



The COFAR VOICE

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

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Key info missing from proposals for group homes *Vendor submitted identical budgets for different houses*

A private human services vendor selected to provide community-based housing for former Fernald Developmental Center residents submitted separate proposals to the state for rehabilitating and constructing five group homes that appear to be both incomplete and identical to one another in several key respects.

Toward Independent Living and Learning, Inc. (TILL) was one of two vendor agencies “conditionally” selected in September by the Division of Capital Asset Management to build or rehabilitate community-based group homes for Fernald residents. COFAR opposes the administration’s plans to shut Fernald, displacing most of its 235 residents.

In a review of proposals submitted for the group home projects obtained under a Public Records Law request, *The COFAR Voice* found that required information in each proposal submitted by TILL was missing or incomplete, and that several pages of each proposal appeared to be photocopies that were used in all of the proposals.

In addition, TILL submitted the same total development budget of \$600,000 in separate proposals for three of the four group homes it was proposing to rehabilitate. Further, the same rehabilitation construction cost of \$110,000 was projected in the proposals for each of the three houses. Yet, the homes were identified as being located in different towns or as being of different ages, sizes and types of construction.

The only rehabilitation improvement specified in any of the proposals was a statement that TILL was proposing to convert a garage in one house into bedrooms. None of the proposals specified the type and age of the windows and roof of each

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Kathleen Houghton (right) and her sister, Mary, who uses the therapeutic swimming pool at the Fernald Developmental Center.

Fernald resource inspires disabled woman’s sister

[One of a series of articles on new COFAR members]

Kathleen Houghton’s sister, Mary, was facing possible surgery and injections to alleviate painful contractures of the muscles behind her knees.

There wasn’t an apparent source of good physical therapy for Mary, who has had cerebral palsy since birth, and who has lived at home her whole life with her family in Somerville. Exercise regimens that doctors prescribed for the 41-year-old woman were too painful.

Then Kathleen, who is the special needs recreation supervisor for the City of Somerville, thought of the therapeutic swimming pool at the Fernald Development

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DMR stays course on eligibility restrictions *COFAR appeals records denial*

Despite opposition from advocacy groups for persons with mental retardation to proposed regulations that appear likely to restrict eligibility for services, the Department of Mental Retardation has indicated that it intends to press ahead with those regulations.

In a January 3 letter to COFAR and other advocacy groups, Marianne Meacham, DMR's general counsel, indicated that the Department would make some revisions to the wording of the regulations. However, the letter did not appear to make any major concessions in response to the advocates' objections. The final regulations are expected to take effect February 1.

COFAR, the Arc of Massachusetts, the Disability Law Center of Massachusetts, and the Governor's Commission on Mental Retardation all filed testimony with DMR in November, arguing that several of the regulatory proposals would narrow the population DMR would continue to serve and make it harder to get residential services, in particular.

"We're extremely disappointed in DMR's response," COFAR Executive Director Colleen Lutkevich said. "We will explore all possible options for defeating these changes in the regulations."

In a related development, COFAR has asked the state Public Records Division to order DMR to release internal reports and records concerning the development of its new eligibility policies. In a November 1 letter to COFAR, Meacham stated that the internal reports were still incomplete and thus exempt from public disclosure.

The following bulleted items are the major changes in DMR's regulations opposed by COFAR and other advocacy organizations:

- The regulations will state 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.

In testimony submitted to DMR in November, COFAR maintained that the proposed language was overly broad and would provide the Department with wide latitude to deny services to all but persons with elderly parents or those in desperate situations. The proposed regulations do not define the "generic" resources or "family" resources that the Department would take into consideration, nor do they establish any standards for such resources, COFAR wrote.

The Arc's testimony stated that the proposed language would discourage special needs planning, the development of family partnerships and other collaborative activities, and that the change had resulted in several negative outcomes in other

states, such as families disinheriting children in order to continue to secure services for them.

In the January 3 DMR response, Meacham maintained that "generic resources" does not refer to the financial assets of the family of an applicant for services, but rather refers to such things as food stamps and Medicaid services. She indicated that DMR would not revise the regulatory change. Lutkevich maintained that this response did not address COFAR's concern that the regulations do not define "generic resources."

- The proposed regulations would remove an individual's "unaddressed needs" as a priority in the provision of services.

