	0	12
VERMONT	0	1	0	1
VIRGINIA	0	61	15	76
WASHINGTON	0	60	DNF	60
WEST VIRGINIA	0	42	DNF	42
WISCONSIN	0	34	DNF	34
WYOMING	0	5	0	5
U.S. Total		2,618	273	2,883
Est. Total		2,857	551	3,408

**Readmissions of Persons With Mental Retardation
and Related Conditions to State-Operated Residential Facilities**

Table 9 summarizes statistics on readmissions to state-operated residential facilities in Fiscal Year 1988. In this survey readmissions were defined as persons who had at least once before been a resident of a state-operated residential facility. However, in a few states this specific statistic was not available, and persons reported as "readmissions" included only people who had previously resided in the specific facility to which they were once again admitted during the year. In those states the number of "readmissions" is somewhat deflated. Statistics on readmissions were not available on large PRF/MR in 10 states, on small PRF/MR in 7 states (including New York and Texas), and on PRF/Other in 13 states. In a few instances this was because first admissions and readmissions are not distinguished in the state data systems.

In Fiscal Year 1988 forty-one states reported 1,810 readmissions to large PRF/MR and thirty-eight states reported 461 readmissions of persons with mental retardation to PRF/Other. Using the average readmission rate of reporting states, the total estimated readmissions to PRF/MR in FY 1988 would be 2,574, or 2.8% of the June 30, 1988 population of those facilities, and the estimated national total of readmissions to PRF/Other would be 946. Therefore, there was an estimated total of 3,520 readmissions to large PRF/MR and PRF/Other in FY 1988 representing 3.6% of the average daily population during Fiscal Year 1988. About 27% of estimated readmissions in FY 1988 were to PRF/Other, even though PRF/Other housed only about 2% of the average daily population. As noted in the discussion of first admissions, these facilities show high activity in all resident movement categories, indicating short-term residential care functions.

In 1988 four states reported no readmissions to large PRF/MR, Alaska, the District of Columbia, Montana, and New Hampshire. Eleven states reported 10 or fewer. The highest reported total was 610 in New York. New York readmissions represented 24% of the total estimated number of readmissions to all large PRF/MR, and New York's reported readmissions to large PRF/MR outnumbered reported first admissions by about 3 to 1.

Table 9

Readmissions of Persons with Mental Retardation and Related Conditions
to State-Operated Residential Facilities During Fiscal Year 1988 by State

State	PRF/MR		PRF/Other	Large (16+) PRF/MR and PRF/Other
	1-15 res.	16+ res.		
ALABAMA	0	4	0	4
ALASKA	0	0	DNF	0
ARIZONA	DNF	DNF	0	DNF
ARKANSAS	0	19	0	19
CALIFORNIA	0	29	0	29
COLORADO	DNF	20	0	20
CONNECTICUT	DNF	DNF	21	DNF
DELAWARE	0	4	0	4
D.C.	0	0	DNF	0
FLORIDA	0	32 ^e	DNF	32
GEORGIA	0	27	27	54
HAWAII	0	2	0	2
IDAHO	0	15	0	15
ILLINOIS	0	112	50	162
INDIANA	0	22 ^e	0	22
IOWA	0	11	0	11
KANSAS	0	74	0	74
KENTUCKY	0	21	48	69
LOUISIANA	0	15	0	15
MAINE	0	103	DNF	103
MARYLAND	3	65	DNF	65
MASSACHUSETTS	DNF	DNF	DNF	DNF
MICHIGAN	0	DNF	0	DNF
MINNESOTA	0	DNF	DNF	DNF
MISSISSIPPI	0	11	0	11
MISSOURI	DNF	DNF	DNF	DNF
MONTANA	0	0	0	0
NEBRASKA	0	13	0	13
NEVADA	0	65	0	65
NEW HAMPSHIRE	0	0	0	0
NEW JERSEY	0	DNF	DNF	DNF
NEW MEXICO	0	28	0	28
NEW YORK	DNF	610	182	792
NORTH CAROLINA	0	98	0	98
NORTH DAKOTA	2	43	14	57
OHIO	0	DNF	0	DNF
OKLAHOMA	0	3	0	3
OREGON	0	20	0	20
PENNSYLVANIA	0	24	0	24
RHODE ISLAND	24	7	0	7
SOUTH CAROLINA	0	21	0	21
SOUTH DAKOTA	0	26	DNF	26
TENNESSEE	0	58	72	130
TEXAS	DNF	DNF	0	DNF
UTAH	0	33	0	33
VERMONT	0	1	0	1
VIRGINIA	0	77	47	124
WASHINGTON	0	40 ^e	DNF	40
WEST VIRGINIA	0	DNF	DNF	DNF
WISCONSIN	0	56	DNF	56
WYOMING	0	3	0	3
U.S. Total		1,810	461	2,250
Est. Total		2,574	946	3,520

**Release of Persons With Mental Retardation
and Related Conditions From State-Operated Residential Facilities**

Table 10 summarizes statistics reported by the states on residents released from state-operated residential facilities in Fiscal Year 1988. For the purposes of this study releases were defined as persons with mental retardation and related conditions who were officially released from state-operated facilities and removed from the rolls during the year. Four states were unable to provide number of releases from large PRF/MR, ten states were unable to report releases of persons with mental retardation from PRF/Other, and six states (including New York and Texas) were unable to report releases from small PRF/MR.

States reported a total of 5,805 releases from large PRF/MR, 80 from small PRF/MR, and 798 from PRF/Other for FY 1988. Estimations of releases from PRF/MR in the four nonreporting states based on average release rate of reporting states produced a total national estimate of 6,323 releases from large PRF/MR in 1988. Similarly imputing PRF/Other releases from nonreporting states yielded an estimated total of 1,360 releases from PRF/Other in FY 1988. Thus, an estimated 7,683 persons were released from large state facilities for an annual rate of 7.9% of the average daily population during Fiscal Year 1988. The ratio of releases to average daily population for large state facilities in 1988 (1:12.2) was considerably smaller than the 1986 rate (1:9.1). The proportion of total releases from state-operated facilities reported for PRF/Other (18%) again reflected the high movement rates of PRF/Other residents, who made up only 2% of the population of all state-operated facilities.

In Fiscal Year 1988 states varied substantially in the total number and rates of release from their large state-operated facilities. Alaska, Nebraska, New Jersey, and Vermont reported fewer than 10 releases, while California, New York, and Pennsylvania all reported over 400. New York reported by far the greatest number of releases from large state-operated residential facilities in 1988 with its total of 937 representing about 13% of all releases nationally. However, relative to each state's average daily population, Colorado, Maine, Nevada, and North Dakota were most active in releasing residents of large state facilities with at least 1 release during the year for every 4 persons in the average daily population.

Table 10

Releases of Persons with Mental Retardation and Related Conditions
from State-Operated Residential Facilities During Fiscal Year 1988 by State

State	PRF/MR		PRF/Other	Large (16+) PRF/MR and PRF/Other
	1-15 res.	16+ res.		
ALABAMA	0	66	0	66
ALASKA	0	3	DNF	3
ARIZONA	DNF	DNF	0	DNF
ARKANSAS	0	59	0	59
CALIFORNIA	0	495	0	495
COLORADO	DNF	154	0	154
CONNECTICUT	DNF	DNF	54	DNF
DELAWARE	0	13	0	13
D.C.	0	0	28	28
FLORIDA	0	112 ^e	DNF	112
GEORGIA	0	185	93	278
HAWAII	0	46	0	46
IDAHO	0	54	0	54
ILLINOIS	0	196	60	256
INDIANA	0	281	0	281
IOWA	0	100	0	100
KANSAS	0	229	0	229
KENTUCKY	0	39	32	71
LOUISIANA	6	157	0	157
MAINE	0	117	DNF	117
MARYLAND	21	141	DNF	141
MASSACHUSETTS	DNF	DNF	DNF	DNF
MICHIGAN	0	DNF	0	DNF
MINNESOTA	1	209	10	219
MISSISSIPPI	33	34	0	34 ^e
MISSOURI	0	44	DNF	44
MONTANA	0	14	0	14
NEBRASKA	0	8	0	8
NEVADA	0	91	0	91
NEW HAMPSHIRE	0	37	0	37
NEW JERSEY	0	7	DNF	7
NEW MEXICO	0	18	0	18
NEW YORK	DNF	580	357	937
NORTH CAROLINA	0	156	0	156
NORTH DAKOTA	5	84	30	94
OHIO	0	128 ^e	0	128
OKLAHOMA	0	108	0	108
OREGON	0	67	0	67
PENNSYLVANIA	0	710	0	710
RHODE ISLAND	8	32	0	32
SOUTH CAROLINA	6	124	0	124
SOUTH DAKOTA	0	75	5	80
TENNESSEE	0	122	119	241
TEXAS	DNF	169	0	169
UTAH	0	63	0	63
VERMONT	0	8	0	8
VIRGINIA	0	166	10	176
WASHINGTON	0	41	DNF	41
WEST VIRGINIA	0	122	DNF	122
WISCONSIN	0	146	DNF	146
WYOMING	0	17	0	17
U.S. Total		5,805	798	6,549
Est. Total		6,323	1,360	7,683

**Deaths of Persons With Mental Retardation
and Related Conditions in State-Operated Residential Facilities**

Table 11 summarizes statistics reported by the states on the number of persons with mental retardation and related conditions who died while on the rolls of state-operated residential facilities in Fiscal Year 1988. Caution must be exercised in comparing or interpreting death rates across states. Residents with life threatening conditions are sometimes transferred to medical hospitals or skilled nursing homes, particularly when acute medical services are not available in a state-operated facility. State facility residents who die in a hospital or skilled nursing facility may or may not still be considered to be on the rolls of the state-operated facility when they die. Caution is also required in making interstate comparisons of deaths among state facility populations because states vary not only in the administrative status of persons transferred to medical facilities, but also in the age and medical profiles of the populations they serve in their state-operated facilities.

In Fiscal Year 1988, 1,255 deaths were reported in large PRF/MR by the 48 states providing this statistic. A total of 22 deaths were reported by 40 states in their PRF/Other. Statistics on deaths in small PRF/MR are not considered reliable in the absence of data from New York and Texas which operate the majority of such facilities in the U.S.

Imputing data for three states unable to report PRF/MR deaths for Fiscal Year 1988, based on their average daily population, and the proportion of deaths to average daily residents in reporting facilities, yielded an estimated 1,333 deaths nationwide. Using the same method of estimation for states unable to report deaths of persons with mental retardation in PRF/Other, an estimate of 40 deaths nationally in PRF/Other was obtained. The estimated total of 1,373 deaths in large PRF/MR and PRF/Other and the national average of 1.5 deaths per 100 average daily residents of large state facilities was very similar to the findings of the Fiscal Year 1986 survey in this series which reported 1,367 deaths and 1.3 deaths per 100 of the average daily residents of large state facilities.

Table 11

**Deaths of Persons with Mental Retardation and Related Conditions
in State-Operated Residential Facilities During Fiscal Year 1988 by State**

State	PRF/MR		PRF/Other	Large (16+) PRF/MR and PRF/Other
	1-15 res.	16+ res.		
ALABAMA	0	15	0	15
ALASKA	0	0	DNF	0
ARIZONA	DNF	DNF	0	DNF
ARKANSAS	0	16	0	16
CALIFORNIA	0	138	0	138
COLORADO	DNF	11	0	11
CONNECTICUT	1	24	1	25
DELAWARE	0	7	0	7
D.C.	0	5	0	5
FLORIDA	0	20	DNF	20
GEORGIA	0	11	7	18
HAWAII	0	6	0	6
IDAHO	0	3	0	3
ILLINOIS	0	45	0	45
INDIANA	0	20	0	20
IOWA	0	9	0	9
KANSAS	0	30	0	30
KENTUCKY	0	12	4	16
LOUISIANA	0	42	0	42
MAINE	0	5	0	5
MARYLAND	0	19	DNF	19
MASSACHUSETTS	DNF	DNF	DNF	DNF
MICHIGAN	0	DNF	0	DNF
MINNESOTA	0	11	0	11
MISSISSIPPI	0	21	0	21
MISSOURI	0	21	DNF	21
MONTANA	0	2	0	2
NEBRASKA	0	11	0	11
NEVADA	0	1	0	1
NEW HAMPSHIRE	0	1	0	1
NEW JERSEY	0	85	DNF	85
NEW MEXICO	0	7	0	7
NEW YORK	DNF	210	8	218
NORTH CAROLINA	0	20	0	20
NORTH DAKOTA	0	6	0	6
OHIO	0	21	0	21
OKLAHOMA	0	10	0	10
OREGON	0	9	0	9
PENNSYLVANIA	0	60	0	60
RHODE ISLAND	2	8	1	9
SOUTH CAROLINA	0	42	0	42
SOUTH DAKOTA	0	11	DNF	11
TENNESSEE	0	39	1	40
TEXAS	DNF	101	0	101
UTAH	0	7	0	7
VERMONT	0	4	0	4
VIRGINIA	0	48	DNF	48
WASHINGTON	0	21	DNF	21
WEST VIRGINIA	0	7	DNF	7
WISCONSIN	0	24	DNF	24
WYOMING	0	9	0	9
U.S. Total		1,256	22	1,277
Est. Total		1,333	40	1,373

Cost of Care in State-Operated Residential Facilities

Table 12 summarizes statistics provided by states on the costs of services for persons with mental retardation and related conditions residing in state-operated residential facilities. The state costs reported are average per resident per day costs. The national averages presented are the average daily per resident costs reported by states weighted by the state's average daily residential population, that is, the national average per resident cost. Every state but Massachusetts reported the average daily cost for large PRF/MR and for PRF/Other for Fiscal Year 1988. Massachusetts' cost data are from Fiscal Year 1987. All but five states were able to provide the per resident per day cost statistic for their small PRF/MR.

