



# The COFAR VOICE

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

Highlights of September 1999 Issue:

Volume 1 / Number 1

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- House 1564 Update: The Access and Choice Bill: A Necessary Next Step
- The Capture of Regulatory Agencies by their Clientele: Who Drives Policy Decisions in Massachusetts?
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## The COFAR Regional Resource Center Model

***The "Large Institutions of Yesterday" should be appropriately right-sized and transformed into Modern Regional Resource Centers encompassing State-of-the-Art Thinking to address the Pressing Needs of Individuals with Mental Retardation and other Disabling Conditions.***

**Individuals with mental retardation, their families, advocacy groups, the executive and legislative branches of government, provider associations, unions and others should work together to design a Model Service Delivery System reflecting a continuum of services that includes both centralized and de-centralized components driven by the needs of those for whom the system is designed.**



The majority of adult individuals with mental retardation are best served in community group homes. However, there are specialized populations that can benefit from more intensive and centralized services within a supportive, therapeutic congregate living setting.

No one is advocating wholesale placement of individuals with mental retardation into facilities. This type of setting is only appropriate for a small percentage of the mentally retarded and multiply-disabled population.

The time has come to use the resources at the facilities for the unserved and underserved and to open admissions to the facilities for appropriate persons. The facilities are a substantial public asset to be prudently managed and utilized. The facilities need to be right-sized and creative thinking and sound management should drive future service development.

## THE REGIONAL RESOURCE CENTER MODEL: Effective Management of Existing MR Resources

A Model Regional Resource Center is characterized by eight specific features some of which are not feasibly offered in a family home, shared living arrangement or in a 4-bed group home setting. Many families in need no doubt have an outdated and inaccurate picture of what the DMR facilities have to offer to them in terms of outpatient and day services. Some advocates maintain that no one wants to avail themselves of the services at the facilities. How can individuals and families make informed choices when they have inaccurate information? Given the closed admissions policy, there has been no attempt made to educate those in need as to what the facilities have to offer. You cannot request that which you do not know exists. Some of the services offered at the facilities, such as adaptive equipment and assistive design and dental services, are not readily available in all communities. Each component of the regional model is described briefly in this article.

### **Medical, Nursing and Therapeutic Services**

On-site interdisciplinary teams are available to the residents of the DMR facilities as needed. This includes occupational, physical and speech therapies, dental services, psychology and social services, nursing services and other specialized care.

### **Specialized Day Programs**

There are a number of day programs available at the DMR facilities such as sensory stimulation, fundamental responding skills, pre-vocational training and vocational programs as well as paid employment.

### **Safety, Security and Permanency Planning**

The DMR campuses offer a level of safety and security that some individuals with mental retardation need as a result of their pervasive needs. The facilities offer comprehensive services that have been available to families for several lifetimes. The Fernald Center celebrated its 150<sup>th</sup> Anniversary in 1998. Regardless of the levels of medical need, the Fernald Center and other DMR facilities can provide lifetime care thus avoiding inappropriate nursing home placements.

### **Adaptive Equipment and Assistive Technology**

The Adaptive Equipment and Assistive Technology Units at each of the facilities have existed for decades and have expertise unmatched elsewhere in the customization of wheelchairs and other equipment to allow individuals the maximum independence possible. These units should become Medicaid providers to address the critical needs of disabled individuals throughout the Commonwealth as

evidenced by the public hearing sponsored by the Governor's Commission on Mental Retardation in May, 1999.

### **Therapeutic Recreation**

Most facilities have therapeutic pools, gymnasiums with specialized equipment and staffing and other avenues of recreation that should be available to individuals living at home and in the community. Dances and other social events are routinely held at each campus.

### **Respite and Crisis Intervention Services**

The regionally located DMR facilities are capable of providing much needed respite and crisis intervention services for individuals and families who need them. Given the geographic location of the facilities, most families would have to drive less than one hour to access a facility nearby. Creative thinking could lead to innovative ways to address the needs of the unserved and underserved.

