



The COFAR VOICE

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

February 2001 Issue:

Volume 3 / Number 1

- COFAR's Year 2001 Legislative Initiatives
- DMR's Strategic Planning Initiative
- COFAR's Broadened Focus and Expanded Membership

COFAR's 2001 Legislative Agenda Highlights Governmental Oversight & Accountability

*ABUSE INVESTIGATIONS, QUALITY ASSURANCE, PRIVATIZATION POLICY
AND ACCESS AND CHOICE INITIATIVES*

Join COFAR's Legislative Agenda and Promote Accountability!

COFAR's Legislative Agenda for 2001 focuses on Accountability. COFAR believes that the functions of oversight, accountability, quality assurance, monitoring and investigations should not be supervised by the agency delivering services. COFAR has submitted four bills into the 2001 Session:

1. **Independent Investigations;**
2. **Independent Office of Quality Assurance;**
3. **Study of Privatization; and**
4. **Open Access and Choice Bill**

A brief summary of each bill is provided followed by the rationale behind each initiative. Copies of the bills can be obtained from the COFAR Office or the Legislative Documents Room 428 at the State House in Boston.

1. Independent Investigations:

This initiative includes two components: (a) Transfer of all Investigations Staff and Budget from DMR to the Disabled Persons Protection Commission (DPPC) to end DMR self-investigation of 19C¹ and non-19C cases; (b) \$3.5 million appropriation to DPPC to hold it accountable for the

¹ Massachusetts General Law Chapter 19C defines cases to be screened in or screened out by the DPPC. Generally, a 19C case results in a serious physical or emotional injury to a disabled person.

investigation of all 19C cases under their jurisdiction & to assure the impartial, objective and independent investigation of all cases of abuse and neglect.

The lead sponsor for the bill mandating independent investigations is Representative Brad Hill (R). Other sponsors, as we go to press, are Senator Susan Fargo (D), Senator Brian Joyce (D), Senator Brian Lees (R), Senator Pam Resor (D), Senator Charles Shannon (D), Representative David Bunker (D), Representative Christine Canavan (D) and Representative David Sullivan (D).

2. Independent Office of Quality Assurance:

This initiative includes three components: (a) Transfer of all currently authorized positions and funds in the Department of Mental Retardation engaged in "internal self-evaluation, monitoring, quality assurance/enhancement and human rights functions" to a newly established Independent Office of Quality Assurance (IOQA); (b) Transfer all currently authorized positions and budget for the Governor's Commission on Mental Retardation to the IOQA; and (c) Four years after the establishment of the IOQA, an independent evaluation, under contract with the State Auditor's Office, will be conducted to determine the effectiveness of the IOQA and recommend appropriate actions such as continuance or other options as may be warranted to include but not be limited to a merger with the

DPPC and/or a broadening of scope to include individuals with mental illness and/or other disabled populations.

The lead sponsor for the IOQA Bill is Representative Angelo Scaccia (D). Other sponsors, as we go to press, are Senator Brian Joyce (D), Senator Bruce Tarr (R), Representative David Bunker (D) and Representative Christine Canavan (D).

3. Study of Privatization:

This bill establishes a Special Commission to study and investigate the effects of privatization policy and the purchase-of-service system for social and human service programs. The lead sponsor for the bill establishing a Commission to study the effects of Privatization is Representative Marie Parente (D). Other sponsors, as we go to press, are Senator Guy Glodis (D), Senator Brian Joyce (D), Senator Pam Resor (D), Senator Marian Walsh (D), Representative Ruth Balsler (D), Representative Charles Murphy (D), Representative Elizabeth Poirier (R), Representative David Sullivan (D) and Representative Anthony Verga (D).

4. The Open Access and Choice Bill:

COFAR Introduced H 1564 into the 1998/99 Legislative Session and this bill is being re-introduced to offer individuals with mental retardation and other disabling conditions access and choice of services. The greatest human freedom is choice. COFAR believes that Individuals and families have a right to make choices about the nature and setting of the services received. Quality services can be delivered in both community and facility settings and the citizens of the Commonwealth have a right to access all housing and service options. The lead sponsor for the Open Access and Choice Bill is Representative Brad Hill (R). Other sponsors, as we go to press, are Senator Susan Fargo (D), Senator Brian Joyce, Senator Pam Resor (D), Senator Richard Tisei (R), Senator Bruce Tarr (R), Representative David Bunker (D) and Representative Christine Canavan (D).

"Fox in the Henhouse" Investigations

In the words of Hubert Humphrey "The moral test of government is how it treats those who are in the dawn of life, children; those who are in the twilight of life, the aged; and those who are in the shadows of life, the sick, the needy and the handicapped." Individuals with mental retardation and other disabling conditions are among the most vulnerable of citizens. As a society, we owe it to them and to their families to assure an objective and independent investigation into all cases of abuse, neglect and mistreatment. It is unrealistic to expect any organization to provide its own oversight and conduct objective investigations of its own staff and vendors and DMR is no exception.

The House Post Audit and Oversight Bureau Report of 1997 recommended "dramatic changes in the investigations process" along with a comprehensive review of the DMR investigations unit to consider such options as; "ceding substantial portions of the investigations unit to DPPC, complete abolition of the unit and transfer to an outside agency, or a complete restructuring of the oversight, monitoring and investigations process."¹ While there have been improvements to the overall investigations process, such as the establishment of the State Police Detective Unit (SPDU) within DPPC, increased involvement of law enforcement and improved training programs for staff within DMR and with DMR services providers, most investigations continue to be conducted by DMR.

Concerns with Current Investigations Process:

Despite DMR's attempts at a "complete restructuring of the investigations process," there remain a number of overriding concerns with the current investigations process.

