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ABSTRACT

In 1977 a survey was conducted of all state-licensed, state-contracted, and state-operated residential facilities serving mentally retarded people in the United States. The survey was replicated in 1982 and this report summarizes and compares the results of the two surveys. Results indicate that the overall size of the residential service system for mentally retarded individuals remained stable between 1977 and 1982; however, the characteristics of the population served changed, with residents in 1982 being slightly older and more severely handicapped than 1977 residents. The number of smaller facilities increased substantially and trends indicate that public facilities are being replaced by smaller community-based programs that serve severely/profoundly handicapped individuals. Changes in the Intermediate Care Facilities for the Mentally Retarded program (ICF-MR) generally paralleled those of the residential care system as a whole. (CL)

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Center for Residential and Community Services

Trends in Residential Services for
Mentally Retarded People: 1977-1982

Brief #23

June, 1984

Department of Educational Psychology
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The Center for Residential and Community Services in the Department of Educational Psychology at the University of Minnesota, formerly the Developmental Disabilities Project on Residential Services and Community Adjustment, has been a primary source of data on residential services for developmentally disabled people in recent years. The purpose of the Center is to collect and disseminate comprehensive information on residential facilities for handicapped people and develop policy analysis including: (a) administrative, financial and personnel data and issues, (b) demographic, behavioral, physical and health characteristics of residents, (c) programs and activities provided to residents, and (d) resident movement.

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Abstract

This paper summarizes and compares the results of two national surveys of residential facilities for mentally retarded people. The results from 1977 and 1982 national surveys of all state licensed, state contracted, or state operated facilities demonstrate a residential population of static total size but changing characteristics. The number of smaller facilities increased substantially. Most notable was a decreasing proportion of children and an increasing proportion of severely/profoundly handicapped residents.

The development of community-based residential facilities for mentally retarded people has generally paralleled the decrease in the number of persons residing in state institutions. This trend, which has brought state institution populations from a high of 194,650 residents in 1967 to 118,982 in 1982 (Lakin, Krantz, Bruininks, Clumpner, & Hill, 1982; Scheerenherger, 1983), has been monitored through a number of related government and private research efforts (Lakin, 1979). The successful execution of research focused on institutions has been facilitated by the fact that state institutions are easily operationally defined, relatively few in number, readily identifiable, and extremely stable in their location.

Research on alternatives to state institutions has faced antithetical conditions. Defining what constitutes a community-based residential facility, and then identifying all such facilities, has been a complicated and highly-variant endeavor, one that has made comparative research difficult. Longitudinal research on community-based facilities has been made even more difficult by the large and rapidly growing number of such facilities, the frequent dispersion of responsibility for various types of facilities across multiple state agencies, the lack of statewide registries, facilities' relative lack of stability, and by the absence of uniform operational definitions and survey methodologies across studies.

The Center for Residential and Community Services (CRCS), University of Minnesota, recently completed the first replicated national study of public and private residential facilities for mentally retarded people in the United States. In this effort, CRCS staff conducted national mail surveys of residential facilities licensed for mentally retarded people as of June 30, 1977 and June 30, 1982. The 1977 survey reported on 6,663 facilities with 219,368 residents, including specialized foster homes and public institutions

(Bruininks, Hauber, & Kudla, 1980; Bruininks, Hill, & Thorsheim, 1982; Scheerenberger, 1978). However, these figures (based on a response rate of 84% of the residential facilities identified in 1977), were underrepresentative because of substantial numbers of "missed" facilities (in 1977 states frequently lacked complete and/or retrievable licensing lists). Upon completion of a 1982 replication of the 1977 survey, it was possible to estimate the proportion of facilities missed in 1977 by means of data gathered on year of opening and closure. Using the adjusted 1977 data and the findings of the 1982 national survey, this paper describes and discusses the changes in residential care for mentally retarded people between June 30, 1977 and June 30, 1982.