### **Human Resource Development and Training Center**

Each of the DMR Facilities provides an ideal opportunity for vocational high schools and institutions of higher learning to offer students internships and valuable hands-on experience that they can put to use when working in this specialized field. Each campus should be considered as a potential training site.

### **Congregate Living Opportunities**

What is a "Congregate Living Center?" Most Americans are familiar with the current state-of-the-art retirement communities that are springing up all over our nation. Many individuals over 55 are choosing to live in retirement communities that provide all the services and activities they want and need, including medical care. Model Congregate Living Communities for the Mentally Retarded are no different except that they specialize in the services required by our citizens with mental retardation. Why is it acceptable for the over 55 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?

The facilities should be viewed as resources to be transformed into model regional service centers. The under-utilization of the facilities is shameful in light of the desperate needs of the many families on the waiting list.

The DMR facilities should offer time-limited treatment programs and permanent housing options on grounds for specialized populations. The majority of adult individuals

with mental retardation are best served in community group homes. However, there are specialized populations that can benefit from more intensive and centralized services within a supportive, therapeutic congregate living setting. Such individuals include:

- *Severely and Profoundly MR*
- *Dually-diagnosed*
- *Medically Fragile*
- *Multiply disabled*
- *Violent towards self or others*

For these specialized populations (less than 13% of all individuals with mental retardation), the security and protection of congregate settings is ideal. State-of-the-art thinking should go into the design and development of modern living arrangements for those individuals for whom congregate settings represent the ideal living environment. It should be emphasized that the congregate living feature of the Regional Resource Center Model represents home for only a small percentage of the population. Other features of the model represent service components that are not offered in community group home settings where the majority of individuals with mental retardation live.

No one is advocating wholesale placement of individuals with mental retardation into facilities. The facility census across the state is less than 1,300 individuals. Even with an open admissions policy, this type of setting is only appropriate for a small percentage of the mentally retarded and multiple-disabled population.

Occasionally, state agencies are required to find appropriate residential placements for a given individual with multiple disabling conditions which cross-over service systems (e.g., mental retardation, mental illness, substance abuse, AIDS). An assessment should be conducted to determine the need for such placements and specific programs should be developed to address these needs instead of inappropriately placing individuals thus creating unnecessary risk to themselves and others.

The time has come to use the facilities as resource centers for the unserved and underserved and to open admissions to the facilities for appropriate persons. The facilities are a substantial public asset to be prudently managed and utilized.

COFAR is accepting feedback from individuals and organizations regarding this Model Regional Approach. Comments and recommendations can be sent to the COFAR Office at P.O. Box 614, Maynard, MA 01754 or faxed to 978-897-3403. Feedback will be summarized in the next issue of The COFAR Voice.

## HOUSE 1564 UPDATE: THE ACCESS AND CHOICE BILL: A Necessary Next Step

House 1564 – The Access and Choice Bill – reintroduces choice into DMR policy. History teaches us that the “policy pendulum” swings from one extreme to the other. Thirty years ago, there was no choice. There were no community programs and facility placement was the only service available. The trend going into the future is to eliminate choice as well. Must the system necessarily be an all-or-none system - total facility living or total community living? One size does not fit all.

H 1564 was filed by COFAR to reintroduce choice into DMR policy and to accomplish two objectives:

1. Increase utilization of outpatient and day programs for all individuals with mental retardation whether they live at home, in group homes or in congregate settings; and
2. Open limited residential admissions and re-admissions to the DMR facilities for appropriate individuals.