1. **"Fox-in-the-Henhouse" Investigations:** COFAR believes that the function of investigations of abuse, neglect and mistreatment should be impartial, vigorous, objective and outside of the agency providing services.
2. **Alternative Dispositions:** Not all investigations referred to DMR by DPPC undergo a "pure" 115 CMR 9.00 investigation. Senior Investigators for each DMR Region have the authority to conduct an "Administrative Review" or alternatively dispose of the complaint. What are the specific criteria governing alternative dispositions? How impartial and objective is such a process? Follow-up with DMR is underway to further clarify this issue.
3. **Annual Systems Audit:** According to DMR Investigations Regulations 9.14 (7) "The Office of Quality Enhancement shall conduct an annual systems audit to determine the effectiveness of the investigations procedures contained in 115 CMR 9.00 and to monitor their implementation." Such audits have never been conducted. This is a required internal control and oversight function that has not been implemented. Regulatory changes are necessary requiring the DPPC to conduct the annual systems audit.

¹ The General Court of Massachusetts. Report on the Massachusetts Department of Mental Retardation: An investigation by the House of Representatives Post Audit and Oversight Bureau including "Are you sure about this guy?" An Analysis of the abuse of two mentally retarded men in Raynham, Massachusetts. The House Committee on Post Audit and the Post Audit and Oversight Bureau, 1997. p.27.

While increased public awareness of abuse and neglect of disabled persons and efforts to implement and train staff in reporting abuse have contributed to the improved likelihood that cases are reported, every case of abuse and neglect should result in an impartial, objective and independent investigation so that the state's most vulnerable citizens are properly protected.

Disabled Persons Protection Commission:

Every month, the Disabled Persons Protection Commission (DPPC) receives approximately 400 abuse reports involving individuals with mental retardation, mental illness and other disabilities. Clearly, as in the case of child abuse, there are many unreported cases. DMR has been asked for statistics regarding the percentage of cases that are investigated under the DMR Regulations as opposed to other dispositions such as the Administrative Review Procedure. The majority of the complaints received by DPPC are in fact sent back to be investigated by the state agency involved (e.g., Department of Mental Retardation, Department of Mental Health, etc). At current staffing levels, DPPC itself is only able to investigate fifteen percent of the 1,500 cases of abuse involving individuals with mental retardation that are screened in annually for investigation, or 225 cases total.

The DPPC was created through legislation in 1987 as an **independent state agency** responsible for the investigation and remediation of instances of abuse against persons with disabilities in the Commonwealth (Massachusetts General Laws Chapter 19C). The mission of the DPPC is to protect adults with disabilities from the abusive acts and omissions of their caregivers through investigation, oversight, public awareness and abuse prevention. Pursuant to its enabling statute, M.G.L. c. 19C, the jurisdiction of the DPPC extends to adults with disabilities between the ages of 18 and 59 who are within the Commonwealth and who suffer serious physical and/or emotional injury through an act and/or omission by their caretaker(s). This protection is provided whether the individual is in state care or in a private setting. The DPPC acts to protect adults with disabilities who are dependent on others to meet a daily living need. DPPC fills the gap between the child protection and elder protection systems.

DPPC is a small agency, located in Quincy, MA with a budget of \$1.7 Million. The agency has a staff of thirty full time employees including seven investigators and eight oversight officers. The DPPC is comprised of six functions including Prevention, Intake/Oversight, Investigation, Legal, Information Technology and Administration and Finance. DPPC's Prevention Unit is comprised of one full time staff person. It is critical that direct care staff and others working with persons with disabilities and the general public be educated about the problem of abuse of persons with

disabilities. Increased efforts are needed to educate caregivers and the general public regarding this critical area.

In fiscal year 1998, a State Police Detective Unit (SPDU) was established within the Commission. This was an important improvement. The SPDU is comprised of a lieutenant, Sergeant and three troopers. The SPDU is physically located within the offices of the DPPC. The majority of the criminal cases (65%) investigated by law enforcement are rape and sexual assault cases. All criminal cases are referred to the district attorneys' offices and/or to the local police.

The DPPC Hotline receives reports 24 hours per day, seven days per week at 1-800-426-9009. During the second quarter of fiscal year 2000 (April-May-June), the Commission received 1,161 reports of abuse. In addition, DPPC staff responded to 300 referral and informational requests. Every abuse report made to the Hotline is reviewed pursuant to the DPPC screening criteria. A determination is made regarding whether the report represents an emergency or non-emergency, and then, whether the situation meets the agency's jurisdictional criteria (19C). During the period April - June of 2000, 353 of the reports to the Hotline were assigned for 19C investigation (to be investigated under the authority of the DPPC). All 19C investigations are conducted under the authority of the DPPC regardless of whether DPPC conducts the investigation or some other state agency.

Each report of abuse or neglect, not within the jurisdiction of the DPPC, is immediately forwarded to the appropriate state agency for review and action as necessary. In such cases, the Department of Mental Retardation is conducting investigations of their own employees and/or investigations regarding their contracted vendors. Only 15% of the total 19C cases are actually investigated by DPPC. DPPC has "oversight" over all 19C investigations conducted by DMR. A DPPC "oversight officer" is assigned to the 19C investigations conducted by DMR.. Discussions are underway with DPPC and DMR as to the extent of this "oversight" and exactly what is involved.

The current DPPC database has the capacity to collect well over 500 pieces of information related to each incident reported. Clearly, DPPC needs resources to update and manage their information system which is critical to following individual cases and to identifying & reporting systemic problems.

