



The COFAR VOICE

The Official Newsletter of the Massachusetts Coalition of Families and Advocates for the Retarded (COFAR)

Highlights of March 2000 Issue:

Volume 2 / Number 1

- DMR's "Phantom Choice"
- House 1564 : Choice and Olmstead
- Thirteen Year Old DMR Admissions Policy is Outdated and Sorely in Need of Revision

- Equal Access to All Housing Options
- A State-of-the-Art Concept: The "Specialized Life Care Community."
- DMR Fiscal Year 2000 Budget

The Department of Mental Retardation's "Phantom Choice"

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 of Massachusetts. DMR offers a "phantom choice" and this policy evades the intent of HCFA's assurance of choice under the Home and Community Based Waiver.

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." The Federal government defines "institution" as either a hospital, nursing facility or intermediate care facility for the mentally retarded (ICF/MR).¹

According to DMR's Compliance Guidelines, "When offered DMR supports, HCBW eligible individuals, or their legal representatives, must be informed of any feasible alternatives under the waiver and given the choice of either institutional or home and community-based services. The only ICF/MRs in Massachusetts are the state facilities and one community ICF/MR on Lake Street in Shrewsbury, operated through the Glavin certification. Admissions to the facilities are closed by virtue of the Final Order of the Consent Decrees. Although persons may clinically qualify for ICF/MR level services, they administratively cannot be admitted into a DMR facility."² It is important to note that in Judge Tauro's Final Order it is clearly stated that "As of this date, admissions to the state schools are closed: however nothing in this Order shall preclude defendants in the future from adopting a different admissions policy, or from Modifying the current policy on admissions." The Final Order does not apply to Glavin or Hogan. Why are Glavin and Hogan not provided as options to families under "institutional choice?" DMR has the authority to open admissions and/or change the admissions policy at will, at anytime. In truth, Admissions to the DMR Facilities are closed by virtue of the DMR 'de facto' closure policy.

¹ Clearly, one would not place an individual with mental retardation needing life-time supports in a hospital setting. That would be cost-prohibitive. The inappropriate placement of individuals with mental retardation in nursing homes was the basis for a lawsuit (*Rolland v. Cellucci Civil Action No. 98-30208-KPN*) in which a new class has been named. On February 2, 1999, the U.S. District Court certified as the class "all adults with mental retardation and other developmental disabilities in Massachusetts who resided in nursing facilities on or after October 29, 1998, or who are or should be screened for admission to nursing facilities pursuant to 42 U.S.C. 1396r(7)(e) and 42 C.F.R. 483.112 et seq." If hospitals and nursing homes are inappropriate, then the only other true "institutional choice" is an ICF/MR. There is a difference between compliance with the "letter of the law" and the "intent of the law." For instance, if a public hearing is required, a state agency can be in compliance with the "letter of the law" by advertising the hearing in .8 type on page 85 of the Tuesday Boston Globe. The "intent of the law" is to notify the citizenry of their opportunity to participate in the affairs of their government. Perhaps an article on page 1 of the Sunday Globe would be more in line to achieve the desired effect. The same concept holds true here. COFAR believes that the intent of the Federal government was to offer "genuine choices."

² Home and Community Based Waiver Services; Compliance Guidelines for DMR Regions/Areas: Department of Mental Retardation (p.9) October, 1998.

The DMR compliance guidelines continue by clarifying this choice as follows: "The choice for people receiving DMR services, therefore, is between the community services that are paid for through the HCBW Waiver and the ICF/MR services offered at the Glavin home on Lake Street. Individuals, or their legal representatives, who choose to receive ICF/MR services (if in Massachusetts, at the Lake Street home) may not continue to receive HCBW reimbursed community services, but they may choose community services until they can receive an ICF/MR placement. Service Coordinators should notify the Regional Director if an individual would like to be on the waiting list for an ICF/MR. It is expected that as states close their large public institutions the Choice requirement will be modified to focus solely on choice among waivered services."¹

The compliance guidelines continue by pointing out that "At the time the ISP or FSP is developed or the ITP is modified at age 22, the subject of choice should be introduced to the individual and/or guardian as the Federal requirement to enable DMR to receive Federal Financial Payment to assist in paying for services and supports to waiver eligible individuals...The service coordinator, after ascertaining whether the individual and/or legal representative has chosen HCBW services, will document that choice on the verification of compliance with HCBW Waiver Choice Assurance form and maintain that form permanently in the individual's record (Exhibit 1)...Note that the choice is NOT between HCBW services and services provided in our facilities (ICF/MR). The Waiver requires only that institutional care be available. The institutional option could be met by large public facilities, community ICF/MRs, nursing homes or facilities in other states."²

