



The COFAR VOICE

The Official Newsletter of the Massachusetts Coalition of Families and Advocates for the Retarded, Inc.

July 2001 Issue:

Volume 3 / Number 2

- Increased Federal Oversight of the Medicaid HCBS Waiver and ICF/MR Programs is needed.
- COFAR's New Website: www.cofar-mass.org
- Update on DMR's Strategic Planning Initiative
- Legislative Update

Increased Federal Oversight of the Intermediate Care Facilities for the Mentally Retarded (ICF's/MR) and Medicaid Home and Community-Based Services (HCBS) Waiver Programs is needed

The capacity of the Federal Centers for Medicare and Medicaid Services (CMS)¹ to conduct Comprehensive Compliance Reviews must be strengthened if the Commonwealth and other States are to be held accountable for statutory and regulatory requirements to protect our most vulnerable citizens.

CMS Contracts with a private vendor to review all ICF's/MR Programs in the Country & Implements a new Protocol for Conducting Reviews of the Medicaid HCBS Waiver.

*The Centers for Medicare and Medicaid Services (CMS) – formerly known as the Health Care Financing Administration (HCFA) - is the Federal agency responsible for operating the Medicare and Medicaid programs. According to an article in **GovExec.Com Today**, by Matthew Weinstock, published on May 11, 2001, "HCFA has long been overworked and under funded. The Medicare program covers 39 million seniors and is expected to distribute \$240 billion in benefits in fiscal 2001. Medicaid covers 34.3 million people. While administered mostly at the state level, federal outlays for the program total nearly \$140 billion. But HCFA's budget for administering Medicare and*

Medicaid is only about \$2 billion per year." The article quotes Representative Sherrod Brown, a Democrat from Ohio as saying "As it is now, we want HCFA to run on a hope and a prayer." Nancy-Ann DeParle, who ran the agency from November 1997 to October 2000, is quoted as saying, "Current resources are inadequate for HCFA to do its job the way Congress and the agency staff want it to."

History of the ICF/MR Program and the HCBS Waiver:

One Hundred and Fifty Three years ago, the first Intermediate Care Facility for the Mentally Retarded

¹ Formerly known as the Health Care Financing Administration or 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 name of the organization at the time.

(ICF/MR) was opened in Waltham, Massachusetts as what is today The Fernald Center. - the first of its kind in our nation. In the late 1800's, the philosophies and methods of Dr. Walter Fernald, Superintendent of Fernald for 37 years, were new and revolutionary. The facility was a model for the world at one time. **Due to a lack of oversight and monitoring,** Fernald deteriorated and, like four other Massachusetts facilities (Belchertown, Dever, Monson and Wrentham) went through its darkest period in history which ended with a twenty year Federal Consent Decree. Between the late 1800's and the early 1980's, individuals with mental retardation either lived at home or at ICF/MR facilities. The initial purpose of the Fernald Center was educational. The students were trained for work in the community and the eventual goal was for them to return to the community. Admissions rose sharply and without appropriate oversight, overcrowding and staffing shortages resulted in inhumane and inexcusable conditions. Many individuals were inappropriately placed in ICF's/MR for any number of reasons. Members of Massachusetts Advocates Standing Strong (MASS), an advocacy group of self-advocates, can attest to such inappropriate admissions and abuses.

The paradigm shift from facility-based to community-based care occurred in 1981. Section 2176 of the Omnibus Budget Reconciliation Act of 1981 established the option for states to provide Medicaid Home and Community Based Services (HCBS) to persons with mental retardation and related conditions. Under this section, the Secretary of Health and Human Services could waive certain existing Medicaid requirements to allow states to finance certain "non-institutional" services for Medicaid-eligible individuals, which is why this is known as the HCBS "waiver" program. This program was designed to provide a variety of home and community services such as personal care, habilitation, respite and family support, adult day health services and other services for persons who were either currently "institutionalized" or "at-risk of institutionalization." Although the HCBS waiver cannot pay for room and board, all states using the waiver provide various types of residential supports and services along with other services to eligible recipients.

In May of 1984, the Commonwealth gained approval from the Health Care Financing Administration (HCFA)¹ for the Massachusetts Omnibus Waiver. This program presented a landmark opportunity for states to expand services for individuals with mental retardation who lived in the community. Prior to this legislation, Medicaid programs were restricted to providing care in the DMR Facilities. The Massachusetts Omnibus Waiver was renewed for an additional five years in July, 1987 and has been renewed every five years since its inception. The Waiver program provides

the foundation for the community-based system under a 50% federal matching funds contract between HCFA and the State Medicaid Agency (Massachusetts Division of Medical Assistance).