Method

In 1977 CRCS, with major funding from the Administration on Developmental Disabilities, undertook a survey of all state-licensed, state-contracted, and state-operated facilities serving mentally retarded people in the United States. In 1982, the Center received major funding from the Health Care Financing Administration to replicate the earlier study. In both studies, an identical operational definition of residential facility was employed:

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

Facility Identification

Similar facility identification procedures were employed in both studies. These involved constructing a comprehensive and liberally inclusive registry of all facilities potentially meeting the operational definition. To do this, Center staff contacted all appropriate state and regional licensing and

program agencies and, when state and regional administrative practices or policies regarding confidentiality necessitated, individual provider agencies. In addition, the 1977 registry included the membership lists of national provider organizations (e.g., the National Association of Private Residential Facilities for the Mentally Retarded), mailing lists used in previous research efforts, and the National Center for Health Statistics' Master Facility Inventory of Inpatient Facilities for Mentally Retarded. These supplementary listings were not used in 1982 because all states or regions indicated an ability to directly provide a means of identifying all facilities meeting the operational definition. In 1982 sources included complete lists of facilities provided by some state agencies, partial lists from regional licensing or county program agencies, lists of administrative offices of licensed or contracted facilities (which were then contacted individually to identify specific facilities), and lists of recipients of state disbursements for services to mentally retarded people (from which residential care facilities had to be identified separately). Finalized registries were resubmitted to the key contacts in each state for review. All facilities participating in the 1977 survey were followed-up in the 1982 survey regardless of whether they still appeared on 1982 licensing lists.

Virtually identical questionnaires were mailed with a cover letter and letters of support in September 1977 and 1982. The initial mailing was followed in approximately two weeks by a reminder postcard and in about a month by a second copy of the questionnaire and cover letter. The final and longest period of data collection involved direct telephone follow-up on all nonrespondents, as well as on respondents who returned questionnaires with incomplete, inconsistent, or questionable information.

In 1982, questionnaires were mailed to 22,150 facilities identified as potentially meeting the operational definition. A total of 15,633 of these

were confirmed to be open and to meet the inclusion criteria. This number included 864 facilities that did not participate in the study, but whose state licensing agency confirmed eligibility and provided licensed bed capacity and number of retarded residents.

Specific addresses serving mentally retarded clients in 1977 that no longer did in 1982 were considered closed/moved. (Facilities that had relocated were surveyed as new to their subsequent address). Also considered closed were facilities that no longer provided full-time supervision (i.e., in operational terms went from qualifying for inclusion in 1977 to not qualifying in 1982). Facilities indicating a change of address were contacted directly to make sure that the new address given was not an administrative address for a facility that had not actually moved/closed. Facilities indicating less than full-time supervision in 1982 were recontacted to make sure that they had been appropriately considered eligible in 1977.

Survey Outcomes

In analyzing 1982 responses to a question on year of opening ("What year did your facility begin serving mentally retarded people at its current address?"), it became apparent that a sizable number of facilities reported to have been operating in 1977 had not been included in the 1977 registry. Analyses of responses from facilities open in both 1977 and 1982 indicated that size of nonmoving facilities was a highly stable variable over the five-year period, permitting estimation of "missed" 1977 residents as well as facilities. In addition to adjusting the 1977 data by the number of facilities/residents missed in 1977, a closure rate multiplier was computed to inflate estimates of missed facilities by the rate at which facilities of the same general size and type had closed between 1977 and 1982 (and thus escaped identification entirely). Closure rates, based upon 6,340 facilities followed

between 1977 and 1982 (38.4% of which were no longer open at the same address in 1982) were computed for each type and size of facility in each state (see Hill, Bruininks, Lakin, Hauber, & McGuire, 1984). The closure rate multiplier was equal to $1/(1-\text{close rate})$. This process resulted in an estimate of 11,025 facilities (243,669 residents) in 1977, compared to 6,663 (219,368 residents) reported upon previously. Most missed facilities were foster care homes or other small facilities located in states that in 1977 were without centralized records of licensed/contracted providers.

Hauber, Bruininks, Hill, Lakin, Scheerenberger, and White (in press) described the results of the 1982 survey. The following sections of the present paper summarize the results of the 1977 and 1982 surveys and discuss longitudinal changes in residential services.

