



The COFAR VOICE

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

November 2005

Volume 7/ Number 6



FIRED UP – Fernald Developmental Center worker and union leader Raymond McKinnon (center) addresses fellow protestors at a vocal October 12 State House rally in support of the facility. [Story on Page 5.]

Selection of Fernald housing contractor raises questions

The state has “conditionally” selected a private human services vendor, which was criticized by the State Auditor for “questionable” financial practices, to construct and rehabilitate community-based residences for residents of the Fernald Developmental Center.

The selection of the Dedham-based Toward Independent Living and Learning, Inc. (TILL) raises a number of questions about the agency’s experience in construction and the past management of its finances, according to a September 28 letter sent by COFAR President Thomas J. Frain and Executive Director Colleen Lutkevich to Department of Mental Retardation Commissioner Gerald Morrissey. TILL’s president, Dafna Krouk-Gordon, was, until last year, a member of the Governor’s Commission on Mental Retardation.

The conditional contract award was made by the Division of Capital Asset Management (DCAM), the state’s public construction management agency, according to Margaret Chow-Menzer, assistant DMR Commissioner for Systems Integration Management. Chow-Menzer said DCAM has also conditionally selected a second agency, identified as CIL Realty of Massachusetts, Inc., under a separate contract to build and rehabilitate additional community homes for Fernald residents. DMR plans to operate group homes containing up to 80 new residential beds in the greater Boston and northeast areas as part of its effort to close Fernald and to move its remaining 235 residents to other state facilities and to state and vendor-operated, community-based, residences.

The COFAR Voice reported in July 2005 that DMR was having trouble finding suitable responses to its Request for Proposals to develop the residences, as part of a 13-point plan proposed in July 2004 to close all but a portion of Fernald. The plan has been rejected by the Fernald League and COFAR because it would force at least 150 current residents to move

DMR plans eligibility changes *Move seen to tighten eligibility for residential services*

The Department of Mental Retardation has announced a new system for determining eligibility for departmental services, raising concerns that residential services, in particular, may become harder to get.

In an October 12 letter sent to advocates for persons with mental retardation, DMR Commissioner Gerald Morrissey said that the new Massachusetts Comprehensive Assessment Process (MASSCAP) would take effect October 17. As of that date, MASSCAP would be used for all applicants for DMR services.

In a related development, DMR announced proposed new
Please see Eligible, Page 4

Please see TILL, Page 3

COFAR presidency to change hands

But Frain and Hart share philosophy of 'choice' in care

In January, the COFAR presidency will change hands for the first time in six years, but the philosophy within the organization that people should be given a choice in their care and services will stay intact.

In interviews, Thomas J. Frain, who has been president of COFAR since 1999, and David Hart, who was recently elected vice president, expressed similar views about a need to continue COFAR's role in advocating for a range of settings of care for persons with mental retardation. Those settings include their homes, community-based residences, and state-run facilities.

Frain, 43, and Hart, 39, will actually switch places, with Frain continuing on the Board as vice president next year, and using the extra time he will have to organize advocacy seminars for the organization and raise funds. Hart will become COFAR's president in January.

Hart said he will work to retain the current use of facility settings for people with the most severe and profound forms of mental retardation. In the facilities, staff turnover is lower and a high-level of care is more likely to be ensured than in community-based settings.

"I realize that times have changed and that the system has to change," Hart said, "but I want to see COFAR have some influence over that change so that everybody's choice will still be there. I don't think anyone is sure how the system is going to look in the future, but you certainly need the state-operated group homes, vendor-run group homes and state facilities available to everyone."

"The community-based system actually keeps people apart and spread out." – Thomas J. Frain

Hart added that: "Right now it's we who believe in choice versus those who believe that everyone should be in the community. I think it's closed-minded to think that the community is the only option. Groups such as the Arc of Massachusetts [which advocates the closing of all facilities] don't know what medically fragile is. What concerns me about the Department (DMR) and the Arc is their need to put everyone in one group. Every one of these people has individual needs and is different. A case-by-case basis is necessary. This is the basis of the ISP (Individual Support Plan process), yet they don't want to do it."