National Review of ICF/MR Programs:

An annual compliance review of the Massachusetts ICF/MR Program is conducted by the Massachusetts Department of Public Health's (DPH) Division of Healthcare Quality. DPH sends a review team to each DMR Facility and they follow a specific survey protocol, which was last revised in April of 1999. The ICF's/MR currently in operation include The Fernald Center, The Templeton Developmental Center, The Hogan Regional Center, the Glavin Regional Center, The Monson Developmental Center and the Wrentham Developmental Center.

In the summer of 2000, HCFA released a request for proposals to conduct federal "look behind surveys" for ICF's/MR. HCFA's intent is to strengthen federal oversight and monitoring of ICF's/MR by engaging a private contractor to assemble a national team of federal surveyors who will review ICF/MR certified facilities on both a regularly scheduled and as-needed basis.

On September 29, 2000, HCFA awarded a \$3.5 million contract to the Council on Quality and Leadership in Supports for People with Disabilities to conduct federal "look-behind surveys," complaint investigations and crisis assignments in ICF's/MR. The Council hired 19 federal contract surveyors and the five teams began their work on December 11, 2000. Ideally, the HCFA surveys will be conducted within 30 days of a survey by the state. The federal surveys will be unannounced.

Why is COFAR Concerned about the ICF/MR Compliance Reviews?

To date, there has been little direct HCFA oversight of the program. DPH's Division of Healthcare Quality conducts the annual review according to the HCFA protocol. The review protocol for ICF's/MR requires the records and ISP review to take place after the site visit, observations and interviews. This makes ISP compliance determination difficult. HCFA requires that the DPH review focus on the record review at the end of the process. It would be more productive to review the records and ISP prior to the visit, observations and interviews. In addition, a federal review of state programs is more independent than one state agency evaluating another state agency. COFAR welcomes the national review team and HCFA's increased efforts to provide oversight and determine compliance.

¹ Now referred to as CMS – The Centers for Medicare and Medicaid Services. The agency was renamed on June 14th of 2001.

The following chart provides the ICF/MR Reimbursements for Fiscal Year 1986 – projected 2001¹.

Fiscal Year	Number of Beneficiaries	Federal Reimbursements
1986	3551	\$ 165 Million
1987	3498	\$ 161 Million
1988	3417	\$ 154 Million
1989	3369	\$ 147 Million
1990	3301	\$ 137.2 Million
1991	3254	\$ 161.7 Million
1992	2643	\$ 163.6 Million
1993	2484	\$ 123.7 Million
1994	2184	\$ 132.5 Million
1995	1995	\$ 152.2 Million
1996	1791	\$ 165.5 Million
1997	1603	\$ 123.5 Million
1998	1445	\$ 123.4 Million
1999	1339	\$ 106.5 Million
2000	1266	\$ 99.3 Million
Est. 2001	1214	\$ 105.9 Million

New HCBS Waiver Protocol:

The purpose of the new Protocol is to provide the HCFA Regional Office staff responsible for reviewing 1915(c) waiver programs with **standardized** and **comprehensive** procedures for assessing the quality of care and services provided through the HCBS Waiver. HCFA conducts a review every five years from a sample of individuals served by a sample of DMR's 265 providers contracting with the department.

HCBS Waiver Assurances:

All HCBS Waiver Programs are required to provide ten assurances as a condition of waiver approval. A listing of the ten waiver assurances is followed by a brief description of each assurance.

1. Health and Welfare;
2. Financial Accountability;
3. Evaluation of Need;
4. Alternatives;

5. Average Per Capita Expenditures;
6. Actual Total Expenditures;
7. Institutionalization Absent Waiver;
8. Reporting;
9. Habilitation Services; and
10. Services to Individuals with Mental Illness.

In order to receive a HCBS Waiver, the State must comply with each of the ten assurances. Section 1915(f)(1) of the Social Security Act requires HCFA to monitor the State's compliance with these assurances. Each of these assurances is briefly described.

Health and Welfare

The Division of Medical Assistance (DMA) provides to HCFA the assurance that "necessary safeguards have been taken to protect the health and welfare of the recipients of the services."² Those safeguards must include (1) adequate standards for all types of providers that provide services under the waiver; (2) assurance that the standards of any State licensure or certification requirements are met for services or for individuals furnishing services that are provided under the waiver; and (3) assurance that all programs are in compliance with applicable State standards for board and care facilities. This assurance is met under DMR's Survey and Certification Program.