Average cost of care in state-operated facilities varied considerably across the United States with a national average of about \$156.00 per day. The highest cost of care in large PRF/MR reported for Fiscal Year 1988 was the estimated \$300.00 per day in Oregon, followed in order by Connecticut (\$296.66), Alaska (\$275.79), and New York (\$271.91). In all, over a third of the states (18) reported annual per resident costs in PRF/MR at or above \$65,000 (\$180 per day). States reporting the lowest daily costs were Mississippi (\$75.00) and Texas (\$76.48). Only 5 states reported per resident per day average costs below \$100 in their PRF/MR. From Fiscal Year 1987 to 1988 the per resident per day average cost of care in large PRF/MR increased from \$149.36 to \$156.77 or 5.0%.

The 22 states providing for persons with mental retardation in PRF/Other and having access to the costs of care for those facilities reported an average per resident cost of \$155.65, nearly the same as reported for large PRF/MR. However, PRF/Other costs usually refer to the costs for the entire facility, not specifically for those residents with mental retardation. Costs of care reported by 11 states for small PRF/MR averaged \$131.25 per resident per day or about 84% of those reported for large PRF/MR residential programs. However, in comparing large and small PRF/MR costs it is important to recognize, as is demonstrated in Part II of this report, that the large facility populations tend to be made up of persons with somewhat more severe intellectual and functional impairments.

Table 12

Average Per Resident Daily Cost of Care in
State-Operated Residential Facilities During Fiscal Year 1988 by State

State	PRF/MR		PRF/ Other
	1-15 res.	16+ res.	
ALABAMA	N/A	\$133.77	N/A
ALASKA	N/A	\$275.79	\$252.24
ARIZONA	\$67.00	\$209.00	N/A
ARKANSAS	DNF	\$112.47	N/A
CALIFORNIA	N/A	\$166.00 ^e	N/A
COLORADO	\$128.00	\$128.00	N/A
CONNECTICUT	DNF	\$296.66	\$253.97
DELAWARE	N/A	\$126.62	N/A
D.C.	N/A	\$235.00 ^e	\$200.00 ^e
FLORIDA	N/A	\$135.00	\$157.31
GEORGIA	N/A	\$190.00	\$187.00 ^e
HAWAII	N/A	\$193.36	N/A
IDAHO	N/A	\$217.98	N/A
ILLINOIS	N/A	\$140.20	\$169.90
INDIANA	N/A	\$125.74	N/A
IOWA	N/A	\$141.16	N/A
KANSAS	N/A	\$144.93	N/A
KENTUCKY	N/A	\$149.21	\$138.46
LOUISIANA	\$69.35	\$92.00	N/A
MAINE	\$157.00	\$207.13	\$167.21 ^e
MARYLAND	DNF	\$164.00	\$178.00 ^e
MASSACHUSETTS	\$231.00	\$251.00 ^e	\$210.63 ^e
MICHIGAN	N/A	\$227.27	N/A
MINNESOTA	\$140.00	\$194.95	\$93.00
MISSISSIPPI	\$30.00	\$75.00 ^e	N/A
MISSOURI	\$83.58	\$124.47	\$201.00 ^e
MONTANA	N/A	\$153.82	N/A
NEBRASKA	N/A	\$113.40	N/A
NEVADA	N/A	\$161.52	N/A
NEW HAMPSHIRE	N/A	\$226.00	N/A
NEW JERSEY	N/A	\$168.00	\$172.09
NEW MEXICO	N/A	\$120.31	N/A
NEW YORK	\$170.70	\$271.91	\$174.06
NORTH CAROLINA	N/A	\$151.64	N/A
NORTH DAKOTA	DNF	\$235.83	\$128.63
OHIO	N/A	\$166.07	N/A
OKLAHOMA	N/A	\$175.00	N/A
OREGON	N/A	\$300.00 ^e	N/A
PENNSYLVANIA	N/A	\$154.89	N/A
RHODE ISLAND	\$106.25	\$218.36	\$209.95
SOUTH CAROLINA	\$85.00	\$110.00	N/A
SOUTH DAKOTA	N/A	\$108.15	\$96.97
TENESSEE	N/A	\$110.25	\$158.66
TEXAS	DNF	\$76.48	N/A
UTAH	N/A	\$121.32	N/A
VERMONT	N/A	\$191.02	N/A
VIRGINIA	N/A	\$132.54	\$144.16
WASHINGTON	N/A	\$159.06	\$155.00 ^e
WEST VIRGINIA	N/A	\$98.51	\$91.20
WISCONSIN	N/A	\$156.00	\$175.00 ^e
WYOMING	N/A	\$96.20	N/A
U.S. Total	\$131.25	\$156.77	\$155.65

PART II: CHARACTERISTICS OF RESIDENTS OF PUBLIC RESIDENTIAL FACILITIES IN 1987

To present a picture of the characteristics of residents of state-operated residential facilities, Part II of this report uses statistics obtained from the Institutional Population Component of the 1987 National Medical Expenditure Survey (NMES) (Lakin, Hill, Chen, & Stephens, 1989). This survey included a sample of 3,618 persons in 691 facilities primarily serving people with mental retardation and related conditions. Of these 1,641 sample members were residents of 200 public facilities. The Institutional Population Component of the 1987 National Medical Expenditure Survey provided considerable detailed information on the demographic, diagnostic, functional and other characteristics of persons in publicly-operated residential facilities. These data provide a fairly detailed description of the characteristics of the individuals enumerated in Part I of this report. In addition, as a point of comparison, the estimates from the 1987 National Medical Expenditure Survey for all residents of all (public and private) mental retardation facilities are included in each table (see "Methodology" for limitations affecting this "all facilities" estimate).

Methodology

The "Mental Retardation Facilities" sample in the Institutional Population Component of the 1987 National Medical Expenditure Survey was based on a three-stage probability sample. The three stages included: 1) development of a universe of all facilities meeting the definition of a "mental retardation facility"; 2) selection of a controlled sample of facilities from that universe; and 3) selection of a random sample of residents of those facilities. Details of the sampling strategy are reported in Edwards and Edwards (1989).

Universe of Facilities

The universe of facilities serving as the sample frame for the National Medical Expenditure Survey was the 1986 Inventory of Long-Term Care Places (ILTCP) (Sirrocco, 1989). The ILTCP was carried out to identify facilities primarily serving persons with mental retardation, verify eligibility as a "mental retardation facility," and to provide statistics on population and administrative characteristics of

facilities on which the sample stratification, selection, and eventual facility weighting for the Institutional Population Component of NMES could be based. The ILTCP defined mental retardation facilities as formally state licensed, or contracted [including state-operated] living quarters which provided 24-hour, 7-days-a-week responsibility for room, board and supervision of persons with mental retardation who were not relatives.

Construction of the registry. Prior to conducting the actual "inventory" stage of the ILTCP, a list of facilities potentially meeting the definition of a mental retardation facility was constructed using a national census of residential facilities for persons with mental retardation conducted by the Center for Residential and Community Services at the University of Minnesota (Hauber, Bruininks, Hill, Lakin, & White, 1984). To that registry of 15,633 facilities were included additional facilities that were identified by states and "relevant associations" as operating in late 1985, but which were not included in the 1982 census survey.

Surveying and screening the registry (the ILTCP). The ILTCP was a simultaneous survey of the mental retardation facilities identified as described above, as well as nursing and related care homes identified in a similar manner using the National Center on Health Statistics' 1982 National Master Facility Inventory as the base registry. The Bureau of the Census carried out the actual ILTCP survey of 56,728 total facilities on the registry. Of these 5,808 could not be surveyed because of insufficient information, inability to locate, or eventual dropping for nonresponse. There were 174 direct refusals. Another 5,500 places were not operating as residential facilities at the time of the survey, or were not providing residential services at the specific address (e.g., were home offices for multiple facilities).

The ILTCP survey outcomes were used by the National Center for Health Services Research (NCHSR) to evaluate all 56,728 facilities in the registry for their status as a mental retardation facility. According to a set of hierarchical decision rules, the process eliminated from the mental retardation facility universe facilities that were determined to be nursing or related care homes, duplicate addresses or facilities that were otherwise out-of-scope (no current residents with mental retardation, administrative offices, not 24-hour residential programs, etc.). In all 15,351 "mental retardation facilities" were identified

in the 1986 ILTCP, 1,347 of which also met the definition of nursing and related care home (Potter, Cohen, & Mueller, 1987).

Facility Sample

In addition to its use as determining the current status of mental retardation facilities and nursing and related care facilities, the ILTCP gathered the basic data needed to structure the facility sample. However, prior to selecting the mental retardation facility sample from the ILTCP, it became evident that the ILTCP contained fewer of the smaller residential settings than were identified in the 1982 mental retardation facility census (Hauber et al., 1984) and far fewer than were reported by state mental retardation/developmental disabilities agencies in 1986 (Lakin, White, Hill, Bruininks, & Wright, in press). Because the underidentification appeared most notable among the smallest facilities, it was decided to exclude all settings of 2 or fewer residents from the ILTCP for the purposes of drawing a sample for the National Medical Expenditure Survey, thus eliminating facilities of that size from the Institutional Population Component of NMES. Remaining mental retardation facilities were then stratified by their status as community-based ICFs-MR (3-15 beds), noncertified community-based facilities (3-15 beds), or facilities with 16 or more residents. Within these strata facilities were further grouped by census region, ICF-MR certification, type of operation, number of "beds," state and zip code area. Facilities were then sampled with probabilities of selection proportional to their size, but with some clustered subsampling of similarly grouped facilities to reduce field costs of the interviewing. A total of 691 separate mental retardation facilities were selected in the sample, 491 of which were privately operated and 200 of which were publicly operated.

Selection of Sample Members

A current resident sample was selected in each facility from a listing of all persons residing in the facility on January 1, 1987. Sampling was random, with a predetermined number of sample members drawn from each facility to insure that representation for residents within strata was equal to

their proportion of all residents in the sample frame. In all 3,618 residents of mental retardation facilities were sampled.

Response Rates

To obtain the final yield of 691 mental retardation facilities, 730 eligible facilities were sampled from the ILTCP. Of these facilities 691 responded to the facility questionnaire, with 31 refusals and 2 other nonrespondents. To obtain the final yield of 3,618 current residents, 3,738 eligible residents were sampled. There were 29 refusals by facilities to provide individual interviews, 86 refusals by individuals or guardians other than the facilities, and 7 other nonresponses. Thus, the overall response rates for selected facilities (94.7%) and for selected residents within facilities agreeing to participate (96.8%) were quite high.

Data Limitations

Originally, the mental retardation facility sample frame was intended to include all types and sizes of mental retardation facilities meeting the operational definition. However, as noted in a NCHSR staff paper on the NMES sample frame:

A final comparison of the 1986 ILTCP MR universe to the 1982 NCRF [National Census of Residential Facilities] universe (Hauber et al, 1984) suggested undercoverage of one and two bed MR facilities by the ILTCP. A likely explanation is that the very small MR facilities are more likely to close or move than large facilities. This jeopardized completeness of the frame, so one and two bed MR's were deleted at the end of the eligibility determination process (Potter, Cohen & Mueller, 1987, p. 826).

Underidentification of persons in small facilities was clearly reflected in the differences between ILTCP and NMES estimates of the total population of persons with mental retardation and related conditions in mental retardation facilities (about 218,000) and the 244,000 identified in the 1982 census (Hauber et al., 1984) and the 252,000 reported by states in 1986 (Lakin et al., in press). But the underestimation appears largely confined to facilities of 6 and fewer residents. The magnitude of the undercount appears on the order of 25,000-30,000 small facility residents (including facilities with 1 or 2 residents), or in the neighborhood of 30% of all small facility residents (Lakin, Hill, Chen, & Stephens, 1989). These limitations likely affect the accuracy of the data presented on "all facilities." However, the limitations described appear to have had a relatively minor effect on the public residential facility

estimates. The population estimates for public residential facilities in the 1987 NMES was 99,174 residents with mental retardation and related conditions as compared with 99,768 reported by states as of June 30, 1987 (Lakin et al., 1989).

The estimates for small "public" facilities (15 or fewer residents) in the NMES and the statistics reported by states for small "state operated" facilities were not wholly congruent because "public" in the NMES also included facilities that were operated by local government agencies. It is estimated that approximately 25% (1,980) of the estimated 7,633 residents with mental retardation and related conditions in small public facilities were in facilities of local government operation. Unfortunately, the NMES data files do not permit disaggregation of these facilities into state operated and local government operated programs.

Findings

Data in the following tables are estimates of the proportion of residents in large (16 or more residents) and small (15 or fewer residents) public facilities and all facilities (public and private). As a general rule it should be noted that with respect to the total residents, estimates of 1% or less of the total population (about 2,200 or fewer people) have a relative standard error of 30% or more.

