



The COFAR VOICE

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

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COFAR has a new blog site at www.cofar-mass.org/cblog/. We welcome your comments!



ON THE HILL—Massachusetts attendees of the annual meeting on June 9 and 10 in Washington, D.C., of the Voice of the Retarded, pose outside the Holiday Inn on the Hill, the site of this year's event. The three also participated in VOR's Washington Initiative, which involved visiting key congressional offices on June 11 and 12 to advocate for legislation benefiting persons with mental retardation. At left are David Hart, COFAR president; Catherine Gover, a newly elected VOR Board member and past COFAR president; and George Mavridis, a past president of COFAR and a VOR member. Not pictured are Mary McTernan, current president of VOR and a past president of COFAR; Thomas J. Frain, COFAR vice president, who delivered a presentation on advocacy at the VOR meeting; and Elizabeth Hart, a COFAR member. [Annual meeting issue story on page 5.]

Message from the Executive Director

This special summer issue of the COFAR Voice is dedicated to Richard Krant, founding member and past president of COFAR, staunch advocate, dear friend, and a voice for over 40 years for those who could not speak for themselves.

For more than 20 years, COFAR has advocated on behalf of people with mental retardation wherever they may live. We began in 1983 as an organization of facility-based families.

Since that time we have grown to include families whose loved ones live at home with them, in group homes, and in a variety of other settings. Increasingly we receive phone calls and emails from younger families, from families of young adults just entering the DMR system, from families concerned about eligibility for DMR services (or who have been denied

Please see DEDICATE, Page 2

DMR implements eligibility regulations

Restrictions seen in residential care

Despite the opposition of several advocacy groups including COFAR, the Department of Mental Retardation has implemented new, more restrictive eligibility regulations for departmental care.

In a memorandum, dated June 1, State Senator Karen Spilka, D-Framingham, Senate chairman of the Legislature's Children and Families Committee, said DMR Commissioner Gerald Morrissey told the committee chairs that the regulations would be implemented as of June 2.

Richard Krant, long-time COFAR activist, dies. Obituary on Page 4.

DMR Commissioner Gerald Morrissey confirmed in a June 12 memo to his staff that the regulations had gone into effect.

COFAR and other advocacy organizations strongly opposed the regulations when they were first proposed last year, contending that the new rules would make it more difficult for persons with mental retardation and their families to obtain residential services, in particular.

"We're disappointed that the Department has apparently not heeded the warnings of several advocacy groups that these regulations may cause more heartache and despair," said COFAR Executive Director Colleen M. Lutkevich.

Sen. Spilka stated in her memo that she and Rep. Shirley Owens-Hicks, D-Boston, House chair of the Children and Families Committee, met with Morrissey on May 17 to discuss concerns about the proposed regulations, including their concern about a provision cutting off eligibility for

Please see ELIGIBILITY, Page 2

Message from the Executive Director

DEDICATE, *continued from Page 1*

eligibility), and from families just looking to become more active and involved in advocacy on behalf of their own children and others in the same situation.

In that light, we are devoting this summer edition to issues affecting younger families who are just beginning to learn about the DMR system. We are also dedicating the edition to our friend, Richard Krant, who passed away on June 19 after four decades of work on behalf of persons and families within the DMR system. We hope we can carry on Dick's spirit in working on behalf of all of them.

Our lead story is about changes in DMR eligibility regulations, which will affect young people the most. These are children of families who are most likely to be entering the DMR system for the first time. Their families are leaving the relative comfort and entitlement of special education's Chapter 766 system. We urge those families to take note of upcoming DMR informational meetings being held on Medicaid waiver changes (see our notice below).

Children in residential care have the most special needs and concerns. We have articles in this edition about two ends of the residential spectrum. One article describes our recent advocacy seminar at the Higashi School (page 5), a wonderful and unique facility for autistic children. Another article discusses the current situation facing the Judge Rotenberg Center (page 3), and our questions about the use and monitoring of "shock therapy" there. There is a need for constant scrutiny of all services for people with disabilities, particularly children.