Results

Table 1 reports the number of facilities (including state institutions and specialized foster homes) and mentally retarded residents, by state, that were within the scope (operational definition) of the 1977 and 1982 surveys. The overall size of the residential service system remained remarkably stable between 1977 and 1982, actually declining in proportion to the U.S. population, which increased by 7% during the same period.

Table 1
Facilities and Mentally Retarded Residents
Surveyed in 1977 and 1982

State	Licensed/contracted MR Facilities		Mentally retarded residents	
	1977	1982	1977	1982
Alabama	29	68	2,106	1,943
Alaska	26	47	243	248
Arizona	76	255	1,454	1,733
Arkansas	25	48	1,913	1,695
California	2,522	2,853	26,179	27,066
Colorado	92	168	2,651	2,829
Connecticut	190	210	4,496	4,553
Delaware	100	80	810	764
Dist. Columbia	15	59	888	886
Florida	444	508	8,104	8,060
Georgia	78	351	3,327	3,557
Hawaii	154	196	927	857
Idaho	38	52	815	860
Illinois	224	321	13,398	12,888
Indiana	190	190	4,854	3,961
Iowa	131	187	3,499	4,541
Kansas	116	115	2,706	2,875
Kentucky	28	100	1,659	1,868
Louisiana	46	62	4,449	5,055
Maine	190	192	1,492	1,464
Maryland	38	138	3,371	3,246
Massachusetts	256	498	7,723	6,722
Michigan	971	1,346	12,647	11,102
Minnesota	182	318	6,182	7,069
Mississippi	2	45	2,173	2,678
Missouri	490	538	6,505	6,251
Montana	63	71	765	761
Nebraska	116	146	2,299	1,722
Nevada	42	46	247	301
New Hampshire	33	71	837	944
New Jersey	217	579	5,313	8,731
New Mexico	43	61	794	846
New York	1,695	2,395	26,550	25,317
North Carolina	85	139	4,424	4,441
North Dakota	19	27	1,376	1,234
Ohio	368	655	10,818	10,872
Oklahoma	18	25	3,112	3,012
Oregon	70	62	2,607	2,488
Pennsylvania	645	1,176	16,705	15,567
Rhode Island	17	64	1,070	1,012
South Carolina	32	38	4,126	3,713
South Dakota	38	61	1,177	1,215
Tennessee	119	194	3,204	3,528
Texas	128	196	14,906	15,763
Utah	44	38	1,380	1,350
Vermont	106	106	921	798
Virginia	60	70	4,716	4,220
Washington	134	137	4,428	3,734
West Virginia	15	20	1,006	1,031
Wisconsin	222	291	5,649	5,685
Wyoming	16	20	682	629
U.S. Total	11,025	15,633	247,796	243,669

Note. 1977 data include 6,377 facilities (219,368 residents) surveyed in 1977, 2,575 facilities surveyed in 1982 that reported they were open in 1977 (but not surveyed), and 2,073 facilities (2,575 x .805) estimated to have been missed in 1977 but closed or moved before 1982. Some variation between 1977 and 1982 in the number of facilities/residents within states is attributed to changes in licensing policies or to movement of residents to or from facilities that were outside the scope of the surveys (e.g., psychiatric facilities, nursing homes, or foster homes that were not specially licensed or contracted as mental retardation service providers).

Table 2 presents comparative data from 1977 and 1982 by type of facility. Facility type (cf. Hill & Lakin, 1984) is based on each respondent's self-selection of the term that best described his or her facility:

A home or apartment owned or rented by a family, with one or more retarded people living as family members (e.g., foster home)

A residence with staff who provide care, supervision, and training for one or more mentally retarded people (e.g., group residence)

A residence consisting of semi-independent units or apartments with staff living in a separate unit in the same building (e.g., semi-independent living facility).