Administrative Characteristics

Table 13 presents basic descriptive data from the 1987 National Medical Expenditure Survey on administrative characteristics of public and total residential facilities primarily serving persons with mental retardation and related conditions.

Occupancy. NMES data indicated that the total maintained capacity of public mental retardation facilities in early 1987 was 113,347 persons. About 93% (105,000) of the maintained capacity was in large public facilities (16 and more residents) with about 7% in smaller public facilities. About 90% of the total maintained capacity was occupied at the time of the NMES survey, with lower occupancy rates for large facilities (89.4%) than for small facilities (93.5%). An estimated 97.5% of residents of public mental retardation facilities were indicated to have mental retardation or related conditions. This included 97.5% of large public facility residents and 97.8% of small public facility residents. Occupancy of the total maintained capacity of public residential facilities was essentially the same as that of all

residential facilities (90%), but public mental retardation facilities in general were estimated to have a considerably higher proportion of their total populations made up of persons with mental retardation and related conditions (97.5%) than did mental retardation facilities in general (91.2%).

Table 13

Basic Administrative Data of Public Residential Facilities by ICF-MR Certification Status

	Public		Total	All Fac.
	15- res.	18+ res.		Total
ICF-MR Certified				
Total maintained capacity	3,501	100,375	103,876	157,033
Total current residents	3,004	89,607	92,610	144,509
Total MR/RC residents	3,004	87,554	90,558	139,161
Total ICF-MR beds	3,501	100,375	103,876	154,663
Direct care per bed	1.07	1.54	1.53	1.33
Per diem by range				
\$1-\$30	7.7	0.0	0.2	5.9
\$1-\$5	0.0	0.8	0.8	10.8
\$6-\$0	20.1	12.5	12.7	18.4
\$1-105	35.5	23.2	23.6	19.6
106+	36.7	63.5	62.8	45.4
Not ICF-MR Certified				
Total maintained capacity	4,847	4,624	9,461	106,746
Total current residents	4,800	4,297	9,098	95,109
Total MR/RC residents	4,631	3,987	8,618	79,472
Direct care per bed	.90	.97	.94	.66
Per diem by range				
\$1-\$30	22.9	13.3	17.6	49.5
\$1-\$5	30.8	0.0	13.9	20.8
\$6-\$0	0.4	11.3	6.4	11.9
\$1-105	19.7	14.3	16.7	6.2
106+	26.1	61.1	45.3	11.7
All Facilities				
Total maintained capacity	8,348	104,999	113,347	265,781
Total current residents	7,803	93,904	101,707	239,619
Total MR/RC residents	7,633	91,541	99,174	218,633
Total ICF-MR beds	3,501	100,375	103,876	154,663
Direct care per bed	.97	1.51	1.48	1.06
Per diem by range				
\$1-\$30	16.3	0.6	1.5	23.5
\$1-\$5	17.5	0.8	1.8	14.8
\$6-\$0	8.9	12.4	12.2	15.7
\$1-105	26.5	22.8	23.0	14.2
106+	30.7	63.4	61.4	31.8

Notes. Total maintained capacity is number of set up beds in reporting unit, estimated from weighted data on facility questionnaire of the National Medical Expenditure Survey. Total current residents and residents with mental retardation and related conditions (MR/RC) are weighted estimates from resident baseline questionnaire. Most facilities with ICF-MR certification are indicated to be 100% certified. For other facilities with ICF-MR certification, total ICF-MR beds are estimated to be the number of set up beds multiplied by the midpoint of multiple categories (e.g., 0-10% = 5%) of the recoded variables "percent of beds certified." Facilities with missing bed certification data but which are ICF-MR certified are assumed to be 100% ICF-MR certified. Per diem by range are the estimated percentage of residents in each facility category living in facilities in each per diem range. Facility size weights are "set up beds." Direct care personnel estimates are expressed as number of FTE direct care staff (registered nurses, licensed nurses, nurses aids/orderlies, recreation/activity staff, and "all other care staff") per set up bed. "Part time" assumed to equal 50% FTE. Data are weighted to represent correct proportions of set up beds (approximately equalling the number of residents).

ICF-MR certification. An estimated 91.3% of all current residents with mental retardation and related conditions of public residential facilities are in facilities with ICF-MR certification. This includes 95.6% of the residents in large public facilities and 39.5% of those in small public facilities. The estimated 139,161 total persons with mental retardation and related conditions in all residential facilities is similar to the number reported by states in 1987 (143,350), as are the estimates for small and large public facilities. Small public ICFs-MR were estimated to have 3,004 residents with mental retardation and related conditions while states reported 2,874 residents. Large public ICFs-MR were estimated to have 87,554 residents with mental retardation and related conditions while states reported 88,424 residents.

Direct-care personnel. Public residential facilities had an estimated 1.48 direct care staff full-time equivalents (FTE) for each bed in the facility. The ratio of direct care FTEs per resident was higher in the larger facilities (1.51) than in the smaller facilities (.97). It was higher in the public ICFs-MR (1.53) than the non-certified public facilities (.94). Among the non-certified public facilities the difference in the ratio of staff FTEs to beds by facility size was minimal (.90 for small facilities and .97 for large facilities). The most notable difference in staff to bed ratios among facilities was between large ICFs-MR and large non-certified facilities (1.54 and .97, respectively). Among both ICF-MR certified and noncertified public facilities, the ratio of direct care FTEs to set up beds was greater than the estimates for all residential facilities.

Daily cost of care. Unfortunately average daily costs of care in the National Medicaid Expenditure Survey data tapes were aggregated into cost categories rather than providing the actual cost statistics reported by facilities. It is, however, clear from the statistics in Table 1 that public facility costs tended to be higher than those of mental retardation facilities in general. This was true for both ICFs-MR and non-certified facilities. Small public facilities showed cost distributions similar to the overall sample of residential facilities, but their average costs per day tended to be considerably higher than the average costs of small private facilities. For example, while an estimated 23.8% of small public facility residents were in facilities with per diem costs of \$55 or less an estimated 62.0% of small private

facility residents were in facilities costing \$55 per day or less. While an estimated 30.7% of small public facility residents were in facilities costing \$106 or more per day, only an estimated 10.3% of small private facility residents were in facilities costing \$106 or more per day (Lakin, Hill, Chen, & Stephens, 1989).

Resident Movement

Table 14 presents summary data on the rate of movement of residents into and out of public residential facilities in Calendar Year 1986, and also the relative size of reported waiting lists. Rate of movement statistics are reported as percent of "set up beds" and includes facilities which opened or closed during 1986. Separate rate statistics are provided for facilities with ICF-MR certification, those without ICF-MR certification and for all facilities. In general people with mental retardation moved into public residential facilities at a slower rate in 1986 than they moved into residential facilities in general, with movement into private facilities occurring at more than twice the rate as reported by public facilities (6.8 per 100 beds in public facilities, and 9.0 per 100 beds in public and private facilities combined). Admission rates to small public facilities (again excluding facilities opening in 1986) were over twice those of large public facilities (13.9 per 100 beds as compared with 6.7 per 100 beds). Admission rates to non-certified public facilities were higher than those to ICFs-MR for both small facilities and large facilities.

In contrast to the admission rates, discharge rates for public facilities were similar to those of residential facilities in general. Discharge rates were also similar between large and small public facilities, although substantial differences were noted depending on whether the small facilities were ICF-MR certified. Small ICFs-MR had much lower discharge rates (3.9 per 100 beds) than did small non-certified public facilities (15.6), or than did large public ICFs-MR (9.7), large noncertified facilities (10.0), or all facilities in general (11.5). Death rates of 1.4 per 100 beds were reported by large public ICFs-MR and large non-certified public facilities. Lower rates were reported by small public facilities. The reported death rates for large public facilities was the same as reported for all residential facilities in general (1.4 per 100 beds). Public facilities reported 2.8 persons on waiting lists for service per 100 beds. Public facilities rates of wait listing varied from 2.6 for large public facilities to 5.9 for small public

facilities. The national average rate of wait listing for all facilities was estimated to be 7.0 persons per 100 beds. This statistic suggests that nearly 20,000 persons were on facility waiting lists for residential placement in 1987. It is likely that large numbers of additional persons were on state and local government agency waiting lists and on the lists of private agencies operating multiple facilities. Even discounting some inevitable duplication on these lists, the wait list data gathered in NMES is another bit of evidence to suggest that there is a growing unmet demand for long-term care. Equally clear is that the unused capacity of large public institutions is not seen as an acceptable alternative for meeting that demand.

Table 14

Rates of Resident Movement in Public Residential Facilities by ICF-MR Certification

	Public		Total	All Fac.
	15- res.	16+ res.		Total
ICF-MR Certified				
Total current residents	3,003	89,507	92,610	144,509
1986 admission rate	10.8	6.6	6.8	9.0
1986 live discharge rate	3.9	9.7	9.5	9.9
1986 death rate	0.0	1.4	1.4	1.4
Rate of wait listing	6.3	2.7	2.8	5.9
Not ICF-MR Certified				
Total current residents	4,800	4,287	9,086	95,109
1986 admission rate	15.9	8.9	12.5	16.2
1986 live discharge rate	15.6	10.0	12.9	14.0
1986 death rate	0.8	1.4	1.1	1.5
Rate of wait listing	5.6	0.7	3.2	8.5
All Facilities				
Total current residents	7,803	93,904	101,707	239,619
1986 admission rate	13.9	6.7	7.3	11.9
1986 live discharge rate	10.9	9.7	9.8	11.5
1986 death rate	0.5	1.4	1.3	1.4
Rate of wait listing	5.9	2.6	2.8	7.0

Notes. Movement data rates are expressed as percent of set up beds. Table includes facilities that were open all of 1986 and excludes a few facilities whose number of admissions or number of releases exceeded bed capacity. Certain facilities serve as diagnostic, placement and/or crisis centers. They receive and discharge large numbers of residents each year. They were excluded in order to reflect the movement status of persons in typical residential settings. Rate of wait listing includes facilities which report no waiting lists.

Level of Retardation

Table 15 presents statistics on the reported level of mental retardation of public facility residents reported to have mental retardation, and on residents reported to have "related conditions" only. It shows that among public facility residents reported to have mental retardation and related conditions,

the vast majority were indicated to have mental retardation (99.8%). A sizable majority of these residents were reported to have profound mental retardation (56.9%), with large public facility residents being considerably more likely to have profound mental retardation (59.5%) than small public facility residents (25.5%) or persons with mental retardation and/or related conditions in residential facilities in general (36.7%). Conversely large public residential facilities had considerably smaller proportions of their residential populations made up of persons with borderline/mild mental retardation (8.7%) or moderate mental retardation (11.4%) than did small public facilities (24.2% and 17.4% for borderline/mild mental retardation and moderate mental retardation, respectively).

Despite the tendency for the populations of small public facilities to be more mildly impaired than residents of large public facilities, there was clearly a shift between 1982 to 1987 in the use of small public facilities for persons with severe impairments. In 1982 only 41.6% of residents of small public residential facilities were reported to have severe or profound mental retardation (Lakin, Hill, & Bruininks, 1985); in 1987 58.2% were estimated to have severe or profound mental retardation, including 25.5% with profound mental retardation.

As shown in Table 15, the estimated number of residents of mental retardation facilities who are reported to have a condition related to mental retardation (i.e., epilepsy, cerebral palsy, autism, spina bifida or a combination of related conditions), but not mental retardation was estimated to be very small (less than 1%). Of course, admission to most state-operated "mental retardation facilities" is likely to require a diagnosis of mental retardation; and because these estimates are based on only 3 sample members reported to have related conditions only, the precision of estimate must be assumed to be low.

Table 15

**Percentage of Residents in Public Mental Retardation Facilities
by Level of Mental Retardation or Related Conditions**

	Public		Total	All Fac.
	15- res.	16+ res.		Total
Mentally Retarded				
Mild/Borderline	24.2	8.7	9.9	20.9
Moderate	17.4	11.4	11.9	21.0
Severe	32.7	20.2	21.1	20.5
Profound	<u>25.5</u>	<u>59.5</u>	<u>56.9</u>	<u>36.7</u>
Total	99.8	99.8	99.8	99.1
Related Conditions Only				
Epilepsy only	0.0	0.2	0.2	0.6
Cerebral palsy only	0.0	0.0	0.0	0.2
Autism only	0.0	0.0	0.0	0.0
Spina bifida only	0.0	0.0	0.0	0.0
Multiple related conditions	<u>0.0</u>	<u>0.0</u>	<u>0.0</u>	<u>0.0</u>
Total	0.0	0.2	0.2	0.8

Notes. Statistics presented are proportion of total estimated population with mental retardation and related conditions in each facility category indicated to have either mental retardation or a related condition by level of mental retardation or, if indicated not to have mental retardation, by the primary related condition. Columns may not add to 100% because of rounding.

Types of Related Conditions

Table 16 presents estimates of the persons with mental retardation and related conditions in public mental retardation facilities with conditions in addition to mental retardation. It was estimated that 38.9% of persons with mental retardation and/or a related condition had epilepsy. Reported epilepsy was clearly linked to severity of mental retardation, ranging from 15.1% of public facility residents with mild or borderline mental retardation to 45.5% of residents with profound mental retardation. Cerebral palsy was reported for 12.3% of the residents of public residential facilities. It, too, was most common among persons with more severe mental retardation; ranging from about 3% among people with borderline, mild and moderate mental retardation, to 9.3% among persons with severe mental retardation and 15.8% among people with profound mental retardation. Autism and spina bifida were rarely reported for persons with mental retardation and related conditions (2.3% and 0.5% respectively). Deafness and/or blindness was reported for an estimated 10.2% of public facility residents. These conditions were also most prevalent among residents with profound mental retardation.