On a positive note, we write about young interns working at Wrentham Developmental Center (page 4), and about the continued efforts of US Attorney Michael Sullivan to investigate conditions at the state facilities and in the community system to assure us that people with mental retardation will always be treated with dignity and respect (page 5). Our article about "Facility care under siege" (page 5) reminds us of the constant need for vigilance, as does the article about the likely showdown over Turning-22 funding (page 3).

Finally, we hope this dedication of our newsletter to Dick Krant reflects in a small way our appreciation of his constant example of moving forward with strength, courage of conviction, courtesy, and kindness.

Colleen M. Lutkevich

DMR holding meetings on waiver changes

DMR has scheduled a series of informational meetings on plans to change the conditions of its Medicaid waiver for community-based care. A discussion about planned changes and schedule of the meetings can be found on our blogsite at www.cofar-mass.org/cblog/ (July 5 entry), or you can call DMR at (617) 727-5608 for further information.

DMR said to implement new eligibility regulations

ELIGIBILITY, *continued from Page 1*

persons with I.Q. scores over 70. Spilka said that the revised regulations did not raise the threshold score to 75, as they had requested, but that the new regulations do broaden the definition of "functional limitations" that are used to determine mental retardation.

Spilka's memo also stated that DMR would give their psychologists "the professional discretion to evaluate and deem eligible individuals who have scored higher than 70 percent on psychometric testing."

COFAR, the Arc of Massachusetts, the Disability Law Center and the Governor's Commission on Mental Retardation all raised objections to several additional provisions of the new regulations. One provision states for the first time that DMR will take an individual's "generic and family resources" into account in determining the person's eligibility for services. COFAR contends this provision will potentially provide the Department with wide latitude to deny services to all but persons with elderly parents or those in desperate situations. The regulations do not define or set any standards for the "generic" or "family" resources that the Department will take into consideration.

The new regulations also remove an individual's "unaddressed needs" as a stated priority in the provision of services. DMR reportedly did not make any revisions to the proposed regulations in response to the concerns other than broadening the functional limitations definition.

Spilka stated in her memo that Morrissey told the committee chairs that anyone who is currently serviced by DMR "will remain within the Department." It wasn't clear, however, whether that meant that all existing services would continue for persons currently receiving services.

Spilka's memo also stated that in response to concerns raised by the chairs, DMR will track all individuals who are denied eligibility for two years. At that time, they will present their report to the committee, which will evaluate the effect of the regulations and determine whether any modifications may be needed.

"We encourage people to read these regulations and know their rights under them," Lutkevich said. The regulations (115 CMR 2.00 and 6.00) can be accessed online at www.mass.gov/dmr/.

The new regulations appear to provide authorization for a new system for determining eligibility for services, which DMR dubbed "MASSCAP." DMR actually implemented MASSCAP last year, according to a May 26 letter to a family member of a prospective DMR client, which COFAR obtained. The letter stated that "MASSCAP examines both clinical need factors of the individual as well as the support available to the individual at home."

Turning-22 showdown looms

Governor Mitt Romney has vetoed a \$2 million increase in funding for DMR's Turning-22 program, setting the stage for a showdown with the Legislature, which had given final approval to the increase.

The veto was one of a total of \$573 million in reductions that the governor made in the \$25.2 billion Fiscal Year 2007 budget, and one of several cuts he made in key line items affecting the developmentally disabled.

A House Senate conference Committee had agreed to boost Turning-22 funding by just over \$2 million in the upcoming fiscal year to ease a likely fiscal strain on the critical transitional program.

The committee adopted the Senate's proposed \$8.5 million for the Turning 22 program—an amount \$1 million higher than the House appropriation and more than \$2 million higher than the level funding that Romney had proposed. Advocates for persons with mental retardation had urged a \$4 million boost in Turning-22 funding.

The Turning-22 program, which had been level-funded for several years, provides transitional funding for persons with mental retardation who reach the age of 22 and are no longer eligible for school-based special education programs.

In other areas, Romney cut in half a \$28 million salary reserve to boost the compensation of underpaid direct-care workers in the DMR system.