Frain said he wants to continue to work through COFAR to preserve a sense of community for people in the DMR system. That sense, he contended, is being eroded by the push for privatization and the shutting of facilities. "The most ironic thing about the community movement," Frain said, "is that families then lose power because they don't know other families in the community. The community-based system actually keeps people apart and spread out."

Frain maintained that COFAR's advocacy seminars can be an important way of spreading COFAR's message around the state and getting people involved in the organization. Frain and COFAR Executive Director Colleen Lutkevich have hosted two seminars in the past six months—both in the Springfield area. The seminars are intended to provide information on advocacy and DMR regulations to families of persons with mental retardation. They are also an attempt to bring together families who might otherwise find themselves isolated in navigating the DMR system. Additional seminars are planned in the Worcester, Boston, northeast, and southeast regions.

"I think COFAR is the only major statewide advocacy group for the mentally retarded that is not an offshoot of the vendor community," Frain said. "The vendors and DMR don't want people to be educated in things like the role of guardianship and Individual Support Planning, and these seminars are an attempt to get out there and educate the public and empower people."

COFAR offered sense of inclusion

Frain, an attorney, joined COFAR in 1995, while he was in the midst of a crisis involving his brother, Paul, who has mental retardation, and who had been living in a vendor-run group home in which he was abused and neglected [See story on Paul Frain in the October 2003 COFAR Voice]. Frain said a social worker of Paul's told him about COFAR at a Christmas Party that year. He said that a subsequent 10-minute conversation with Lutkevich "straightened out my understanding of what we could and couldn't do [about improving Paul's situation]. "COFAR was instrumental in helping us navigate the labyrinth of DMR."

Frain said that the key advice Lutkevich gave him was to contact the Disabled Persons Protection Commission. The DPPC opened an investigation of the group home and substantiated numerous allegations of neglect and abuse there. Frain used the report as leverage with DMR in getting Paul into a state-operated residence, where he has lived ever since and has received good care.

"Like other families, I was stressed out," Frain said. "She (Lutkevich) was like a beacon in the night. She told me exactly what to do." When Frain attended his first COFAR meeting that year, there were 50 people in the room, he said. "They all just listened to my brother's story," he said. "I knew every single one could finish my sentences. It was one of the most soothing moments in the crisis."

Frain became vice president of the COFAR Board in 1998, and a year later became president. He has headed the organization during COFAR's campaign that began in 2003 in conjunction with the Fernald League and other advocacy organizations to prevent the closure of the state facilities. He also took an active role in a successful advocacy effort a few years ago on Beacon Hill to prevent the privatization of state-operated group homes in Massachusetts.

"Being in COFAR has given me an enormous appreciation of the political system and how much of a challenge it is to change it," Frain said.

Following in his father's footsteps

Hart, an account executive and an adjunct faculty member at Gibbs College in Boston, is currently president of the Concerned Citizens for the Mentally Retarded, Inc. CCMR is the family advocacy organization at the Hogan Regional Center in Danvers, where Hart's brother Chris, lived for more than 20 years. Chris died in 1996 at the age of 32. CCMR was co-founded in 1976 by Hart's father, Charles, who remains active in both CCMR and COFAR.

David Hart said that he became active in CCMR after his brother died. "I felt a responsibility to the people who were still there at Hogan," he said. "They don't have a voice. That sense of obligation is important to both me and my father."

Hart said continuing the work of his father, who is now 79, was another other major reason for joining CCMR and COFAR. "I grew up watching what he did," Hart said. "He's been an advocate for 30 years, and watching him do that was a source of inspiration to me." And Hart said his wife Elizabeth has also been a driving force behind his advocacy. Five years ago, Elizabeth Hart founded a non-profit agency, Tailored for Success, Inc., which offers career development training to low-income persons and immigrants in the greater Malden area. TFS also offers self-esteem building workshops to teens in the Department of Youth Services and Social Services systems.