The above description of the HCFA Choice Assurance under the Home and Community-Based Services (HCBS) Waiver describes a "phantom choice" and this policy evades HCFA's assurance of choice. The ICF/MR on Lake Street in Shrewsbury is a 5-bedroom group home. The same individuals have lived at the home for over five years thus, the home cannot be offered to other individuals since there are no available beds. How can there be a valid "institutional choice" if admissions to the consent decree facilities are closed, Hogan and Glavin are not presented as options, and there is no availability at the Lake Street ICF/MR? COFAR strongly supports the building of more group homes, such as the Lake Street home at Glavin, on the grounds of the various facilities as they offer a "service rich" alternative not available in non-ICF/MR group homes.

¹ Ibid (p.10).

² Ibid.(p.10).

Exhibit 1

Department of Mental Retardation Verification of Compliance with HCBS Waiver Choice Assurance

Instructions: Form is to be completed ONLY ONCE after initial ISP/FSP/ITP meeting. Form is to be maintained permanently in individual's record.

Individual and/or Legal Representative

Was informed of any feasible alternative services and supports available under the HCBS Waiver on _____ Date

and was given the choice of either institutional or home and community-based services. Home and community-base services were chosen.

Service Coordinator

Date

Is there a genuine choice of either "institutional or home and community-based services" in the Commonwealth of Massachusetts? COFAR believes that the intent of the Federal government was to offer "real choices." Technically speaking, DMR is not out of compliance with the HCFA choice assurance. Federal officials from the Health Care Financing Administration (HCFA) confirmed, however, that it was the intent of the federal government to offer "genuine choice." "Certain assurances are required in order for states to utilize Medicaid moneys and compliance with these assurances is assessed by the Medicaid Agency, Health Care Financing Administration (HCFA) and sometimes by external auditing agencies. Some assurances are the responsibility of the Area Directors (or their designee) and will be completed by Service Coordinators, Family Support Coordinators and 688 Coordinators."³ In Massachusetts, "It is the responsibility of the DMR Area Director to assure that the choice of alternatives has been presented to all waiver-eligible individuals and/or their legal representative and that documentation of the process is permanently maintained in the individual's record. The process is completed only once."⁴ Individuals and guardians sign a HCBW Service Recipient Choice Form indicating they understand the 'choice'. "Lack of compliance with the required assurances is a serious

³ Home and Community Based Waiver Services: Compliance Guidelines for DMR Regions/Areas: Department of Mental Retardation (p.4) October, 1998.

⁴ Ibid. p.9.

matter.¹ Is the fact that a signed HCBW Service Recipient Choice Form is found in the file evidence that a "genuine" choice was offered?

HOUSE 1564: Choice and Olmstead

Give Families A Choice – Support H 1564

If passed, House 1564 offers "a genuine choice" under the Social Security Act, HCFA Regulations and the Supreme Court Decision of Olmstead – not a "non-choice" based on legal technicalities and paper assurances. It is the issue of choice that founded COFAR.

The original COFAR families were founding members of both the statewide and local ARCs in Massachusetts. In fact, one member of the COFAR Board of Director's currently sits on the ARC Massachusetts Board of Directors. It was in 1983, when, at the ARC National Convention, a decision was made to close all facilities that our founding families left the ARC. The COFAR of today, evolved in response to this anti-facility bias. It is the continued official position of The Arc U.S. that "large congregate facilities (institutions) are no longer necessary or appropriate for anyone, regardless of the type or severity of their disabilities."²

Three chapters of The Arc U.S. have been disqualified from membership in the national organization because they joined The Voice of the Retarded (VOR) Amicus Brief in Olmstead. The Board of The Arc U.S. "voted to sever ties with the Lawrence County Association for Retarded Citizens of New Castle, PA, the Misericordia Family Association of Chicago, IL and the Sacramento Association for the Retarded of Sacramento, CA.³" The article went on to note that "During the grievance process, The Arc was criticized for denying chapters' rights to "form and express opinions" and for suppressing "independent thought and freedom of speech." The Arc U.S. President, Brenda Doss, noted that "debate and free expression on issues are in fact encouraged, and all chapters are given many opportunities to review and comment on organizational goals and positions as they are being formulated and/or reviewed and updated. A delegate body votes on major positions at The Arc's annual national convention every fall. Once consensus is achieved, active public opposition to The Arc's beliefs 'sends confusing messages to legislators, the news media and professionals within the disability community.' Doss said, "They may ask, 'Exactly what does The Arc stand for? Apparently they're not sure themselves⁴.'