In its testimony, the Arc stated: "We question the motivation behind removal of this criteria beyond an effort to restrict services and expenditures."

Meacham responded that DMR disagrees with this criticism and believes that the removal of the priority in providing services will actually "enhance the Department's ability to identify and address needs." Lutkevich contended that Meacham's response "flies in the face of logic. Removal of a priority in providing services simply will not enhance those services," she said. "That is Departmental doublespeak."

- The proposed regulations would change the current definition of mental retardation, which is based on guidelines adopted by the American Association on Mental Retardation (AAMR).

In testimony submitted to DMR, the Disability Law Center stated that the current AAMR guidelines state that an IQ score of 70 should not be considered as an absolute cut-off point because of limitations in the accuracy of intelligence testing. Despite this, the DMR's proposed regulations would create an absolute cut-off for individuals who score above a 70, according to the DLC.

In the DMR response, Meacham said the Department has redrafted a portion of the definition of mental retardation relating to "significant limitations in adaptive functioning."

- The proposed regulations include new language that would appear to require that a person who has been determined eligible for Department services, but who has not been provided with those services, wait three years before even being permitted to re-apply for those services.

COFAR submitted testimony stating that a person who has been determined eligible for Department services should receive those services with reasonable promptness. If the eligible person has not received services, that person should retain his or her eligibility and not be required to re-apply for it.

In the DMR response, Meacham said it has been DMR's policy that only persons who have refused all services, moved out of state, or been determined not to need services would be required to reapply for services after three years. Lutkevich responded that this policy should be explicitly stated in DMR's regulations.

In addition to proposing the regulations, DMR has referred on its website to a new system of determining eligibility for services, which it has dubbed "MASSCAP." A DMR "Strategic Plan Summaries" document, dated April 2005, stated that MASSCAP had been developed as a new tool for assessing eligibility and that it would be used to determine a new "prioritization system for adults."

In an October 3 Public Records law request, COFAR asked for several internal reports referred to in the Strategic Plan Summaries. In her November 1 letter in response, Meacham stated that those reports were in the process of being revised or were otherwise incomplete and therefore fell within the exemption to the Public Records law for "inter-agency or intra-agency memoranda or letters relating to policy positions being developed by the agency."

In a December 7 response to Meacham, COFAR noted that the exemption also states that it does not apply to "reasonably completed factual studies or reports on which the development of such policy positions has been or may be based."

COFAR's letter also stated that DMR Commissioner Gerald Morrissey has previously stated that the MASSCAP process has been in effect since mid-October. Therefore, this policy was no longer being developed, but was in effect. In addition, COFAR noted that the withheld reports were described in the Strategic Plan Summaries document as having been completed.

Fernald a resource for disabled woman

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Center in Waltham, where she often brings special-needs children from her recreation programs. The warm temperature of the water there might loosen her sister's tight muscles in a way that nothing else had been able to do.

Her hunch was right. Mary was able to move her legs and kick them in the Fernald pool without any pain. "We started going there once a week and it resolved the problem," Kathleen Houghton said. The surgery and injections wouldn't be needed.

Houghton recently recounted the experience as she explained what it was that drew her about a year ago to join COFAR. She said that the success of the Fernald pool as a therapy for her sister made her aware of Fernald's value as a community resource and what a mistake it would be to shut the facility down.

"After that, I wanted to get involved," she said, referring to the campaign that has been ongoing for the past three years by

Fernald advocates against the Romney administration's plans to close the center and the five other remaining state facilities for persons with mental retardation in Massachusetts. "I thought that the fact that Fernald is used by the community was missing from the debate. I wanted to call attention to the fact that Fernald is a resource for the community."

Houghton said she joined COFAR after reading a newspaper article about the organization. Since joining, she said, she has become a Board member and has participated in COFAR telephone advocacy efforts urging lawmakers on Beacon Hill to support Fernald and other legislation of benefit to persons with mental retardation.

"I wanted to call attention to the fact that Fernald is a resource for the community." – Kathleen Houghton

"I'm really impressed with the families I've met who belong to COFAR," Houghton said. "It's amazing what they're doing to keep the organization going. I'd like to help keep it going as well. I've been on a lot of different communities and boards, but this is the first one I've joined for personal reasons."

