



The COFAR VOICE

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

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Special Issue on Advocacy



Colleen Lutkevich, COFAR Executive Director, opens April 10 advocacy seminar at Western New England College

COFAR kicks off advocacy and outreach effort

SPRINGFIELD – Are you facing uncertainty over the care of a mentally retarded son or daughter who is about to reach his or her 22nd birthday?

Are you being coerced to move a family member out of a state facility, which has been his or her home for decades? Are you afraid you're getting too old to continue to advocate effectively on behalf of a ward or loved one?

Those were among the questions explored by COFAR President Thomas Frain and Executive Director Colleen Lutkevich at a seminar held on April 10 at Western New England College.

Please see SEMINAR, Page 4

Note to Readers:

We hope that the current issue of *The COFAR Voice* is one you will keep as you navigate the complex system of care for your wards and family members with mental retardation.

This issue of *The Voice* follows in the wake of COFAR's first of several planned seminars around the state, which are intended to help guardians and family members in their advocacy efforts by providing information on rights to care, services, and the humane and dignified treatment of their loved ones. Our first seminar was held April 10 at Western New England College in Springfield [see story on this page]. Additional events are planned for Worcester, Boston, and other locations to be announced in coming months.

Starting on page 3 are key DMR regulations, which every guardian should know. We would also like to let you know that we are working on expanding the information we have been collecting on advocacy and rights, and will be publishing it as soon as possible on the Resources page of our redesigned website. If you haven't already, please take a look at our new website at www.cofar-mass.org.

House waters down Stanley amendment

The House of Representatives has approved an amendment to the 2006 Fiscal Year state budget that would remove references in the budget language to the closure of the Fernald Developmental Center in Waltham.

The amendment, however, does not delete language calling for the consolidation or closure of all state Intermediate Care Facilities, which have served as home for decades to the state's most severely and profoundly retarded residents.

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Stanley amendment watered down

STANLEY, *continued from Page 1*

Despite this setback, House Speaker Salvatore DiMasi has given his commitment that a hearing will be held within a month on a bill to be filed that will protect the facilities, said Colleen Lutkevich, COFAR executive director.

Earlier this month, State Representative Thomas Stanley, D-Waltham, filed an amendment to the budget, which would have required the Department of Mental Retardation to maintain capacity at all six remaining state facilities for those residents who wish to remain there. Amendment 745 would also have eliminated long-standing language in the budget legislation implying that the 1999 U.S. Supreme Court decision in *Olmstead v. L.C.* mandates the closure of state facilities for the mentally retarded.

Since Fiscal Year 2003, the budget has contained language stating that the DMR should take steps to consolidate or close the remaining state facilities "in order to comply with the provisions of the *Olmstead* decision." Lutkevich termed this language "offensive" and "an inaccurate and incomplete interpretation" of the *Olmstead* ruling.

In *Olmstead*, the High Court ruled that states are required to provide community-based services for people with mental disabilities only if treatment professionals determine that it is appropriate and the affected individuals do not object to such placement. The Court further ruled that states must have available resources to provide community-based services.

In a November 2004 hearing, U.S. District Court Judge Joseph Tauro, who oversaw the DMR for two decades, backed the COFAR interpretation of the Supreme Court decision, saying he thought a brief jointly filed on the issue by COFAR and the national Voice of the Retarded "accurately cites the *Olmstead* case."

Approximately 1,100 of the state's most severely and profoundly retarded residents currently remain in six state facilities. The Romney administration announced in 2003 that it intended to close and consolidate the facilities, starting with the Fernald Developmental Center.

House budget plan is a mixed bag for DMR

A House Ways and Means Committee state budget plan for the upcoming fiscal year would slightly increase overall DMR funding over Governor Mitt Romney's proposal for 2006, but several line items would get less funding than the Governor proposed.

The House Ways and Means budget plan, which was unveiled April 13, would earmark \$1 million for a new initiative to fund programs for children with autism.

However, the autism funding is offset by nearly \$1 million in proposed reductions from the Governor's proposal in funding for the state DMR facilities (\$85,779 reduction), regional administration (\$362,718 reduction), community residential (\$121,500 reduction), and community-based state-operated group homes (\$422,226 reduction). The regional administration cut is a setback for funding for service coordinators, for whom the Governor had proposed a \$1.5 million increase, after cutting their funding by \$1 million in the current fiscal year [see SEIU service coordinator story below.]

The House Ways and Means plan does earmark an additional \$10 million into a salary reserve for direct care workers. But the House Ways and Means plan also roughly cuts in half a proposed \$45,000 increase to the Disabled Persons Protection Commission.