The DMR facilities provide services to less than 5.3% of individuals with mental retardation according to the Wellesley Center for Research Special Report issued in March of 1999.<sup>1</sup> According to DMR’s Year 2000 Facilities Five Year Plan issued in 1996, the primary populations living in the facilities at that time consisted of individuals with mental retardation who: (1) have complex medical needs and who require a pervasive level of supports in their lives; (2) have psychiatric and behavioral conditions requiring close supervision and, in nearly all cases, psychoactive medication; and/or (3) may pose a threat to themselves or others. The individuals residing at the facilities today are now among the most costly and difficult-to-serve with pervasive needs. A DMR admissions policy allowing for residential placement at facilities would affect only a small number of individuals but it would offer a vital option to those families that want and need it. Arguments that admissions should not be opened because history will simply repeat itself and mass “dumping” of individuals into the facilities would take place make no more sense than saying that the community-based system should be dismantled because it is not feasible to monitor and ensure quality of care in a decentralized system comprised of 2,000+ group homes.

<sup>1</sup> Wellesley College Center for Research on Women: Special Report: An Industry Study of Services for People with Mental Retardation and Severe Mental Illness in Massachusetts: The Client/Consumers, the Workforce, the Providers, and the State. Dorie Seavey, Ph.D., March 1999.

House 1564 offers a fiscally sound policy for the utilization of current resources. It is a first step towards breaking down the artificial barrier between community group home and congregate lifestyles to create one system incorporating a continuum of services. Residents should be able to move between facility and group home settings as their needs dictate. The lack of movement between residential settings is indicative of a systemic problem.

The artificial barrier has impeded state-of-the-art thinking about MR services across the country. COFAR is not recommending a build-up of the facilities at the expense of community programs. Both living options, in addition to living at home, should be viable and honorable choices – each respected for the benefits it provides. Highly specialized services are most cost-effective when provided in centralized settings (e.g., assistive technology, dental services, etc). The congregate care component of the facilities is one small component although it engenders the most controversy.

### **SSA & HCFA Regulations & Choice Policy**

Families are concerned. Who has the right to decide what the acceptable family options should be for comprehensive services and residential care for individuals with profound mental retardation and other disabling conditions? National experts? Special Interest Groups? Academicians? Bureaucrats? Politicians? COFAR holds that the decision should be made by clinical specialists in conjunction with the individual and/or their family.

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). The alternatives made available to any given eligible individual are at the discretion of the state. Currently, DMR has closed admissions to the facilities (ICF/MR’s) across the state.

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. Individuals and guardians sign a HCBW Service Recipient Choice Form indicating they understand the choice. How can that “choice” be valid if “institutional” placement is not an option due to closed admissions?

### **System-Wide Inequities**

DMR Commissioner Morrissey is viewed by many COFAR families as a man of integrity and commitment, but

change is difficult in an entrenched bureaucracy even for a man of principles. Clearly many of the challenges faced by DMR existed well before Mr. Morrissey became Commissioner and the bureaucratic machine moves slowly to respond to long standing problems.

Commissioner Morrissey has the challenge of assuring equal and fair services to all citizens with mental retardation. It appears to many people that outplaced residents from the DMR facilities receive “Nirvana” services while many families who have been caring for their loved ones at home for 30-40 years are receiving little or no services. While additional funds have been allocated to address the needs of the families on the waiting list, the inequity of the system as a whole continues. Currently, those individuals being outplaced from facilities appear to be ‘getting the best deals’ as DMR entices them into the community showing them model homes and living arrangements.

There are many questions. Do class members truly receive the lions share of the DMR resources? Will there ever be money to address the needs of all the families on the waiting list within DMR’s current structure? What will happen to those living in community group homes when their families are no longer around or able to advocate for them? What will happen to those in shared living arrangements when their loving caregivers age and are no longer able to provide for them?

### **The Human Services and Elderly Affairs Committee Continues to Hold House 1564 in Committee**

The Human Services and Elderly Affairs Committee (HS&EAC) continues to hold the bill in Committee. Chairman Michael Cahill (D) has indicated that H 1564 is one of the most difficult issues facing the Committee. DMR and the HS&EAC cite three reasons for holding the bill:

1. Class Status Entitlement;
2. Cost of Facility-based Services including Capital Costs; and
3. Polarity of Opinion on the “Facility Question.”