DPPC investigates alleged cases of abuse whether they take place in one of DMR's large facilities or in state- or vendor-operated group homes. Reports of alleged abuse, determined to be within the jurisdiction of the Commission, are immediately assigned to a 19C investigator and a DPPC Oversight Officer. The 19C investigator may be one of seven

of DPPC's investigators or the complaint is referred back to the state agency involved, and in the case of DMR, is referred to the regional senior investigator.

DMR Investigations:

After the DPPC Review, if the case is referred to DMR for investigation, the senior investigator for the region immediately logs the complaint and sends a copy of the complaint to the chairperson for the appropriate human rights committee within three days of logging. According to the DMR Investigations Regulations, no later than three days after receiving the complaint, the senior investigator determines and sets forth in a written disposition letter, how the case is to be handled. In addition to an active investigation (as per 115 CMR 9.0), the senior investigation has the authority to determine whether the complaint will be;

1. dismissed as filed because it did not meet the criteria of a reportable condition;
2. resolved without an investigation;
3. referred for resolution to the regional director as beyond the scope of the responsibilities of the Investigations Unit;
4. designated as requiring investigation but deferred pending investigation by outside authorities; or
5. resolved through a combination of dispositions.

Complaints may be dismissed when they are (a) frivolous, (b) the allegations were previously investigated and no new facts or evidence have materialized or (c) if the matter alleged is not within the scope of 115 CMR 9.05. When a complaint is dismissed, the disposition letter must list the reason(s) for the dismissal. According to the DMR Investigations Regulations, a complaint may undergo an "expedited resolution...without investigation if the matter complained of involves no dispute as to the facts, or may be resolved fairly and efficiently within a five day period."¹

The senior investigator can refer the complaint to the regional director where "(1) the matter alleged falls outside the scope of 115 CMR 9.05(1), but falls within the scope of other of the Department's regulations; or the matter falls within the scope but (1) appears to be or is alleged to be the result of implementation of, or the failure to implement, an individual's ISP; or (2) concerns or alleged program conditions that are in violation of the Department's regulations on program standards, 115 CMR 7.00."²

The investigation can also be deferred if the case is being investigated by criminal justice or other outside authorities. In such cases, the senior investigator defers the DMR

investigation pending completion of the outside investigations.

If the senior investigator determines that the complaint cannot be fully resolved without investigation, then the senior investigator, "no later than 24 hours after receiving the complaint, prepares a written, dated appointment of an investigator (who, in the judgment of the senior investigator, is capable of proceeding with the investigation in an impartial and objective manner)."³ Can the very agency responsible for the provision of services conduct impartial and objective investigations? What are the specific criteria used by the senior investigator to justify a given disposition? What internal controls are in place at DMR to assure that proper investigations are taking place?

In summary, both the DPPC Investigation Unit and the DMR Investigation Units conduct abuse investigations. The DPPC protects individuals with all types of disabilities including mental retardation, mental illness, head injury, cerebral palsy and others. By an overwhelming majority, most reported abuse cases involve individuals with mental retardation. Sixty six percent of all the abuse reports received by DPPC during April – June of 2000 were screened out and sent back to the agency in question as they were deemed not to fall under 19C jurisdiction. In such cases, the investigation is conducted by the agency directly providing the services or contracting with a vendor for the services. COFAR feels this is a direct conflict-of-interest and tantamount to sending the "mouse to watch the cheese" or putting the "fox in charge of the henhouse."

Massachusetts Quality Assurance Program

A stronger, more clearly defined, system of monitoring and quality assurance is required on the state level for individuals with mental retardation. COFAR believes that the function of oversight, monitoring and quality assurance should be independent of the agency providing the services. These programs are critical. In the words of Judge Tauro, "The retarded have no potent political constituency. They must rely on the good will of those of us more fortunate than they, and the Constitution which controls the manner in which all of us must meet our varied responsibilities."⁴ The current quality assurance program for individuals with mental retardation in the Commonwealth is comprised of four components: (1) HCFA Oversight, (2) The GCMR, (3) DMR Survey and Certification and (4) DPH ICF/MR Surveys. Each of these agencies and programs assume an important public trust.

³ DMR Investigations Regulations 115 CMR 9.07(7).

⁴ U.S. District Court, District of Massachusetts, Remarks by Chief Judge Joseph L. Tauro, May 25, 1993, p.4.

¹ DMR Investigations Regulations 115 CMR 9.07(5).

² DMR Investigations Regulations 115 CMR 9.07(6).

HCFA Oversight:

The Federal Health Care Financing Administration (HCFA) conducts compliance reviews of the State Waiver Programs. HCFA manages and oversees more than twenty waiver programs. The Commonwealth's Medicaid waiver for the mentally retarded/developmentally disabled is authorized under the provisions at 1915(c) of the Social Security Act. Massachusetts has the fourth largest Home and Community Based Services (HCBS) Waiver for individuals with Mental Retardation in the United States.¹ In 1985, the first year of the program, there were 235 individuals receiving services through the waiver. In 1997, there were 8,027. The Commonwealth is in its fourth year of the 1997 contract with HCFA under the Waiver (9/1/00 – 6/30/01). During this time period, the Waiver will serve approximately 12,000 individuals for a total cost of \$499 million.² The next HCFA Compliance Review will be conducted in 2001. An application for renewal of the waiver is required in June of 2002. HCFA issued a new, more comprehensive Waiver Review Protocol in the Fall of 2000 which became effective 01/01/01.

There are ten assurances under the HCFA HCBS Waiver. States must make assurances to HCFA that these requirements are in place. They include **health and welfare, financial accountability, evaluation of need, alternatives (i.e., ICF/MR or community-based services) and average per capita expenditures** among others. Since the inception of the program fifteen years ago, HCFA has issued three official compliance reviews, each of which address the above assurances. The HCFA Region I Office employs twelve surveyors responsible for reviews for 21 waivers involving nursing homes, hospitals, home health agencies, dialysis units, etc. HCFA does not however have the staff to conduct comprehensive reviews and historically the agency has only been able to focus on a limited sample of service recipients. COFAR has held several meetings with HCFA officials in an attempt to understand their system of oversight.

