



The COFAR VOICE

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IS CLOSING STATE OPERATED ICF'S/MR ACROSS THE UNITED STATES REALLY ABOUT QUALITY CARE, SELF-DETERMINATION AND HUMAN RIGHTS?

Individuals with Mental Retardation suffer discrimination when they are not offered the choice of ICF/MR care as mandated by the Olmstead Supreme Court Decision, the Social Security Act and the Federal Centers for Medicare and Medicaid Services (CMS) Choice Assurance under the Home and Community Based Waiver Program.

Why are predominantly state-owned and operated Intermediate Care Facilities for the Mentally Retarded (ICF's/MR) being threatened with closure? Have we simply substituted state-owned and operated facilities with privately-owned and operated facilities? Could it be that the deinstitutionalization movement is less about quality of care and human rights and more about shifting tax dollars from government to private vendors? Has this shift from government employees to contracting with private vendors resulted in cost savings and better quality care as proponents of privatization promised a decade ago? How does this shift effect access to ICF/MR care for non-white and/or non-native speaking families?

Governor Weld's Privatization Initiative:

In Massachusetts, Governor Weld established the Special Commission on the Consolidation of Health and Human Services Institutional Facilities. The Commission issued a final report in June of 1991. The Commission recommended the closure of nine state operated facilities across the

Commonwealth operated by Department of Mental Retardation (DMR), Department of Mental Health and Department of Public Health. The facilities closed and many claims were made ten years ago. To date, an objective study of the Purchase-of-Service System has not been conducted to determine whether privatization delivered promised cost savings and increased quality care, yet the Commonwealth continues to support this policy. Why?

State and Non-State owned-and Operated ICF's/MR Beds Across the United States:

What follows is a chart of the state operated and non-state operated ICF/MR beds by state including the grand total and the percentage of non-state ICF/MR beds. What is not included here are other private residential programs that may be similar to ICF's/MR but are not licensed as such and thus do not fall under the Federal ICF/MR standards or the Federal monitoring system. Also not included is data reflecting the number of out-of-state ICF/MR placements by states with no state-operated ICF/MR beds.

¹ Formerly known as the Health Care Financing Administration of HCFA. The agency was renamed on June 14, 2001. While readers should recognize that the agency has been renamed, the term HCFA will be retained throughout this issue of the Newsletter to avoid confusion as quotations, contracts with the agency, etc. should reflect the names of the organization at the time.

State and Non-State ICF/MR Beds

State	Total State	State 16 +Beds	Total Non-State	Non-State 16 + Beds	Grand Total	% Non-State
AL	633	633	0	0	633	0
AK	0	0	0	0	0	0
AZ	131	89	42	42	173	24%
AR	1,236	1,236	530	230	1,766	30%
CA	3,850	3,850	7,308	1,208	11,158	66%
CO	122	122	16	0	138	12%
CT	966	960	310	0	1,276	24%
DE	253	253	0	0	253	0
DC	0	0	840	0	840	100%
FL	1,357	1,357	2,083	1,831	3,440	61%
GA	1,536	1,535	110	110	1,645	7%
HI	0	0	96	0	96	100%
ID	110	110	482	0	592	81%
IL	3,191	3,191	7,119	3,736	10,310	69%
IN	797	797	4,626	835	5,423	85%
IA	673	673	2,355	1,710	3,028	78%
KS	389	389	464	201	853	54%
KY	620	620	500	500	1,120	45%
LA	1,820	1,743	3,800	1,002	5,620	68%
ME	34	0	264	59	298	89%
MD	525	525	0	0	525	0
MA	1,266	1,266	0	0	1,266	0
MI	269	269	0	0	269	0
MN	138	48	2,637	722	2,775	95%
MS	1,857	1,368	630	630	2,487	25%
MO	1,278	1,278	93	27	1,371	7%
MT	130	130	0	0	130	0
NE	399	399	249	240	648	38%
NV	140	140	112	0	252	44%
NH	0	0	24	24	24	100%
NJ	3,414	3,414	73	73	3,487	2%
NM	0	0	405	16	405	57%
NY	2,508	2,411	7,601	1,237	10,109	75%
NC	1,936	1,936	2,584	539	4,520	57%
ND	153	153	472	47	625	76%
OH	1,990	1,990	5,701	3,374	7,691	74%
OK	339	339	1,462	1,339	1,801	81%
OR	60	60	0	0	60	0
PA	1,969	1,969	2,975	1,869	4,944	60%
RI	18	0	0	0	18	0
SC	1,103	1,103	1,073	90	2,176	49%
SD	196	196	35	0	231	15%
TN	903	903	608	144	1,511	40%
TX	5,740	5,470	7,713	2,491	13,453	57%
UT	236	236	522	512	758	69%
VT	0	0	12	0	12	100%
VA	1,653	1,653	215	132	1,868	12%
WA	857	857	91	32	948	10%
WV	0	0	444	0	444	100%
WI	869	869	1,996	1,969	2,865	70%
WY	106	106	0	0	106	0
TOTAL	47,769	46,636	68,672	26,971	116,441	59%

Source: Lakin, Charlie, K. Polister, Barbara, Prouty, Robert W., and Smith, Jerra. (2001). Utilization of and Expenditures for Medicaid Institutional and Home and Community Based Services. In R.W. Prouty, Gary Smith and K.C. Lakin (Eds). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2000*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, page 90.