Left intact was \$3 million for children's autism services, which was \$800,000 higher than the House plan. Also, the state facilities account will receive a \$6 million, or 3.63 percent, increase in funding under the final conference committee plan. The community residential account received a \$24.6 million, or 4.91 percent, increase; while the community state-operated account received a \$2 million, or 2 percent, increase.

Also approved was a \$2 million residential rate initiative to address rate disparities in residential contracts.

Your contributions are needed

Every month we answer dozens of phone calls from people needing help in navigating the DMR system. We are also working to advocate on behalf of families and guardians through seminars, and by making phone calls and visits in support of crucial legislation on Beacon Hill and annually on Capitol Hill. And we put out a bimonthly newsletter and now a blog at www.cofar-mass.org/cblog/ that we try to make as helpful and informative as possible.

All of this is getting more expensive every year, however. Please make a donation of whatever amount you can afford. Our mailing address is on the back of this newsletter. Or contribute online at www.cofar-mass.org/page3.html. Thank you.

COFAR calls for commission on aversive therapies

A Massachusetts legislative conference committee has rejected a legislative provision banning the use of electric shocks and other forms of so-called aversive therapy at the Judge Rotenberg Educational Center in Canton.

However, lawmakers were reportedly continuing to look for a resolution of the issue.

The Senate had inserted a provision in the Fiscal Year 2007 budget, which would have banned state-funded or licensed agencies from using therapies that cause physical pain, such as electric shock, hitting, and pinching. The provision would also have banned the denial of sleep, food, shelter, bedding, or bathroom facilities to persons with mental or physical disabilities.

The privately run JRC, which treats children with mental retardation, autism, and other emotional disabilities, has come under fire for the inappropriate use of the aversive therapies, untrained staff and other unsafe activities.

The criticism of the Center culminated in a report issued on June 14 by the New York Department of Education, which threatened to withdraw approval for the treatment of students there from New York unless JRC immediately took "corrective actions to cease certain interventions that threaten the health and safety of students at the school."

The report noted that staff at the Center are not sufficiently trained or prepared to oversee the treatment of children with severe emotional and behavioral problems. A skin shock device is used for relatively minor behaviors, such as nagging, swearing and failing to keep a neat appearance.

Further, skin shock is used in a manner inconsistent with safety precautions required by the U.S. Food and Drug Administration. For instance, skin shocks have been administered to some students while they have been bathing or showering. Various injuries to students have been reported.

According to the report, potentially harmful psychological effects of the use of aversive interventions have not been adequately assessed or addressed.

New York regulators voted on June 20 to ban the use of electric shocks and other aversive therapies unless the Center could prove the treatment was justified for individual students, according to *The Boston Globe*. In Massachusetts, the Board of Registration of Psychologists began an investigation of the use of unlicensed psychologists at the Center by the Center's founder Matthew Israel, *The Globe* reported. In addition, the newspaper reported that the Disabled Persons Protection Commission had begun an investigation of 10 claims in the past six months that the shocks had caused burns to the students.

COFAR has called for the appointment of a commission consisting of clinical experts, lawmakers, state officials, advocates, and some of the JRC parents to investigate

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Continued from previous page

cases in which such interventions have proved effective and to determine whether a set of uniform standards and a monitoring system for aversive interventions could feasibly be developed.

In an email to the legislative conference committee members, COFAR Executive Director Colleen M. Lutkevich stated that COFAR supported a ban on the therapies until such time as adequate standards and a monitoring system could be developed. "We respect the convictions of parents of children at the Rotenberg Center that the treatment provided there has proved effective for their children," Lutkevich's email stated. "However, the mounting evidence of abuses at the Center... appear at this point to outweigh whatever good the Center may be doing."

Richard Krant, long-time COFAR activist, dies

Richard Krant, 81, a founding member and past president of COFAR, died June 19 of a heart attack after mowing his lawn.

Krant, a retired agent with the Federal Bureau of Investigation, was also a long-time member and a past president of the Wrentham Association for the Retarded, and was a member of the Wrentham Developmental Center Board of Trustees and the Friends of Wrentham. He was also a member of DMR Area and Regional boards.