A residence which provides sleeping rooms and meals, but no regular care or supervision of residents (e.g., boarding home)

A residence in which staff provide help with dressing, bathing or other personal care, but no formal training of residents (e.g., personal care home)

A nursing home (e.g., ICF or SNF)

Type and size of facility. Between 1977 and 1982, there was a substantial increase in the total number of facilities, from 11,025 to 15,633. With the total number of mentally retarded residents in these facilities remaining essentially the same (actually declining from 247,800 to 243,700), the average size of facilities decreased from 26.2 to 18.0 residents. The proportion of mentally retarded residents in facilities with 15 or fewer residents increased from 16.3% in 1977 to 26.1% in 1982. Most new facilities were specially licensed foster homes or small group residences. The number of specially licensed or contracted placements in boarding homes, personal care homes, and nursing facilities was relatively stable between 1977 and 1982 (17,081 and 18,316 respectively). There were, of course, many additional mentally retarded people in "generic" foster, boarding, personal care, and nursing homes (i.e., those not specially licensed or contracted for mentally retarded people).

Table 2

Characteristics of Residential Facilities for
Mentally Retarded People in the United States:
June 30, 1977 and June 30, 1982

Characteristics	Spec. Foster		Group res. 1-15		Group res. Private 16+		Group res. Public 16+		Semi-Independent		Board & Room		Personal Care		Spec. Nursing		Total	
	1977	1982	1977	1982	1977	1982	1977	1982	1977	1982	1977	1982	1977	1982	1977	1982	1977	1982
Facility characteristics																		
Number of facilities	5,332	6,587	3,225	6,414	850	886	362	369	236	306	210	185	561	583	249	303	11,025	15,633
Number of residents	15,435	18,252	24,331	43,588	43,336	46,068	167,212	134,943	2,356	3,155	2,955	2,559	9,185	7,956	21,103	24,521	285,913	281,042
M	2.9	2.8	7.6	6.8	51.6	52.0	464.2	365.7	10.5	10.3	14.8	13.8	16.4	13.6	86.0	81.1	26.2	18.0
SD	2.0	1.9	3.2	3.2	60.4	55.7	540.1	383.9	11.4	8.8	19.6	20.3	24.4	19.8	65.3	61.8	129.8	83.0
Number of MR residents	14,418	17,147	22,449	42,018	36,998	40,347	154,856	122,971	1,993	2,870	1,665	1,264	4,141	4,070	11,275	12,982	247,796	243,669
Operator																		
Private/proprietary	100.0%	100.0%	40.0%	27.1%	50.7%	50.2%	.0	.0	15.0%	13.4%	93.5%	94.6%	90.9%	90.4%	76.5%	70.6%	72.4%	62.2%
Non-profit	.0	.0	48.2%	63.8%	49.3%	49.8%	.0	.0	75.8%	80.4%	5.5%	4.3%	4.5%	4.8%	18.0%	23.1%	20.2%	31.2%
Public	.0	.0	11.8%	9.2%	.0	.0	100.0%	100.0%	9.2%	6.2%	1.0%	1.1%	4.6%	4.8%	5.5%	6.3%	7.3%	6.6%
Avg. per diem per resident	\$9.41	\$16.15	\$16.52	\$38.31	\$22.78	\$45.15	\$43.53	\$85.84	\$16.20	\$27.40	\$9.60	\$15.97	\$12.60	\$17.0%	\$25.92	\$49.81	\$34.23	\$61.89
Movement																		