The first compliance review was conducted in February of 1992 and included 20 licensure file reviews and the review of 20 cases. In four of the 20 files, the vendor did not have a current license. The seven page report stated that "some of the other 16 had numerous, significant deficiencies" but no details were provided. The second compliance review was conducted in July 1997. The purpose of the review was to

determine the adequacy of the assurances given by the Commonwealth to HCFA. The scope of this second review included nine of the twenty-six area offices for a review of services for 28 individuals. Five of the twenty-eight people reviewed were not eligible for the level of care required by the HCBS Waiver. Eligibility for services under this waiver requires that absent the waiver, the person would be eligible for services, in an Intermediate Care Facility for persons with Mental Retardation (ICF/MR), or a Nursing Facility. HCFA recommended that "As the level of care review is done annually, the State should evaluate/reevaluate all individuals receiving community-based services under the federal waiver using the federal level of care criteria."³ The 1997 15-page compliance review report concluded that HCFA supports the State "on any initiatives that expand the availability of necessary services to beneficiaries in the community and that improve the mechanisms that measure quality of care and outcomes of care."⁴ While HCFA does conduct a compliance review every five years, the agency largely holds the states accountable to assure quality services through their survey and certification processes.

The Governor's Commission on Mental Retardation:

The Governor's Commission on Mental Retardation (GCMR) evolved from the court-mandated Office of the Court Monitor, later the Office of Quality Assurance, which was formed to oversee the needs of 6,000 individuals with mental retardation who brought a class action lawsuit against the Commonwealth. The lawsuit was filed in 1972, and until 1993, the Federal Court retained oversight authority over the Class members and monitored the treatment that they received. In 1993, Judge Joseph Tauro signed a Disengagement Order⁵ which ended the court's oversight role. As one of the conditions of the order, the Judge established the Governor's Commission on Mental Retardation for a three-year period, subject to re-appointment. In 1993, the GCMR replaced the Office of Quality Assurance. The Commission's mandate was broadened beyond monitoring the Class members to include all people with mental retardation.

Judge Tauro intended for the commission to be "an independent citizen oversight body whose multi-faceted

³ Home and Community-Based Waiver Review: Massachusetts #0064.92 Target Group: Mentally Retarded. Paul Miller, Richard Shaw, Ray Porter, HCFA – Region I, July, 1997, p. 9.

⁴ Ibid, p.15.

⁵ This court order replaced each of the consent decrees and all previous orders of the court in these matters. According to the Judge's statements, "A key factor in my decision to do so is Governor Weld's commitment to make permanent the historic improvements that have been achieved during the past twenty years – a commitment manifested and memorialized by the Executive Order... creating the Governor's Commission on Mental Retardation."

¹ The HCBS Waiver includes respite care, residential habilitation, supported employment, transportation and day services/supports. These services are provided to eligible persons who would otherwise require the level of care provided in an intermediate care facility for the mentally retarded (ICF/MR).

² Waiver Amendment approved, March 21, 2000 memo to Mark Reynolds, Acting Commissioner, EOHHC, Division of Medical Assistance from George Jacobs, Regional Administrator HCFA.

mandate and authority will include monitoring the quality and effectiveness of the Commonwealth's programs for services designed to address the wide variety of needs of people with mental retardation."¹ He commended Governor Weld for "his foresight and sensitivity in creating this atmosphere of citizen inclusion with respect to the critical responsibility for monitoring the efforts of the Department of Mental Retardation."²

Through Executive Order 396, the Governor's Commission was re-established and Article III of the Order enumerates the powers and duties of the Commission. "The Commission, the Administrator, or any person they may designate, shall have access at any and all reasonable times to any mental retardation facility, residence, program, or part thereof, and to all relevant records, reports, materials, and employees, in order to allow them to enhance their appreciation of the needs of persons with mental retardation and to monitor the quality with which such needs are being met." The Commission was to have oversight responsibility for monitoring quality assurance. Unfortunately, the Commission has not utilized this power to the fullest extent possible and the Commission has not emphasized quality assurance and monitoring in its work over the last six years. As of this printing, Governor Cellucci has not appointed a third Commission. The second Commission expired in May of 2000.

DMR Survey and Certification:

DMR issued the 3rd edition of its Survey and Certification Procedures Manual in March of 1999. The revised process is the culmination of over a year of intensive review and work by Quality Enhancement staff, DMR staff, providers, families and individuals. 2001 represents the seventh year of implementation of the process. In 1998, DMR served 27,169 individuals with mental retardation. The Survey and Certification Process is the quality assurance mechanism for all individuals served under the Home and Community-Based Waiver. In 1998, 7,110 individuals resided in community residential programs. The HCBS Waiver also provided supported employment programs to 4,730 people, and family support to 17,805 families.³

Vendor agencies receive an application packet 120 days prior to the expiration date of their current certification. All agencies subject to recertification must submit an application for certification 90 days prior to the expiration of the agency's certification. Once the DMR Quality Enhancement Office receives the completed application, the process of scheduling

the survey begins. Once the specific sample is selected for review, the survey team leader notifies the vendor agency liaison 21 days in advance of the survey. Individuals and their service coordinators selected as part of the sample are notified in writing 15 days prior to the survey.