Each of these issues is addressed in the following section.

#### **Class Status Entitlement:**

The Class Status issue is clouded in confusion. Many people are ill informed regarding its true meaning and intent. Ultimately, DMR was established to provide services to those most disabled individuals with mental retardation and other disabling conditions. Is that population reflected in the DMR Client Registry?

At the 150<sup>th</sup> anniversary celebration of The Fernald Center in Waltham, Massachusetts, Martha Field, Professor of Law at Harvard University and keynote speaker, stated that "There is a doctrine in law that once government starts to care for a person, it must continue if needed, even if there was no obligation to assist in the first place." **Persons served by DMR are typically service recipients for the duration of their lives. That is, once consumers or clients enter the DMR system, they are unlikely to exit.**

Who is protected by the Final Order issued by the Honorable Joseph Tauro, Chief Judge of the Federal Court of Massachusetts? Anyone identified as a class member in DMR's Class Identification List as of April 30, 1993, regardless of where the person now lives. Those listed are individuals who were residents of the state schools on or after the following dates: Belchertown (2/2/72); Dever (12/17/75); Fernald (7/23/74); Monson (9/17/75); and Wrentham (12/4/75). The Hogan and Glavin Centers are not consent decree schools. These are the dates the original lawsuits were filed. Class status was provided to those individuals living in the "institutions" due to the conditions that were identified by the plaintiffs in the lawsuit. But Judge Tauro went beyond that. He decreed in his final order that if, after April 30, 1993, someone lives at a state school for more than 30 consecutive days, or for more than 60 days during any twelve-month period, that person would also become a class member. Perhaps it would benefit individuals on the waiting list or those in group homes who are not receiving the services they deserve, to support H 1564 and gain access to the facilities if for no other reason than to make the point that they also need lifetime services through DMR.

Class status only has meaning when an individual has an active and informed advocate. DMR cannot deny services to class clients due to budget limitations. But it takes active and persistent advocacy to enforce that right. Recent information indicates that many class members may have been lost to DMR's Client Registry System over the years even though tracking of their whereabouts was mandated by the Final Order of the Consent Decree. How can lifetime services be assured when the whereabouts of the individuals are not known!

Some legislators view the Class Status Issue as an entitlement and argue that the budget implications will be unpredictable and certainly beyond the coffers of the Commonwealth. On the other hand, if an individual is eligible for ICF/MR level services, then they SHOULD be a class client and under the care and responsibility of the DMR. What does class status really mean? Once an individual becomes a DMR client receiving residential services, that

individual is a lifelong client regardless of whether they are a class member. So...the issue is moot.

***Class Status is not an obstacle...it is an excuse not to open admissions.*** If the class were closed, then individuals admitted to the facilities would not gain class status and the "barrier" would be removed. Class status appears to be used as a convenient excuse to perpetuate the policy of closed admissions. At the very least, admissions could be allowed due to attrition. Such admissions have no budget impact. Even such limited admissions are not allowed. The Hogan and Glavin Centers are not consent decree schools; so why are admissions not open there?

#### **Cost of Facility-based Services including Capital Costs:**

H 1564 is cost neutral. Admissions could be opened through attrition with no DMR budget impact. Strict admissions criteria are already in place in the current DMR Admissions Policy. The use of the facilities for the provision of emergency residential services may actually save public dollars. What is currently being spent on emergency care and where is it being provided?

When comparing group homes to facility costs one must look at both sides of the equation to be certain to compare "apples to apples". Where are the facts on the cost of maintaining 2,000 + group homes located throughout the Commonwealth? Do we have any information on the capital and maintenance costs of these homes? Are all necessary capital improvements being made in a timely fashion on the community-based side or will this become a major budget issue as these homes age and require extensive maintenance?