Twenty-six states have more private ICF/MR beds than public. Overall, 59% of all US ICF/MR beds are privately owned. Five states have no state-owned ICF/MR beds but they have private beds and thus have been 100% privatized. Nine states have only state operated ICF/MR beds. Alaska is the only state in the country with no ICF/MR beds – state or non-state. While the total number of private ICF/MR beds and/or number of facilities has not grown over the last few years, with the downsizing of the large state owned- and operated ICF's/MR, the proportion of private to state-owned and operated has increased.

98% of the state-operated ICF/MR beds are in residential settings of more than sixteen beds while only 39% of the non-state operated ICF/MR beds are in larger settings. In six states all non-state facilities house sixteen or more while thirty-four states have all state operated beds in residences of sixteen or more individuals. The state operated ICF's/MR are larger than those operated in the private sector but they are all ICF/MR certified. If smaller ICF/MR campuses are preferable, Massachusetts should carefully review that model.

Models of ICF/MR care are not openly discussed in Massachusetts. While creativity and state-of-the-art thinking has been brought to bear on the community-based residential options, there has been no effort placed on the development of models for state-operated congregate residential settings. Why not? Models of ICF/MR service delivery have never been studied by DMR officials and yet it is clear that the “large institutions of yesterday” must be appropriately right-sized and transformed into Modern Regional Resource Centers.

Mental Retardation is not a collective noun yet it is commonly used as such. There is as much diversity among individuals with MR as there is diversity in the normal population. The cost of ICF/MR care is due in part to the pervasive needs of the current residents compared with the range of needs reflective of individuals living in community programs. Also contributing to the cost of ICF/MR care is the fact that the facility campuses have never been right-sized despite drastic and predictable reductions in census over the last twenty years.

While it is an overly simplistic calculation and not reflective of actual costs, the average annual cost per resident at the ICF's/MR is often quoted as being simply the total budget divided by the total number of residents. Using even this methodology, which anti-facility advocates have used to demonstrate the costliness of facility-based care, annual costs range from a low of \$94,043.29 at Templeton to a high of \$151,402.34 at Monson.¹

¹ DMR Facility Comparison Data 6/13/01. Margaret Chow-Menzer

DMR Facility	Total Budget	Census	Annual Cost
Glavin	\$7,239,351	63	\$114,910.33
Fernald	\$ 42,098,503	297	\$141,745.80
Hogan	\$19,888,533	156	\$127,490.59
Monson	\$30,583,273	202	\$151,402.34
Templeton	\$14,576,710	155	\$ 94,043.29
Wrentham	\$45,818,552	337	\$135,960.09

DMR facility costs for adults appear to be in line with the average costs of the care provided at Chapter 766 residential schools serving children across the Commonwealth who have complex needs and are in need of intensive services. The primary populations remaining in the facilities consist of individuals with mental retardation who also (1) have complex medical needs (2) have psychiatric and behavioral conditions requiring constant close supervision and/or (3) may pose a threat to themselves or others.

Chapter 766 Approved Private Residential School Programs, Location, Total Residents and Average Annual Cost²

Vendor	City/Town	Ave Annual Cost
Boston Higashi School	Randolph	\$87,346.13
Brandon Residential Tx Ctr	Natick	\$95,256.94
Cardinal Cushing School	Hanover	\$90,993.80
Castle School Inc	Cambridge	\$76,235.47
Concord Assabet Adol Svs	Acton	\$73,704.30
Devereaux Foundation ³	Rutland	\$93,112.95
Evergreen Center	Milford	\$129,110.93
Harbor Schools Inc	Newbury	\$76,533.34
Home for Little Wanderers	Boston	\$80,968.07
Germaine Lawrence School	Arlington Heights	\$97,312.75
Harbor Schools	Newbury	\$76,533.34
Hillcrest Educational Center ⁴	Pittsfield	\$111,479.44
Hillcrest Educational Center ⁵	Pittsfield	\$192,372.87
Institute for DD ⁶	Assonet	\$129,572.51
Institute for DD ⁷	Assonet	\$111,977.89
Institute for Family & Life	Danvers	\$71,111.38
Judge Rotenberg Educational	Canton	\$177,892.02
Learning Ctr for Deaf Children	Framingham	\$166,151.26
May Institute Inc	Braintree	\$107,259.72
NE Center for Children ⁸	Southboro	\$125,890.87
NE Center for Children ⁹	Southboro	\$199,047.17
Perkins School for Blind ¹⁰	Watertown	\$211,603.49
Stetson School, Inc	Bare	\$108,779.43
Walker Home for Children	Needham	\$108,820.34

² www.magnet.state.ma.us/osd/pos/dps.htm

³ Residential Treatment Program

⁴ Residential Program

⁵ Intensive Treatment Unit

⁶ Residential Program

⁷ Main Program

⁸ Residential Program

⁹ Severe Program

¹⁰ Severely Impaired Residential

The Hillcrest Educational Center Inc in Pittsfield is an Intensive Treatment Unit with an average cost of \$192,372.87. The Justice Resource Institute Inc (JRI) in Swansea has an average annual cost of \$123,788.87. The Institute for Developmental Disabilities / Crystal Springs-BDU in Assonet has an average annual cost of \$129,572.51. While COFAR would not recommend closure of these obviously critical programs, why are these residential centers not targeted for closure by proponents of “deinstitutionalization?” Why are anti-facility advocates only targeting state-operated ICF’s/MR?