Financial Accountability

The Department of Medical Assistance (DMA) "assures financial accountability for funds expended for home and community-based services, provides for an independent audit of its waiver program (except as HCFA may otherwise specify for particular waivers), and it will maintain and make available to Health and Human Services, the Comptroller General or other designees, appropriate financial records documenting the cost of services provided, including reports of any independent audits."³

Evaluation of Need

DMA provides "assurance that the Department of Mental Retardation (DMR) will provide for the following: (1) **Initial Evaluation:** An evaluation of the need for the level of care provided in a hospital, a Nursing Facility or an ICF/MR when there is reasonable indication that a recipient might need the services in the near future (that is, a month or less) unless he or she receives home or community-based services. For purposes of this section, 'evaluation' means a review of an individual recipient's condition to determine – (i) If the recipient requires the level of care provided in a hospital, as defined in section 440.40 of this subchapter, a Nursing Facility, as defined in section 1919(a) of the Social Security

¹ Data from State's 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.

² Health Care Financing Administration, HHS 42 CFR Ch. IV, Section 441.302: State Assurances. (10-1-95 Edition)

³ Ibid.

Act, or an ICF/MR as defined by section 440.150 of this subchapter; and (ii) That the recipient, but for the provision of waiver services, would otherwise be institutionalized in such a facility. (2) **Periodic reevaluations:** Reevaluations, at least annually, of each recipient receiving home or community-based services to determine if the recipient continues to need the level of care provided and would, but for the provision of waiver services, otherwise be institutionalized in one of the following institutions: (i) A hospital; (ii) a Nursing Facility; or (iii) An ICF/MR.

Alternatives

Assurance that when a recipient is determined to be likely to require the level of care provided in a Skilled Nursing Facility, ICF or Intermediate Nursing Facility or ICF/MR, the recipient or his or her legal representative will be – (1) Informed of any feasible alternatives available under the waiver; and (2) Given the choice of either institutional or home and community-based services.”¹

COFAR believes that it was the intent of the federal government to offer “real choices.” There is no “genuine choice” of either “institutional or home and community-based services” in the Commonwealth. DMR offers a “phantom choice.” The only ICF’s/MR in Massachusetts are the state facilities and one 6-bed community ICF/MR on Lake Street in Shrewsbury, operated through the Glavin certification. Admissions to the DMR facilities are closed as per DMR’s 1987 policy. Thus, the only “choice” is a six-person group home that has been full since it was built. The closed admissions policy evades the intent of HCFA’s assurance of choice under the Home and Community-Based Waiver.

Average Per Capita Expenditures

DMA provides HCFA with the “²assurance that the average per capita fiscal year expenditures under the waiver will not exceed 100 percent of the average per capita expenditures that would have been made in the fiscal year for the level of care provided in a hospital, Nursing Facility or ICF/MR under the State plan had the waiver not been granted. (1) These expenditures must be reasonably estimated and documented by the agency (2) The estimate must be on an annual basis and must cover each year of the waiver period.”³

Actual Total Expenditures

DMA provides HCFA with the assurance that DMR’s “actual total expenditures for home and community-based and other Medicaid services under the waiver and its claim for FFP (Federal Financial Participation) in expenditures for the services provided to recipients under the waiver will not, in any year of the waiver period, exceed 100 percent of the

amount that would be incurred by the State’s Medicaid program for these individuals, absent the waiver, in; (1) A hospital; (2) A Nursing Facility; or (3) An ICF/MR..”⁴

Institutionalization Absent Waiver

DMA provides HCFA with the assurance that “absent the waiver, recipients in the waiver would receive the appropriate type of Medicaid-funded institutional care (hospital, nursing facility or ICF/MR) that they require.”⁵

Reporting

DMA provides the “assurance that annually, the agency will provide HCFA with information on the waiver’s impact. The information must be consistent with a data collection plan designed by HCFA and must address the waiver’s impact on – (1) The type, amount, and cost of services provided under the State plan; and (2) The health and welfare of recipients.

Habilitation Services

Assurance is given that “prevocational, educational, or supported employment services, or a combination of these services, if provided as habilitation services under the waiver, are – (1) Not otherwise available to the individual through a local educational agency under section 602 (16) and (17) of the Education of the Handicapped Act (20 U.S.C. 1401 (16 and 17) or as services under section 110 of the Rehabilitation Act of 1973 (29U.S.C. 730) and (2) Furnished only to individuals who have been deinstitutionalized, regardless of discharge date from a Medicaid certified nursing home or ICF/MR. (3) Furnished as part of expanded habilitation services on or after April 7, 1986, if the State has requested and received HCFA’s approval under a waiver or an amendment to a waiver.”⁶

Services to Individuals with Mental Illness

DMA must assure HCFA that “FFP⁷ will not be claimed in expenditures for waiver services including, but not limited to, day treatment or partial hospitalization, psychosocial rehabilitation services, and clinic service provided as home and community based services to individuals with chronic mental illnesses if these individuals, in the absence of a waiver would be placed in an Institution for Mental Diseases (IMD) and are; (1) Age 22 to 64; (2) Age 65 and older and the State has not included the optional Medicaid benefit cited in section 440.140 or (3) Age 21 and under and the State has not included the optional Medicaid benefit cited in section 440.160.”⁸

⁴ Ibid.