Krant's son, Bryan, has lived at Wrentham for more than 40 years.

"Dick was selfless and tireless," said Colleen Lutkevich, COFAR Executive Director. "He devoted himself to his son and to the cause of persons with mental retardation with an energy that few others could match."

In March 2004, Krant received the Gunnar Dybwad Leadership Award from DMR, the Department's top award to individuals who have made "outstanding contributions to people with mental retardation and their families."

In accepting the award, Krant maintained that "there should be a place in the future for the facilities." He had been involved for several decades in citizen and advisory panels representing both facility and community-based recipients of DMR care.

According to *The Boston Globe*, besides working with his wife, Muriel H. (Fitzpatrick), to care for their own son, Krant volunteered to become a guardian for three other residents of the Wrentham center who had no families to advocate or make decisions for them. He had taken on the last of his wards when he was 80.

Krant, who had a law degree, was highly respected as an FBI agent, a job he held from 1953 to 1978, starting out in Indianapolis, then working in Washington, D.C., and coming to Boston in 1961, according to *The Globe*. During his 17 years in the Boston bureau, part of Krant's job involved training police departments around New England.

Krant leaves his wife; his sons Richard Jr. and Bryan; his daughters Patrice, Susan, and Janis; and four grandchildren.

Interns learn on job at Wrentham

The work can be demanding and it cuts into summer vacation, but nearly half the interns who participated last year in a direct-care program at the Wrentham Developmental Center are back this year.

"It's been very successful," said Cindy Shepherd, assistant facility director at Wrentham, who supervises the summer Urban Youth Collaborative Program, which was begun by the Department of Mental Retardation more than 10 years ago. This is Wrentham's third summer of participation in the 12-week program, which introduces young people to the experience of working in state facilities with people with mental retardation and other developmental disabilities.

Shepherd said their tasks include helping with all daily living needs, including dressing, feeding, bathing residents, and assisting them with their day programs. The interns don't administer any medications.

The interns also attend once-a-week classes on disability awareness, the history of service delivery, drafting Individual Service Plans, giving and receiving respect, and other issues.

This summer, Shepherd said, 18 interns are participating. Roughly half of the group is returning from last year. The new interns, she said, get a full week of orientation, covering essential training issues from respecting resident rights and dignity to how to lift people. Returning students get a brief reorientation.

One of the major goals of the program is to try to recruit new talent to the field, Shepherd said. Of the 30 interns participating in the first two years, eight or nine have remained to work part-time or full-time at Wrentham.

The interns work eight-hour shifts, five days a week and are paid the same as an entry-level direct worker hired at Wrentham. The must be at least 18 years old. Most are either high school graduates or are either heading to college or attending college. Most commute from their homes in southeastern Massachusetts and Rhode Island.

"Some of the rewards for us are watching interns form lovely friendships and relationships with the people who live here, and watching how they are changed by the experience and work they've done," Shepherd said. "A lot of assumptions about people with developmental disabilities get changed. The goal, even if they don't work here is that they go out into the world and become advocates for the people who live here," she said.

Shepherd said the program was first developed by Gerry Scott, DMR's civil rights manager. Coordinators at Wrentham include Jim O'Brien, a social worker, Kim Pariseau, assistant unit director, and Laura Homer, an MRW IV.

COFAR holds seminar at Higashi School

COFAR Executive Director Colleen Lutkevich and Vice-President Thomas Frain conducted an advocacy seminar on May 24th for parents and staff of the Higashi School, a residential and day school in Randolph for children with autism.

The seminar—one in a series of advocacy workshops begun last year by COFAR—provided information to families on how to get services as their children turn 22 and require transition into the Department of Mental Retardation's adult service delivery system. The seminar also covered issues such as guardianship and the establishment of trusts.

Founded in Japan, the Higashi School runs a unique program for students with autism. The school offers academics, physical education, music, pre-vocational training, and transitional training, where students learn to begin to live more independently in a group home setting and go to work at a variety of local businesses with job coaches. The school is funded largely by private tuitions as well as by local cities and towns through the Department of Education, and students come from all over the world to participate.