Houghton says she doesn't know what she would do if the Fernald pool were no longer available as a resource for her sister. "There is really nothing else available to us on our budget," she said. "There is really no other way for her to get exercise."

Kathleen and other family members take Mary to the pool once a week. Using an inner-tube, she is able to extend her arms and to kick back and forth for the entire length of pool. Kathleen said Mary has a tendency to contract bronchitis and pneumonia, and that the weekly swimming exercise provides her with good lung expansion. "We've looked into hotel pools," she said, "but the water temperature in them is far too cold."

Kathleen added that she continues to bring special needs children from her city-based programs to the Fernald pool as well. Many of those children have mental retardation or autism. "It's nice to go to a place where a behavior episode won't cause a problem," she said.

Cared for at home

Kathleen Houghton is one of a growing number of COFAR members who make use of state facilities such as Fernald, but who don't necessarily have family members who live there. Mary Houghton has lived at home her entire life, even though she is severely disabled. Kathleen says the family's large size may be the reason they have been able to care for Mary at home. Mary is the youngest of eight children—seven girls and one boy. "There was always a lot of support. We were all able to help," she says.

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Mary contracted cerebral palsy as a result of oxygen deprivation at birth. The doctors knew immediately that she had suffered severe brain damage, but they weren't able to give Mary's parents much information about how that might manifest itself later in her life. "I remember my parents going from doctor to doctor, trying to get therapy for her," Kathleen says.

To this day, Mary remains nonverbal and can't use her hands. But when she was still a toddler, family members taught her to communicate by nodding and shaking her head for "yes" and "no." She was also able to indicate with facial expressions whether she was enjoying something or whether something was bothering her.

In the early 1970s, when Mary was a child, there were few special needs programs available, Kathleen pointed out, and her parents became involved in the effort to pass Chapter 766, the Massachusetts Special Education law. When Mary was nine, her parents sent her to public school, but her needs couldn't be met there. Then they discovered a program for severely disabled people at Boston College, and enrolled her there. At the time, the program was developing one of the first computers to enable people with severe disabilities to communicate.

At the Boston College program, Mary was fitted with a toggle switch attached to a headrest on her wheelchair, which enabled her to spell out words on a computer screen. Today, at her day habilitation program at the Walnut Street Center in Somerville, she uses a much more advanced computer, which she can use to do simple math problems, play games, and even operate a kitchen blender.

Kathleen describes Mary as family and people oriented. "Her main interest is being around people," she says. "She loves to walk around the mall and to go to community events." Kathleen explains that when she says "walk," she means Mary is pushed in a wheelchair. Mary also uses a separate wheelchair fitted by a sister of hers with wide plastic wheels to "walk" around the beach. "She loves to observe people," Kathleen adds. "She's very social."

Group home proposal info missing

PROPOSALS, *continued from Page 1*

house as required in DCAM's Request for Proposals.

Beryl Cohen, attorney for the Fernald plaintiffs in ongoing litigation before U.S. District Judge Joseph Tauro involving the Fernald closure, reacted strongly to *The COFAR Voice's* findings, saying the process appeared to have been geared toward "favored developers."

"The proposals by TILL and CIL (Realty of Massachusetts, Inc., the second vendor selected by DCAM to develop the community-based housing for Fernald residents) are obviously

the pilot process that the Romney administration is using to jumpstart the sale of over 160 acres of prime real estate presently occupied by Fernald," Cohen said. He added that "COFAR is to be congratulated" for exposing flaws in the procurement process.

Cohen further criticized DCAM's RFP for the housing project, saying it contained only one statement describing the residents to be served. He noted that the RFP stated that in the Metro Boston region, 13 beds must be proposed for persons with special needs, including eight beds for persons with impaired vision and five beds for persons with "certain behavioral needs." Cohen maintained that given the multiple medical and clinical needs of a majority of the remaining 235 residents at Fernald, a requirement that only 13 beds be proposed for residents with two specified impairments "shows a lack of understanding of the population and no consideration for ongoing active treatment programs at Fernald."

"The proposals are obviously the pilot process ...to jumpstart the sale of over 160 acres of prime real estate..." – Plaintiff attorney Beryl Cohen.

The Voice submitted a list of written questions to DCAM on December 21 and again on January 3 about the completeness of TILL's responses to the RFP to develop the houses. As of January 6, DCAM had not responded to the questions. The Department of Mental Retardation previously referred all questions about the procurement process to DCAM.