⁵ Ibid.

⁶ Ibid.

⁷ Federal Financial Participation

⁸ Health Care Financing Administration, HHS 42 CFR Ch. IV, Section 441.302: State Assurances. (10-1-95 Edition.

¹ Ibid.

² Ibid.

³ Ibid.

Past HCFA Compliance Reviews:

HCFA conducts a Compliance Review of the HCBS Waiver Program every five years. Since the Waiver was established in 1985, HCFA has conducted three such reviews. The first Compliance Review was conducted in 1989. The review produced a six-page report for a \$13 million program serving 1,210 individuals. The sample size was twenty individuals. The second Compliance Review was conducted in 1992. The review resulted in a seven-page report for a \$39 million program serving 2,710 individuals. The sample size was twenty. The third and last Compliance Review was conducted in 1997. The result was a 15-page report on a \$216 million program serving 7,782 individuals. The sample size was 28 individuals. Readers are encouraged to read the HCFA compliance reviews to develop their own conclusions as to the rigor under which the reviews have been conducted. COFAR asks why these reviews are so superficial? HCFA officials indicated they would like to conduct a more comprehensive review, but they lack the staff to do it. A federal hiring freeze has worsened the situation as staff cannot be replaced and existing employees are simply asked to do more. Without the resources to conduct a comprehensive review, it is difficult to say whether the new protocol will result in improvements to the review.

The next Compliance Review will be conducted this year. Only time will tell whether more “teeth” will go into the review.

Why is COFAR Concerned about the HCBS Waiver Program's Compliance Reviews?

COFAR has been closely tracking the developments across the United States citing systemic failures resulting in poor care, abuse and/or neglect. Various states have had serious problems, most recently, even the seat of our national government – Washington D.C.

In December of 1999, Katherine Boo, a Washington Post Staff Writer exposed incidents of abuse and neglect in residential group homes in Washington D.C. for people with mental retardation.¹ Deplorable conditions were cited as well as financial mismanagement. The articles document a shameful history of deaths, delayed treatment, neglect of the District's most vulnerable including falsification of records and a lack of investigations or missing documentation into 47 deaths.

HCFA's San Francisco Regional Office conducted a comprehensive review of the California Waiver in January of

¹ The Department of Inhuman Services, December 7, 1999, D.C. Vows Review of Deaths in Homes, December 6, 1999 and Invisible Deaths: The Fatal Neglect of D.C.'s Retarded, December 5, 1999. The Washington Post.

1998.² The California review produced a 68-page comprehensive report in addition to a substantial appendix. The sample size was 100 individuals. In a letter from the HCFA Regional Administrator to the State Department of Health Services, it was stated that the State of California was found to be “not in compliance with the statutory and regulatory requirements set forth to protect the health and welfare of waiver participants and to safeguard the integrity of Federal funds expended. Because of the severity of the deficiencies found in the review, HCFA will not entertain a request for a renewal of this waiver. The waiver expired on September 30, 1997 and is on a temporary 90-day extension that expires on December 29, 1997.”³ The letter goes on to point out that “Because HCFA does not wish to penalize individuals currently receiving waiver services, we will allow no more than two more temporary 90-day extensions. During this period, the State will be expected to demonstrate that it has established and implemented policies and procedures that conform with the statute and regulations.”⁴ The letter continues “Effective immediately, HCFA will impose a freeze on new admissions to the waiver. California may continue to provide waiver services to individuals currently receiving them under this program, but Federal Financial Participation (FFP) will not be available for any new admissions to the program. Failure to adhere to these requirements or to make progress in protecting the health and welfare of the recipients of these waiver services will result in immediate termination of the waiver.”⁵ The California Department of Health Services issued a 17-page response to HCFA's Compliance Review document and the State is taking rigorous steps to come into compliance.

Why are Federal Compliance Reviews Important?

COFAR believes that a stronger system of monitoring, quality assurance and oversight is required on both the State and Federal Levels of both the ICF/MR and HCBS Waiver Programs. Here in Massachusetts, accountability for quality of care rests with DMR, DMA and DPH. HCFA defers the oversight of the quality assurance function to the state. COFAR has reviewed the DMR Survey and Certification System as well as the DPH Review Process for ICF's/MR. We are concerned about these review systems as oversight and accountability are critical functions. COFAR's intent is to work with HCFA and the various state agencies to

² Compliance Review of California's Home and Community –Based Services Waiver Program for the Developmentally Disabled. Control Number 0129.91. Health Care Financing Administration. San Francisco Regional Office, January 12, 1998.