Facilities provide all the necessary services for the residents and that is reflected in the facility budgets. In what budgets are all services accounted for on the community-based side (e.g., medication, transportation, therapies, dental care, leasing costs)? When citing the costs of facility care, it is important to look at the management of the resources. The costs of maintaining the physical buildings at each of the facilities are often cited as a reason for closure. The number of buildings at the existing facilities has not changed in the last thirty years although the census has declined drastically. Certainly the 324 residents at the Fernald School in Waltham, Massachusetts do not need 187 acres of land and 75 buildings. In the 1960's there were over 2,600 residents living at Fernald. Why were the facilities not appropriately downsized when the many individuals who were inappropriately placed there were transitioned into the community? What management decisions have been made at the facilities over the last thirty years as the census has dropped so drastically? Perhaps if the facilities were "right-sized" the capital costs would be more in line with current management theory. Has there been an

active effort to reuse empty buildings to generate rental income? Has there been any strategic planning done to examine centralized models of care and the use of the existing facilities? One only has to attend the Dever Reuse Commission meetings to see that development companies, municipalities and yes – even other state agencies – see incredible value in the Dever Campus. Why are the DMR facilities, which provide such specialized services, not seen as resources to be used for the benefit of the mentally retarded? After thirty years of deinstitutionalization, it is time to make the management decisions that should have been made decades ago. Such decisions must be based on a careful analysis of the current system, as well as a needs assessment of difficult-to-serve populations, to assure that the new system is responsive to the needs of those it intends to serve.

MR service system implementation involves complex funding sources including personal, local, state and federal expenditures. An understanding of the cost-sharing among and between these sources is necessary for an accurate picture. COFAR contends that a true analysis of the cost of services has never been conducted. Such an analysis would need to include charges for care and DOE, DMA, DPH, Commission for the Blind, Massachusetts Rehabilitation Commission, Housing Authority and other agency expenditures to determine the actual cost of community-based services.

According to DMR's Year 2000 Facilities Five Year Plan, issued in 1996, "community placement costs range from \$56,000 to \$110,000 with very few special placements costing in the \$150,000 range. Placement costs depend on the intensity of need. It is important to note that a large majority of the people who are projected to move from the facilities to the community over the next five years have extensive and pervasive levels of need. Consequently, the cost of the necessary array of services will be at the higher end of the range." Clearly, the cost figures today are even higher and the advisability of moving all individuals into the community needs careful analysis based on facts, not ideology.

DMR admits that the closure of all facilities will not provide adequate savings to serve the families on the waiting list and that in fact, current transfers from DMR facilities into the community result in higher costs. Those remaining in the facilities are among the most difficult to serve as they have pervasive needs. Individual placement costs for some individuals transitioned into community group homes are in excess of \$200,000 per year.

The facilities need to be appropriately downsized to accommodate the needs of the residents and to address the unmet needs of those individuals living at home and in the

community who select that option. Creative thinking and sound management should be used as the regional resource center models are developed. Creative thinking has been commonplace as innovative community based residential options have been developed. However, there has been a total lack of state-of-the-art thinking and models development for congregate settings and centralized service provision. A rational process based on data is critical.

### **Polarity of Opinion on the "Facility Question."**

There is a polarity of opinion on the future of facilities. Some advocates are adamant that all facilities should be closed while others advocate for utilization of existing resources and limited admissions. Some individuals see the issue as black and white: Community programs are good and facilities are bad. Life is never quite that simple.

The DMR facilities offer many types of services of which residential care is but one. Why are families on the waiting list not told of the resources that could be available to them in terms of respite, recreation, day programs, dental services, therapies, etc. Why are the resources of the facilities not marketed to families to offer them the services they need – even if only on a temporary basis?