"Observing Elizabeth's daily drive and commitment in advocacy is the number one factor I am, and always will be, involved in advocacy," Hart said.

Contractor selection raises questions

TILL, *continued from Page 1*

off the campus.

Under the contracts with TILL and CIL, the homes constructed or rehabilitated would be operated by state personnel, according to Chow-Menzer. Chow-Menzer said actual sites had not yet been selected for all of the homes and that the awards of the contracts were "conditional on suitable

sites being found" [See sidebar on next page on the site-selection issue].

DCAM records reviewed by COFAR, based on a Public Records law request, indicate that DMR would sign 20-year lease-purchase agreements with TILL and CIL to construct or rehabilitate an unspecified number of single family group homes and duplexes. Five proposals were received. The proposals for the base rent to be paid by the state varied widely from a low of \$741,000 over the 20 year period to \$2.2 million for a single-family, five-bedroom home. CIL proposed a 20-year schedule of rents totaling \$1.15 million for a five-bedroom home, among other proposed residences; and TILL proposed a schedule totaling \$1.2 million for the same sized residence. CIL appeared to have proposed to build nine duplexes and one single-family group home; while TILL appeared to have proposed building or rehabilitating four single-family homes and one duplex.

In addition to the base rental cost, the state would pay TILL and CIL the cost of real estate taxes, water and sewer charges, liability and casualty insurance. The state would pay separately for heating and utility costs.

State Auditor criticizes TILL

A January 2002 report by State Auditor Joseph DeNucci stated that TILL had spent more than \$4 million in state funds in "unallowable, undocumented, and questionable business activities."

The audit stated that Krouk-Gordon, TILL's president, had billed and received more than \$267,300 as a full-time employee of the agency during a three-year period from 1997 through 2000, during which she also billed the state for more than \$120,000 in full-time salary from a related company in New Hampshire.

In addition, TILL inadequately documented \$3.2 million in payroll costs and used almost \$927,000 in state funds to pay for non-reimbursable activities involving related-party organizations. As part of that, TILL improperly used \$25,000 to make a down payment on property purchased by a related company, according to the audit.

Krouk-Gordon did not return calls seeking comment. In an October 20 response to the September 28 letter from COFAR with written questions about the procurement process, Chow-Menzer wrote that "the Department is working toward resolving these outstanding audit issues."

Chow-Menzer stated in the previous interview that both TILL and CIL would be "contractor/developers" in the construction and rehabilitation of the residences. She said TILL has experience in housing construction and that CIL does as well. However, proposal documents reviewed by *The COFAR Voice* did not appear to indicate extensive or specific construction experience on TILL's part. CIL, however, appeared to have more extensive experience in constructing housing for persons with mental retardation.

TILL was one of dozens of human service vendors that

Continued on next page

Continued from previous page

signed a memorandum issued by the Arc of Massachusetts in July 2004 in favor of closing Fernald—an outcome which could bring those vendors additional revenue [see September 2004 *COFAR Voice*].

“It appears that our concerns that the vendors would view the closing of Fernald as an opportunity to cash in are starting to be borne out,” Frain said.

In June 2004, DMR presented a 13-point facility closure plan to Fernald residents that could allow some of the existing residents to remain; but the plan has been rejected as inadequate by Fernald advocates. The plan called for DMR to build or renovate 40 state-operated group homes for Fernald residents in the greater Waltham area and another 40 beds in the northeast region of the state.

In 2003, the administration announced plans to close all of the state facilities, starting with Fernald. Advocates contend that the DMR Fernald closure plan could be highly disruptive and involve multiple relocations and that it relies on an underfunded community-based system to provide care to relocated Fernald residents. Fernald is the oldest facility of its kind in the nation. It has been the home for its current residents for decades and enjoys the broad-based support of the residents’ families. Fernald advocates have proposed that a portion of the campus be set aside for housing for all current residents, allowing for the development of the remainder of the campus.