³ Letter from Elizabeth C. Abbott, HCFA Regional Administrator to Kim Belshe, Director of the Department of Health Services Dated December 4, 1997.

⁴ Ibid.7182

⁵ Ibid.8832

strengthen these systems so as to avert systemic failure as has been documented in Washington D.C. and states across the U.S.

The following chart provides the Omnibus Medicaid Waiver Reimbursements for Fiscal Year 1986 –2000¹.

Fiscal Year	Number of Beneficiaries	Federal Reimbursements
1986	470	\$ 4.9 Million
1987	531	\$ 6.4 Million
1988	838	\$ 7.6 Million
1989	1255	\$ 11.9 Million
1990	1645	\$ 17.1 Million
1991	2147	\$ 28.7 Million
1992	3161	\$ 33.3 Million
1993	4168	\$ 53.4 Million
1994	7308	\$ 92.0 Million
1995	7182	\$ 109.8 Million
1996	8832	\$ 124.3 Million
1997	9068	\$ 138.1 Million
1998	10,255	\$ 157.1 Million
1999	10,009	\$ 195.8 Million
2000	10,244	\$ 211.8 Million
Est. 2001	10,771	\$ 222.0 Million

COFAR has asked DMR to address the data for 1994/95 and 1998/99. In 1994/95, the number of HCBS Waiver recipients dropped by 126 persons. In 1998/99, the total recipients dropped by 246 persons. There is a steady increase in the numbers of individuals served under the waiver over time with the exception of these two years. For those same years the census at the facilities dropped by 189 and 106 respectively. Other than death, one would “assume” that the individuals leaving the facilities would either transfer to HCBS Waiver or State-Operated Group homes.

Clearly, the Home and Community-Based Waiver Program is growing significantly each year and it would stand to reason that a program of this size would warrant appropriate oversight. **The growth in the mental retardation service delivery system has apparently out-stripped the ability of**

¹ Data from State’s 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.

Federal and State Government to adequately oversee these programs.

Strengthening HCFA’s capacity to conduct a comprehensive review of both the HCBS Waiver and ICF/MR Programs is in the best interests of the Commonwealth’s citizens with mental retardation. How else will families and advocates have confidence that Massachusetts is in compliance? Either the review system is strengthened or HCFA will continue with their superficial reviews to avoid potentially exposing the State as out of compliance with the statutory and regulatory requirements set forth to protect the health and welfare of waiver participants and to safeguard the integrity of Federal funds expended.

It goes without saying that the HCBS Waiver and ICF/MR Programs provide services to the most vulnerable of the Commonwealth’s citizens. It goes without saying that no one wants to limit service provision to individuals and families in need, particularly with the desperate need for services of individuals in the Boulet (Waiting List Lawsuit) and Rolland (Nursing Home Lawsuit) Classes. But if we do not strengthen HCFA’s oversight capacity – what are we saying about the importance of accountability? It is the lack of oversight and accountability that resulted in the inhuman conditions at the Massachusetts ICF’s/MR which came to light in the seventies when families sued the State. Do we close our eyes to federal oversight for fear of what we might find?

COFAR announces website

COFAR’s website – www.cofar-mass.com - has been up and running since June 1, 2001. Now, individuals and organizations interested in our advocacy work can learn about COFAR on line. While the site is evolving, basic information is available.

Update on DMR’s Strategic Planning Initiative

The Department of Mental Retardation (DMR) entered into a contract with the University of Massachusetts Donohue Institute in May of 1999 to accomplish four goals.

1. Increasing the skills in strategic thinking and management of key Department Leaders.
2. More effectively using strategic information and methods to drive the agency.
3. Aligning key employees and stakeholders toward a common vision and direction and;
4. Developing the Department’s first strategic plan in a decade.

The Donahue Institute concluded its work with the publication of DMR’s Strategic Plan in November of 2000.

DMR also entered into a contract with the Health Services Research Institute (HSRI) for an external evaluation of the Department for a total contract amount of \$402,900. The original contract included 600 consumer interviews, six consumer focus groups and five public forums as well as 25 key informant interviews. These interviews, focus groups and public forums were intended to inform DMR's Strategic Planning process. The initial contract period for the HSRI study was April 1, 1999 – April 30, 2000. The HSRI Final Report was issued in June. COFAR is expecting to receive a copy of the full report in mid-August.