The Arc U.S. Position that the DMR Facilities "are no longer necessary or appropriate for anyone, regardless of the type or severity of their disabilities" is a philosophy that leaves little room for compromise. We believe that the future of the

facilities should not be an all-or-none issue. There must always be room for compromise.

Quoting the U.S. Supreme Court decision of Olmstead v. L.C., the Department of Health and Human Services (HHS) 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." HHS 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."

The January 14 release is the product of a HHS workgroup convened to coordinate implementation of the principles established in the Olmstead decision. The HHS Olmstead workgroup is chaired by Timothy Westmoreland, Director, Center for Medicaid and State Operations, and Thomas Perez, Chair, Office of Civil Rights.

In offering guidance to the States, HHS 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 decision offers reassurance to organizations that support choice of residential settings.

In Olmstead, decided June 22, 1999, the Supreme Court ruled that unjustified institutionalization is discrimination under the Americans with Disabilities Act (ADA). Under the Court's decision, States are required to provide community-based services for persons with disabilities who would otherwise be entitled to institutional services when: (1) the State's treatment professionals determine that community placement is appropriate; (2) the affected persons do not oppose the transfer; and (3) the community placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

The Court also suggested that a State is generally in compliance with ADA requirements if it has (1) a comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings; and (2) a plan to address the waiting list so that it moves at a reasonable pace not controlled by a State's objective to keep its institutions fully populated.

In its letter to State Medicaid Directors, HHS offers guidance for the development of comprehensive plans that effectively strengthen community service systems and serve people with disabilities in the most integrated setting appropriate to their needs. In development and implementation of these plans, HHS encourages active participation by individuals with disabilities and their families. Significantly, HHS urges that "individuals with disabilities and their families [be afforded] the opportunity to make informed choices regarding how their needs can best be met in community or institutional settings." The issue is one of choice.

¹ Ibid. p.4.

² Where People Live, The Arc, October, 1995

³ The Arc Today, Volume 48, Number 3, Fall 1999.

⁴ The Arc Today, Volume 48, Number 3, Fall 1999.

Thirteen Year Old DMR Admissions Policy is Outdated and Sorely in Need of Revision

DMR's current facility admissions policy should be scrapped because it is antiquated and not responsive to today's needs. The current DMR Admission/Readmission Policy (#89-4) dates back to November 23, 1987. It pre-dates Judge Tauro's Final Order which was issued in 1993¹. According to the policy, "The moratorium on admissions to Dever and Wrentham shall be continued until such time as the populations at each facility have been reduced to the number of beds that have been fully renovated pursuant to the Dever and Wrentham consent decrees.²" This compliance requirement was fulfilled years ago, however, DMR has never lifted the moratorium of admissions to either Dever or Wrentham. Outdated language such as "consent decree compliant beds" and "Local Service Centers" and references to the Belchertown State School, which closed on December 31, 1992, are used in the policy. The policy refers to an "Admissions Committee" at each of the State School/Centers appointed by the "Superintendent" which is to review the applications for admission and evaluate the individual. Such committees do not exist. The policy also refers to the position of "Assistant Commissioner for Facilities Management" – a position that was eliminated years ago and to an "Office of Quality Assurance" which was disbanded on June 30, 1993. Clearly this policy is sorely outdated and in need of review. The policies of state agencies are typically reviewed every 2-3 years. The current DMR Admissions Policy is thirteen years old.

New admissions to the DMR facilities are under the control of DMR via the DMR Admissions Policy. If a current resident at one of the facilities dies, a funded bed becomes available. That bed, could be filled – with no additional budget impact. Such admissions have not been allowed even though there are individuals on the waiting list who may need and want this level of care. With thousands of families on the waiting list, it is logical to assume that some may request a placement at one of the facilities - if given the choice.³ The

¹ U.S. District Court: District of Massachusetts (Ricci vs. Okin) Judge Joseph Tauro's Disengagement Order, May 25, 1999. For more information about the Final Order and the Class Status Issue see the COFAR position statement entitled, "Class Status and House Bill 1564."