DMR Commissioner Morrissey has consistently advocated "getting the stakeholders together to discuss common ground." The foundation building for this effort is to begin later this year (1999) according to Jon Johanson, Chairman of the DMR Statewide Advisory Committee. Such an initiative will require careful planning and the commitment and involvement of all "stakeholders." COFAR is looking forward to participating in a rational discussion focused on long range planning for the MR system. It is important that the system as a whole is examined – not just the facility or the community-based component – so as not to perpetuate the divisiveness that already exists. The questions are: What steps need to be taken at the DMR facilities to transform them into efficient model regional resource centers? How can community and facility programs cooperate to meet the needs of our citizens with mental retardation?

### **THE CAPTURE OF REGULATORY AGENCIES BY THEIR CLIENTELE**

All organizations go through a life cycle. DMR is no exception – nor are advocacy organizations. The natural progression of organizational behavior must be averted through careful analysis and redirection and an acknowledgement and assessment of where the agency is in the life cycle. The polarity of opinion on the "Facility Question" has resulted in the continuance of the status quo.

Should DMR policy be driven by powerful special interest groups?

The following excerpt is taken directly from Dynamics of Public Bureaucracy: An Introduction to Public Management. This is a textbook published through the University of Massachusetts in Amherst that has been used for graduate level students in public administration. It contains a lesson for all organizations.

### The Life Cycle View of Regulation

“It is easy to see how service-oriented agencies develop close ties with those they are supposed to serve...Regulatory agencies often develop close ties with the regulated...There is a life cycle to the regulatory process...Many regulatory agencies pass through four stages in their organizational lives:

1. Gestation
2. Youth
3. Maturity
4. Old Age

During the gestation period, political forces favoring governmental action in a particular area build up...Most of the major new social (and regulatory) programs of the United States, whether for the good of the few or the many, were initially adopted by broad coalitions appealing to general standards of justice or to conceptions of the public weal. These broad coalitions get the legislature to establish certain agencies and programs...Once legislation is passed, however, many groups in the supporting coalition become symbolically reassured. They...receive the rewards they want by seeing a government agency created to protect their interests. They then cease to be a major political force in making policy in the area in which the legislation was passed.

Although the coalition of forces that created the agency begins to break up at its birth, the agency attracts, during its youth state, active people who are interested in carrying out the mandate of the legislation. In this state, there is still significant support from broad aspects of the environment. In the regulatory agencies, the youth stage is a period of aggressive regulation. Sometimes, exuberant efforts at carrying out the legislative mandate galvanize political forces seeking to reduce the impact of the legislation. These more specialized...groups set the state for maturity.

During the mature phase, the attitudes of the personnel of the agency mellow, and the agency tends to look for accommodation rather than confrontation. Agency personnel emphasize being “reasonable” with the regulated. A partnership develops in which the public interest is ostensibly protected by statesmanship on both sides. During this state, its clientele becomes the most important environmental factor affecting the agency. The regulated groups and the agency develop strong symbiotic relationships during

maturity. These relationships are further developed until the teeth fall out of the regulatory agency altogether during old age.

Old age marks the capture of the agency by the groups that it is supposed to regulate. In old age, regulatory agencies become protectors of the regulatees. Although the agency continues to exist and still has its original legislative mandate, during old age, it has only symbolic value. It does not perform its stated functions, but it survives.

As Kenneth Culp Davis<sup>1</sup> has noted:

‘Some of the most important regulatory agencies may be kept, not because of their success, but because the degree of their failure is approved by politically powerful interests that are regulated. An ineffective regulatory agency often goes through the motions of regulating, thereby silencing the sponsors of the legislation that brought the agency into existence, but at the same time the agency is careful for the most part to regulate in the interest of the regulated, thereby silencing them.’

Many regulatory agencies provide symbolic reassurance to the public at large while presiding over the division of tangible rewards to their clientele. The ineptitude of the first “independent” regulatory agency, the Interstate Commerce Commission (ICC) is one of the grossest examples of government regulation gone astray.”

Where is the power base in Massachusetts when it comes to policies affecting our citizens with mental retardation? On what basis are policy decisions made and who influences those policies? Where is DMR in the Life Cycle View of Regulatory Organizations? The answer probably depends on where you sit. Where is COFAR in the life cycle and where are the other relevant organizations?