DMR is now in Phase II of the Strategic Planning Process. In late February, DMR announced the formation of ten work groups. They are as follows: (1) Eligibility; (2) Regional Eligibility Teams, (3) Assessment and Cost Corridors; (4) Facility Planning, (5) Partnership; (6) Recruitment and Retention; (7) Diversity; (8) Training and Development; (9) Health, Clinical and Behavioral Supports; and (10) Quality Management. In early April, the work group structure was refined. Work groups 1 and 2 were combined into one group addressing eligibility. A new group focusing on Interagency Collaboration was established. The Diversity Work Group was dissolved as DMR determined that diversity issues would be addressed in existing multiple groups. Another new work group was established to address the Advanced Planning Document – the development of DMR's new management information system. A third new work group was established entitled "Rulebook." This group will be "identifying organizational infrastructure and organizational development needs to support the Strategic Plan" including the articulation of "underlying assumptions and principles that guide organizational practice." The timeframe for the implementation of the plan is three years. Not all workgroups will proceed at the same pace with the Eligibility Work Group being the first to likely complete its tasks.

Commissioner Morrissey Commended for Strategic Planning Initiative

Commissioner Morrissey is to be commended for initiating DMR's first comprehensive strategic planning process. DMR has evolved into a soon-to-be billion-dollar agency without the benefit of a management plan for over a decade. The problems that are being addressed through this process have evolved over many years and it is to the Commissioner's credit that he has taken on this challenge. It is COFAR's hope that this planning initiative will truly involve a critical assessment of the agencies structure and functions and that the recommendations resulting from this effort will be data driven and client-centered. While COFAR supports strategic planning and the development of a management plan for the agency, there are concerns as to the strategic planning process itself.

No Public Access to Strategic Planning Steering Committee:

COFAR has expressed concerns over the work group structure and the planning process to Commissioner Morrissey over the last six months. Participation on the overall Strategic Planning Steering Committee is restricted to DMR executive level staff. Whether it is the Steering Committee or some other structure, there does not appear to be a forum in which advocates and families can participate in the overall vision and understanding of the integration and linkages among work group activities. Access to specific data and analyses conducted by the various work groups is limited. COFAR views this as unnecessarily restrictive and recommended to the Department in April that any interested party be allowed to attend the Steering Committee Meetings. COFAR was informed by DMR's General Counsel, Marianne Meacham that "The Strategic Planning Work Group meetings are not governed by the Massachusetts Open Meeting Law...which does not apply to individuals or to boards informally appointed by individual officials to carry out duties that are assigned to those officials. The Commissioner has informally appointed committees consisting of staff and of members of the public, to assist him in the development of policy through their work; the exclusive authority to make policy rests with the Commissioner. From another perspective, the strategic planning committees are not subject to the open meeting law because they do not 'deliberate' or decide questions of public policy. Decision-making on all matters of public policy rests with the Commissioner." COFAR does not dispute this. Clearly, the Commissioner has decision-making authority on public policy matters. It is understood that the work groups established by DMR are "advisory" in nature. Although clearly "advisory," the Commissioner will give considerable weight to the recommendations of the work groups. If this were not the case, one would have to question the value of the entire process. Access to a forum, such as the Steering Committee, would be of invaluable benefit to the process.

Current Work Group Structure leads to Limited Participation and Fragmentation of Efforts

Given the large number of work groups, as DMR has defined them, and the frequency with which they meet, full participation by any advocacy group, would require an estimated 168 hours of volunteer time per month. This precludes meaningful involvement. COFAR considers it unnecessarily restrictive that DMR does not allow open access to the meetings of these various work groups as well as the overall Steering Committee. If an advocate or family member wishes to attend a particular meeting would they be asked to leave? COFAR considers this to be a public policy initiative (regardless of the technicalities of the Open Meeting Law) and as such, anyone interested in the process should be welcomed at the various meetings, if only to observe.

COFAR recommended to DMR in April that the Department welcome advocates and family members to attend the various work group meetings. DMR requires that the named representative from an advocacy group attend all meetings of a given work group and that two individuals cannot share the responsibility for one work group. With few exceptions, COFAR Board members and volunteers cannot make a six-eight month commitment, twice a month for ten or more hours. As a result, the COFAR Board had to make decisions about whether eligibility is more or less important than quality assurance. Or, whether partnerships are more important than the design of information systems (Advanced Planning Document). Or, whether recruitment and retention is more or less important than health, clinical and behavioral supports. Twelve work groups facilitated by nine different DMR staff are likely to result in fragmentation particularly for "external stakeholders" because we do not have the benefits of the linkages that have been built into the structure for DMR staff. In our view, four major work groups reflecting the four major objectives of the plan, meeting once a month, would be more manageable, more defensible and more reasonable and would allow for more participation by advocates and families. Given the demands of the Strategic Planning process on DMR's key staff, one is left to wonder what is not being addressed during this staff-intensive process.