With the exception of cerebral palsy, persons in public facilities were more likely to have related conditions than were people in residential facilities in general. Residents of small public facilities were less likely to have these conditions than were residents of large public facilities, even controlling for level of mental retardation. Again, the reported presence of cerebral palsy was the exception.

Table 16

Number and Types of Related Disabilities Among Residents with Mental Retardation and Related Conditions in Public Mental Retardation Facilities

	Public		Total	All Fac.
	15- res.	16+ res.		Total
Mentally Retarded				
Borderline/Mild				
Epilepsy	4.8	17.5	15.1	15.2
Cerebral Palsy	7.4	2.6	3.5	5.5
Autism	0.0	0.0	0.0	1.4
Spina Bifida	0.0	0.0	0.0	0.5
Blind or Deaf	0.0	2.1	1.7	2.3
Moderate				
Epilepsy	17.1	33.4	31.5	21.5
Cerebral Palsy	3.1	3.2	3.2	6.4
Autism	0.0	3.2	2.9	3.3
Spina Bifida	0.0	1.1	0.9	0.8
Blind or Deaf	7.6	4.8	4.9	3.7
Severe				
Epilepsy	31.9	36.1	35.6	26.5
Cerebral Palsy	26.7	6.7	9.3	9.2
Autism	2.2	3.7	3.5	5.6
Spina Bifida	0.0	0.5	0.4	0.4
Blind or Deaf	3.3	4.4	4.2	4.4
Profound				
Epilepsy	25.1	46.3	45.5	43.2
Cerebral Palsy	17.4	16.8	15.8	19.5
Autism	0.0	2.2	2.2	2.6
Spina Bifida	0.0	0.6	0.6	0.5
Blind or Deaf	12.3	15.1	15.0	13.6
Related Conditions Only				
Epilepsy	0.0	100.0	100.0	74.1
Cerebral Palsy	0.0	0.0	0.0	24.0
Autism	0.0	0.0	0.0	5.4
Spina Bifida	0.0	0.0	0.0	0.0
Blind or Deaf	0.0	0.0	0.0	0.0
Total Residents with MR/RC				
Epilepsy	21.0	40.4	36.9	29.6
Cerebral Palsy	16.2	12.0	12.3	11.7
Autism	0.7	2.5	2.3	3.5
Spina Bifida	0.0	0.6	0.5	0.5
Blind or Deaf	5.5	10.5	10.2	7.2

Notes. Blindness is defined as inability, with use of corrective lenses, to recognize (because of visual acuity) familiar people at a distance of 2 or 3 feet. Deafness is defined as inability with a hearing aid, to hear things said to him or her. Data are percent of residents within each of five groups, who have the additional handicap listed. Within groups, columns do not total 100% because some residents had no additional handicap, some had more than one.

Age Distribution

Table 17 presents estimated age distributions of persons with mental retardation and related conditions in public residential facilities. It should be noted with respect to the comparative statistics in the 'All Facilities' column that the underidentification of the small private facilities, including removal of all 1 and 2 person facilities from the sample frame caused considerable underestimation of children and youth in the 0-14 years and 15-21 years age categories. Based on 1982 statistics on the number of children and youth in such facilities (Hauber et al., 1984), it would appear that approximately 18.5% to 19.5% of persons in 'All facilities' would have been 0-21 years in 1987. Among public facilities, where representation appeared appropriate, children and youth (0-21 years) made up about 13.6% of residents. Children and youth made up an estimated 13.3% of large public residential facility residents. This compares with 13.6% indicated in a census survey of large public facilities in 1987 (Scheerenberger, 1988). A majority of large public facility residents (54.8%) are in the relatively narrow age range of 22 years to 39 years, a statistic again confirmed by the 1987 census survey count of 54.3% (Scheerenberger, 1988). Among small public facilities there were somewhat higher proportions of individuals in the childhood and middle age group than in the large public facilities (8.9% as compared with 3.5% in the 0-14 years group and 35.8% as compared with 24.8% in the 40-64 years group).

Breakdown of resident samples by ages and mild/moderate and severe/profound mental retardation revealed only a few notable differences in age distribution by level of retardation between small and large public residential facilities. Within the small public facilities children (0-14 years) with severe/profound mental retardation made up a higher proportion of all residents with severe/profound mental retardation (12.5%) than children with mild/moderate mental retardation did of all residents with mild/moderate mental retardation (4.0%). Among large public facilities older adults (55 years and older) with mild/moderate mental retardation made up a larger proportion of all residents with mild/moderate mental retardation (22.8%) than older adults with severe/profound mental retardation did of all residents with severe/profound mental retardation (11.5%).

Table 17

Percentage of Residents of Public Mental Retardation Facilities by Age and Level of Retardation

	Public		Total	All Fac.
	15- res.	16+ res.		Total
Mentally Retarded				
Bord./Mild/Mod.				
0-14 years	4.0	3.9	3.9	3.3
15-21 years	8.2	5.7	6.1	6.9
22-39 years	43.1	51.0	49.8	49.2
40-54 years	26.2	16.6	18.3	22.5
55-64 years	10.5	9.8	9.9	9.4
65+ years	6.0	13.0	12.0	6.7
Severe/Profound				
0-14 years	12.5	3.4	3.9	5.6
15-21 years	8.4	10.9	10.6	12.3
22-39 years	37.7	56.0	54.9	53.9
40-54 years	23.2	18.2	18.5	17.8
55-64 years	10.5	6.2	6.4	6.3
65+ years	7.7	5.3	5.4	4.3
Related Conditions Only				
0-14 years	0.0	0.0	0.0	7.7
15-21 years	0.0	0.0	0.0	11.6
22-39 years	0.0	0.0	0.0	24.7
40-54 years	0.0	32.4	32.4	14.2
55-64 years	0.0	0.0	0.0	21.7
65+ years	0.0	67.6	67.6	20.0
Total MR and RC				
0-14 years	8.9	3.5	3.9	4.6
15-21 years	8.3	9.8	9.7	10.8
22-39 years	40.0	54.8	53.7	51.6
40-54 years	25.3	17.9	18.5	19.8
55-64 years	10.5	6.9	7.2	7.7
65+ years	7.0	7.0	7.0	5.5

Notes. Borderline/Mild/Moderate category includes the 2.5% of the total estimated population reported to have mental retardation, but whose level of retardation was not reported. The "Related conditions only" estimates in large public facilities are based on only 3 sample members, 1 person in the 40-54 age category and 2 persons in the 65 years or older age category.

Medical Conditions

Table 18 presents estimates of the proportion of residents of small, large and total public residential facilities with various medical conditions/ailments. A comparison estimate for all residential facilities is also provided. Because of the association of the medical conditions studied with age, age breakdowns are provided for residents who are 54 years and younger and 55 years and older.

The most commonly indicated medical condition was frequent constipation. It was reported for an estimated 30.6% of public facility residents, including 31.3% of large public facility residents and 22.9% of small public facility residents. An estimated 20.9% of residents of all public and private residential facilities were indicated to have frequent constipation. Unlike most of the medical conditions

shown in Table 6, frequent constipation was not associated with age. However, it was quite highly associated with profound mental retardation (36.3% of persons with profound mental retardation were reported to have frequent constipation as compared with 12.5% of other residents with mental retardation and related conditions). Of course, the primary factors in the more often reported constipation among persons with profound were related to the amount of movement, amount of upright positioning and mobility. In addition profound mental retardation is more often associated with neuromuscular disorders and abdominal muscle weakness which also contribute to frequent constipation. The association between constipation and the physical conditions frequently accompanying profound mental retardation was a major factor in the higher rates reported in large public facilities.

With the exception of constipation, the distribution of medical conditions and ailments of residents of public facilities was very similar to the estimates for the residential population of public and private facilities as a whole. An estimated 10.1% of public facility residents had circulatory conditions (including the conditions of current high blood pressure, hardening of the arteries or heart disease, or past stroke or heart attack). An estimated 4.7% of public facility residents had arthritis or rheumatism and 1.8% were reported to have diabetes. Cancer was reported for 1.6% of the public facility population.

Approximately 12% of public facility residents were reported to be "obese," defined simply as a resident's "being very overweight." Obesity was more commonly reported among small public facility residents (18.4%) than among residents of large public facilities (11.4%). This may relate to the greater regulation of diet and access to food in institutional settings, although reported obesity among small public facilities was slightly higher than for small facilities in general (18.4% and 15.1%, respectively).

Table 18

Percentage of Residents of Public Mental Retardation Facilities
with Selected Medical Conditions/Ailments

	Public		Total	All Fac.
	15- res.	16+ res.		Total
54 Years and Younger				
Circulatory conditions	8.4	6.3	6.4	7.8
Arthritis or Rheumatism	3.3	2.0	2.1	2.2
Diabetes	2.9	0.9	1.1	1.4
Cancer	0.0	0.2	0.2	0.4
Frequent constipation	21.6	31.7	30.9	20.9
Obesity	18.0	10.9	11.4	12.8
55 Years and Older				
Circulatory conditions	30.9	32.4	32.3	31.4
Arthritis or Rheumatism	14.5	20.6	20.2	20.0
Diabetes	13.2	5.5	6.2	6.3
Cancer	7.0	10.4	10.1	6.8
Frequent constipation	28.9	28.5	28.6	20.7
Obesity	20.2	14.7	15.2	16.0
All Residents				
Circulatory conditions	12.4	9.9	10.1	10.9
Arthritis or Rheumatism	5.3	4.6	4.7	4.6
Diabetes	4.7	1.6	1.8	2.0
Cancer	1.2	1.6	1.6	1.2
Frequent constipation	22.9	31.3	30.6	20.9
Obesity	18.4	11.4	12.0	13.2

Notes. Statistics are percent of residents within each group who were reported to have selected medical conditions/ailments. Columns do not add up to 100% because some sample members had more than one condition and some had none. "Circulatory conditions" include present high blood pressure, hardening of the arteries or heart disease or past stroke or heart attack.

Activities of Daily Living

Table 19 presents estimates of the participation of residents of public residential facilities in selected activities of daily living. In general the data showed residents of large public facilities to be less frequently independent in major activities of daily living than residents of small public facilities or residents of all types of residential facilities in general.

Bathing or showering. An estimated 23.9% of residents of public facilities were able to bathe or shower without assistance from other individuals. This included 22.2% of the large public facility residents and 44.7% of the small public facility residents. An estimated 39.1% of all residents of mental retardation facilities were able to bathe or shower independently.

Dressing. An estimated 29.6% of residents of public facilities were reported to dress without assistance, including 27.3% of residents of large facilities and 57.1% of residents of small facilities. The

proportion of persons in all public facilities reported to be able to dress independently (29.6%) was lower than the estimated proportion of persons in all residential facilities (45.6%).

Table 19

Percentage of Residents of Public Mental Retardation Facilities
Performing Various Activities of Daily Living

Activity	Public			All Fac.
	15- res.	16+ res.	Total	Total
Bathing or Showering				
No difficulty w/o help	44.7	22.2	23.9	39.1
Received assistance or supervision	55.3	77.8	76.1	60.9
Uses special equipment/no other assistance	0.0	0.0	0.0	0.0
Dressing				
No difficulty w/o help	57.1	27.3	29.6	45.6
Received assistance or supervision	42.1	72.7	70.4	54.3
Uses special equipment/no other assistance	0.8	0.0	0.2	0.1
Using the Toilet				
No difficulty w/o help	79.6	51.7	53.9	68.1
Received assistance or supervision	12.5	32.2	30.3	22.4
Uses special equipment/no other assistance	0.6	0.1	0.2	0.2
Did not do at all	6.8	16.1	15.4	9.4
Getting In/Out of Bed				
No difficulty w/o help	85.9	68.9	70.2	60.3
Received assistance or supervision	9.5	24.0	22.9	15.1
Uses special equipment/no other assistance	0.0	0.0	0.0	0.1
Did not do at all	4.6	7.0	6.8	4.6
Feeding Self				
No difficulty w/o help	84.7	64.6	66.2	77.2
Received assistance or supervision	9.1	23.4	22.3	15.8
Uses special equipment/no other assistance	0.5	0.6	0.6	0.4
Did not do at all	5.6	11.4	11.0	6.6
Walking Across Room				
No difficulty w/o help	83.4	66.0	67.4	77.3
Received assistance or supervision	8.5	11.3	11.1	8.4
Uses special equipment/no other assistance	1.9	1.2	1.3	1.2
Did not do at all	6.3	21.4	20.3	13.2

Using the toilet. An estimated 53.9% of residents of public facilities used the toilet independently, including 51.7% of large facility residents and 79.8% of small facility residents. These estimates compared with 68.1% of all residents of all (public and private) mental retardation facilities.

Very small numbers of persons were reported to use the toilet independently with the aid of equipment. An estimated 30.6% of residents of public facilities received assistance of another person or supervision in using the toilet, including 32.2% of large public facility residents and 12.5% of small facility residents. An estimated 15.4% of public facility residents were reported to not use a toilet either with or without assistance. This included 16.1% of large public facility residents and 6.8% of small facility residents, and compared with an estimated total of 9.4% for persons in all public and private facilities.