² DMR Policy # 87-3: Admission and Readmissions Policy State Schools, Regional Centers, Developmental Center: 11/23/87, p3.

³ **Special Note:** A survey of caregivers with family members on the DMR Waiting List for Residential Services was conducted by Family-to-Family and funded by the Kennedy Foundation. Survey results were issued in November 1997. This study is often cited as "proof" that families do not want facility-based residential care.

DMR facilities and the services they offer are a well kept secret from families in need. DMR has the authority to offer families clinical services and respite through the facilities and to change the admissions policy at will, at anytime. Such a change in policy would be in keeping with the intent of the SSA, HCFA Regulations and the Supreme Court Decision of Olmstead.

Equal Access to All Housing Options

Mental Retardation is not a collective noun yet it is commonly used as such. There is as much diversity among individuals with MR as there is in the normal population. The DMR facilities are not appropriate for individuals who are mildly retarded and can live independently with limited supports. The facilities are appropriate for those multiply disabled individuals who are medically fragile, non-verbal, dually diagnosed, and/or behaviorally disordered and/or a threat to themselves or others.

In our American society, non-disabled individuals have a choice to live in a private home, a duplex, an apartment, a retirement community, a life care community, an exclusive community, an assisted living facility and/or in a nursing home. Disabled and non-disabled persons should have equal access to all housing options. The DMR facilities are no different from private life care communities except that they specialize in serving citizens with mental retardation. Why is it acceptable for our elder population to live in congregate settings but it is not acceptable for individuals with MR to do so? If individuals and families with financial means select private congregate living centers as the residential setting of choice for even mildly retarded individuals, why has the state closed admissions to the DMR facilities for the profoundly retarded and multiply disabled without financial means?

While the Family-to-Family Survey may be the best available information on the waiting list, results of the study must be carefully interpreted due to the methodology used. In fact, a special note appears on page five of the report itself: "A special note should be made regarding the limitations of the sampling scheme. Because the sample was recruited only after caregivers returned a postcard expressing their interest in Family-to-Family, there is a notable self-selection bias. Due to this bias, data presented here cannot be generalized to all caregivers on the DMR Waiting List. It can only be generalized to caregivers who returned an initial Family-to-Family postcard and who meet the sample criteria." Despite this warning, the study continues to be cited to 'prove' anti-facility bias. At the time of the survey, there were over 3,000 families on the DMR Waiting List. Only 250 were included in the survey and they were clearly not a random sample. Making conclusive statements about the nature of families on the DMR Waiting List on the basis of this survey are questionable.

Given the closed admissions policy, there has been no attempt made by DMR to educate those in need as to what the facilities have to offer. How can individuals and families make informed choices when they have incomplete and inaccurate information? The facilities are often described as the "institutions" of the fifties and sixties. Go for a tour of a DMR facility today and you will see the potential that exists. Residents should be able to move between facility and group home settings as their needs dictate. The lack of movement along the continuum of residential settings is indicative of a systemic problem. The artificial barrier has impeded state-of-the-art thinking about MR services. For example, if an individual living in the community were to have a major operation that required a 60-day rehabilitation, they currently would not have access to the closest DMR facility within their region, even though that may be the most appropriate setting for their recuperation and rehabilitation.

COFAR is not recommending a build-up of the facilities at the expense of community programs. Both options, in addition to living at home, should be viable and honorable choices – each respected for the benefits provided. The DMR Facilities are Specialized Life Care Communities (SLCC)¹ offering the convenience of all the necessary supports and services and the protection of a safe environment for individuals with mental retardation in a centralized setting.

The Social Security Act and the Health Care Financing Administration regulations mandate choice, yet DMR's compliance with the HCFA Choice Assurance is a "phantom choice." To date, DMR has not made a commitment to facility-based care going into the future. Each year, individuals transfer from the facilities into the community. Each year, individuals residing at the facilities die. With no possibility of new admissions, the DMR 'de facto' closure plan is clear. Families feel insecure and can no longer rely on the permanency planning that the facilities once offered.