Lack of Communication Regarding Work Group Progress:

Over thirty work group meetings have been held since the process began in late February yet there has been little communication regarding the **specific** work of these groups. You have to be a member of a work group in order to access meeting reports and other documentation. In April, COFAR recommended that DMR post updates on their website and/or include updates on their periodic e-mail reports. COFAR recommended that the schedule of meetings, agendas, meeting reports and interim draft documents be shared via DMR's website so that advocates and family members will be in a position to decide when input would be of most value to DMR.

DMR indicated that it was the Department's intention to provide regular informational updates through a variety of mechanisms such as feedback forums at regular intervals. The DMR Strategic Planning Work Groups began their work in February of 2001. DMR's "Strategically Speaking Update II" has only reported on the work of the "Rulebook" and Recruitment and Retention Work Groups. The report of the "Rulebook" Work Group, after approximately 24 hours of meetings over a four month period of time, was to announce five principles of organizational behavior: (1) Stewardship, (2) Respect, (3) Professionalism, (4) Commitment of Excellence and (5) Organizational Integrity. The Retention and Recruitment group is charged with "creating a plan to address

recruitment and retention, ensuring sufficient members of qualified staff and care providers at all levels within the provider community, the Department, and family managed supports." The summary of four months of meetings was condensed to a listing of six general areas¹ and the mention of a recruitment and retention survey distributed to Regional, Area, Facility and State Operated Group Home Directors. Needless to say, COFAR was not invited to provide input on the survey instrument prior to distribution. COFAR specifically has asked DMR for the minutes of all work group meetings. We wait patiently.

COFAR applauds DMR's Reconsideration of Initial Facility Work Group Process based on Input from Statewide Advocacy Groups:

Goal 1.6 of the DMR Strategic Plan is to develop a plan to identify short and long term roles for the facilities. DMR's Internal Planning Group has been meeting over the last several months and the Department invited representatives from the five Statewide Advocacy Groups² to participate in the planning initiative on the future of the facilities on June 25, 2001. The initial planning process proposed by DMR for the Facility Work Group was different from all the other groups. External Stakeholders or advocates were not invited to participate on the work group itself, on an ongoing basis, as is the case with all other workgroups, but rather would be asked for their input on a periodic basis as determined by DMR. At the first meeting of the Facility Work Group, opened up to outside advocacy groups, held on June 25th, all five statewide advocacy groups agreed that the proposed process was unnecessarily restrictive and requested the Chairperson, Margaret Chow-Menzer, to ask the Commissioner and the Steering Committee to reconsider their position on the input process. All five statewide advocacy groups wanted to be involved in all ongoing meetings of the Facility Work Group. To DMR's credit, the agency reconsidered their position.

Goal 1.7 of the Plan is to Conduct a study based on current community bed capacity as well as likely future expansion needs in order to develop a three to five year residential plan. If a seamless system is to be established both components should be integrated. Separate facility and community-based planning plagues the system and continues to support the deep chasm that exists between these two currently isolated service systems. The future of facility-based services should be examined within the context of the overall community-based system and vice-versa. A second recommendation of the DMR Work Group on Facilities, which included

¹ . Recruitment of a diverse work force, Retention practices, Hiring process, Support strategies (once hired), Specific training recommendations and Quantifying the problem

² The five Statewide Advocacy Groups include the Advocacy Network, ARC Massachusetts, COFAR, MFOFC and MASS.

consensus of all five statewide advocacy groups, was to focus on data and to conduct an objective, cost-comparative study of facility and community-based services. To their credit, DMR appears to concur with this second recommendation.

Legislative Update

The Executive Session on Disability was held by the Joint Committee on Human Services and Elderly Affairs on May 30th. A brief summary of the Committee's decisions follows which includes decisions made after the Executive Session. Those bills marked with an asterisk (*) are supported by COFAR. Bills marked with two asterisks (**) are opposed by COFAR and a position was not taken on the other bills.

H 1026 Study **	DPPC Abuse Reviews
H 1027 Study **	Abuse Reporting
S 663 Favorable	DPPC Information Disclosure
S 664 Favorable	Authority of DPPC
S 666 Favorable *	Definition of Disabled Person
S 712 Favorable	Lawsuit Filing Requirement
H 1399 Hold	DPPC Statute Rewrite
H 3736 Hold *	Abuse Investigations
H 1410 Favorable *	Office of Quality Assurance
H 276 Favorable	Services for Older Persons
S 661 Carried by *	Templeton Farm
House 3333	
H 1402 Study **	Waiting List Bill (facility closure)
H 3333 Favorable *	Study Commission on Facilities
H 2342 Study *	Hogan Regional Center
H 3737 Carried by *	Access and Choice
H 3333	
H 274 Favorable *	Turning 22
H 451 Favorable	Autism Services
H 1398 Study	Low Interest Loans
H 2187 Study	Low Interest Loans
S 686 Favorable *	Family Support Bill
H 3118 Favorable *	Family Support Bill
S 718 Favorable	Brain Injury Program
H 1771 Study	Employment of Disabled
S 704 Study	Employment of Disabled
H 2531 Favorable *	Living Wage Bill
S 683 Study *	Personal Care Attendants
S 719 Favorable *	Study of Autism Services
H 457 Hold	Treatment Choices
H 2331 Hold	Aversive Therapy
H 2332 Hold	Aversive Therapy
H 2333 Hold	Aversive Therapy