SEIU cites rising service coordinator caseloads

The average service coordinator caseload has grown to over 50, resulting in delays in completions of Individual Support Plans for residents with mental retardation, according to a survey by a state employee union.

The survey by the Service Employees International Union, Local 509, was submitted to U.S. District Court Judge Joseph Tauro in February. Tauro, who has continued to issue oversight directives to the DMR under the *Ricci v. Okin* lawsuit, asked for responses to the survey in March.

According to a February 14 letter to Tauro from the SEIU, numerous coordinators were carrying caseloads of 58 to 60 clients. In 1990, when the Court intervened to prevent the layoffs of service coordinators, the average caseload was 42. By 2000, the average caseload rose to 48.

COFAR, one of several parties that responded to Tauro, noted that as service coordinator positions have been cut, the DMR population has increased from approximately 21,000 clients in 1993 to approximately 33,000 today.

The SEIU letter also stated that the union had not been able to obtain accurate data from DMR regarding caseloads and the completion of ISP reviews.

The Wrentham plaintiffs in the *Ricci* case responded to Tauro, stating that the service coordinator problem "represents a systemic violation" of Tauro's 1993 disengagement order in the *Ricci* case, requiring an annual ISP for each class member. The Dever plaintiffs joined the Wrentham plaintiffs in recommending appointment of a special discovery master to supervise an extensive disclosure process for service coordinator information.

Know the regulations...

As part of our special issue on advocacy, we are listing some key DMR regulations, which every guardian and family member should know in advocating effectively on behalf of their wards and loved ones. These regulations can be found in full on the DMR's website at <http://www.mass.gov/dmr/>

Definition of Mental Retardation: 115 CMR 2.01

Mental retardation means, consistent with the currently (1994) accepted clinical authority of the American Association on Mental Retardation, substantial limitations in present functioning. Mental retardation begins before age 18, and is manifested by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skills areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work.

Standards to Promote Dignity: 115 CMR 5.00

5.03 General Principles

...Services and supports are to be provided in a manner that promotes:

1) Human dignity, 2) humane and adequate care and treatment, 3) self-determination to the person's fullest capacity, 4) least restrictive care, 5) the opportunity to undergo normal developmental experiences, provided that the person's safety and well-being are not unreasonably jeopardized, and 6) the opportunity to engage in activities and styles of living which encourage and maintain the integration of the person in the community through individualized social and physical environments.

Eligibility: 115 CMR 6.06

6.04: General Eligibility

(1) Persons who are 18 years of age or older are eligible for supports provided, purchased, or arranged by the Department if the person:

- (a) is domiciled in the Commonwealth,
- (b) is a person with mental retardation as defined in 115 CMR 2.01, and
- (c) is in need of specialized supports in three or more of the following seven adaptive skill areas: communication, self-care, home living, community use, health and safety, functional academics, and work.

6.05: Special Eligibility

(1) Any person identified in the [Ricci] Class Member Identification List as of April 30, 1993, regardless of current

place of residence, or any person who, on or after April 30, 1993 has resided at Monson Developmental Center, Fernald Developmental Center, Wrentham Developmental Center, Templeton Developmental Center or Dever Developmental Center during more than 30 consecutive days or for more than 60 days during any 12-month period shall have special eligibility for services provided, purchased, or arranged by the Department.

(2) A person with special eligibility is entitled to:

- (a) an assessment of eligibility;
- (b) a designation of area of service;
- (c) assignment of a service coordinator;
- (d) an Individual Support Plan and substantial provision of the services or supports recommended in his or her Individual Support Plan for so long as such services or supports are needed and authorized by the individual and his or her guardians; and
- (e) the least restrictive, most typical, appropriate residential environment, together with the most appropriate treatment, training and support services suited to that person's individual needs.

6.06: Eligibility Based on Developmental Disability

(1) A person under 18 years of age may be eligible for family supports provided, purchased, or arranged by the Department if he or she has a developmental disability and is domiciled in the Commonwealth. A determination of General Eligibility will be made when the individual turns 18.

6.07: Prioritization for Supports

(1) Priority Determination.

- (a) Except as to individuals who have special eligibility pursuant to 115 CMR 6.05, all supports, including assessments, planning and the development and implementation of Individual Service Plans, are subject to the availability of resources. The Area Director shall determine priority for supports on the basis of criteria set forth in 115 CMR 6.07.

Introduction to Individual Support Planning: 115 CMR 6.20

- (b) Individual support planning is an on-going process of establishing goals for individuals consistent with the outcomes described in the quality of life areas set forth at 115 CMR 6.23(2) and of identifying supports and strategies that will promote achievement of those goals. Successful support planning requires the greatest possible involvement of the individual, his or her family, guardian, and designated representative, if any, the Department, and providers of supports to the individual.