Write in to our “**Readers Write**” section with your thoughts on the issue.. Submissions will be published in the next newsletter issue to the extent that space allows.

### WHAT IS COFAR? A BRIEF INTRODUCTION: HISTORY AND LEADERSHIP

COFAR is a non-profit, family support, education and advocacy organization funded entirely by member families. COFAR’s mission is “to promote the general welfare of individuals with mental retardation wherever they may be.”

Some of the original COFAR families were among the members of both the statewide and local Arcs. It was in 1983,

<sup>1</sup> Kenneth Culp Davis, Administrative Law and Government (St. Paul, Minn: West, 1960) p. 39

when, at the Arc National Convention, a decision was made to close all facilities across the country that our founding families left the Arc. In addition, many local Arc's are now service providers, which our families believe represents a conflict of interest. The COFAR of today has evolved in response to this anti-facility bias and the service provision conflict.

For the past fifteen years, COFAR has been the only family-based advocacy organization in Massachusetts supporting facility-based services as a critical component of the service delivery system. Across the state, COFAR will continue to speak for the full spectrum of services needed to assist people with mental retardation and their families to live with their unique challenges and vulnerabilities. COFAR is committed to replacing the myths of the past with the realities of today and we advocate for public policy based on facts, choice and the needs of the citizenry.

#### EXECUTIVE DIRECTOR'S NOTE:

Sabine M. Hedberg

As Executive Director of COFAR, it is my honor to represent the families who advocate on behalf of all individuals with mental retardation and multiple handicaps wherever they may be. The COFAR families all have or have had loved ones living at home, in the DMR funded community group homes or at one of the DMR facilities. COFAR is an organization comprised of caring families.

As Executive Director, over the last ten months, I have met with individuals and organizations across the state as I attempt to unravel the complexities of the Massachusetts MR system. I have met numerous times with the DMR Commissioner, his senior staff and leaders of advocacy groups such as Advocacy Network, ArcMassachusetts, Families Organizing for Change and the Family to Family Network. I have familiarized myself with the work of the Governor's Commission on Mental Retardation and the DMR Statewide Advisory Committee. I have listened to professionals, parents and family members of diverse orientations. I have visited community programs as well as public and private congregate care centers.

COFAR members advocate for quality care across all settings and we advocate for individual/family choice. For the majority (over 80%) of individuals with mental retardation, living at home or in the community is appropriate. However, one must have compassion for the many families who have devoted their lives to preserving quality congregate living centers (DMR facilities) for those individuals with severe and profound retardation and multiple handicaps. COFAR is

continuing this crusade on behalf of those who cannot speak and advocate for themselves. I believe that everyone has the right to advocate for the individuals they love without being insulted and depreciated by others who lash out at them in judgement. There is ideology and there is reality. The system must continue to offer choices based on facts and needs.

The concept of a comprehensive continuum of services is nothing new; as it has been talked and written about for decades. It is time to make it a reality and let Massachusetts be the **first in the nation** to develop a truly seamless and integrated system just as it was the first in the nation to publicly fund care for individuals with mental retardation 150 years ago! It is my hope that the key individuals in decision-making positions will **respect choice**. It is my hope that we can all sit at a table and talk about the future in a respectful, rational and constructive way. It is my hope that we can face the reality that individuals need different things and that cooperation, not divisiveness is needed. It is my hope that people will respect the intent and wishes of families and guardians who speak for those who cannot advocate for themselves. I hope that we can put aside our differences and accept that not all families choose the same route and that a number of options are honorable. One size does not fit all. I look forward to working with individuals and organizations as we all struggle to address access, quality and cost issues.