The future is clearly stated in DMR's Compliance Guidelines Document in one sentence: "It is expected that as states close their large public institutions the choice requirement will be modified to focus solely on choice among waivered services." Nowhere in that sentence does DMR make a commitment to facility-based care going into the future. At what point will it no longer be feasible to operate each of the remaining facilities? For example, if the census reduction rate over the last five years were to continue, as per DMR's current policy, the Fernald Developmental Center could close in the year 2006. This is not about bricks and mortar. This is about giving individuals and families "genuine choice" of residential setting under the law. While the facilities exist first

and foremost for their residents. There is no reason why the rich clinical services and other day programs could not be made available to families caring for their loved ones at home or others living in group homes.

Do not allow DMR to close off access to the specialized life care communities for the mentally retarded through the silent implementation of their 'de facto' closure policy. Support a revision of the 13-year old DMR admissions policy and educate policy makers. Support House Bill 1564² which will result in increased utilization of each of the DMR facilities across the state³ and open limited admissions to those individuals who need the intensity of services and the protection of such a specialized community.

A State-of-the-Art Concept: "Specialized Life Care Community."

While most individuals with mental retardation who can function independently are best served in community programs, for the severely or profoundly retarded with multiple disabling conditions, Specialized Life Care Communities (SLCC's) offer the convenience of all the necessary supports and services and the protection of a safe environment. The primary populations remaining in the DMR SLCC's consist of individuals with mental retardation who: (1) have complex medical needs, (2) have psychiatric and behavioral conditions requiring constant close supervision (3) require a high level of support due to their degree of retardation and/or (4) may pose a threat to themselves or others. The DMR Specialized Life Care Communities are safe havens for these most vulnerable citizens. DMR's facilities uniquely service the complex medical, clinical and behavioral needs of individuals with mental retardation.

References are made to the congregate care centers managed by the State Department of Mental Retardation (DMR) as "institutions," "state schools," "developmental centers" and "facilities." In keeping with state-of-the-art developments in the elder care field, these centers are actually "life care communities" (LCC's) and should be viewed as regional centers" In the private sector, a LCC provides a continuum of residential options from independent living to assisted living and skilled nursing. Such communities also offer shopping, dining and comprehensive recreational opportunities in addition to medical and dental care. These private sector LCC's generally serve individuals over sixty years of age. They are different from retirement communities

² Refer to COFAR Position Paper 2000-6 for more information.

³ Refer to COFAR Position Paper 2000-6 for more information.

¹ Refer to **COFAR** Position Paper 2000-4 for more information.

in that once an individual's health deteriorates and they need a more intensive level of care, they are typically transferred from the retirement community to a nursing home. A life care community makes a commitment to provide life-long services regardless of medical need and levels of support. Once an individual is accepted into a LCC, the lifetime commitment to services exists regardless of financial status, providing certain basic guidelines are followed.

An example of one such private sector life care community is Brooksby Village in Peabody, Massachusetts owned and managed by Senior Campus Living. The complete build-out for the village includes 1,350 independent living units, 192 assisted living units and 160 skilled nursing beds for a total census of 1,702 residents. As their marketing materials indicate, "Besides the convenience of having just about everything you need right on campus, one of the great advantages of living in a campus-style community is the opportunity for socializing and fun...Brooksby Village means 'no more worries.'" Brooksby Village is the newest of six such life care communities across the country. As one couple state, "We love living here - the security, the sense of community, the convenience. But the best part is knowing that we are prepared for any health problems down the road. We have a home for life here." "Brooksby Village is nestled in a beautiful and secluded 90-acre valley adjacent to the 230-acre historic Brooksby farm...From security to health care, and from housekeeping to grounds maintenance, you will quickly appreciate the care and commitment of your staff...as staff are dedicated to making sure you enjoy a worry-free lifestyle that cannot be found anywhere else. Here is what one resident had to say, "Having independent living, assisted living and the medical center all on the same campus means I don't have to leave the community if my health needs change...Having the medical center so accessible is a unique advantage...I feel secure knowing help is always close by when I need it."

Consider the Peabody Community Life Center. According to the brochure, the center is "situated on beautifully landscaped grounds in a quiet setting with 30,000 square feet of adaptable space. The center meets the diverse interests and needs in areas such as entertainment, fitness, education, social services, daycare and recreation. Located at the Center is the Roger B. Trask Adult Day Health Center. The Adult Day Health Center provides skilled nursing care, assistance with personal hygiene and toileting, medication management, supervision, meals, exercise, group and individual activities, socialization, information and referrals, and other social services as needed. The center is adjacent to the Seegritz Elderly Housing Building. Is this a small "facility" within the "community" providing residential, medical, therapeutic, recreational and other specialized day programs?