Prior notice is given to all providers and they are informed of the date the review team will arrive. According to DMR, "Notification to the individuals selected as part of the sample is critical for two important reasons. First QE staff need to be respectful of an individual's right to be fully informed of the process in which he/she will be involved. Second, the survey process is much more productive and results in richer information if the individual is an informed and cooperative partner in its implementation. The primary responsibility for speaking with the individual rests with the service provider. The guardian of the individual selected as part of the sample also receives a notification letter at this time."⁴ "Providers are informed of the survey team composition well in advance of the survey and are given the opportunity to request a change in membership prior to the onset of the survey. The basis for any request, however, must be consistent with the criteria outlined in the conflict-of-interest statement."⁵ Surveys include observations, discussions with the individual in the sample and key people in their life and review of documentation. A situation where the life, health, safety and/or dignity of an individual is severely jeopardized, if not immediately corrected, is deemed to be an "Immediate Jeopardy." A situation judged to be an Immediate Jeopardy must be addressed within 24-48 hours. If corrective action is required the survey team issues an "Action Required" notice and the issue is followed-up within 30-days. The results of the survey are shared with the provider during the service enhancement meeting and a written provider report is issued. The final report is sent to the provider within 30 working days after the service enhancement meeting. Upon completion of the survey, the provider receives one of five levels of certification:

1. Two-Year Certification with Distinction;
2. Two-Year Certification
3. One-Year Certification
4. Certification with Conditions
5. Decertification

A provider's final level of certification can be "deferred" pending follow up on flagged outcomes and "providers in deferred status are given up to 60 days to correct the flagged issues and are subject to a very specific and rigorous follow-up procedure."⁶ "The implementation of the 'deferred status'

¹ U.S. District Court, District of Massachusetts, Remarks by Chief Judge Joseph L. Tauro, May 25, 1993, p.3.

² Ibid. p. 4.

³ DMR In Partnership with Communities. Annual Report. July 1, 1997 – June 30, 1998. p. 24.

⁴ Department of Mental Retardation. Executive Office of Health and Human Services, Survey and Certification Procedures Manual. 3rd Edition, March, 1999. p. 20.

⁵ Ibid. p. 21.

⁶ Ibid. p. 31.

in March 1999 allowed some providers to receive a higher level of certification than they would have received before that date. These providers had excellent results in most aspects of the survey, but had some identified issues related to health, safety or rights. If, after rigorous follow-up, the outstanding issues were corrected, providers in deferred status are able to receive a 2 year certification. Should the issues not be corrected, providers would receive a one year.”¹ Administrative reconsideration and formal appeal processes are in place when providers disagree with the survey findings.

According to the DMR Office of Quality Management’s Quality Enhancement Division, only one provider out of 190 surveyed was granted a two year certification with distinction during the first cycle of the reviews. By the fourth cycle, 30% of the providers were granted two year certifications with distinction. During the first cycle of reviews a full 62% of the vendors obtained one year certifications with conditions while only 10% received that level during the fourth cycle. During the last four cycles of reviews, no vendor has ever been decertified. The following chart provides the various certification percentages for the first four cycles of the survey and certification review process.

Certification	1	2	3	4*
2 yr/Distinction	less than 1%	18%	19%	30%
2 year	8%	39%	47%	40%
1 year	30%	18%	20%	17%
1 yr/Conditions	62%	25%	14%	10%
Decertified	0	0	0	0

*3% of providers in cycle 4 are currently in deferred status

DPH ICF/MR Survey:

A team of surveyors from the Department of Public Health conduct an annual review of all the DMR facilities. There are currently 1,277² individuals residing in the six state facilities across the state. The facilities must comply with the requirements of 42 CFR 483, Subpart I and the surveys center on the fundamental requirements that produce outcomes for individuals. The principal focus of the services is on the “outcome” of the facility’s implementation of ICF/MR active treatment services. Observation and interview are the primary methods of data collection although record reviews are also conducted. The survey process is divided into three stages: The fundamental, extended and full survey. In the presence of problems, more in-depth reviews are conducted however, every certification and annual re-certification requires a complete Life Safety Code Survey.

¹ Correspondence, Dorothy Mullen, DMR, 1/30/01.

² The People’s Budget FY 01 20th Anniversary Edition: An Annual Analysis of the Budget of the Commonwealth of Massachusetts for Health, Social and Human Services. The Massachusetts Human Services Coalition, October, 2000. p. 47.

The Study of the Privatization Policy

The delivery of Health, Social and Human Services has become a multi-billion dollar industry. 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.

1991 Governor’s Special Commission on Consolidation:

In 1991, the Governor’s Special Commission on Consolidation of Health and Human Services Institutional Facilities recommended the closure of nine state facilities and two satellite campuses. The facilities and campuses slated for closure included 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 Governor’s Commission concluded in 1991, 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 need to be evaluated.

Cost Comparative Research Across Residential Settings:

COFAR is currently researching available objective data and statistics for review specifically to compare service settings, costs and models of care in an effort to assist in the development of an equitable system of services for the Commonwealth responsive to the needs of all individuals and families. The studies reviewed to date frequently stress the cost-effectiveness of community programs but often have significant methodological problems. Appropriate public policy demands methodologically sound research. The issue is the age old unfortunate problem of comparing “apples to oranges.” Apparent methodological problems inherent in cost comparative studies include the following:

1. Level of care and thus service need are often not specifically defined nor comparable across residential settings. Researchers and advocates often compare the lesser cost of providing community services to people with mild and moderate mental retardation with the greater cost of providing around-the-clock

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.

care to persons with severe and profound mental retardation and other disabling conditions being served in congregate settings. For example, relatively few individuals with mild or moderate MR, who do not also have multiple disabling conditions, reside at residential campuses (DMR facilities). Dispersed or de-centralized community-based settings serve individuals across the full spectrum of disabilities, whereas the residential campuses have retained their focus on supporting individuals with more severe and complex disabilities and challenging behavioral issues. Thus “apples are being compared to oranges.”