Families and guardians with loved ones at the DMR ICF’s/MR are told that anyone, regardless of their level of disabilities and needs, **can and should** be served at home or in the community. While COFAR believes that Chapter 766 Schools provide a critical service, why are Chapter 766 Schools and other residential campus settings not under threat of closure? Could it be because they are owned and operated by private vendors? The chart on the previous page provides the average annual cost for a number of Chapter 766 programs. Costs range from a low of \$71,111.38 at the Institute for Family and Life to a high of \$211,603.49 at the Perkins School for the Blind.

University of Minnesota data¹ tells us that there are no private ICF’s/MR in Massachusetts. Private residential congregate campus like settings, such as New England Villages in Pembroke Massachusetts, are considered “community programs” and are billed under the Home and Community Based Services Waiver.

What is really going on in Massachusetts with respect to both children and adults with mental retardation who need out-of-home placements in residential programs? You have to ask yourself if the deinstitutionalization movement is truly more about money and privatization than it is about quality of care and human rights.

The future of the ICF/MR level of care and its continued availability to current residents and the possibility of extending a genuine choice to non-residents is an issue that has been ignored for decades. The hope is that 2002 will bring rational thought to this issue and that ICF/MR choice, facility- and community-based comparative costs and the development of ICF/MR models will be objectively addressed in a reasonable and respectful manner..

¹ Lakin, Charlie, K, Polister, Barbara, Prouty, Robert W., and Smith, Jerra. (2001), Utilization of and Expenditures for Medicaid Institutional and Home and Community Based Services. In R.W. Prouty, Gary Smith and K.C. Lakin (Eds). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2000*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

The Delivery of Services to Individuals with Mental Retardation is a Multi-billion Dollar Industry & the Trend is Privatization:

The goal of the privatization initiative was to cut government expenditures while maintaining a standard of quality in its services. The governmental policy of “entrepreneurial government and the privatization of state services” was initially implemented in the early 1990’s. A decade of privatization policy has passed and before all human services programs are privatized, it makes good management sense to evaluate the outcome of this public policy.²

In 1991, the Governor’s Special Commission on Consolidation of Health and Human Services Institutional Facilities recommended the closure of four Department of Mental Health facilities, three Department of Public Health facilities and four DMR facilities: Belchertown State School, Dever Developmental Center and the Berry Campus of the Hogan Center and the Foxboro Center of the Wrentham Developmental Center. The Commission concluded that “once fully implemented, the net savings to the state are anticipated to be approximately \$60 million annually.”³ This is only one of many projections that needs to be evaluated. Has the privatized system resulted in cost savings and “equal or better services” for the Commonwealth’s citizens with mental retardation? The taxpayer investment in the Human Services industry is staggering. It would behoove all of us to take a critical look at the policy of privatization and evaluate the industry outcomes in terms of access, cost and quality prior to completely privatizing the entire human services network of care for the mentally retarded.

National Historical Perspective: Skilled Nursing Facilities, ICF’s/MR and Home and Community-Based Services Waiver Programs

What follows is a brief overview of Medicaid programs for persons with mental retardation and related developmental disabilities (MR/DD). This information has been excerpted from the University of Minnesota publication, [Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2000](#).

² Compliance with the Commonwealth’s Privatization Law (Chapter 296 of the Acts of 1993) is currently under review.

³ Actions for Quality Care: A Plan for the Consolidation of State Institutions and for the Provision of Appropriate Care Services. Report of the Governor’s Special Commission on Consolidation of Health and Human Services Institutional Facilities. Published by the Office of the Secretary of State, Michael J. Connolly, Secretary, PLU # 23, June 1991, page. vii and viii.

ICF/MR Program:

“Before 1965 there was no federal participation in long term care for persons with MR/DD. In 1965, Medicaid was enacted as Medical Assistance, Title XIX of the Social Security Act. It provided federal matching funds of from 50% to 82%, depending on each state’s per capita income, for medical assistance, including Skilled Nursing Facilities (SNFs), for people in the categories of elderly, blind, disabled, and dependent children and their families.

It was only shortly after the introduction of federal reimbursement for skilled nursing care in 1965 that government officials noted rapid growth in the number of patients in SNFs. It was further documented that many of these individuals were receiving far more medical care than they actually needed, at a greater cost than was needed, largely because of the incentives of placing people in facilities for which half or more of the costs were reimbursed through the federal Title XIX program. Therefore, in 1967, a less medically oriented and less expensive “Intermediate Care Facility” (ICF) program for elderly and disabled adults was authorized under Title XI of the Social Security Act.

In 1971, the SNF and ICF programs were combined under Title XIX. Within the legislation combining the two programs was a little noticed, scarcely debated amendment that for the first time authorized federal financial participation (FFP) for ‘intermediate care: provided in facilities specifically for people with MR/DD.’ Three primary outcomes of the new ICF/MR legislation appear to have been intended by proponents of the legislation: 1) to provide substantial federal incentives for upgrading the physical environment and the quality of care and habilitation being provided in large public MR/DD facilities; 2) to neutralize incentives for states to place persons with MR/DD in nonstate nursing homes and/or to certify their large state facilities as SNFs; and 3) to provide a program for care and habilitation (“active treatment”) specifically focused on the needs of persons with MR/DD rather than upon medical care. It was also a way to enlist the federal government in assisting states with their rapidly increasing large state facility costs, which were averaging real dollar increases of 14% per year in the five years prior to the passage of the ICF/MR legislation (Greenberg, Lakin, Hill, Bruininks & Hauber, 1985).