In every forum that I have found myself in where the "Facility Question" is brought up, the air becomes thick, the hair on the back of people's necks stands straight, rational thought is lost and some even lose their common sense. The land upon which the facilities exist is not contaminated. Those fighting over the Dever Campus in Taunton can attest to that. When you cross Trapelo Road in Waltham from a typical residential neighborhood onto the grounds of the Fernald Campus – you will not be transformed into something evil. The emotional and controversial nature of the "Facility Question" has clouded all rational thought. The Wellesley College Special Study concluded that, "the mental health and mental retardation service delivery systems have a reputation for being driven by anecdotes and impressions not hard data, research or statistical analysis."<sup>1</sup> Sound public policy is based on accurate and timely facts. Where are the true facts surrounding the MR Service Delivery System?

The Wellesley Study also concluded that, "state government has adopted a relatively ambiguous and uncoordinated role with respect to planning for future services. As a result, the key constituent components of the service delivery systems – clients/consumers, providers, and the workforce – have no choice but to engage in politicized strategies to effect change, which, because of the exigencies of the political process, is

<sup>1</sup> Ibid

likely to be palliative and short term.”<sup>1</sup> Where is the leadership coming from as state-of-the-art policy is set for the MR System in the Commonwealth? Will Commissioner Morrissey “do the right thing” and “stick to the facts” and engage in strategic system-wide planning, or will political forces dictate that the status quo be maintained?

COFAR has extended a welcome to the MR family advocacy organizations to establish a Family Advocacy Forum. The organizations include The Advocacy Network, ArcMassachusetts, The Massachusetts Chapter of the Autism Society, Families Organizing for Change, Family to Family and COFAR. This Forum is envisioned as an ongoing effort designed to provide the various organizations with an opportunity to share priorities and initiatives and to understand and discuss various perspectives relating to critical funding and policy issues. A first meeting is planned for the late Fall, 1999

I believe that The Family Advocacy Forum has the potential to bring together the various family advocacy organizations advocating on behalf of individuals with mental retardation and their families. I believe that we will be able to accomplish more together than we have been able to address in a divisive and isolated environment. An update on this effort will be included in the next issue of The COFAR Voice.

Before a more comprehensive “stakeholders” initiative can be broached, it is important that the groundwork be laid to set the stage for a long range effort involving all groups with a vested interest. COFAR looks to the DMR to accomplish this more comprehensive initiative.

#### COFAR GENERAL MEMBERSHIP

COFAR welcomes new members and is committed to hearing the voices of all families with loved ones living at home, in foster care, in community group homes, shared living arrangements or in congregate settings such as the DMR facilities.

COFAR was initially a coalition of organizations and the leadership of the organization gradually evolved into what it is today. For the first time since its inception fifteen years ago, COFAR has established a general membership. Application forms are included in the newsletter insert for those individuals who are able to support our guiding principles and wish to support our initiatives. Feel free to call the COFAR Office at (978) 897-7179 for additional information..

<sup>1</sup> Ibid

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

### SUBSCRIBE TO THE COFAR VOICE

Individuals can become general members of COFAR by submitting the enclosed Membership Application. For those who only wish to receive the newsletter, the subscription-only annual fee is \$20.00.

### ARTICLES IN NEXT ISSUE OF THE COFAR VOICE

There are five issues that are currently under review by COFAR:

1. **H 110 Proposed Amendments**
2. **Vendor Indemnification Contracts**
3. **Amendments to the Policy on Class Clients in Nursing Homes**
4. **Newly Proposed DMR Investigations Process &**
5. **New DMR Survey and Certification Process**

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

## THE COFAR VOICE

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

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# THE COFAR VOICE

## The COFAR Voice

### *COFAR Regional Resource Center Model*



### IN THIS ISSUE

- **COFAR Regional Resource Center Model: A cost-effective use of existing resources to address issues of access and quality**
- **House 1564 Update: The Access and Choice Bill: A Necessary Next Step**
- **The Capture of Regulatory Agencies by their Clientele: Who Drives Policy Decisions in Massachusetts?**
- **What is COFAR? A Brief Introduction: History and Leadership**

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