6.23: Development of Individual Support Plans

(1) ISP Meeting. The service coordinator shall convene and facilitate a meeting with the individual and other members of the ISP team in order to develop a support plan which sets forth the goals of the individual; the supports needed by the individual in order to attain those goals...; the availability of needed supports; the party responsible for providing supports;

Continued on next page

Know the Regulations (cont.)

the frequency and duration of supports; and strategies for meeting unmet support needs of the individual.

(3) Timing of the ISP Meeting. The service coordinator shall convene a meeting to develop an ISP within 60 days after the individual begins receiving supports which require the development of an ISP... and every two years thereafter.

(5) Distribution, Approval, and Implementation of the ISP.

(a) Within 30 days following the ISP meeting, the ISP shall be reviewed by the Area or Facility Director or his or her designee, approved or disapproved in part or in whole, and mailed to the individual, family, guardian, designated representative, if any, and providers. The service coordinator shall notify the individual and his or her family and guardian, if any, of their right to have, upon request, a meeting with the service coordinator to explain the ISP within ten days of receipt and of their appeal rights under 115 CMR 6.30 through 6.34.

(b) The individual, his or her guardian, if any, and any family members who participated in the development of the ISP will be asked to signify, in writing, their approval or appeal of the ISP... Any participant with a right of appeal under 115 CMR 6.32, will be deemed to agree to the plan unless an appeal is filed within 35 days of mailing of the ISP or of the explanatory meeting held pursuant to 115 CMR 6.23(5)(a).

6.24: Annual Review of Individual Support Plans

(1) Frequency of Review. The ISP shall be reviewed and updated on an annual basis. The individual or other team members may request more frequent reviews depending on the individual's desires, goals, needs, and circumstances.

6.25: Modification of Individual Support Plans

(1) The ISP shall be modified when necessary to reflect changes in the individual's goals and needs, to promote a quality of life for the individual which is consistent with the outcomes described in the quality of life areas set forth at 115 CMR 6.23(2), or to provide for the least restrictive, most adequate and appropriate supports consistent with the individual's desires and needs...

6.32: Initiation of an Appeal

(3) An appeal must be filed within 30 days after receipt of the eligibility decision or ISP which is the subject of the appeal, except that an appeal on the grounds that the ISP is not being implemented may be initiated at any time...

6.33: The Appeal Process

(1) The Informal Conference.

(a) The Regional Director or designee or, if requested by the appellant, an ombudsperson designated by the Commissioner, shall hold an informal conference within 30 days of notification of the appeal.

(2) Fair Hearing.

(a) If the issues being appealed are not resolved at the informal conference, then the appealing party may

petition the Commissioner, within 30 days of the conclusion of the informal conference, for a fair hearing.

(b) Within 60 days of the filing of the appeal, the Department shall hold a fair hearing on the appeal in a manner consistent with M.G.L. c. 30A and 115 CMR 6.33(2).

(c) The fair hearing shall be conducted by an impartial hearing officer designated by the Commissioner.

(j) Within 45 days after the conclusion of the fair hearing, the Commissioner shall issue a decision which shall be the final decision of the Department on all issues. The decision shall include a summary of the evidence presented, findings of fact, a decision on each of the issues appealed and the reasons for such decision, and a notice of the individual's right to appeal the decision to the Superior Court pursuant to M.G.L. c. 30A.

6.63: Transfers: Special Requirements

(2) All parties eligible to participate in the modification meeting pursuant to the Department's regulations on the modification of individual service plans shall be given written notice of the proposed transfer [from one residential location to another] at least 45 days prior to the date of the proposed transfer.

(3) If any party to the ISP modification, other than a current or proposed provider of services and supports to the individual, files an objection to the proposed transfer in accordance with the provisions of 115 CMR 6.63(3), the transfer shall not occur unless: the party withdraws the objection; the individual, if not under guardianship and capable in fact, consents to such transfer; the guardian consents to such transfer and the individual does not object; or the Department prevails at an adjudicatory proceeding held pursuant to 115 CMR 6.63(4).

COFAR seminar kicks off advocacy effort

SEMINAR, *continued from Page 1*

During the hour-and-a-half seminar, Frain and Lutkevich discussed a range of advocacy issues, including getting appropriate services, understanding the Individual Support Plan process, and becoming a guardian. Frain, an attorney, also talked about his own advocacy experiences involving his mentally retarded brother, Paul, who had suffered serious neglect and abuse at a privately run group home in Leominster a decade ago, before Tom was able to get him transferred to a state-run residence in Lancaster [see October 2003 *COFAR Voice* for a full account of the case].