Getting in and out of bed. An estimated 70.2% of residents of public facilities were reported to be able to get into and out of bed without assistance. This included 68.9% of large public facility residents and 85.9% of small facility residents. It compared with an estimated 80.3% of residents of all public and private facilities. An estimated 6.8% of public facility residents were bed fast or were totally dependent on others to be lifted into and out of bed. This included 7.0% of larger public facility residents and 4.6% of small public facility residents, and compared with an estimated 4.6% of the total residential population of persons with mental retardation and related conditions.

Feeding self. An estimated 66.2% of residents of public facilities fed themselves without assistance. This included 64.6% of large public facility residents and 84.7% of small public facility residents. An estimated 22.3% of public facility residents ate with the assistance of another person, including 23.4% of large public facility residents and 9.1% of small public facility residents. An estimated 11.0% were reported to be unable to feed themselves with the assistance of another person or of special equipment. This included 11.4% of large public facility residents and 5.6% of small public facility residents.

Walking across room. About two-thirds (67.4%) of public facility residents were reported to walk across a room without the assistance of another person or equipment. This included 66.0% of large public facility residents and 83.4% of small public facility residents. A small proportion of residents (1.3%) were reported to be able to walk across a room without assistance from other

persons, but only if aided by equipment (e.g., walkers, canes). An estimated 11.1% of public facility residents (11.3% of large facility residents and 8.5% of small facility residents) were able to walk across a room only with assistance from another person. About one in five public facility residents (20.3%) was reported to be unable to walk across a room even with mechanical or human assistance. This included 21.4% of large public facility residents and 6.3% of small public facility residents. The comparable estimate for all facilities was 13.2% of residents with mental retardation and related conditions.

Instrumental Activities of Daily Living

Table 20 presents estimates of the proportions of residents of public facilities performing 4 basic instrumental activities of daily living. Estimates are provided for the proportions of public facility residents performing the activity independently, with help or not at all. Estimates are provided for small, large and all public facilities and for all public and private facilities.

Using telephone. An estimated 9.9% of public facility residents were reported to use the telephone independently. This included 27.3% of small public facility residents and 8.5% of large public facility residents. The comparable estimate for all public and private facility residents was 25.8%. In contrast 71.5% of public facility residents were reported to not use the telephone at all, with or without help. This included 73.9% of large public facility residents and 41.2% of small facility residents. It compared with an estimated 48.7% of all people in mental retardation facilities.

Managing money. About one in five residents (20.8%) of public facilities was reported to be involved in managing their money ("keeping track of expenses or paying bills") either independently or with assistance. Independent money management was reported for only 6.0% of public facility residents, including 5.1% of large facility residents and 17.3% of small facility residents.

Shopping for personal items. An estimated 7.4% of residents of public facilities were reported to be independently involved in "shopping for personal items, such as toilet items or medicines." This included 6.0% of large public facility residents and 24.6% of small public facility residents. It compared with an estimated 15.6% of all residents in both public and private mental

retardation facilities. In contrast an estimated 65.9% of public facility residents were not at all involved in shopping for personal items, either with or without assistance. An estimated 69.1% of large public facility residents were not involved in shopping for personal items, with or without assistance, as compared with 24.9% of small public facility residents and 45.6% of persons with mental retardation and related conditions in both public and private facilities.

Table 20

Percentage of Residents of Public Mental Retardation Facilities Performing Various Instrumental Activities of Daily Living

Activity	Public			All Fac.
	15- res.	16+ res.	Total	Total
<u>Using Telephone</u>				
Without help	27.3	8.5	9.9	25.8
With help	31.5	17.6	18.6	25.5
Not at all	41.2	73.9	71.5	48.7
<u>Managing Money</u>				
Without help	17.3	5.1	6.0	11.4
With help	29.7	13.7	14.8	27.8
Not at all	53.1	81.2	79.2	60.8
<u>Shopping for Personal Items</u>				
Without help	24.6	6.0	7.4	15.6
With help	50.5	24.9	26.8	38.7
Not at all	24.9	69.1	65.9	45.6
<u>Using Own or Public Transport.</u>				
Without help	20.1	5.8	6.9	17.3
With help	69.9	38.4	40.7	44.9
Not at all	10.1	55.8	52.5	37.8

Notes. Instrumental activities of daily living items were asked only about sample members who were 18 years or older. Percentages are based only on residents who were 18 years or older.

Using own or public transportation to get around the community. Only an estimated 6.9% of public facility residents were reported to get around the community by using personal or public transportation. Proportions ranged from 5.8% of large public facility residents and 20.1% of small public facility residents. Over half (52.5%) of all public facility residents were reported to not get around the community "at all" with personal or public transportation either independently or with help. Proportions ranged from 55.8% of large public facility residents to 10.1% of small public facility residents. The proportion of small public facility residents who were able to use personal or public

transportation to "get around the community" was 69.9%, as compared with 38.4% of large public facility residents and 44.9% of residents of all types of facilities.

Use of Special Equipment/Devices

Table 21 presents estimates of the proportion of residents of public facilities using different types of special equipment or devices to compensate for various types of impairments. The most commonly used assistive device was a wheelchair. An estimated 28.3% of public facility residents used wheelchairs, including 29.8% of large public facility residents and 10.8% of small public facility residents. Another 4.0% of public facility residents were reported to use walkers, cane or crutches. It was estimated that 17.9% of public facility residents use corrective lenses and 8.5% hearing aids.

Table 21

Percentage of Residents in Public Mental Retardation Facilities Using Special Equipment and Devices

Equipment/Devices	Public			All Fac.
	15- res.	16+ res.	Total	Total
Corrective lenses	44.1	15.8	17.9	30.7
Hearing aid	8.5	2.3	2.7	3.6
Special underwear or diapers	12.0	23.9	23.0	15.5
Wheelchair	10.8	29.8	28.3	17.9
Walker, cane or crutches	2.6	4.1	4.0	4.5
Special dishes, cups, utensils	17.2	24.0	23.5	14.7
Mechanical devices for eating	0.0	1.7	1.6	1.1
Velcro fasteners or snaps	13.9	18.3	17.9	12.4
Symbol system/communication board as primary means of communication	1.3	1.2	1.2	1.0
Shower seat or tub stool	3.1	21.7	20.2	14.7
Portable toilet	2.7	5.4	5.2	3.2
Urinary catheter	0.0	1.1	1.1	1.0
Colostomy bag	0.0	0.2	0.2	0.3

Use of these devices was considerably lower among large public facility residents than among residents of the small facilities (15.8% and 44.1%, respectively for corrective lenses, and 2.3% and 8.5%,

respectively for hearing aids). Special cups, dishes and utensils were used for eating by an estimated 23.5% of public facility residents, including 24.0% from large facilities and 17.2% from small facilities. Special underwear or diapers were used by an estimated 23% of public facility residents, including 23.9% of large facility residents and 10.8% of small facility residents. Shower seats or tub stools were used by an estimated 20.2% of public facility residents, but relatively infrequently in small public facilities (3.1%). Velcro fasteners and snaps were used by an estimated 17.9% of public facility residents, including 13.9% from small facilities and 18.3% from large facilities. Other devices used relatively infrequently by residents of public facilities included: mechanical devices for eating (1.6% of residents), symbol systems/communication boards as *the primary means of communication* (1.2%), portable toilets (5.2%), urinary catheters (1.1%), and colostomy bags (0.2%).

Employment Status

Table 22 presents data gathered in the 1987 National Medical Expenditure Survey on the employment status of persons with mental retardation and related conditions who were living in mental retardation facilities. These statistics include only sample members who were 18 years or older.

It was estimated that in 1987 27.0% of persons with mental retardation or a related condition in public residential facilities worked at a job for which they were paid. These persons included 25.4% of the population of large public facilities and 49.2% of the population of small public facilities. About 70% of the public facility residents who worked for pay had their jobs at the residential facility where they lived. These persons included an estimated 80.3% of public facility residents with paid jobs (20.4% of all residents), but only an estimated 4.7% of small public facility residents with paid jobs. An estimated 38.8% of residents of both public and private residential facilities worked for pay. Of these about 68% worked away from the facility.

By far the most common employment for public facility residents who worked for pay was a sheltered workshop. About 20% of all public facility residents were employed in sheltered settings; these were 72.9% of all public facility residents working for pay. An estimated 18.3% of large public facility residents worked for pay in sheltered employment settings (72.0% of all paid workers). An

estimated 40.3% of all small public facility residents worked for pay in sheltered employment settings (81.2% of all workers). Supported/transitional employment was used by only an estimated 3.0% of public facility residents in 1987 (2.5% of large public facility residents and 8.4% of small public facility residents). Competitive employment was reported for only 2 people in the sample of 1,641 residents of large and small public residential facilities; both of these lived in large facilities. Next to sheltered employment the most commonly indicated paid work for residents of public facilities were "other" jobs, that is, work not fitting in the categories of sheltered workshop, supported/transitional employment or competitive employment. About 4.2% of public facility residents were reported to do "other" work for pay. Most of this other work was performed in the residential settings.

Table 22

Percentage of Adult Residents of Public Mental Retardation Facilities by Employment Status

	Public		Total	All Fac.
	15- res.	16+ res.		Total
<u>Works for Pay</u>				
In facility	2.3	20.4	19.0	12.5
Away from facility	46.9	5.0	8.0	26.3
Total	49.2	25.4	27.0	38.8
<u>Type of Employment</u>				
Sheltered employment	40.3	18.3	19.9	29.8
Supported/transitional employment	8.4	2.5	3.0	3.0
Competitive employment	0.0	0.2	0.2	1.4
Other	0.8	4.4	4.2	4.8
Total	49.3	25.4	27.3	39.0
<u>Works with Nonhandicapped People</u>	4.4	4.6	4.5	7.1
<u>Hourly Wages by Type</u>				
Sheltered workshop	1.64	0.97	1.09	1.02
Supported/transitional	1.94	1.65	1.70	2.15
Competitive employment	0.0	5.00	5.00	3.87
Other	-	0.71	0.71	1.35
Average hourly wage	1.69	1.02	1.13	1.25

Notes. Table includes residents age 18 or older. Total by type of employment may not equal total employed because of varying item response rates. A "-" denotes missing data. An estimate of "0.0" for a cell indicates that no sample members were reported in the cell.

Opportunities to work alongside people who were not handicapped were not commonly reported. Only 4.5% of public facility residents were reported to work directly with nonhandicapped people, with no differences reported for residents of large and small facilities.

On average public facility residents who worked for pay received \$1.13 per hour. Large public facility residents averaged \$1.02 per hour, small public facility residents averaged \$1.69 per hour. Average wages were, of course, dominated by the wages of sheltered workshop employees, who made up substantial majorities of the public facility residents who had paid jobs. On average sheltered workshops paid \$1.09 per hour to public facility residents in 1987, including \$0.97 to large facility residents and \$1.64 to small facility residents. Presumably these pay differences related to population differences associated with production.

PART III: LONGITUDINAL TRENDS IN LARGE STATE-OPERATED RESIDENTIAL FACILITIES, 1950-1988

Part III of this report presents a longitudinal view of changing patterns in the placement of persons with mental retardation and related conditions in large state-operated residential facilities from 1950 to 1988. Although in recent years states have begun to develop small (15 or fewer residents) state-operated facilities, the vast majority of persons in state-operated facilities remain in the large institutions. As the once overwhelmingly predominant model of residential care, few statistics serve as better indicators of the changing patterns of residential services in the United States than the changes taking place in large state institutions. Therefore, the statistics presented here focus exclusively on large state-operated facilities.

The longitudinal data presented here derive from several sources. Data for both PRF/MR and PRF/Other for the years 1950 to 1968 are from the National Institute of Mental Health's surveys of "Patients in Institutions." Data on state mental retardation facilities for Fiscal Years 1969 and 1970 come from surveys conducted by the Division on Mental Retardation, now the Administration on Developmental Disabilities. Data on state mental retardation facilities for 1971 through 1977 come from the surveys of National Association of Superintendents of Public Residential Facilities for the Mentally Retarded. Data on PRF/Other 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 PRF/MR and PRF/Other for the years 1978 through 1988 come from the National Recurring Data Set Project of the Center for Residential and Community Services, University of Minnesota. Data from the latest survey in this series are presented in Part I of this report. Appendix C provides notes on the specific uses of the data from these sources. The reference list includes specific citations for the surveys and statistical summaries used to complete the sets of longitudinal data on changing patterns in the utilization of state-operated residential facilities that are presented in the following pages.

Average Daily Population of Large State-Operated Mental Retardation Facilities

The gradual depopulation of state-operated residential facilities for persons with mental retardation has been apparent in national statistics since 1967. There has been a decreasing total residential population in state institutions for all types of mental disability since 1956. Although the total population in state mental hospitals peaked in 1955, the number of persons with a primary diagnosis of mental retardation in state-operated facilities primarily for persons with mental illness (i.e., PRF/Other) 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 mental retardation and related conditions in state-operated residential facilities (PRF/MR and PRF/Other) in 1961 was 209,114. By 1967 the number of persons with mental retardation in state hospitals for persons with mental illness had decreased to 33,850, but the total number of persons with mental retardation and related conditions in all state-operated residential facilities had increased to 228,500, 194,650 of whom were in state mental retardation institutions. This was the highest total ever.