The ICF/MR program was initiated in a period of rapid change in residential care for persons with MR/DD. By Fiscal Year 1973 state facility populations had already decreased to 173,775 from their high of 194,650 in Fiscal Year 1967 (Lakin, 1979). Nevertheless, states overwhelmingly opted to certify their public institutions to participate in the ICF/MR program, with two notable outcomes: 1) nearly every state took steps to secure federal participation in paying

for large state facility services, and 2) in order to maintain federal participation, most states were compelled to invest substantial amounts of state dollars in bringing large state facilities into conformity with ICF/MR standards. Forty states had a least one ICF/MR certified state facility by June 30, 1977. Nearly a billion state dollars were invested in facility improvement efforts in fiscal years 1978-1980 alone, primarily to meet ICF/MR standards (Gettings & Mitchell, 1980).

In the context of growing support for community residential services, such statistics were used by a growing number of critics to charge that the ICF/MR program 1) had created direct incentives for maintaining people in large state facilities by providing federal contributions to the costs of those facilities; 2) had diverted funds that could otherwise have been spent on community program development into facility renovations solely to obtain FFP; 3) had promoted the development of large private ICF/MR facilities for people leaving large state facilities through available FFP (11,943 people were living in large private ICF’s/MR by June 1997); and 4) had promoted organizational inefficiency and individual dependence by promoting a single uniform standard of care and oversight of ICFs/MR residents irrespective of the nature and degree of their disabilities and/or their relative capacity for independence. These criticisms, and the growing desire to increase residential opportunities in community settings, along with the continued desire of states to avail themselves of the favorable Medicaid cost-share, helped stimulate the development of community ICF’s/MR and the eventual clarification by the Health Care Financing Administration (HCFA) of how the ICF/MR level of care could be delivered in 4-15 person group homes.”¹

Community ICF/MR Group Homes

“Expansion of ICF/MR services to privately-operated programs in the late 1970s and the 1980s was a major development in the evolution of the program. Private residential facilities were not an issue at the time of original ICF/MR enactment in 1971, probably because: 1) most private facilities were already technically covered under the 1967 amendments to the Social Security Act authorizing private ICF programs, and 2) in 1971 large state facilities were by far the predominant model of residential care. Indeed, the 1969 Master Facility Inventory indicated a total population in non-state mental retardation facilities of about 25,000.

¹Lakin, Charlie, K, Polister, Barbara, Prouty, Robert W., and Smith, Jerra. (2001). Utilization of and Expenditures for Medicaid Institutional and Home and Community Based Services. In R.W. Prouty, Gary Smith and K.C. Lakin (Eds). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2000*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration., pages 83-84.

compared with a large state MR/DD facility population of 190,000 (Lakin, Bruininks, Doth, Hill & Hauber, 1982).

Although Congressional debate about the ICF/MR program had focused on large public facilities, the statute did not specially limit ICF/MR coverage either to large public facilities, or to "institutions" in the common meaning of the term. The definition of "institution" which served as the basis for participation in the ICF/MR program was (and remains) the one that also covered the general ICF institution: 'four or more people in single or multiple units' (45 CFR Sec. 448.60 (6)(1)). Although it cannot be determined whether Congress, in authorizing a "four or more bed" facility, purposely intended the ICF/MR benefit to be available in small settings, it does seem reasonable to suppose, in the absence of specific limitations, that Congress was more interested in improving the general quality of residential care than it was in targeting specific types of residential settings. ICF/MR regulations, first published in January 1974, also supported the option of developing relatively small settings, delineating two categories of ICF's/MR, those housing 16 or more people ("large") and those housing 15 or fewer people ("community") and providing several specifications that allowed greater flexibility in meeting ICF/MR standards in smaller settings.

Despite the regulatory recognition of community ICF's/MR, the numbers of such ICF's/MR actually developed varied enormously among states and regions. In some DHHS regions (e.g., Region V) hundreds of community ICF's/MR were developed while other regions (e.g., II and X) had none. By mid-1977 three-quarters (74.5%) of the 188 community ICF's/MR were located in just two states (Minnesota and Texas), and by mid-1982 nearly half (46.4% of the 1,202 community ICF's/MR were located in Minnesota and New York and nearly two-thirds (65.1%) were located in Minnesota, New York, Michigan and Texas. These variations reflected what some states and national organizations considered a failure of HCFA to delineate clear and consistent policy guidelines for certifying community settings for ICF/MR participation and/or reluctance on the part of some regional HCFA agencies to promote the option.