Group home siting process may prove expensive

The process of locating group homes for Fernald residents may prove more expensive than anticipated because sites for the homes were not proposed by one of the winning proposers, according to a document review by COFAR.

The Request for Proposals states that the Division of Capital Asset Management reserves the right to approve “adjustments” in the proposed rent charged the state to account for development costs once a site is identified.

CIL Realty of Massachusetts, Inc. was conditionally selected by DCAM without having identified any sites. DCAM records show that CIL proposed to build 9 duplexes, with rent to DMR starting at \$21.61 per square foot in the first year; and one single-family five-bedroom group home, starting at \$21.97 per square foot. CIL’s proposal for the single-family home was the second lowest among the five proposers for a structure that size.

“There’s a saying that the ‘devil is in the details,’” said Mary McTernan, a former COFAR president and a current member of the Governor’s Commission on Mental Retardation. “Without knowing the details, such as the sites for these homes, how can DMR assure the families that their loved ones will be in a setting that is financially sustainable for the rest of their lives?”

DMR seen tightening eligibility

Eligible, continued from Page 1

eligibility regulations, which state that the Department will take “generic and family resources” into account in determining eligibility for services. DMR scheduled public hearings on the proposed regulations for November 14 in Boston and November 17 in Worcester.

COFAR Executive Director Colleen Lutkevich said she was concerned that DMR’s plan to take family resources into account in eligibility determinations could mean that DMR could deny services to all persons other than those without any relatives or whose caregivers are elderly or otherwise incapacitated. She noted that the proposed regulations don’t define “generic or family resources” or set standards for them. “Apparently residential services in the future may go only to those in desperate situations,” Lutkevich said.

“We’re very concerned that the DMR is planning to tighten eligibility,” added COFAR President Thomas J. Frain. “It is already incredibly hard for many people to get residential care for their loved ones with mental retardation. It could be devastating if the Department is going to make it even more difficult.”

With cuts in federal Medicaid funds looming, COFAR asked DMR in early October for detailed information on possible departmental plans to tighten eligibility requirements for residential services.

“Apparently, residential services in the future may go only to those in desperate situations.” – Colleen Lutkevich

In a Public Records request, dated October 3, to Morrissey, Frain and Lutkevich asked for records relating to an April 2005 DMR planning document that discussed the MASSCAP proposal in general terms. Frain and Lutkevich also asked for a meeting with Morrissey or his staff to pose specific questions about the issue. As of October 25, DMR had not responded to the letter. As a result, Frain and Lutkevich were preparing an appeal of the public records request to the Secretary of the Commonwealth.

The DMR planning document, which is titled, “The Department of Mental Retardation Strategic Plan 2001-2004 Summaries,” provided no specifics on changes that are being contemplated. Instead it contained a series of strategic goals and objectives to deal with “the eligibility question.”

Lutkevich and that in addition to the planning document and Morrissey’s letter, she saw “ominous signs” in several

statements made by Morrissey and other DMR officials in recent meetings with advocates and other stakeholders.

Florence Finkel, a COFAR Board member and a member of DMR's workgroup on eligibility issues, said her recollection of Morrissey's statements at a recent stakeholders' meeting was that persons with mental retardation, whose parents were elderly or who had no other relatives, would be given priority under the new eligibility system. She said, though, that she had not seen a draft of the new eligibility manual or the MASSCAP assessment tool

Lutkevich agreed with Finkel that Morrissey said persons with elderly parents or without other relatives would get priority in services. But, she said, left unsaid was what would happen to younger parents who were still unable to care for children with developmental disabilities. She also maintained that "there is a real difference between eligibility for DMR services and eligibility for residential services. Many people are found eligible and then only get funding for a small day-hab program," she said.