Since 1967 the number of persons with mental retardation and related conditions in all state-operated residential facilities has decreased by about 59%. During this period the numbers of persons with mental retardation in PRF/Other decreased much more rapidly than did the number of persons with mental retardation in PRF/MR. The different rates of depopulation reflect a number of factors. For one, the total rate of depopulation of state mental health facilities has been much more rapid than the rate of depopulation of state mental retardation facilities. Between 1965 and 1985 the total population of state mental health institutions decreased from about 475,000 to 114,000 residents (Zappolo, Lakin, & Hill, 1990). This rapid depopulation and frequent closing of facilities caused major reductions in residents with all types of mental disability, including mental retardation. Relatedly over the years, many PRF/Other became primarily dedicated to populations with mental retardation or developed independent PRF/MR programs on the grounds of what was historically a public psychiatric facility.

A driving force in the reduction of residents with mental retardation in PRF/Other has been the general movement toward deinstitutionalization and specific concerns about the appropriateness of

placement in psychiatric facilities. However, extremely important, too was the Medicaid legislation in the late 1960s and early 1970s which allowed states to obtain federal cost-sharing of residential services to persons with mental retardation and related conditions in mental retardation facilities and in nursing homes. This legislation continued exclusion of institutions for "mental diseases" from participation in Medicaid, except for children and elderly residents. However, distinct units for persons with mental retardation and related conditions within those institutions could become ICF-MR certified. Many have and within the definitions employed in this study are classified as PRF/MR.

Figure 1 shows the relative contribution of PRF/MR and PRF/Other programs to the total average daily population of persons with mental retardation in large state-operated residential facilities. The average daily number of persons with mental retardation in large PRF/MR in FY 1988 (91,582) was only 47.0% of the average number in large PRF/MR in 1967. More impressively the average number of persons with mental retardation and related conditions in all large state institutions in FY 1988 (93,515) was just 40.9% of the average number in FY 1967 (228,500). The combined national total of people with mental retardation and related conditions in PRF/MR and PRF/Other in 1988 was the lowest total since 1933.

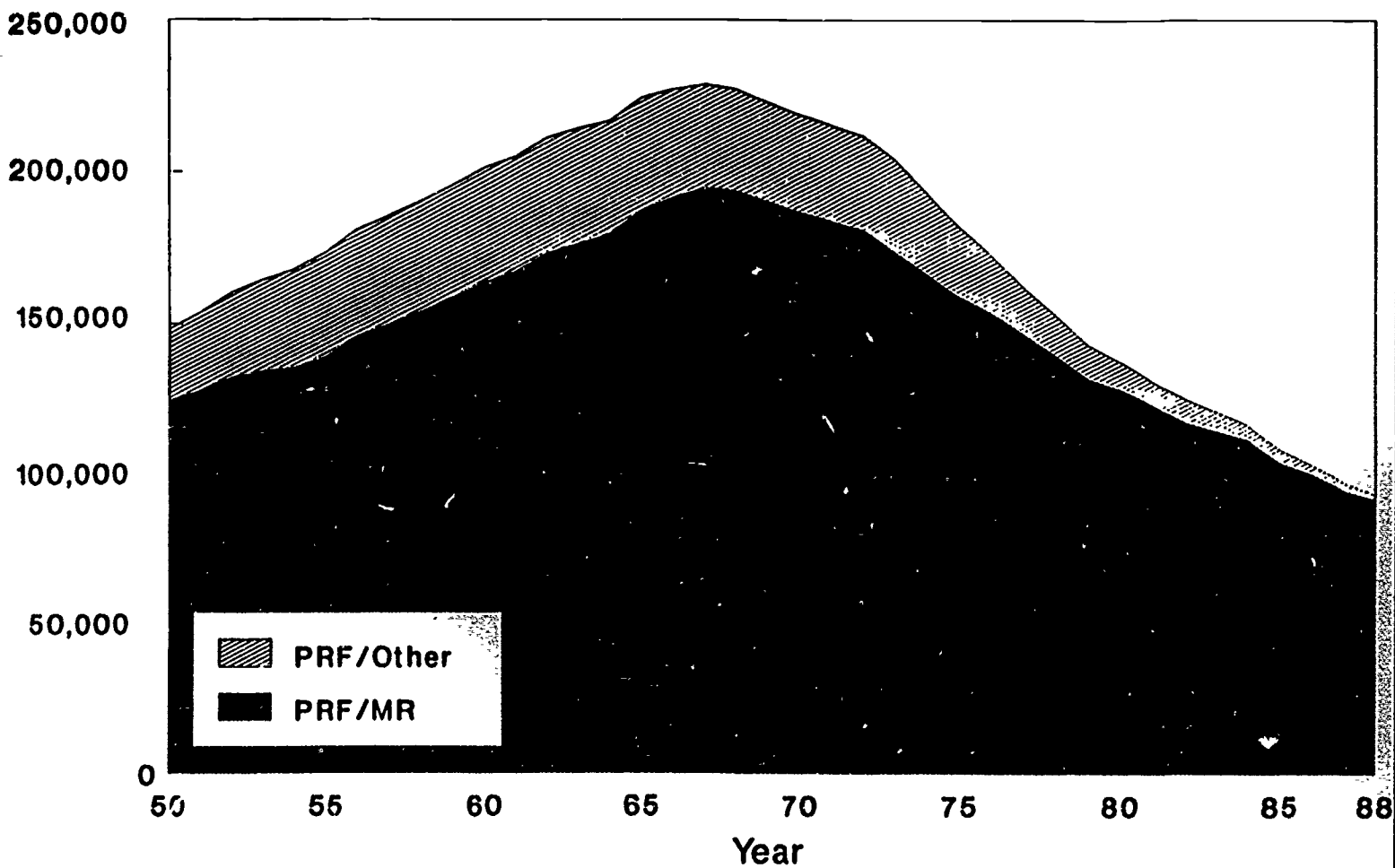
Selected Data Points for Figure 1: Average Daily Population of Large State-Operated Mental Retardation Facilities, 1950-1988

Year	PRF/MR	PRF/Other	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
1981	122,898	7,866	130,764
1982	117,160	7,865	125,026
1984	111,333	5,096	116,429
1985	103,629	4,536	108,165
1986	100,190	3,106	103,296
1987	94,696	2,837	97,533
1988	91,582	1,933	93,515

Note. Some PRF/Other data are estimated (see notes in Appendix C).

Figure 1

Average Daily Population of Large State-Operated Mental Retardation Facilities



Average Daily Population of Large State-Operated Mental Retardation Facilities per 100,000 of the General Population

Since 1967 there has been a substantial decrease in the number of people with mental retardation and related conditions in state-operated residential facilities. But as notable as has been the reduction in total residents, it appears even more substantial when indexed for the growing total population of the United States. Comparing the population of state-operated facilities to the general population of the U.S. permits a better picture of the relative use of state-operated facilities as residential placements for persons with mental retardation and related conditions. The average annual placement rates per 100,000 of the total U.S. population for PRF/MR and PRF/Other are shown in Figure 2.

The trends in the placement rates of persons with mental retardation and related conditions in all state-operated residential facilities are generally similar to trends for the total populations. However, the rate of change in the placement rate is substantially greater because the U.S. population has increased as the population of state-operated facilities has decreased. Another notable difference between the two figures is in their peak years. While the total number of persons with mental retardation and related conditions residing in all state-operated residential facilities and the number residing in facilities primarily for persons with mental retardation peaked in 1967, the placement rate of persons with mental retardation in all state-operated facilities (PRF/MR and PRF/Other) peaked in 1965 at 115.8 per 100,000 of the general population. This compares with 38.0 in FY 1988. The highest placement rate in state-operated facilities primarily for persons with mental retardation was in 1967. That year's placement rate of 98.6 compares with the 1988 rate of 37.3. The 1988 placement rate for state-operated mental retardation facilities fell below the rate of 39.3 in 1922, when there were 66 PRF/MR operating in 40 states, and approached the rate of 30.0 in 1916, when there were only 40 PRF/MR operating in the United States, with 16 states not yet having one (Lakin, 1979).

As noted earlier, some of the decrease in the placement rate in "PRF/Other" facilities between 1973 and 1988 may reflect changing definitions. During that period some facilities historically serving psychiatric populations either through official or operational designation became facilities primarily

serving persons with mental retardation. Others developed specific administratively distinct units of traditional psychiatric facilities for these purposes. The decrease shown between 1977 and 1980 was also to a minor extent affected by the inclusion in the PRF/Other totals of only those residents with mental retardation in mental retardation units or in PRF/Other with 10 or more residents with mental retardation. But far more important in this trend were the major changes in philosophy and federal reimbursement of the costs of care that brought considerable disfavor to providing residential services to persons with mental retardation in psychiatric facilities. The statistics in Figure 2 show clearly a substantial decrease in the rate of placement of persons with mental retardation and related conditions in state-operated residential facilities. The placement rate in 1988 for large PRF/MR was only 37.8% of the 1967 placement rate. The placement rate for all large state-operated facilities (PRF/MR and PRF/Other) in 1988 was just 32.9% of the 1967 placement rate.

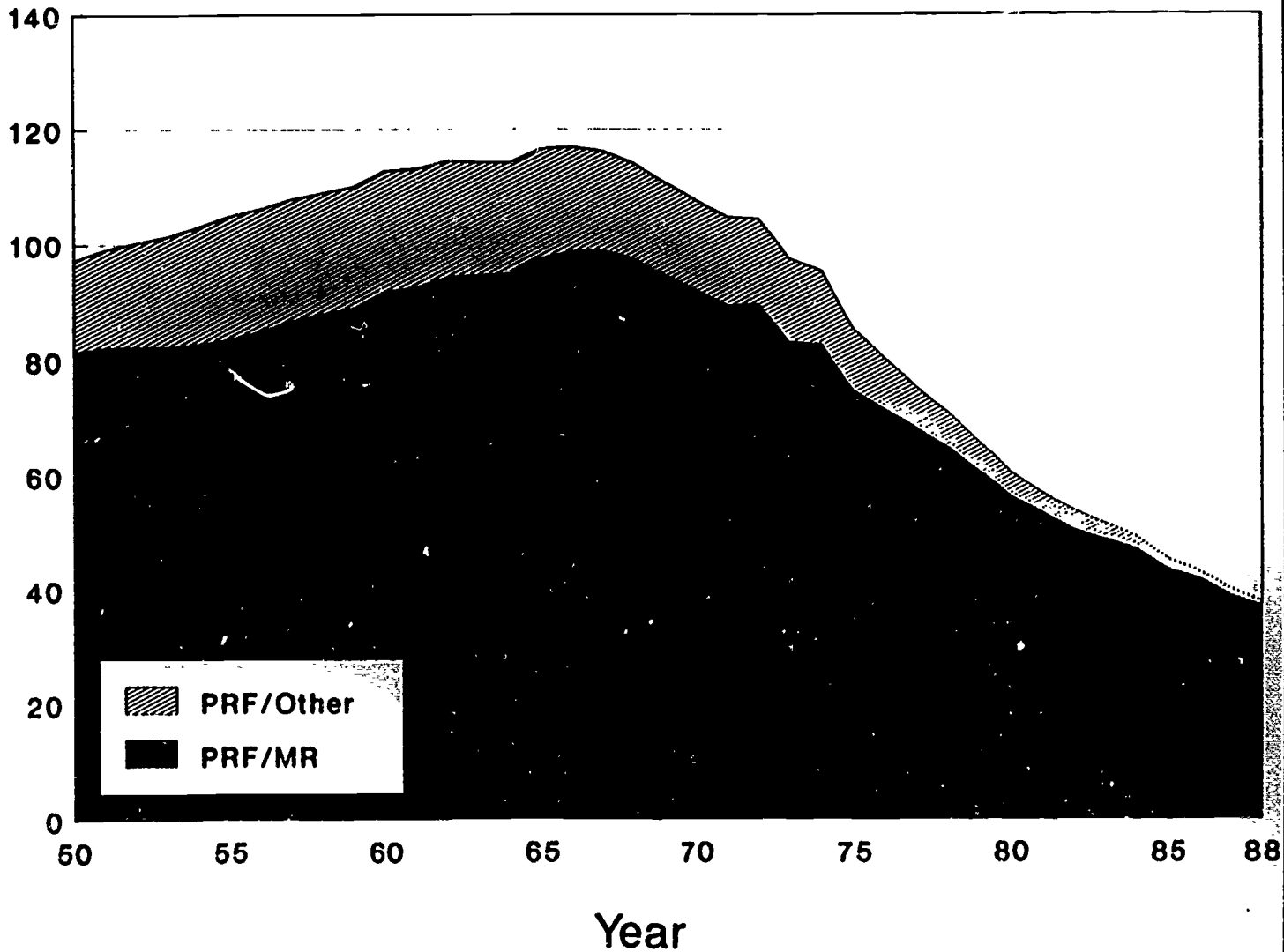
Selected Data Points for Figure 2: Average Daily Population of Large State-Operated Mental Retardation Facilities per 100,000 of the General Population, 1950-1988

Year	U.S. Population in 100,000s on 7/1	PRF/MR	PRF/Other	Total
1950	1,518.68	81.85	15.74	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
1977	2,197.60	68.95	7.06	76.01
1980	2,272.36	56.35	4.14	60.49
1981	2,295.42	53.54	3.43	56.97
1982	2,318.22	50.54	3.39	53.93
1984	2,361.58	47.14	2.16	49.30
1985	2,382.91	43.49	1.90	45.39
1986	2,387.70	41.96	1.30	43.26
1987	2,433.05	38.92	1.17	40.09
1988	2,458.07	37.26	0.79	38.04

Note. Some PRF/Other data are estimated (see notes in Appendix C).