In response to continued complaints from the states that there was a need to clarify policy regarding the certification of community ICF's/MR, in 1981 HCFA issued 'Interpretative Guidelines' for certifying community ICF's/MR. These guidelines did not change the existing standards for the ICF/MR program, but clarified how the existing standards could be applied to delivering the ICF/MR level of care in community settings with 4-15 residents. The publication of the 1981 guidelines was followed by substantially greater numbers of state exercising the option to develop community ICF's/MR. Ironically, these guidelines were published in the same year (1981) that Congress enacted legislation that would

give even greater opportunity and flexibility to states to use Medicaid funding for community services through the Medicaid Home and Community Based Services waiver authority (Section 2176 of P.L. 97-35)."¹

Home and Community Based Services (HCBS) Waiver

"Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35), passed on August 13, 1981, granted the Secretary of Health and Human Services the authority to waive certain existing Medicaid requirements and allow states to finance 'noninstitutional' services for Medicaid-eligible individuals. The Medicaid Home and Community-based Services (HCBS) waiver program was designed to provide noninstitutional, community services to people who are aged, blind, disabled, or who have MR/DD and who, in the absence of alternative noninstitutional services, would remain in or would be at a risk of being placed in a Medicaid facility (i.e., Nursing Facility or an ICF/MR). Final regulations were published in March 1985 and since then a number of new regulations and interpretations have been developed, although none have changed the fundamental premise of the program, that of using community services to reduce the need for institutional services.

A wide variety of noninstitutional services are provided in state HCBS programs. Most frequently these include service coordination/case management; in-home supports; vocational and day habilitation services; and respite care. Although not allowed to use HCBS reimbursements to pay for room and board, all states provide residential support services under categories such as personal care, residential habilitation, and in-home supports. HCBS recipients with MR/DD use their own resources, usually cash assistance from other Social Security Act programs and state supplements to cover room and board costs. In Fiscal Year 2000 about 64% of HCBS recipients in the 44 states reporting such data received services in settings other than the home of natural or adoptive family members.

Given both its flexibility and its potential for promoting individualization of services, the HCBS program is recognized in all states as a significant resource in the provision of community services as an alternative to institutional care. Beginning in the early 1990s, stringent standards that previously required states to demonstrate reductions in projected ICF/MR residents and expenditures roughly equal to the increases in HCBS participants and

¹Lakin, Charlie, K, Polister, Barbara, Prouty, Robert W., and Smith, Jerra. (2001). Utilization of and Expenditures for Medicaid Institutional and Home and Community Based Services. In R.W. Prouty, Gary Smith and K.C. Lakin (Eds). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2000*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration., pages 84-85.

expenditures were considerably relaxed and then dropped in the 1994 revision of the HCBS regulations. As a result, from 1992 – 2000 there was dramatic growth (366%) in the number of HCBS participants, even as the number of ICF/MR residents declined by 37%. All states now provide HCBS and two and one-half times as many persons with MR/DD (291,003) participate in the HCBS program as live in ICF's/MR (116,441)."¹

Medicaid Nursing Facilities

“Almost from the inception of Medicaid, states noted incentives for placing persons with MR/DD in Medicaid certified nursing facilities. Almost as soon as this began to happen there was a sense among the advocacy community that many more people with MR/DD were living in nursing homes than were appropriately served in them (National Association for Retarded Citizens, 1975). In 1987 Congress responded to these and other criticisms of nursing facility care in the Omnibus Budget Reconciliation Act (OBRA) of 1987 (P.L. 100-203). Provisions of this legislation restricted criteria for admissions to Medicaid reimbursed nursing facilities, so that only those persons requiring the medical/nursing services offered would be admitted. Current residents not in need of nursing services were required to be moved to “more appropriate” residential settings with the exception of individuals living in a specific nursing home for more than 30 months should they choose to stay. In either case nursing facilities were required to assure that each person’s needs for “active treatment” (later termed “specialized services”) were met. The estimated number of people with MR/DD in Medicaid-certified nursing facilities in June 2000 (32,195), based on the reported data from 41 states and estimates based on 1999 OSCAR data for 10 states not reporting, was significantly fewer than the number in 1970 (38,000), the year before the ICF/MR program began and the number in 1986 (39,528), the year before OBRA 1987 reform was enacted.”²

State and Privately owned & operated ICFs/MR (Facilities):

“The vast majority of all ICF's/MR (88.9%) on June 30, 2000 were community facilities (15 or fewer residents), of which more than three-fifths (60.6%) had six or fewer residents.”³ **“Most large ICFs/MR (68.6%) were operated by nonstate agencies (predominantly private sector vendors). Almost all ICFs/MR (97.7%) with six or fewer residents were nonstate operated, as were almost all**

¹ Ibid. p. 85.

² Ibid. p. 85.

³Lakin, Charlie, K, Polister, Barbara, Prouty, Robert W., and Smith, Jerra (2001), Utilization of and Expenditures for Medicaid Institutional and Home and Community Based Services. In R.W. Prouty, Gary Smith and K.C. Lakin (Eds). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2000*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, page 87.

ICFs/MR (97.0%) of 7 to 15 residents. Of the total 6,671 ICFs/MR reported on June 30, 2000, (94.2%) were operated by nonstate agencies.”⁴

“In June 2000 the largest numbers of ICF/MR residents were in Texas (13,453) and California (11,158). California, Illinois, New York, and Texas all had over 10,000 ICF/MR residents.”⁵ **“Throughout the period from 1977 to 2000, there has been a steady and substantial shift toward nonstate (predominantly private sector vendor) operation of ICFs/MR, although significantly less than the shift toward nonstate residential services generally.”⁶**

The following chart provides the total U.S. nonstate ICF/MR residents and the percentage of nonstate ICF/MR residents of the total ICF/MR residents.