2. The theory of probability and statistics deals with random samples. Studies often do not employ a random or stratified random sample of organizations, facilities or residents. This is a critical statistical & research design flaw.
3. Researchers often do not aggregate the specific and varied sources of funding for various community-based programs in comparison to the single source of funding for facility-based care. The services provided in congregate settings are often all-inclusive, resulting in all costs being reflected in total cost. In the community, funding for services is scattered among various agencies & levels of government making it difficult to determine total costs. Cost shifting between state and federal funding sources also occurs & the overall implications of such cost shifting to the American taxpayer have not been determined.
4. Psychometric properties of various survey tools used in some studies are unknown (e.g., internal consistency, inter-rater reliability, bias, etc). If the tests used to measure certain program qualities are not valid, then the results are questionable.
5. It is common for studies to compare the costs of state-of-the-art and creative community programs with the cost of underutilized & neglected facilities devoid of leading edge models development. Here, the costs of the facilities are skewed upwards by the high fixed costs associated with a capacity indicative of decades gone by. DMR facility assets (land, buildings & staff) have been poorly managed over the last few decades despite known and predictable changes in service need and state-of-the-art models of care. Creative and locally-based plans for the future of the facilities should be developed drawing upon state-of-the-art congregate care models thus reaping the benefits of economies of scale and other

cost-effective measures. DMR's strategic planning initiative offers hope that a rational plan for the future of the facilities will be developed.

6. Studies often use a small number of participating organizations in their samples thus limiting the extent to which the results may be generalized within acceptable confidence levels. There is little confidence in the estimate of the standard error when sample sizes are small.

Comparative studies of the cost and nature of services provided under various models of care should apply appropriate statistics and research design methodologies otherwise all conclusions are questionable. **Public policy must be driven by data, facts and consumer/family choice.**

Bill on the Study of Privatization:

The bill to study the effects of privatization, sponsored by Representative Marie Parente, establishes a 15-member special commission to investigate and study the Commonwealth's privatization policy and purchase-of-service system for its social and human services programs. The special commission will review and evaluate related party transactions including but not limited to subcontracting or consultant contracting with parent organizations, compensation levels for direct care workers and agency administrators, provider fraud, cost-comparative analyses comparing centralized and decentralized models of human service delivery on the delivery of services in the Departments of Mental Health, Mental Retardation, Social Services and Corrections. Support for the special commission will be provided through the State Auditor's Office including the establishment of one full-time equivalent position to be named Director for the Commission on Privatization. The Commission shall report to the General Court the results of its investigation and study, and its recommendations with the clerks of the Senate and House of Representatives within two years of the date of the Commission's first meeting. The bill specifies the membership of the Commission as well as the areas for study and analysis. Copies of the bill are available through the COFAR Office and/or the State House.

The question is whether or not the privatized system has resulted in cost savings and “equal or better services” for the Commonwealth's citizens with mental retardation and/or other disabling conditions. Many of the DMR vendors serve both the mentally retarded and mentally ill populations and combining efforts in the areas of investigations, oversight and quality assurance represents good resource management. The initial phase of the investigations and quality assurance bills is to focus on the mentally retarded with the intent to expand, over time, to the mentally ill population. Privatization policy

effects all agencies providing human services. The taxpayer investment in the human services delivery system is staggering. It would behoove all of us to take a critical look at the policy of privatization and evaluate the system outcomes in terms of access, cost and quality prior to completely privatizing the entire human services network of care. The table that follows lists the top eight vendors by DMR and DMH expenditure levels.

Fiscal Year 1999 DMR & DMH Expenditures by Vendor¹ (Millions)

Vendor	DMR	DMH	TOTAL ²
Seven Hills ³	21.5	-	28.9
May Institute	16.9	.6	18.5
VINFEN Corp	14.8	30.3	45.8
Horace Mann	13.9	-	14.0
Greater Lynn	12.5	7.6	20.4
South Shore MH	9.1	4.7	14.9
North Shore ARC	8.5	.3	10.8
North Suffolk MH	6.3	7.5	16.1

DMR's Strategic Planning Initiative

The DMR Strategic Plan, developed under contract with the University of Massachusetts Donahue Institute, was made available 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. From COFAR's perspective, the Twenty-one page DMR Strategic Plan does not reflect the depth of work that has taken place over the last eighteen months engaging over 3,200 individuals⁴ and in the opinion of the COFAR Board, the plan does not reflect a \$538,540 investment of taxpayer funds.⁵ COFAR was expecting a more explicit, substantial

¹ Legislative Committee on Local Affairs, 1999 EOHHS Expenditures over \$1 Million.

² Total expenditures include DMR, DMH, DPH, DSS, DYS, MRC OFC and eight other state agencies.

³ Seven Hills Foundation subsidiary corporations when combined hold \$21.5 million in contracts with DMR. Each subsidiary has a different vendor code and thus is listed separately, but Seven Hills Foundation is the largest DMR Provider. Included subsidiaries are New England Residential Services, Seven Hill Community Services, Seven Hills Family Services and Seven Hills Occupational and Rehabilitation Services.

⁴ DMR Strategic Management Plan, November 2000, p. 5.

⁵ The DMR Contract with the University of Massachusetts Donahue Institute was \$ 135,640. The HSRI External Evaluation

and comprehensive plan incorporating data, timeframes, responsibilities, etc. DMR received information from 1,150 employees, 257 providers of service, 280 citizen board members, 64 key public leaders, interviewed 617 consumers, received 592 family surveys, facilitated focus groups with 81 families as well as took written feedback and phone calls from all interested parties. In addition, the Department worked with their management staff around the change process in multiple meetings and at a management conference. According to the Department, the HSRI Final Report is not yet available. It is COFAR's hope that the depth of effort to date is reflected in that subsequent report.