New admissions	22.4%	19.0%	37.2%	25.7%	20.3%	15.7%	5.7%	5.1	54.2%	31.9%	30.0%	12.7%	19.8%	14.7%	23.0%	14.4%	13.3%	12.8%
Readmissions	2.3%	.9%	2.6%	1.2%	1.3%	1.3%	1.9%	1.1	1.1%	1.0%	3.0%	.9%	3.6%	2.3%	4.7%	2.7%	2.0%	1.6%
Releases	7.0%	7.9%	18.5%	13.4%	13.9%	12.0%	9.2%	11.41	24.8%	18.5%	16.4%	13.0%	10.2%	8.5%	15.5%	8.0%	11.1%	11.5%
Deaths	.9%	.9%	.6%	.5%	.8%	.8%	1.5%	1.5%	.4%	.3%	.9%	.9%	1.1%	.8%	3.1%	2.3%	1.3%	1.2%
Est. move due to close	.7%	8.8%	6.2%	5.8%	2.4%	2.4%	.4%	.5%	9.5%	9.4%	7.4%	6.8%	6.7%	5.7%	2.5%	2.6%	2.0%	2.7%
Est. net 12 month change	1.1%	2.3%	14.5%	7.3%	4.5%	1.7%	-3.5%	-5.6%	20.6%	4.9%	8.3%	-7.1%	4.6%	2.0%	6.6%	4.3%	.9%	-8.5%
Opened within 4 1/2 years	52.7%	46.7%	71.0%	60.0%	36.1%	19.7%	19.9%	8.8%	88.0%	62.5%	38.6%	21.4%	37.9%	27.4%	42.5%	23.4%	55.2%	48.6%
Resident characteristics																		
Age																		
< 22	39.6%	37.4%	28.6%	19.8%	44.4%	32.0%	35.8%	22.0%	17.7%	7.7%	10.1%	5.9%	14.7%	10.2%	52.9%	38.2%	36.8%	24.8%
22-39	24.7%	32.0%	47.9%	53.3%	36.7%	41.8%	41.3%	50.2%	61.3%	65.4%	33.8%	38.3%	28.6%	31.6%	22.3%	33.6%	39.3%	47.0%
40-62	26.7%	23.1%	21.2%	23.8%	16.3%	22.1%	19.2%	22.9%	20.3%	25.5%	42.0%	40.5%	43.4%	41.1%	18.3%	21.8%	19.9%	23.3%
63+	9.1%	7.6%	2.2%	3.0%	2.6%	4.1%	3.7%	5.0%	.7%	1.5%	14.2%	15.3%	13.4%	17.1%	6.6%	6.4%	4.1%	4.8%
Level of retardation																		
Borderline/mild	28.0%	25.9%	34.4%	29.3%	29.8%	26.8%	9.3%	7.0%	66.1%	61.8%	49.5%	47.1%	30.6%	31.2%	12.6%	9.2%	16.9%	16.8%
Moderate	37.7%	37.7%	41.7%	37.9%	34.9%	29.9%	16.0%	12.9%	31.1%	32.5%	40.8%	33.6%	40.4%	9.8%	21.6%	16.2%	23.4%	22.8%
Severe	26.5%	26.0%	19.5%	23.2%	23.4%	24.0%	27.9%	24.3%	2.7%	5.3%	7.1%	17.6%	18.0%	20.6%	35.9%	26.2%	26.2%	24.0%
Profound	7.8%	10.4%	4.4%	9.5%	12.2%	19.3%	46.9%	55.8%	.1%	.4%	2.6%	1.7%	11.1%	8.4%	30.0%	48.5%	33.5%	36.5%
Nonambulatory	7.0%	9.3%	3.5%	5.3%	8.4%	14.4%	23.3%	25.5%	6.0%	3.7%	1.0%	2.7%	6.6%	5.4%	49.3%	48.3%	18.9%	19.5%
Cannot talk	18.6%	24.9%	11.7%	17.4%	19.7%	24.1%	43.5%	49.1%	3.3%	3.7%	6.5%	4.8%	13.0%	16.1%	48.5%	54.0%	34.7%	36.7%
Not toilet trained	8.8%	11.1%	4.2%	6.7%	11.6%	16.1%	34.1%	38.0%	.8%	.1%	1.0%	3.9%	6.8%	6.5%	45.2%	49.0%	26.1%	26.7%

The number of staffed semi-independent living facilities increased from 236 to 306, but this model still served only 1.2% of all people in residential care. Although there was some growth in the number of residents served by large private group residences, the population of large public facilities decreased by 20.6% over the five-year period.

Facility operator and reimbursement. There was a moderate increase in the proportion of private nonprofit operators (from 20.2% to 31.2%) during the period, primarily because of the growth in the number nonprofit small group residences. Most semi-independent living programs continued to be nonprofit, and most boarding homes, personal care homes, and specialized nursing facilities continued to be proprietary.