Year	Total Nonstate ICF/MR	% of all ICF/MR
1977	13,312 residents	12.5%
1987	53,052 residents	36.8%
1995	73,437 residents	54.6%
2000	68,672 residents	59.0%

“The proportion of ICF/MR residents living in state facilities has been decreasing steadily since 1982. FY 2000 was the eighth year that fewer ICF/MR residents lived in state facilities than in nonstate facilities; 41.0% of all ICF/MR residents on June 30, 2000.”⁷ While the total number of private ICF/MR beds and/or number of facilities has not grown over the last few years, with the downsizing of the large state owned- and operated ICF's/MR, the proportion of private to state-owned and operated has increased.

From June 30, 1982 to June 30, 2000 there was a national net decrease of almost 62,000 residents of large state ICFs/MR, as compared with a net increase of 14,856 residents between June 30, 1977 and June 30, 1982.”⁸ Between 1977 and 1982 there was an average increase of about 3,000 ICF/MR recipients each year compared to an average decrease of about 3,444 per year between 1982 and 2000.”⁹

Massachusetts ICF/MR and HCBS Recipients for the Years 1984 - 2000¹⁰ are presented in the table on the next page.

Year	ICF/MR	HCBS	Total ²
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⁴ Ibid. p. 89.

⁵ Ibid. p. 89.

⁶ Ibid. p. 89.

⁷ Ibid. p. 89.

⁸ Ibid. p. 91.

⁹ Ibid. p. 91.

¹⁰ Data from the Massachusetts Accounting System and HCFA 372 Reports as reported on the State Fiscal Year (July 1 through June 30). Reported by William Hetherington, DMR Assistant Commissioner of Management and Finance, July 9, 2001.

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	Beneficiaries ¹	Beneficiaries	
1986	3551	470	<i>not available</i>
1987	3498	531	<i>not available</i>
1988	3417	838	<i>not available</i>
1989	3369	1255	<i>not available</i>
1990	3301	1645	<i>not available</i>
1991	3254	2147	<i>not available</i>
1992	2643	3161	21,000
1993	2484	4168	22,000
1994	2184	7308	22,052
1995	1995	7184	23,855
1996	1791	8832	24,221
1997	1603	9068	25,930
1998	1445	10255	27,169
1999	1339	10009	28,508
2000	1266	10244	29,786
Current	1209 ³	10771	30,852

The Massachusetts Department of Mental Retardation (DMR) currently serves 30,852 individuals with mental retardation. 19,996 adults aged 22 and older are served by DMR. Of those 19,996 adults, 8,089 individuals currently reside in community residences while 1,204 reside in ICF/MR residential settings. The majority of the Commonwealth's citizens with mental retardation live at home with their families. Forty-one percent of DMR beneficiaries live in community settings and six percent reside in ICF's/MR. The guardians and families of individuals living at the facilities are convinced that the ICF/MR setting is the most appropriate residence for their loved one.. Some advocates support the eradication of all Massachusetts ICF's/MR. This is an unjustifiable policy because eviction of disabled individuals from their homes is unacceptable and the denial of ICF/MR settings as an honorable and viable option is discriminatory.

The DMR population grows steadily each year. DMR's budget between Fiscal Year 1998 and 2000 increased by almost \$30 million.

Rather than a focus on continued deinstitutionalization while ignoring the need for a scientific study to determine outcomes, the state should give serious consideration to the development of ICF/MR models and the search for a more cost-effective statewide service delivery model before the Commonwealth completely privatizes the system of care for our most vulnerable of citizens.

¹ DMR has been asked to explain how the number of HCBS Waiver beneficiaries decreased from 1994 – 1995 and 1998 – 1999..

² DMR Annual Reports

³ DMR, Margaret Chow-Menzer, July 2001.

DMR's Strategic Planning Initiative

The DMR Strategic Plan, developed under contract with the University of Massachusetts Donahue Institute, was made public in November 2000. Concurrent with the planning process, DMR signed a contract with the Human Services Research Institute (HSRI) for an external evaluation of the agency, which is part of the National Core Indicator Project, sponsored by the National State Developmental Disabilities Directors. The data and interviews conducted under the HSRI Study were incorporated into the environmental assessment phase of the DMR Strategic Planning Process. COFAR received the HSRI Report in late August and is currently reviewing the document.

The overall DMR Strategic Planning effort focuses on four goals:

1. Create a Systemic Plan to Serve the Population
2. Recruit and Retain a Competent Workforce
3. Create a Clinical, Health, and Behavioral Agenda
4. Create a Comprehensive Quality Management System set forth in the Strategic Plan adopted by the Department last winter.

DMR has maintained a distinction between Strategic Planning and work plans since the inception of the process. According to DMR, the work plans, under development over the last nine months, will identify recommended strategies and assign responsibilities and timelines. The initiative has involved a substantial commitment of time and effort by DMR staff and external stakeholder participants and it should be viewed as both an internal management and a policy initiative. Janet George, DMR Assistant Commissioner of Policy Planning and Children's Service directs the statewide Strategic Planning initiative. Each of thirteen work groups have been charged with a particular set of tasks which are designed to create new systems and approaches to the Department's work and most importantly, move the Department forward to a new way of managing itself. DMR has operated for over a decade without a strategic plan. **Commissioner Morrissey is to be commended for initiating DMR's first comprehensive Strategic Planning process.**

According to Ms. George, the workgroup on Intake and Eligibility is the first to complete a work product by recommending the creation and functions of Regional Eligibility Teams. The implementation of the Regional Eligibility Teams will begin during the first few months of 2002. The work group on Intake and Eligibility has also recommended some changes to DMR eligibility which are under review. When the Regional Eligibility Teams begin their work they will continue to use the existing eligibility standards and operations manual set forth in the Department's current regulations. Ms George states that "If

the Department moves forward with a proposal to alter its current eligibility, the Department is committed to a public regulatory process to accomplish such a change.”