DMR makes a distinction between strategic planning and work plans. According to DMR, the work plans, developed in the next phase of the process, will assign responsibilities and timelines. As part of the implementation phase of DMR's Strategic Planning Process, the Department intends to include external stakeholders in the process of creating work teams and, according to DMR, the structure to manage this undertaking is currently underway. Having said that, we recognize DMR's "Plan-to-Plan" as a first step and look forward to working with the Department to further define the plan to implement policies and strategies to achieve stated objectives.

The current plan states that "appropriate boundaries for input from different external stakeholder groups" would be established by DMR. At a meeting on November 15th, to which DMR invited all the Presidents and Executive Directors of the five statewide advocacy organizations, Commissioner Morrissey indicated that DMR would make a determination at the end of December as to which activities and work groups would involve participation from external stakeholders. COFAR supports an open public policy development process so that families, advocates and citizens can get involved in all critical areas. From COFAR's perspective, the development of the November 2000 Strategic Plan represented one-way communication. Individuals, family members and citizens were allowed to provide input but there was no room for a give-and-take discussion. Citizen involvement should not preclude constructive interaction. COFAR is interested in participating in all policy development discussions. It is hoped that future involvement will represent a more open process resulting in a true dialogue.

As an advocacy organization, COFAR was encouraged to see that DMR has incorporated into the plan a future for the facilities and has committed to some capacity for ICF/MR level care as one option from which individuals and families can choose. We look forward to participating in discussions

Contract with DMR was \$ 402,900. In total, the strategic planning and external assessment process cost the taxpayers of the Commonwealth \$ 538,540.

and interactions with DMR concerning the issues highlighted in the DMR Plan and COFAR has submitted formal recommendations to DMR regarding the Strategic Plan.

COFAR Broadens Focus and Expands Board Membership

The Massachusetts Coalition of Families and Advocates for the Retarded, Inc. was incorporated on January 15, 1988. For the past ten years, the organization has focused on advocating for quality care for adults with mental retardation living at the Massachusetts Intermediate Care Facilities for the Mentally Retarded (ICF's/MR). Largely through the Ricci et al lawsuits and the resultant Federal Consent Decree, conditions at the ICF's/MR's have improved markedly and the community-based system has flourished. COFAR is the only statewide advocacy organization advocating for congregate settings as an honorable choice for families.

As the community-based system has grown, COFAR has gradually broadened its focus to include community-based services. Last year, COFAR underwent a dramatic organizational development initiative resulting in a Board of Directors with equal representation of facility- and community-based members. This initiative has established some vacancies on the COFAR Board of Directors for community-based representatives. This represents a major broadening of scope for an organization that was heretofore focused on facility-based services. COFAR has always advocated for a comprehensive continuum of services emphasizing choice of residential settings and other program options. COFAR's broadened focus will allow the organization to analyze and direct efforts toward the development of an integrated service delivery system for the Commonwealth's citizen's with mental retardation and their families regardless of their residential setting.

In May of 1999, COFAR established a formal general membership. General members complete an application, pay an annual fee as set forth in the by-laws and become non-voting general members of the organization. They are entitled to receive the COFAR periodic newsletter and attend all COFAR meetings. General members must subscribe to COFAR's Statement of Purpose as outlined in ten principles.

COFAR's Current Mission is to promote the general welfare of individuals with mental retardation, wherever they may be. This is achieved through increased family and citizen involvement in systems design and evaluation advocating choice among all residential options and a focus on strengthening governmental and provider performance and accountability.

COFAR's Philosophy encompasses Three Priorities:

1. Governmental Performance and Accountability:

To review relevant executive agency expenditures, legislative appropriations and proposed bills as well as government agency strategic policy and planning initiatives and documents to assure governmental performance and accountability in the areas of access and choice, cost-effectiveness and quality of care for individuals with mental retardation and their families. COFAR is a citizen oversight group for the state Department of Mental Retardation and other agencies providing services to individuals with mental retardation.

2. Advocacy and Support for families of individuals with Mental Retardation:

To support responsible legislation and governmental policies to benefit individuals with mental retardation in an effort to provide access and choice and cost-effective, quality services. To provide empathetic support to families dealing with loved ones with mental retardation living at home, in community-based group homes and/or in DMR Facilities.

3. Public Information and Education on Systemic Issues:

To collect, analyze and report on data and issues, publish a periodic newsletter and provide information to benefit individuals with mental retardation and their families as well as the general citizenry. To serve as an information collection and dissemination/referral center.

Ben Ricci Dinner and Testimonial :

The Friends of Ben Ricci are planning a dinner and testimonial to honor him for his many years of involvement in advocating on behalf of the mentally retarded. There are few individuals that have accomplished more for the Commonwealth's citizens with mental retardation. The event is scheduled for Thursday May 3rd, 2001 and will be held at the Chez Josef Banquet House in Agawam. Dinner will be served at 7:00 with a 6:00- 7:00 cocktail hour. Cost for the evening is \$50.00 per person. Former Governor Dukakis and the Honorable Judge Joseph Tauro have been invited. Choice of entrees include Roast Prime Rib of Beef Au Jus, Boneless Breast of Chicken Supreme, Baked Boston Scrod, or Portabello Mushroom Ensemble (vegetarian). For reservations make checks payable to Advocacy Network Charitable Trust. Indicate the number of choice of entrees along with your name and address and mail to: The Friends of Ben Ricci, Robert Jurczyk, 27 Westbrook Avenue, Ware, MA 01082.