Figure 2

Average Daily Population of Large State-Operated
Mental Retardation Facilities per 100,000 of the General Population



Movement Patterns In Large State-Operated Mental Retardation Facilities

From the beginning of this century until the mid-1960s, resident movement statistics of state-operated residential facilities for persons with mental retardation were relatively stable. During that period first admissions and discharges both steadily increased, but state facility populations grew as first admissions substantially outnumbered discharges. During this same period readmissions remained relatively low because once placed, people tended to remain institutionalized. From 1903 to 1965 the annual number of deaths in state institutions increased substantially, but death rates (deaths per 1,000 average daily population) decreased steadily from 41.3 to 19.1.

By the mid-1960s these historical patterns began to change. In 1935 the number of first admissions to state-operated 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 institution was a frequently used solution to problems in community facilities. Since 1980 readmissions have been reduced fairly steadily, but readmissions remain nearly as frequent as new admissions (2,574 and 2,857, respectively in 1988). Over this same period the sum of first admissions and readmissions has remained consistently between 2,300 and 3,000 less than the number of discharges. However in 1988, there were only about 1,200 more discharges than admissions. Because of differences among states in methods of defining and counting transfers, first admissions, and readmissions, all types of admissions have been combined for 1950 to 1988. These are reported as the data points for Figure 3.

In recent years, the number of discharges has fallen below the numbers apparent in the first 12 years of PRF/MR depopulation. The greatest number of discharges ever was almost 17,000 in 1979. In 1988 there were only about 6,300 discharges, down considerably from about 9,400 in 1986 and 8,000 in 1987. Deinstitutionalization literally connotes a process of discharging people from institutions, but Figure 3 shows clearly that it has also encompassed important efforts to avoid initial institution placements. The resident movement patterns shown in Figure 3 indicate that this latter "preventative" policy (i.e., reducing admissions to state institutions) has actually accounted for relatively more of the

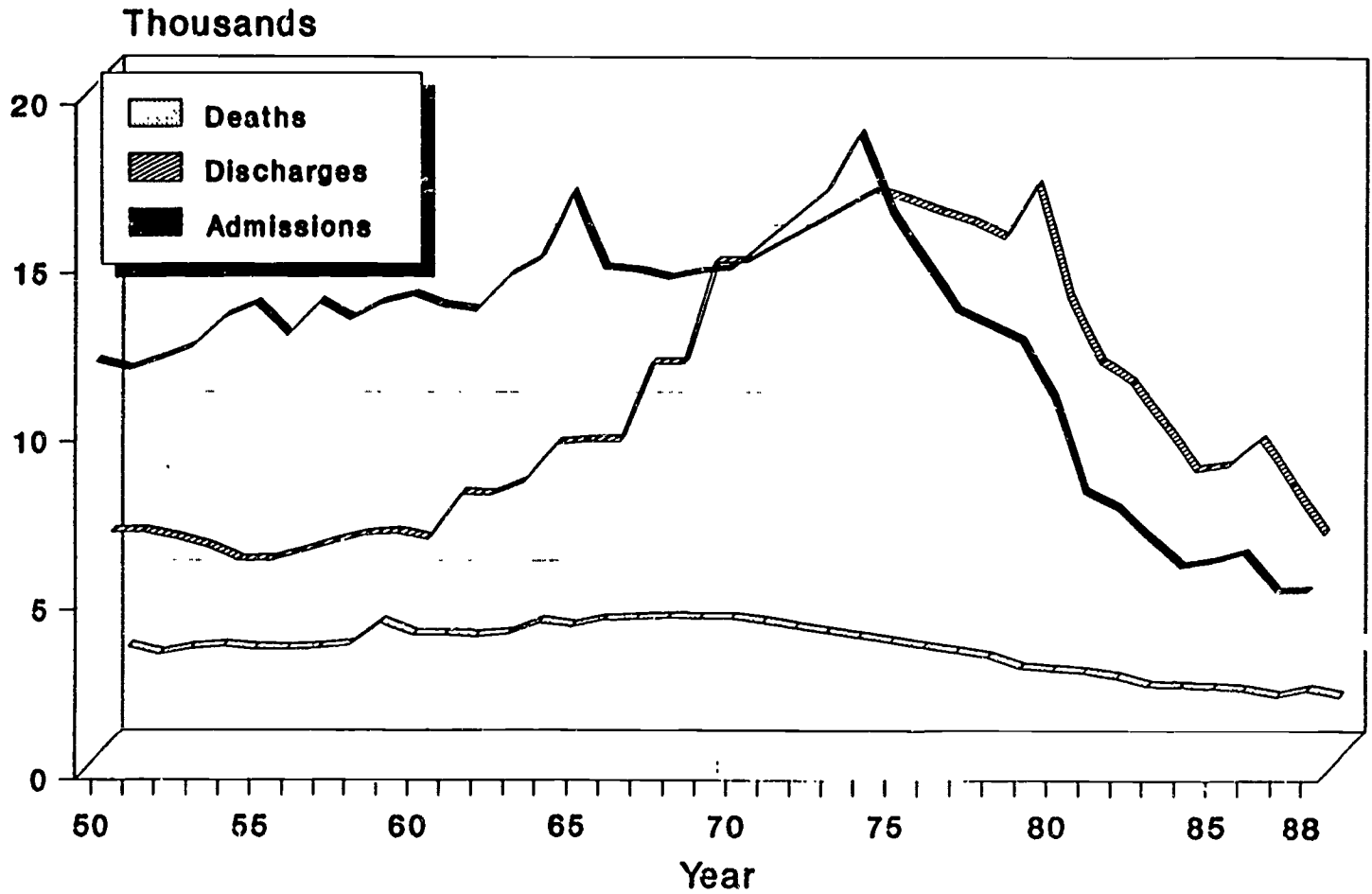
reduction in state mental retardation facility populations over the past decade than has the number of releases, although both clearly have been crucial to reducing PRF/MR populations. In the eight year period from 1979 to 1988 there were substantial decreases in both admissions to and discharges from state-operated facilities (from 12,802 to 5,431 and from 16,980 to 6,622 respectively). However, admission and discharge rates have been relatively stable in the last five years. While state institutions would appear from the statistics to be considerably less dynamic in terms of resident movement than in earlier years, it must be remembered that in 1988 these facilities had less than half their total populations of 1967. Total deaths reported for 1988 was similar to previous years. There was a decrease from 1987 when the rate was higher than might have been expected based on previous years. In 1988 the number of deaths as a percentage of residents at the end of the year was 1.45%. This compares with 1.32% in 1985, and 1.59% in 1987. Deaths as a percentage of residents at year's end have ranged between 1.3% and 1.6% in each of the years between 1978 and 1988.

Selected Data Points for Figure 3: Movement Patterns in Large State-Operated Mental Retardation Facilities, 1950-1988

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
1979	12,802	16,980	2,087
1980	11,141	13,622	2,019
1981	8,329	11,713	1,873
1982	7,844	11,076	1,634
1984	6,123	8,484	1,555
1985	6,276	8,619	1,508
1986	6,535	9,399	1,322
1987	5,398	8,049	1,513
1988	5,431	6,323	1,333

Figure 3

Movement Patterns in Large State-Operated Mental Retardation Facilities



Annual Per Resident Costs for Care In Large State-Operated Mental Retardation Facilities

The costs of care provided in state-operated residential facilities for people with mental retardation have increased dramatically since 1950, when the annual cost of care for state-operated facility residents was about \$750.00. Thirty-eight years later the cost of care in state residential facilities was on the average over \$57,000 per year. Even in dollars adjusted for changes in the Consumer Price Index over this period, costs of care in 1988 were over 15 times as great as in 1950. Figure 4 shows the trends in residential care costs in both actual and adjusted dollars (\$1=1967) between 1950 and 1988. In terms of "real dollar" equivalents, the annual cost of care in state residential facilities for people with mental retardation increased from just over \$1,000 to nearly \$16,000 over the 28 year period. That rate of increase represents an annual after inflation compounded growth of about 11% per person per year.

A number of factors have contributed to the increasing costs of residential care. One contributing factor has been the increasingly disabled population of persons served in state-operated facilities. For example, in 1940 about 65% of all residents of state-operated facilities for people with mental retardation had borderline, mild, or moderate retardation. In 1964, 40% of residents were so classified. By 1977, that proportion had decreased to 27% and in 1987, only about 20% of all residents were identified as having borderline, mild, or moderate retardation (see Part II). Associated with these changes have been increased intensity and specialization of professional staff to service existing residents and the relatively lower reliance on residents with less severe disabilities in operating and maintaining facilities.

Other important contributions to increasing costs have come from legislative and judicial efforts to upgrade the quality of living and habilitation provided within public residential facilities. While the desire to improve care in state-operated facilities was evident in the 1950s and 1960s, two major factors began to exercise considerable upward pressure on the costs of care in the early 1970s. The first of these was the Intermediate Care Facility for the Mentally Retarded (ICF-MR) program enacted in 1971.

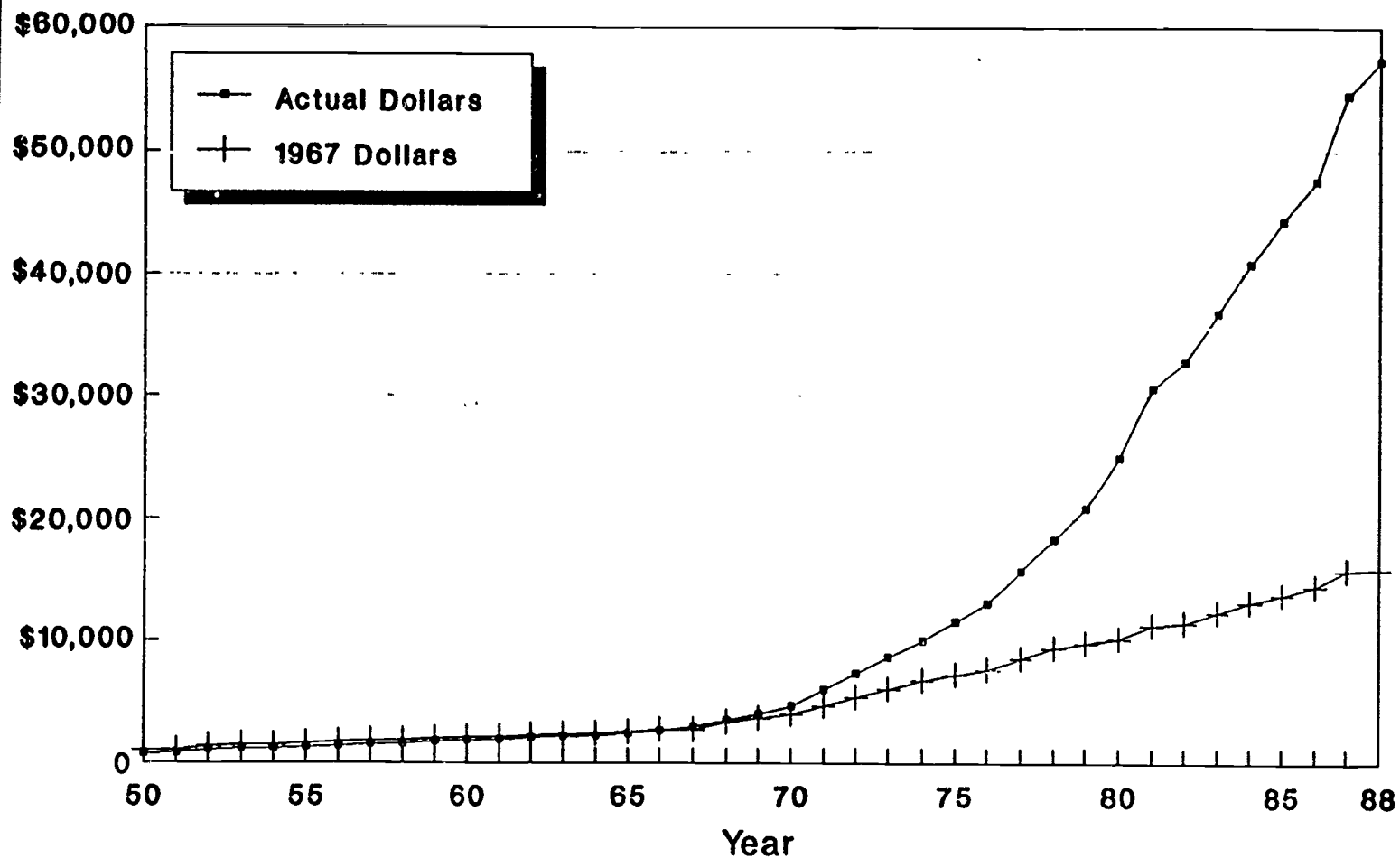
This program currently offers Federal sharing through Medicaid of half to three-quarters of the costs of residential care depending on the relative wealth of states, under the condition that facilities meet fairly demanding program, staffing, and physical plant standards. This program has significantly cushioned the impact of rapidly increasing institution costs for the states. For example, in 1970, one year before enactment of the ICF-MR program, the average annual per resident cost of state institution care was about \$4,000. In 1988, with the average annual per resident cost in real dollars over \$11,000 more, states' share of those increases was less than \$3,000 per resident per year. Court decisions and settlement agreements have also had significant impact on institution costs nationally in their frequent requirement of substantial effort by states to upgrade the quality of supervision, habilitation, and residential environments in state-operated residential facilities.