The seminar was the first of several planned by COFAR in different parts of the state, and was made possible in part by a grant from the Fernald Corporation. The event marks the start of an outreach and advocacy effort by COFAR.

During the seminar, Tom related how the staff supervisor of the private group home had refused his request at one point

that Paul be taken to a hospital to relieve a painful ear condition. The reason was that there was one staff person for 11 residents. "I became aware at that point of how bad things were for my brother," Tom said. At a Christmas Party that year, someone mentioned COFAR, and Frain contacted the organization. That, he said, marked the beginning of his personal and successful advocacy push on his brother's behalf.

"The Problems We Face"

Funding cuts in both the community and facility accounts have reduced services available in each, Frain said. "The community is not a panacea," he said. "It requires enormous resources to regulate." That is combined with the fact that people with mental retardation don't vote and are often wholly dependent on others.

Additional problems are caused by the administration's decision to close remaining state facilities, which house the Commonwealth's most severely and profoundly retarded residents.

Advocacy tips

Frain and Lutkevich emphasized that effective advocacy is critically important in dealing with these problems in obtaining quality care for loved ones. "Don't be afraid to pick up the telephone," Frain said. "If you are writing, use certified mail, especially with the DMR." Frain said he called the DMR area office, the regional director and finally the Governor's Office regarding his brother's situation. "It did force people to call me back," he said.

"Don't get stuck in dead-end dialogues with people who aren't doing anything for you. Go up the chain of command. Know your state representatives and senators," Frain added. The Disabled Persons Protection Commission can be of help as well, although budget cuts have forced the agency to deal almost exclusively with the most serious situations involving abuse and injury.

"Never quit," Frain said. "Never be afraid [of what DMR might do]. Remember that whenever you start pushing large organizations, they will push back."

Getting Services

Frain suggested that guardians and family members develop a "wish list" of the most comprehensive and appropriate services and residential settings for their wards, including good day programs, nursing services, physical and occupational therapy. The wish list should be addressed during the ISP process.

The first step in getting services is to determine the eligibility of a ward or family member. [See regulations on page 3]. Lutkevich noted that DMR requires that a person demonstrate an IQ below 70 in order to qualify for services. "If you have a child who you believe is mentally retarded and you have a school psychologist who can determine that your

child's IQ is below 70, life will be much easier for you," Lutkevich said.

Class Member protections

Frain and Lutkevich discussed a range of services to which eligible persons are entitled under the DMR system. They noted that DMR regulations state that a priority is placed by DMR on services to class members of the Ricci v. Okin lawsuit, which brought about upgrades to care of the mentally retarded beginning in the 1970s. Each Ricci class member has a right to have the state "substantially provide services on a lifetime basis," according to a DMR class member information handbook. These services are described in the person's Individual Support Plan.

Persons who are not Ricci class members and who are found to be eligible for services, are entitled to them "subject to the availability of resources." The problem non-Ricci members have faced has been the lack of availability of such resources—a situation, which has led to the placement of thousands of people on waiting lists for care. That situation resulted in the filing of two additional federal lawsuits.

The importance of ISPs

In moving any resident from a facility, DMR must first obtain a modification of their ISP. U.S. District Court Judge Joseph Tauro, who presided over the Ricci case for two decades, has also issued a number of orders in recent months that are intended to ensure that the ISPs continue to provide adequate protections, particularly to Ricci class members at Fernald, which is first on the administration's list of facilities slated for closure. In January, Tauro ordered the DMR to provide Beryl Cohen, the attorney for Fernald plaintiffs, with records relating to the ISPs for all Fernald residents, including those who are transferred elsewhere. DMR further entered into a stipulated agreement in December 2004 with the Fernald plaintiffs that DMR will not discuss alternative placements during a facility residents annual ISP meeting. In April, Tauro further directed the DMR to provide a "Right of Return letter that every individual transferred out of Fernald "can always come back." This letter is to be part of the record for any individual transferred from Fernald in the future.

Guardianship

Lutkevich and Frain maintained that becoming a guardian is a key element of the advocacy process when a mentally retarded family member turns 18. Lutkevich noted that when a child turns 18, parental rights are effectively terminated. At that point, a parent should apply in probate court to become a guardian if the mentally retarded person is incapable of handling his or her personal or financial affairs. Frain said that if a parent or other family member fails to apply for guardianship, DMR may appoint a stranger to fulfill that task.

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, visit our website at www.cofar-mass.org, or write to:**

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