Centralized programs and services make good management sense and are cost effective and accessible. Rather than focus on the residential component of the DMR facilities, there should be a recognition that the facilities have well-trained, specialized clinical staff and unique offerings such as Multisensory Rooms and therapeutic pools and recreation opportunities specifically geared to the MR population.

What is the real difference between a group home located in the "community" and a group home located on the grounds of one of the DMR facilities? It all boils down to access, convenience and safety and security. Living in the "community" means coordinating and being transported to all the services you may need (e.g., medical, nursing and therapeutic services, specialized day and/or vocational programs, recreation, etc). At the DMR Specialized Life Care Communities (SLCC), all such supports and services are located right on campus - just as they are at Brooksby Village and the Peabody Community Life Center. Individuals and families should have a choice.

Who has the right to deny a profoundly retarded individual with multiple disabling conditions the option of a centralized life care community? The time has come to infuse creative and state-of-the-art thinking into the DMR facilities. The time has come to accept specialized life care communities as a critical, necessary and viable component of the delivery system for individuals with mental retardation along the continuum of care.

COFAR believes that, just as it is acceptable for non-disabled elders to invest their life savings in a life care community, it should be equally acceptable for profoundly retarded individuals with multiple disabling conditions to enjoy that same choice and not be discriminated against. Disabled individuals should have the same options as non-disabled individuals.

Time to Fuse the Chasm

The time has come to admit that Massachusetts needs a better system of monitoring and quality assurance. Well informed individuals know that there is room for improvement of both facility and community programs. It is naïve and inaccurate to simply assume that "facility is bad and community is good." It is inaccurate to assume that the facilities are not part of the community. It is wasteful not to foster productive working relationships between the facilities and the vendor community. It is shameful not to educate families about the clinical and other resources available to them at the facilities. There are dedicated and caring staff across the board - professionals who come to the home,

those who work in vendor and state-operated programs and those who are employed at the DMR facilities. These staff should work together for the benefit of the individuals they are so committed to and care so very much about.

DMR Fiscal Year 2000 Budget:

The Massachusetts Human Services Coalition has published [The People's Budget for Fiscal Year 2000](#). 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 budgets for FY 99 and 2000, excerpted directly from the document, are as follows:

	FY98	FY99	FY2000
Administration:	\$ 84.2	\$ 47.7	\$ 50.6
Capital Improvements:	-	-	\$ 2.2
Provider Worker Certification:	?	\$ 1.5	\$ 1.5
Transportation:	\$ 24.9	\$ 25.0	\$ 24.9
Insurance Assessments:	\$ 11.9	\$ 9.6	-
Residential/Day:	\$291.7	\$314.7	\$331.7
State Operated Residences:	\$ 68.2	\$ 87.6	\$ 91.3
Day/Work Programs:	\$ 73.3	\$ 76.8	\$ 81.2
Community Health	\$ 10.7	-	-
Respite:	\$ 40.9	\$ 44.4	\$ 28.0
Waiting List:	\$ 5.8	\$ 15.8	\$ 27.8
Turning 22:	\$ 4.4	\$ 7.0	\$ 7.0
Older Unserved:	\$ 6.8	\$ 6.8	\$ 6.8
Child/Adolescent	\$ 5.0	\$ 5.1	\$ 5.1
Child Residential:	\$.5	\$.4	\$.4
Facilities:	\$174.7	\$169.3	\$167.0
Residential Services Pilot:	?	\$ 6.0	\$ 7.1
Templeton Retained Revenue:	?	\$.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

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.