Reimbursement rates for foster homes, semi-independent living programs, boarding homes, and personal care homes increased approximately 13% per year between 1977 and 1982, somewhat above the 10% annual average in the Consumer Price Index over the same period. Reimbursement rates for group residences and nursing facilities increased much more rapidly, a change largely attributable to an increase in the number of ICF-MR certified beds from 98,097 in 1977 to 138,738 in 1982. ICF-MR costs nearly doubled from \$41.96 in 1977 to \$79.53 per resident per day in 1982.

Resident movement and facility opening. Each facility was asked to report the number of new admissions, readmissions, releases, and deaths in the year preceding each survey. Facilities that closed or moved during the 12 months prior to June 30, (1977/1982) were not surveyed, and therefore did not report their residents as having moved. The facilities into which these residents transferred, however, reported transferred residents as new admissions. Despite the expected reporting error among 15,633 questionnaires, the number of new admissions plus readmissions minus the number of deaths, releases, and estimated releases from facilities that closed approximates

(+ 1%) the net change in numbers of residents served in each type of facility during a given year. These estimates generally correspond to changes in total numbers of residents in each type of facility between 1977 and 1982. The most rapid growth in facility beds continued to be among small group facilities (15 or fewer residents) that added 3,255 new beds in 1977 and 2,773 new beds in 1982. Large public facilities (16 or more residents) accelerated their net outflow of residents with slightly increased rates of release and substantially increased numbers of "closed" beds. Large private facilities continued to grow in fiscal year 1982 but at a substantially decreased rate.

Information on year of opening accounts for both system growth and replacement of facilities that closed or moved. While the total number of residents in specialized foster homes, for example, grew less than 20% between 1977 and 1982, approximately half the foster home beds operating on June 30, 1982 had opened during the five-year period. On the other hand, while on the majority of small group residence beds were newly opened between 1977-1982, these beds tend to be more stabled and, therefore, reflected in a nearly doubled number of beds. The highest percentage of new beds was in the semi-independent category. This reflects a significant growth in bed capacity (34%), but even more so the ease and frequency with which residents of such programs, like nonhandicapped apartment dwellers, can move.

Resident characteristics. During the five-year period, the number of residents age 21 or younger decreased by 30,000 (from 36.8% to 24.8% of all residents). This change is attributable primarily to a decrease in the number of children being placed outside their natural family homes before adulthood (Lakin, Hill, Hauber, & Bruininks, 1982). The proportion of severely/profoundly retarded residents in residential care settings increased slightly between 1977 and 1982 (59.7% and 60.5%, respectively). The near

doubling in the number of small group homes between 1977 and 1982 accommodated most of the 33,000 residents released or diverted from public institutions, increasing the proportion of severely and profoundly retarded residents in small group residences from 23.9% to 32.7%. The proportion of profoundly retarded residents in small group homes increased from 4.4% to 9.5% but was still exceeded by the proportion in foster homes, large private, and large public institutions (10.4%, 19.3%, and 55.8% in 1982, respectively). Boarding homes and personal care homes tended to serve mildly handicapped adults, whereas specialized nursing facilities (nursing homes with mental retardation program licenses) served primarily severely handicapped children and young adults.

Information on level of retardation was consistent with data gathered on functional skills of residents. Respondents reported that 19.5% of all residents were nonambulatory, 36.7% could not talk, and 26.7% were not toilet trained, slight increases from 1977. The most severely functionally impaired population was reported by specialized nursing homes.

ICF-MR certified facilities. Data on Intermediate Care Facilities for the Mentally Retarded (ICF-MRs) are not reported separately on Table 2 because ICF-MR certification (permitting reimbursement with federal Medicaid funds) is available to any type of facility that meets requirements contained in the regulations. Between June 30, 1977 and June 30, 1982, the total number of ICF-MR reimbursed beds in the United States increased from 98,077 to 138,788 (41.5%). (Including Skilled Nursing Facility [SNF] beds in state institutions for mentally retarded persons and SNF or ICF beds that were recertified as ICF-MR beds by 1982, the change was from 108,397 to 143,150 beds [32%]). Most of the change in the number of ICF-MRs (577 in 1977, 1,854 in 1982) occurred among small facilities, which grew from 188 facilities with 1,710 residents to 1,202 with 9,714 residents. Despite this substantial growth in i-15 bed ICF-

MRs, less than 7% of all ICF-MR certified beds on June 30, 1982 were in facilities that had 15 or fewer residents.