The Department intends to create five (5) Regional Eligibility Teams responsible for all aspects of the intake and eligibility process for both children and adults. Each Team will have a variety of staff trained in the diagnosis of mental retardation and developmental disabilities. At a minimum, each Team will consist of a full-time doctoral-level, licensed psychologist (Ph.D), one full-time Masters-level Social Worker (preferable an LICSW), one half-time (1/2) Registered Nurse (RN) allocated to the Team through either a consultation or nursing pool model, two full-time Service Coordinators, and one half-time clerical support staff. The Teams will vary in size based on the size of the region. One of the clinical staff will be the Team leader. The Teams will be managed and supervised centrally through the Office of the Deputy Commissioner or his designee for the first full year of implementation which, according to Ms. George “will allow for consistent training, development and workload assessment.” There will be a transition period. Ms. George states that “There may be times during this period that the workload fluctuations or volume requires limited or permanent reassignment of Team members to a new region. Once the Teams are well established and they have successfully met their management benchmarks, the management of the Teams will return to the Regions. However, the ongoing clinical oversight of the eligibility process will remain a centrally supervised activity through the Deputy Commissioner's Office.”

Ms George states that “It is the Department's intention to make the application process for DMR as easy and as accessible as possible for potential applicants. To that end we intend to widely distribute the application which may be found at the Area offices, providers, and other places where individuals who wish to apply may be found. The simple application may then be mailed, faxed or delivered to the Regional Team for processing. It is also our intention to make the application and materials available in a variety of languages consistent with the demographics in the state. Each applicant will be seen by a member of the eligibility Team. The Regional Eligibility Teams will be solely responsible for determining eligibility. Eligibility determination is the front door to the Department's service system; the creation of the Regional Eligibility Teams will insure the consistent. clinical application of the Department's regulations.”

Ms. George announced that “The creation of the Regional Eligibility Teams is the first Strategic Plan work product which is ready for implementation. We estimate that by the end of the year, we will have received recommendations from the Rulebook workgroup, the Partnership workgroup, and

the Facility workgroup which we will also need to process and review.”

How can families and advocates participate in this process as policy recommendations are issued by DMR? Ms. George announced that “DMR is in the process of planning a series of public forums in early 2002 to share with our stakeholders the status of our work.” Little is currently known about the specific work of the other twelve DMR Work Groups since they began their work in February of 2001. The upcoming public forums in early 2002 will be the first opportunity that families and advocates will have to learn about recommended changes.

COFAR supports Commissioner Morrissey's Strategic Planning initiative but we continue to have concerns around process. The Strategic Planning work groups and committee meetings are not open to the public. Individuals volunteering on the various groups are instructed not to distribute materials to people outside the group. DMR is not open to recommendations for additional participants for various committees that are being established.

The work of the Intake and Eligibility Work Group is the first of a series of announcements regarding the work of these various groups. It is hoped that once DMR publishes proposed policy documents that there will be adequate time for public review and comment.

DMR Prohibits Indemnification Agreements in Vendor Contracts:

Clearly, vendors doing business with DMR are responsible for the health and safety of the DMR clients under their care. Commissioner Morrissey demonstrated his willingness to listen and act on the concerns of families regarding the use of indemnification agreements as a condition of service delivery, and supervision. Requiring such agreements to be signed by family members and guardians is inappropriate and results in sleepless nights for family members. Such agreements threaten the system of accountability for abuse and neglect of the Commonwealth's most vulnerable citizens. As a result of Commissioner Morrissey's responsive action, indemnification agreements are now prohibited under the DMR standard vendor contract form. COFAR thanks Commissioner Morrissey for being responsive to family concerns regarding the indemnification issue.

Olmstead Planning Begins in Massachusetts

Governor Swift has appointed a Massachusetts Olmstead Working Group to “create a comprehensive plan, with short and long term goals, to enhance accessibility to community-

based long term supports including residential, for individuals with disabilities.” Members of the working group include:

Charlie Carr, Executive Director,
Northeast Independent Living Program

Judi Chamberlain, Co-Chair,
State Mental Health Planning Council and National
Empowerment Center

Christine Griffin, Executive Director
Disability Law Center in Boston

Ben Haynes, Board Member
Mass Senior Action Council and Disability Policy Consortium

Bill Henning, Director
Cape Organization for Rights of the Disabled (CORD)

Sandra Houghton
Self Advocacy Leadership Institute

Linda Long, Deputy Executive Director,
Governor’s Advisory Commission on Disability and
Deputy Executive Director, North Shore ARC.