Data Points for Figure 4: Average Annual Per Resident Costs of Care in Large State-Operated Mental Retardation Facilities, 1950-1988

Year	Cost	Cost (\$1=1967)
1950	745.60	1,034.15
1955	1285.50	1,603.02
1960	1867.70	2,104.90
1965	2,361.08	2,498.02
1967	2,965.33	2,965.33
1970	4,634.85	3,985.25
1974	9,937.50	6,728.17
1977	16,143.95	8,894.74
1980	24,944.10	10,127.30
1981	30,645.40	11,246.86
1982	32,758.75	11,400.04
1984	40,821.60	13,103.73
1985	44,270.85	13,723.96
1986	47,555.85	14,456.98
1987	54,516.40	15,755.24
1988	\$57,221.05	\$15,881.50

Figure 4

Average Annual Per Resident Cost of Care
in Large State-Operated Mental Retardation Facilities



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APPENDIX A

CENTER FOR RESIDENTIAL AND COMMUNITY SERVICES

Institute on Community Integration

207 Pattee Hall
150 Pillsbury Drive SE
University of Minnesota
Minneapolis, MN 55455
Phone (612) 624-6328

March 3, 1989

Dear State Data Person:

In the Developmental Disabilities Assistance and Bill of Rights Act of 1987, Congress authorized three years of continued funding for an Ongoing Data Collection System. One of the three activities funded under this authorization is what we called the "Recurring Data Set Project." In this Project, from 1978 to 1987 the Center for Residential and Community Services (CRCS) conducted state surveys to gather statistics on persons with mental retardation in state and nonstate-operated residential facilities. Statistics gathered in the Recurring Data Set Project last year are reported in three publications: 1) Project Report #26, *Persons with Mental Retardation in State-Operated Residential Facilities: Year Ending June 30, 1987 with Longitudinal Trends from 1950 to 1987*, which was mailed to you approximately one month ago; 2) Brief Report #32, *Populations of Residential Facilities for Persons with Mental Retardation: Trends by Size, Operation and State, 1977 to 1987* (enclosed), and 3) Project Report #27, *Medicaid Services for Persons with Mental Retardation: State Trends in Utilization and Projections for the Future* (in preparation). You will receive a copy of this latter report as soon as it has been completed. Needless to say, your assistance in this effort is greatly appreciated. Additional copies of any of these reports, or any of the other CRCS reports listed on the enclosed publications list, are available to you free upon request.

Also enclosed is this year's questionnaire requesting data for Fiscal Year 1988. It again consists of three parts. Part 1 asks for data regarding state-operated facilities; Part 2 asks for data on nonstate-operated facilities (usually private, but in some states operated by counties or regional agencies); Part 3 asks for additional data on state and nonstate ICF-MR certified facilities (ICF-MR certified facilities should also be included in Parts 1 and 2). This year's questionnaire contains one significant change in format. A number of states have suggested that the 15 and fewer residents (15-) and 16 and more residents size categories do not adequately reflect the nature of their residential care systems. Therefore, in this year's survey we have broken down the 15- residents category into 1-6 residents and 7-15 residents. However, states which are unable to breakdown their populations into these new categories without inordinate effort are urged to continue reporting by 15-/16+ only.

We would greatly appreciate receiving the completed questionnaire by March 31, 1989, if at all possible. If you have any questions about any aspect of this survey, please call Carolyn White (612-624-5510) or Charlie Lakin (612-624-5005). Please return completed surveys or individual sections, using the enclosed envelope to Carolyn White, CRCS, 207 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455.

Thank you for your help in completing this survey. As usual, we will send you a summary of state statistics before the report is published for confirmation of the data you provide.

Sincerely,

Carolyn White
Project Coordinator

Enclosures

RECURRING DATA SET - FISCAL YEAR 1988

Part 1. Residents with Mental Retardation (MR) in State-Operated Residential Facilities

Please mark estimated numbers with an "e".

If data are not available for specific cells, please mark "UNK" (unknown); use "0" to indicate "0".

If data provided are from a date other than 6-30-88, please indicate date used: _____ .

	Small (1-15 bed) state-operated MR facilities			Large (16+ bed) state-operated MR facilities and large facilities with special MR units	Other state-operated facilities* serving one or more persons with MR (not in special MR units)
	1-6 beds	7-15 beds	Total 1-15 beds		
NUMBER of state-operated (staffed by state employees) facilities on (6-30-88)	+	=			
RESIDENTS with MR on roll** beginning of year (7-1-87)	+	=			
FIRST ADMISSIONS--the number of residents with MR admitted between 7-1-87 and 6-30-88 who had <u>never before</u> lived in <u>any of your state-operated facilities</u> . Please <u>do not</u> include respite care residents or transfers between state-operated facilities.	+	=			
READMISSIONS--the number of residents with MR who had at one time lived in a state-operated facility and were readmitted to a state-operated facility from a nonstate-operated facility between 7-1-87 and 6-30-88.	+	=			
RELEASES--the number of residents with MR who were released and removed from the rolls of state-operated facilities between 7-1-87 and 6-30-88. Please <u>do not</u> include releases from respite care or transfers to other state-operated facilities.	+	=			
DEATHS--the number of residents with MR who died while on roll (7-1-87 to 6-30-88).	+	=			
RESIDENTS with MR on roll** end of year (6-30-88)	+	=			
AVERAGE DAILY RESIDENTS with MR on site in Fiscal Year 1988	+	=			
PER DIEM (average daily cost of care per resident)	+	=			

*A state-operated residential facility designated primarily for persons with disabilities other than mental retardation (e.g., a mental health facility) but in which resides one or more persons with a primary diagnosis of, or formal dual diagnosis including, mental retardation, not in a special MR unit.

**includes residents on temporary leave or trial placement that lasted less than one year.

If your definitions of first admissions, readmissions, and releases differ from those above, please explain _____

Completed by: _____

Phone: _____

Please return to: Carolyn White
CRCS - University of Minnesota
207 Pattee Hall
150 Pillsbury Drive SE
Minneapolis, MN 55455

Sent to:

Phone: (612) 624-5510

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APPENDIX B

State Notes

- AZ** Statistics from Arizona are estimates derived from secondary sources. The use of these secondary data sources was necessary because Arizona was temporarily unable to report the requested statistics as it was installing a new management of information system. Two data reports compiled prior to this temporary difficulty in accessing state data were used to supply the statistics used in this report. They were the 1988 state profile developed for the "Third National Study of Public Spending for Mental Retardation and Developmental Disabilities" and the "Survey on Housing" by *New Ways* which gathered a number of statistics on the housing arrangements used in about half of all states in 1988, including Arizona. A number of estimates were made using these base statistics. Each was predicated on a basic assumption that Arizona's total, residential population was stable between FY 1987 (when Arizona last reported full systemwide statistics) and FY 1988. It was further assumed that the decreases in populations of state-operated facilities were equal to the growth in small private facilities. The statistic shown for persons with mental retardation in state facilities at the end of FY 1988 is actually the reported average daily population for 1988. Historically average daily and end of year statistics are very similar in Arizona (within 1% each year for each of the previous 4 years). Per diem costs for state facilities were actually reported by the state.
- AR** Average daily cost per resident in the small community based facility could not be separated from the per diem for large state-operated facilities.
- CA** First admission data may include some individuals who previously lived in a state-operated facility but had been discharged.
- CO** Colorado was able to report some Fiscal Year 1988 data for the 36 community group homes that have been operated by the state since 1981. Data on these small facilities have been included in the data on large state-operated facilities in previous reports in this series.
- GA** Georgia has eight physically separate facilities that are considered to be separate for licensing purposes. Two of the facilities have "sister" facilities that share administration. Southwestern State Hospital Thomasville (a mental health facility with a unit serving persons with mental retardation) shares administration with Bainbridge State Hospital and School (a facility exclusively for persons with mental retardation). Georgia Retardation Center-Atlanta shares administration with Georgia Retardation Center-Athens. Both of these facilities serve only mentally retarded populations. Georgia also has group residences that are state funded, contracted to local Boards of Health for operation, and staffed by county employees who work under state guidelines and the state merit system. These facilities are not included in this report.
- KS** One large state-operated facility (Norton) closed during Fiscal Year 1988 which accounts for part of the large number of releases.
- MD** PRF/Other data is an estimate based on data from Fiscal Year 1987.
- MA** Estimated data are from Fiscal Year 1987.
- NY** Data are for fiscal year ending March 31. Population data for one discrete mental retardation unit is included with PRF/MR, 16+ beds, but not counted as a separate facility.

- ND One large state-operated facility (San Haven) closed during Fiscal Year 1988 affecting the releases and readmissions data.
- OH Seven of the large state PRF/MR are mental retardation units in state psychiatric facilities.
- OK Data are from January, 1989.
- TX Data are reported for fiscal year ending on August 31.

APPENDIX C

Procedures, Assumptions, and Limitations In Longitudinal Data Presentation

The following notes refer to the statistics used to develop Figures 1-4 of Part III of this report. The notes appear under the Figure to which they pertain. Full citation of these documents referred to here are found in the "References" section of this report.

Figure 1: Average Daily Population of in Large State-Operated Mental Retardation Facilities.

Data presented in Figure 1 for years 1950, 1955, 1960, 1965, and 1967 are from the National Institute of Mental Health, "Patients in Institutions." Data for nonreporting facilities were proportionally adjusted from the data of reporting facilities. Data for 1970 are from Office of Mental Retardation (Current Facility Reports) and NIMH (1975). Data for 1973 are from Scheerenberger (1974) and NIMH (1975). Data for 1977 are from Scheerenberger (1978) and NIMH (1979). Data for 1978-1988 are from the Recurring Data Set Project of the Center for Residential and Community Services in this series.

Because of the rapidly dwindling numbers of people with mental retardation in mental hospital units not primarily for people with mental retardation, and because of the tendency toward regionalization of state facilities (whereby a facility is used for both mentally retarded and mentally ill populations in a particular catchment area), a clear distinction between PRF/MR and PRF/Other cannot always be made. For example, in FY 1986 state-operated facilities in both Minnesota and Indiana were reclassified from PRF/Other to PRF/MR. For comparability in the most recent statistics, data from the Minnesota and Indiana facilities classified as PRF/Other in 1984 and 1985, but as PRF/MR in 1986, have been incorporated into the longitudinal movement data for FY 1984 and FY 1986. Some minimal duplicative counting may have occurred in the 1960s and 1970s in the statistics of mental retardation facilities and units for people with mental retardation within mental health facilities. After 1977 state reported statistics on PRF/Other evidenced two problems leading to some degree of undercounting: 1) a number of states were unable to report statistics on persons with mental retardation in PRF/Other, and 2) respondents were asked only to report persons with mental retardation in facilities with 10 or more mentally retarded residents (until 1987). The former problem has improved considerably in the last few years, the latter has a minor effect on statistical trends after 1977.

Totals for the mentally retarded population of PRF/Other for nonreporting facilities for the years 1950-1977 were estimated from the totals of reporting facilities. During this period, the facility response rate for the annual NIMH surveys was never less than 87.7%. Totals for the mentally retarded population of PRF/Other for nonreporting states for the years 1980-1986 were estimated from the totals of reporting states. During this period the number of states not reporting PRF/Other populations ranged from 2 to 8. In FY 1987, average daily residents of PRF/Other were estimated by 12 states. States providing estimates for FY 1988 are indicated by an "e."

Figure 2: Average Daily Population of Large State-Operated Mental Retardation Facilities per 100,000 of the General Population.

The statistics presented in Figure 2 are drawn from the same sources as the statistics presented in Figure 1. The average daily resident population statistics have been indexed by the Bureau of the Census population statistics for U.S. population in 100,000s for each year presented in Figure 1. (See Bureau of the Census. *Statistical Abstract of the United States* [annual]. Washington, DC: U.S. Government Printing Office.) The value of these statistics is that it controls increases and decreases in the use of state institutions for growth in population.

Figure 3: Movement Patterns in Large State-Operated Mental Retardation Residential Facilities.

Data for total admissions, discharges, and deaths are from National Institute of Mental Health reports from 1950-1967, Administration on Developmental Disabilities surveys for 1968-1970; National Association of Superintendents (Scheerenberger) survey for 1974; Center for Residential and Community Services surveys for 1978-1988. Estimations were made for nonreporting states by assuming rates of first admissions, readmission, and discharge equal to those of reporting facilities.

Figure 4: Average Annual Per Resident Cost of Care in Large State-Operated Mental Retardation Facilities.

Data for Figure 4 come from the same sources as the statistics on populations of state-operated mental retardation facilities reported in Figure 1. Missing data were minimal (reporting rates were 95% or greater for data elements). Because points are means of state averages until 1984, no adjustments were made for nonreporting facilities. State cost statistics for 1984 through 1988 have been weighted by the number of PRF/MR residents in that state. Adjustments of cost to 1987 dollars are based on the Department of Labor's Consumer Price Index multipliers, as reported in the Statistical Abstract of the United States (published annually by the U.S. Bureau of the Census).