Major changes occurred in the characteristics of residents populations in ICF-MR facilities between 1977 and 1982. Medicaid facilities of all sizes had more severely/profoundly retarded residents in 1982 than five years earlier. The proportion of severely/profoundly retarded residents in smaller facilities (15 or fewer residents) increased from 29% to 43%. The proportion of children and youth (ages 0-21) in ICF-MR facilities decreased dramatically. This group constituted 36% of ICF-MR residents in 1977 but only 22% in 1982 a trend most pronounced in ICF-MRs with 151-300 residents (42% to 22%) and ICF-MRs with more than 300 (35% to 21%). For a complete discussion of the ICF-MR program, see Lakin, Hill, and Bruininks (1984).

Discussion

Overall, the comparison of the 1977 and 1982 data indicates a highly dynamic service system of static total proportion. Residents in 1982 were older and slightly more severely handicapped than those who were being served five years earlier. Public facilities, which continue to depopulate at a fairly constant rate of 6,000 residents per year, are being replaced by smaller community-based programs that serve severely/profoundly handicapped individuals. The number of residents in large private facilities did not decrease between 1977 and 1982, but the rate of growth slowed considerably and the population shifted toward older, more severely retarded and functionally impaired residents.

Changes in the ICF-MR program generally paralleled those of the residential care system as a whole. The number of smaller ICF-MRs grew rapidly, mostly through the creation of new facilities. Of the 1,161 ICF-MR facilities with 15 or fewer residents in 1982 about 70% opened in 1978 or

later. While the total number of ICF-MR beds in larger facilities (76 or more residents) increased substantially between 1977 and 1982 (101,709 to 122,456), almost all of this growth came through the certification of already existing facilities. Less than 10% of these larger facilities opened after 1977.

In general, then, previous trends in residential services for mentally retarded/developmentally disabled people in the United States were largely maintained between 1977 to 1982. However, the period also produced significant changes, some of which are evident in the statistics reported. For example, the decrease in the number of children and youth in the residential care system is a dramatic and socially significant finding. This result of social policies creating and funding community-based education and support programs for children and their families is one in which advocates may feel some justifiable pride. The increases in the number of severely/profoundly retarded persons in foster care and small group care is a trend that will continue to show that severe/profound retardation does not constitute a justification for institutional placement, while at the same time providing numerous good (and, no doubt, some bad) examples of community-based care for severely handicapped persons.

Other changes are not evident in the data collected in this study, but may well be reflected in future research. Most significant is the increased recognition of the importance of federal policy and state responses to it in shaping the residential, social, and habilitative opportunities for severely handicapped people. While it would be hard to argue based on the data gathered in this research that the social policies represented by Medicaid regulations have accelerated the institutionalization of individuals, or even decelerated the depopulation of institutions, there is increasing dissatisfaction with Medicaid policy that is, at best, benign. The

communication of this dissatisfaction has had substantial impact on state responses to the Medicaid waiver authority, in which most states propose an acceleration of deinstitutionalization over the previous five-year period (Lakin, Greenberg, Schmitz, & Hill, in press; Rotegard, Bruininks, & Krantz, 1984). Dissatisfaction has also been expressed through proposed legislation (S. 2053) to limit the use of Medicaid funds for facilities that do not provide what can reasonably be defined as community-based care.

Efforts of this nature, as well as research and testimony, will undoubtedly continue to develop the perception that appropriate care is community-based care and that such a perception is no less true for severely/profoundly retarded people than for mildly retarded or nonretarded people. While a formal national policy of noninstitutionalization may not be imminent, there is considerable longitudinal evidence that through continuing program development efforts of the past few years, that end will be essentially realized in most states by the end of the century.

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