Lutkevich said she was currently working with parents who placed their severely retarded and autistic son in a residential school, which has been paid for by the public school system for several years. "Now that he is turning 22, DMR asks 'why don't you want him at home with you? We'll give him a day program,'" Lutkevich said. "Well, if he couldn't do well at home as a child he certainly can't do well at 22."

George Mavridis, a Board Member and former President of COFAR, noted that at the federal level, Congress has been trying to tighten Medicaid eligibility for people with mental retardation and to cut Medicaid funding to states for services.

Mavridis, who is also a member of the national Voice of the Retarded, has sent letters to members of the Massachusetts Congressional delegation, urging them to oppose the Bush administration's proposed legislation to cut Medicaid and to impose numerical benchmarks on the states requiring the transfer of residents from facility-based settings to the community. VOR contends that a far greater percentage of persons with mental retardation have been moved out of facilities and into the community than have the elderly or people with physical disabilities.

Vocal crowd supports Fernald at State House

Some 50 Fernald Developmental Center family members and staff workers braved blustery weather at an on October 12 rally at the State House to protest the Romney administration's efforts to shut the Center and five other state facilities for persons with mental retardation [See photo on page 1].

Sporting yellow T-shirts and carrying signs, the crowd directed its anger toward both Governor Mitt Romney and Attorney General Tom Reilly, whom speakers accused of siding with the Governor in the closure issue. The rally,

which began on Beacon Street in front of the State House and proceeded to the McCormack State Office Building, was organized by the Fernald League.

"The DMR is putting Fernald residents back in isolation," said Dorothy Rouleau, a Fernald League and COFAR member, referring to plans to place all remaining state facility residents in community-based care.

Fernald League President Diane Booher said that 50 Fernald residents have been transferred thus far from the facility, with 44 going to other state facilities and six to nursing homes. Four of those residents have died in their new locations—a statistic that Booher termed "a terrible death rate."

Booher told the crowd that the "good news" was that since January, only six residents had left Fernald. The remaining population totals 235.

"I want to know why Mr. Reilly hasn't answered our letters. Mr. Reilly, what's your position [on the closure of Fernald]? – Raymond McKinnon

Representative Thomas Stanley, D-Waltham, who addressed the crowd, maintained that the Romney administration has eyed the potential sale of the Fernald land as a source of a "quick infusion" of cash. He noted that on October 11, the House rejected an attempt by the administration to revive a fast-track process it had been using to sell state property. The two-year fast-track authorization had expired on June 30 [see surplus land sale story in the July 2005 *COFAR Voice*.]

Also addressing the rally was State Senator Susan Fargo, D-Lincoln. Fargo joked that given Romney's penchant for traveling, "at least nothing bad can happen when he's out of the state."

Shortly after the rally began at the State house at noon, AFSCME Local 402 union members marched up Park Street to join the family members, chanting "Hey, Hey, Ho Ho, Mitt Romney must Go!"

The crowd was repeatedly fired up by Raymond McKinnon, a direct-care supervisor at Fernald and vice president of the union local. "I want to know why Mr. Reilly hasn't answered our letters," McKinnon yelled repeatedly through a bullhorn. "Mr. Reilly, what's your position [on the closure of Fernald]?"

Joseph Hughes, a Fernald League and COFAR member, who was recovering from a heart bypass operation in June, told the protestors that he fought in the Philippines in World War II "to preserve freedom." Now, he said, "they (the Romney administration) are taking my freedom of choice away."

After spending roughly 45 minutes in front of the State House, the crowd marched around the corner to Bowdin Street and down the block to the McCormack Building, where Reilly's office is located on the 21st floor.

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:**

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

Thomas J. Frain, Esq. President tjf@frainlaw.com
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
FOR ALL PERSONS WITH MENTAL RETARDATION

COFAR
3 Hodges St.
Mansfield, MA 02048