Olmstead Bills: S 474 & 676 and H 1030, 1589 & 2343

Any legislation purporting to incorporate components of the Supreme Court's Olmstead Decision into Massachusetts Statute must include the language of the three-pronged test known as the "Olmstead Rule." Olmstead set forth a three-

part test to determine if community placement is appropriate (i.e., institutionalization is unjustified)

"(a) The State's treatment professionals have determined that community placement is appropriate;
(b) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and
(c) the placement can be reasonably accommodated taking into account the resources available to the State and the needs of others with mental disabilities" (119 S. Ct. at 2181)"

Quoting the U.S. Supreme Court decision of *Olmstead v. L.C.*, the Department of Health and Human Services (DHHS) recognized recently in a letter to all State Medicaid Directors that, "nothing in the ADA condones termination of institutional settings for persons unable to handle or benefit from community settings." DHHS also notes, "States may choose to utilize their Medicaid funds to provide appropriate services in a range of settings from institutions to fully integrated community support."¹ In offering guidance to the States, DHHS carefully balances the commendable objectives of expanded community-based placement options for individuals with disabilities with the recognition that for some individuals, institutional care will always be necessary.

The Social Security Act (SSA) 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."

Governor Swift is in the process of appointing an Olmstead Commission and COFAR has asked for the opportunity to name a representative.

Tufts Dental Budget Line Item

The Tufts Dental Facilities have provided comprehensive dental care to special needs individuals since 1976. Tufts operates eight clinics throughout the Commonwealth of Massachusetts offering comprehensive oral health services to over 9,000 special needs patients and has a community component which provides preventive services to over 4,000 developmentally disabled adults and children in the community. The clinics are located in Amherst, Baldwinville, Danvers, Palmer, Shrewsbury, Taunton, Waltham and Wrentham. They have been specifically designed to accommodate individuals with disabilities and their associated limitations. Each of the clinics treats patients that are nearly exclusively MassHealth members and have low-income status. There has been no funding for capital improvements since the inception of the program in 1976. Most of the program equipment is over 30 years old. Five of the eight

¹ January 14, 2000 letter to State Medicaid Directors from DHHS, p. 2.

dental facilities can no longer accept new patients. The Oral Health Budget Amendment increased the appropriation for dental health services from \$1,323,984 to \$1,560,000. Senate Line Item 4512-0500 has unfortunately been level funded after a concerted effort by many advocates to increase funding for the Tufts Dental Program. House Bill 1191 - An Act making an Appropriation for certain dental services including an increase in the budget for the Tufts Special Needs Dental Program - provides another avenue to obtain additional funding for this critical program.

Senate Bill 701 - An Act Establishing a Public Guardianship Commission:

The issue of guardianship is a critical and complex one. This bill may contain unintended consequences to individuals and families and COFAR recommends a study commission prior to making any statutory changes.

House Bill 2917 - Resolve providing for an Investigation and Study by a Special Commission relative to the Effect on Privatization on the Delivery of Human Services.

A public hearing was held on Licensing and Miscellaneous

Issues on June 4 before the Joint Committee on Human Services and Elderly Affairs. The Executive Session on

House 2917 was held on June 25th. The bill has been favorably reported out and is likely to be assigned to Ways and Means.

JOIN COFAR's GENERAL MEMBERSHIP &
Receive your periodic Issues of *The COFAR Voice*

COFAR

P.O. Box 614

Maynard, Massachusetts 01754

Phone: 978-897-7179

Fax: 978-897-3403

www.cofar-mass.org

Thomas J. Frain, Esq. President

Colleen Lutkevich, Vice-President

Edward Stefaniak, Treasurer

William Stefaniak, Assistant Treasurer

Sabine M. Hedberg, M.A., M.P.A.,

Executive Director

THE COFAR VOICE

JOIN COFAR IN OUR ADVOCACY EFFORTS TO STRENGTHEN THE SYSTEMS OF QUALITY ASSURANCE AND MONITORING FOR CITIZENS WITH MENTAL RETARDATION

COFAR

P.O. Box 614

Maynard, Massachusetts 01754