Angelina Ramirez, Program Coordinator,
Stavros Independent Living Center of Amherst & Springfield

Henri Rauschenbach, Undersecretary,
Executive Office of Administration & Finance

John O’Neill, Executive Director
Somerville/Cambridge Elder Services

Bob Gittens, Secretary
Executive Office of Health & Human Services

Lillian Glickman, Secretary
Executive Office of Elder Affairs

Elizabeth Morse, Assistant Chief of Staff,
Governor’s Office

Betty Anne Ritcey, Director of Client Services,
Executive Office of Health and Human Services

Larry Swartz, General Counsel,
Executive Office of Health & Human Services

Linn Torto, Assistant Secretary,
Executive Office of Administration & Finance

The Olmstead Working Group is convening four committees: (1) Individuals in Institutions, (2) Individuals at Risk of Institutionalization/Emerging Populations; (3) Current and Future Services/Support; and (4) Housing. Committee Membership is currently being finalized.

The Olmstead Working Group is holding four public forums across the state to solicit input. Two forums have already been held: one on November 14th in Westfield and a second on November 27th in Fairhaven, Massachusetts. The last two forums are scheduled as follows:

Thursday, December 6th 1:00 – 4:00 pm
Worcester Senior Center
128 Providence Street

Worcester, Massachusetts

Monday, December 10th 1:00 – 4:00 pm
One Ashburton Place
21st Floor

Boston, Massachusetts

Individuals and families are encouraged to participate in these forums to emphasize the individual and guardian’s right to choose ICF/MR settings. Written testimony is also accepted if attendance at the forum is not possible. You may send written testimony to: Larry Swartz General Counsel EOHHS One Ashburton Place Rm. 1109 Boston, MA 0210. 8Please feel free to call the COFAR Office for more information and/or directions to either public forum.

The Olmstead Supreme Court Decision¹ is often misinterpreted as requiring the closure of all ICF’s/MR. The Supreme Court Decision states that “We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings.”² The Decision also states “Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it. Nothing in this part shall be construed to require an individual with a disability to accept an accommodation...which such individual chooses not to accept. Persons with disabilities must be provided the option of declining to accept a particular accommodation.”³ In addition to the Olmstead Supreme Court Decision, the Social Security Act 1915(c)(2) (C) and the Health Care Financing Administration (HCFA) regulations 42 CFR Ch. IV 441-302(d)(2) mandate that eligible individuals be “given the choice of either institutional or home and community-based services.”

COFAR believes that individuals with mental retardation have the same legal rights and responsibilities guaranteed all

¹ Olmstead v. L.C., 119 S. Ct. 2176 decided on June 22, 1999.

² Tommy Olmstead, Commissioner, Georgia Department of Human Resources, et al., Petitioners v. L.C., by Jonathan Zimring, guardian ad litem and next friend, et al. No. 98-536, United States Supreme Court, Decided June 22, 1999, p. 9.

³ Ibid. p. 9.

other individuals by the United State Constitution and the Constitution and laws of the State of Massachusetts. Disabled and non-disabled persons should have equal access to all housing options, otherwise this is discriminatory. As such, ICF/MR settings should be viewed as positive alternatives and honorable choices for those eligible individuals for whom this is the most appropriate and least restrictive environment.

VOR Publishes Report summarizing Media Coverage across the Country Highlighting Need for More Effective Federal and State Protections

Tamie Hopp, Executive Director of Voice of the Retarded, Inc. (VOR) has compiled 28 accounts of media reports from fourteen states and Washington D.C. The publication is

entitled "Media coverage highlighting the increasing need for more effective federal and state protections in the ever-expanding community system of care for people with mental retardation." According to Attorney Hopp, "Since 1990, over 47,000 people have been transferred from large, congregate residential facilities. The number of persons living in smaller, community-based living arrangements more than doubled from about 98,000 in 1990 to almost 239,000 in 2000... There is little doubt that the explosion in the number of small, community-based residential sites is posing substantially greater quality management and system infrastructure challenges for states and local developmental disabilities authorities." These media accounts are telling examples that increased monitoring and strengthened quality assurance systems need to be developed. Copies of the report can be obtained from the COFAR Office or by contacting VOR directly at 605.339.1624 or vor@compuserve.com.

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The Purposes of COFAR are:

1. **To promote the general welfare of individuals with mental retardation.**
2. **To unite organizations and concerned individuals in promoting the delivery of adequate and appropriate services for persons with mental retardation, irrespective of whether these people reside at home with their families, in state or vendor operated group homes or in public/private congregate settings such as the DMR facilities (ICF's/MR).**
3. **To intercede when necessary with anyone or any entity which would in any way seek to control or direct the lives of individuals with mental retardation, contrary to their wishes or those of their family or guardian.**
4. **To insure that resident/family/advocate and/or guardian choice is paramount in selecting alternative placement or programs models.**
5. **To publicize and support facility availability for individuals with mental retardation in need of emergency, short or long term services as well as outpatient and day programs.**
6. **To support any family/guardian of an individual with mental retardation denied choice in determining an appropriate living environment, active treatment, medical care and/or other services.**
7. **To promote the assurance and delivery of quality medical, therapeutic, psychological, nursing, dental and other resources for individuals with mental retardation, regardless of residential site.**
8. **To insist that individuals with mental retardation have access to community resources such as churches, stores, theaters and recreational centers.**
9. **To support the well being of dedicated employees caring for individuals with mental retardation.**
10. **To encourage cooperation with public, private, professional, religious and other groups in furtherance of these aims.**