DMR Fiscal Year 2001 Budget:

The Massachusetts Human Services Coalition has published The People's Budget for Fiscal Year 2001. This document provides a comprehensive analysis of the Commonwealth's spending on Health, Social and Human Services. .

A Summary of DMR expenditures for FY 98 and FY 99 and budgets for FY 2000 and 2001, excerpted directly from the document, are as follows:

	FY98	FY99	FY2000	FY2001
Administration:	\$ 84.2	\$ 47.7	\$ 50.6	\$ 54.7
Capital Improvements:	-	-	\$ 2.2	-
Monitoring Com-Based				\$.6
Provider Worker Certific.	\$ 1.5	\$ 1.5	\$ 1.5	\$ 1.5
Transportation:	\$ 24.9	\$ 25.0	\$ 24.9	\$ 25.1
Insurance Assessments:	\$ 11.9	\$ 9.6	-	\$ 9.5
Residential/Day:	\$291.7	\$314.7	\$331.7	\$ 353.7
State Operated Resid.	\$ 68.2	\$ 87.6	\$ 91.3	\$ 100.0
Day/Work Programs:	\$ 73.3	\$ 76.8	\$ 81.2	\$ 90.2
Community Health	\$ 10.7	-	-	-
Respite:	\$ 40.9	\$ 44.4	\$ 28.0	\$ 50.2
Waiting List:	\$ 5.8	\$ 15.8	\$ 27.8	\$ 35.8
Turning 22:	\$ 4.4	\$ 7.0	\$ 7.0	\$ 7.0
Older Unserved:	\$ 6.8	\$ 6.8	\$ 6.8	\$ 6.8
Child/Adolescent	\$ 5.0	\$ 5.1	\$ 5.1	\$ 5.0
Child Residential:	\$.5	\$.4	\$.4	\$.4
Facilities:	\$174.7	\$169.3	\$167.0	\$ 164.8
Residential Srvs Pilot:	?	\$ 6.0	\$ 7.1	\$ 7.5
Templeton Ret Rev:	?	\$.1	\$.1	\$.1

Total DMR total comparative figures by fiscal year are as follows:

Fiscal Year 1998	\$ 803.0 Million
Fiscal Year 1999	\$ 817.8 Million
Fiscal Year 2000	\$ 832.7 Million
Fiscal Year 2001	\$ 912.9 Million

DMR's 2001 budget represents an \$80.2 Million increase over last year's budget. The Human Services Coalition Analysis provides more detailed information on each DMR budget line item. For copies of the full document, published by the Massachusetts Human Services Coalition, call 617-482-6119.

COFAR 2001 Election of Officers:

Thomas J. Frain, Esq., President

Tom received his law degree from the New England School of Law and has a general practice in Bolton which offers a

broad array of legal services. His brother resides in a community-group home in central Massachusetts.

Colleen Lutkevich, B.A., Vice-President

Colleen was COFAR's Secretary from 1985-1995. She holds a Bachelor's Degree in Psychology from the University of Massachusetts at Dartmouth and lives in Mansfield with her husband and three children. She is the Vice-President of the Wrentham Association for the Retarded, a family organization for the Wrentham Developmental Center, where her sister is a resident.

Edward Stefaniak, B.S., Treasurer

Ed is a graduate of MIT and a retired structural professional Engineer. Ed is married with four children and lives in Concord. He has a son who makes his home at The Fernald Center in Waltham.

William Stefaniak, A.S., Assistant Treasurer

Bill is a Production Planning Administrator at Lund International Corp. in Hudson, MA. He is Married with 2 Children and his brother lives at The Fernald Center.

Updates :

H 110 Proposed Amendments: Due to concerns that families had regarding changes to The Transfer Statute, DMR voluntarily withdrew H 110 during the 1999 Legislative Session and made a commitment to discuss any future proposed changes to the Transfer Statute with COFAR representatives prior to filing.

Vendor Indemnification Contracts: Families expressed concern last Fall regarding indemnification agreements mandated by select DMR vendors. As a result of a cooperative effort, in conjunction with DMR, all DMR Vendor Contracts currently disallow the use of indemnification clauses.

DMR releases New Consolidated Diversion Plan: On December 22, 2000, DMR released a plan designed to prevent inappropriate admissions of persons with mental retardation and other developmental disabilities to nursing facilities. According to DMR, the plan is responsive to certain obligations that the Department has assumed under the Rolland Settlement Agreement. Information in addition to the plan is expected to be made available shortly. Copies of the plan are available from DMR and/or the COFAR Office.

Newly Proposed DMR Investigations Process: A public hearing on the new process, incorporating regulatory changes, will be scheduled sometime in the year 2001 to allow for citizens and advocacy groups to give their public input.

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

**Join Us in Our Commitment
to the Mentally Retarded
Wherever They May Be**

THE COFAR VOICE
COFAR's Official Newsletter

COFAR
P.O. Box 614,
Maynard, Massachusetts 01754
Phone: 978-897-7179
Fax: 978-897-3403

Thomas J. Frain, Esq. President
Colleen Lutkevich, B.A. Vice-President
Edward Stefaniak, B.S. Treasurer
William Stefaniak, A.S. Assistant Treasurer
Sabine M. Hedberg, M.A., M.P.A.,
Executive Director

COFAR MEMBERSHIP APPLICATION & INFORMATION

*COFAR Membership applications and information packets can be obtained by writing to:
COFAR / Memberships & Information / P.O. Box 614 / Maynard, MA 01754
or by calling 978-897-7179*

COFAR
P.O. Box 614
Maynard, MA 01754



THE COFAR VOICE

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