DMR's Strategic Planning Process

In December of 1999, DMR announced a major strategic planning process designed to "accurately assess the needs and desires of consumers, families, organizational partners and funding agencies and to balance these with their internal

capacity."¹ This planning process involves a reexamination of DMR's core objectives and operations and evolved out of a six month internal strategic initiative. DMR has contracted with the UMASS Donahue Institute for this process. The lead consultant for the project, Gretchen Cherington will be conducting 50-60 interviews during the environmental assessment phase which is due to be completed this month. This is a very comprehensive undertaking and includes other state agencies, departments and commissions, advisory, advocacy, citizen groups and centers, labor and trade organizations and legislators. State agencies include the Secretary of EOHHS and staff, the Commissioners of the EOHHS agencies, DMR staff, the State Human Resource Division staff, the State Attorney General's Office and the State Auditor's Office, the Disabled Persons Protection Commission and the Governor's Commission on Mental Retardation. Advocacy organizations involved include Advocacy Network, COFAR, ARC Massachusetts, MFOC and MASS. The Statewide Human Rights Advisory Committee and Statewide Advisory Committee and Area and Regional Boards are also included as well as the Center for Public Representation, the Disability Law Center, the Shriver Center and the Institute for Community Inclusion. Labor and trade organizations include AFSCME, SEIU, MNA, NAGE, MACRO and ADDP.

The plan development phase will take place during the next five months and DMR hopes to have a draft plan by the Fall of this year to be finalized later in year 2000. This is a critical initiative since it will craft the priorities and direction of the Department over the next 3-5 years. More details on the strategic planning process will be reported in the next issue of The COFAR Voice.

Other Issues:

H 110 Proposed Amendments: The Transfer Statute (Chapter 123B of the General Laws), also referred to as the "Parental Consent Law," is a strong tool for guardians to utilize against inappropriate transfers. The statute provides for a rapid dispute resolution process. COFAR strongly opposes H 110 which contains both proposed language updates and substantive changes that would erode guardian and family rights and services. COFAR met with DMR on several occasions to present our concerns regarding the bill and its potential impact. H 110 is currently on hold in the House Ways and Means Committee at Commissioner Morrissey's request. Mr. Morrissey made a commitment to share the

¹ Letter from Commissioner Gerald Morrissey to Colleagues, Friends and Members of the DMR Community, December, 1999.

DMR intended language changes with COFAR and other groups prior to taking any further action.

Vendor Indemnification Contracts: The use of an indemnification and release agreement by a DMR vendor organization came to our attention last Spring. DMR addressed that particular situation, however, the concern is that this may not be an isolated instance and other vendors may be requiring parental and guardian consent to such agreements. DMR is currently conducting a survey to determine the pervasiveness of this practice by vendors receiving DMR funding across the Commonwealth.

Amendments to the Policy on Class Clients in Nursing Homes: DMR has issued the revised policy effective February 15, 2000. Copies are available through the COFAR Office. COFAR is currently reviewing the new policy.

Newly Proposed DMR Investigations Process: DMR has held four public process meetings on the re-design of the investigations process. The Department is currently drafting the regulations which will go to public hearing within the next several months.

Ongoing updates on these issues will be included in the next issue of ***The COFAR Voice***.

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

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

The next issue of The COFAR Voice will be dedicated to Quality Assurance and System Monitoring.

THE COFAR VOICE

A Publication of
**The Coalition of Families and Advocates
for the Retarded**

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

Thomas J. Frain, President
Catherine Gover, Vice-President
Edward Stefaniak, Treasurer
Sabine M. Hedberg, Executive Director

**Tear along dotted line, complete form and return along with check made payable to COFAR at:
COFAR / P.O. Box 614 / Maynard, MA 01754**

General membership in COFAR is open to all persons sympathetic to the purposes of the Coalition. We ask that all members share a commitment to a comprehensive array of services and residential settings that allows flexible choice and access based upon individual needs over time. COFAR is the only family-based advocacy organization in Massachusetts actively supporting facility-based services as a critical component of the service delivery system.

Please indicate whether your check is for:

\$25.00 General Membership and Newsletter Subscription \$20.00 Newsletter Subscription Only

Name: _____ Home Telephone Nbr: _____

Mailing Address: _____

Work Telephone Nbr: _____ Fax During the Day: _____

E-Mail Address: _____

THE COFAR VOICE

The COFAR Voice

COFAR Regional Resource Center Model



IN THIS ISSUE

- The Department of Mental Retardation's "Phantom Choice"
- House Bill 1564: Choice and Olmstead
- Thirteen Year Old DMR Admissions Policy is Outdated and Sorely in Need of Revision
- Equal Access to all Housing Options
- A State-of-the-Art Concept: The DMR "Specialized Life Care Community"
- DMR Fiscal Year 2000 Budget

COFAR
P.O. Box 614
Maynard, MA 01754