"Tom and Colleen's seminar was truly inspirational for us," said Sharon Hickey, a parent of a student at the school and a new COFAR member. "It was packed with the kind of information we needed."

Groups interested in hosting a free COFAR advocacy seminar should contact us at the address on the back of this newsletter.

US Attorney review proceeds

United States Attorney Michael Sullivan, who was appointed in February to investigate the state's process of transferring residents from the Fernald Developmental Center, has personally met with family members at Fernald and has thus far visited the Wrentham Developmental Center and Hogan Regional Center, advocates reported.

Sullivan and his deputy, Ray Farquhar, met for more than four hours on June 4 with Fernald family members and listened to 37 speakers, many of whom discussed what they considered to be harassment by facility administrators.

Sullivan is also considering the cases of six residents at Fernald who were "in the pipeline" to leave the facility and were blocked from doing so by U.S. District Court Judge Joseph Tauro's order in February to stop further transfers pending Sullivan's review. Sullivan told the Fernald families that any recommendation he makes on that matter to Judge Tauro would not necessarily be indicative on what he might ultimately recommend to the judge regarding Fernald itself.

Sullivan has planned a return visit to Fernald and was scheduled to visit an undisclosed number of privately run group homes this summer.

During the Fernald Center meeting on June 4, COFAR member George Mavridis urged Sullivan to consider a "postage-stamp idea," under which a portion of the Fernald campus would be permanently reserved for Fernald residents.

VOR annual meeting

Facility care seen as under siege around country

WASHINGTON—An anti-institutional philosophy is pervasive around the country, but there are some encouraging exceptions, according to advocates for facility-based care, who attended the annual meeting here on June 9 and 10 of the National Voice of the Retarded (See photo on page 1).

About 60 VOR state coordinators and members, speaking at an opening forum of the meeting on June 9, told of efforts by governors, state administrators, and privatization advocates in state after state to shut down remaining state-operated facilities for persons with mental retardation. Despite this, many of those states have waiting lists in the tens of thousands for residential services.

Several speakers at the VOR coordinators forum said it makes little fiscal or clinical sense to try to close state facilities when the community system around the country remains under-funded and incapable of providing equal or better care for the facility residents facing eviction.

Nevertheless, the Jeb Bush administration has been trying to close remaining state facilities in Florida even though there are over 15,000 children on a waiting list for residential placements in the community system in that state, according to Ed Carraway, Florida VOR coordinator. A similar number of people were on a waiting list in Ohio, as the administration there attempts to adopt a system in which all services are provided under a waiver of federal Medicaid regulations that specify ICF/MR-level care. In Wisconsin, Governor Jim Doyle has been attempting to close the three remaining ICFs/MR despite 10,000 persons on a waiting list for care there, according to Kevin Underwood, the Wisconsin state coordinator.

Robert Greene, VOR coordinator for Arizona, noted that the last new resident admitted to any of Arizona's remaining ICFs/MR was a decade ago.

"The state doesn't want any more placements," he said.

There were some exceptions, though. Sybil Finken, Iowa VOR coordinator, said there are no plans for closure of the two state facilities in that state, and that those two facilities are "increasingly being seen as part of a whole service delivery system." The government has in fact been spending money to rehabilitate them, Finken said.

COFAR is a family support, education and advocacy organization funded by member families. **Become a COFAR member and receive your monthly issues of *The COFAR Voice*.** For membership information and information on how to donate and to be on our mailing list, visit our website at www.cofar-mass.org, or write to:

COFAR
3 Hodges Street
Mansfield, MA 02048
Phone: 508-339-3379
Fax: 508-339-5034

David Hart, President djhartd@comcast.net
Colleen Lutkevich, Executive Director colleen.lutkevich@verizon.net
David Kassel, Newsletter Editor dkassel@earthlink.net

The COFAR VOICE
JOIN COFAR IN OUR ADVOCACY EFFORTS TO PROVIDE
COMPREHENSIVE CARE
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COFAR
3 Hodges St.
Mansfield, MA 02048