A voicemail message left with TILL President Dafna Krouk-Gordon, a former member of the Governor's Commission on Mental Retardation, was not answered. Kevin Stock, TILL's vice president of operations, referred all questions about the firm's proposals to Krouk-Gordon.

DCAM "conditionally selected" TILL and CIL Realty of Massachusetts, Inc., from a pool of five proposers to build and rehabilitate group homes containing up to 80 new residential beds in the greater Boston and northeastern Massachusetts regions as part of its effort to close Fernald and move its remaining residents to other locations. Under the proposed contracts, the two firms will lease the homes for 20 years to DMR, which will staff them with state personnel.

In November, *The Voice* reported that a 2002 report by the State Auditor found that TILL had spent more than \$4 million in state funds in "unallowable, undocumented, and questionable business activities." A DMR official told *The Voice* that the Department was "working toward resolving these outstanding audit issues."

In addition, the newsletter reported that CIL had been conditionally selected to construct up to nine group homes without having identified any sites for the houses. Documents provided by DCAM in December indicate that CIL had signed purchase and sale agreements for sites for two of its proposed homes.

As of December 21, DCAM had yet to sign actual lease-purchase agreements with either CIL or TILL, even though it conditionally selected them in September to develop the housing for Fernald residents. As a result, DCAM has declined to disclose its internal evaluations of the CIL and TILL proposals, citing a Public Records law exemption that shields internal departmental records from public disclosure prior to the signing of contracts.

In its review of the actual TILL proposals, *The Voice* found that photographs of the same two unidentified houses were included in each proposal, including the proposal for new construction. With one possible exception, no photographs of houses actually specified in the proposals appear to have been included in the documents made public by DCAM. In that one case, a picture of a house and a swimming pool were included, but there was no identification of the house in the documents provided.

In addition, the same timeline for completing the rehabilitation improvements was provided in each proposal. In fact, the timeline description appeared to have been photocopied and inserted into each proposal.

DCAM has yet to sign lease-purchase agreements with TILL or CIL.

Each rehabilitation proposal and the new construction proposal further identified the neighborhood surrounding each proposed house with an identically worded description: "Very safe neighborhood--listed as one of the safest in the state." This page of each proposal also appeared to have been photocopied and inserted in each proposal.

In only one case were required plot plans included with the proposals, and no floor plans or drawings were provided that were specific to the houses for which renovations were proposed. In the proposal to construct the new house, schematic design and working drawings were listed as "to be completed," and permits as "to be obtained."

Further, in none of the proposals did TILL provide the required information about how it would finance the rehabilitation improvements or construction of the one new home it proposed. In each case, the proposals listed three banks as possible options for financing. Required information about loan terms, such as the interest rate, was not provided.

In addition, none of the proposals identified the contractor expected to complete the rehabilitation improvements or new construction, as the RFP required. The proposals either stated that the contractor had yet to be selected or left the item blank.

The Voice has questioned TILL's experience in housing construction. Each of the proposals included a statement that TILL had built four houses and done "numerous renovations," but provided no specific examples of those activities other than that the vendor was working to rehabilitate an unspecified commercial building in Chelesa into affordable housing units.

Medicaid cuts seen affecting services

The difficulties families have in qualifying for services from the Department of Mental Retardation are likely to be increased by significant cuts pending in federal Medicaid funding.

Congress is poised to pass a federal budget bill that will cut Medicaid by at least \$6.9 billion over the next five years, according to the national Voice of the Retarded. Medicaid is a major source of revenue for the states in providing services for persons with mental retardation.

"Every state is rewriting their eligibility regulations to conform with federal requirements and restrictions in Medicaid funding," said Mary McTernan, President of VOR and a past president of COFAR. "States can't keep expanding services the way they have in last decade. Medicaid is cutting the funding and states have to live with that."

McTernan added that "Massachusetts has even been late to this process. I think there will be further restrictions to tell you the truth."

COFAR Executive Director Colleen Lutkevich noted that while Massachusetts may not have any choice but to restrict eligibility for services, DMR should develop an "open and inclusive" process for doing so. "Giving themselves total discretion to pick and choose who gets services with few explicit standards isn't the right way to go," Lutkevich said [see eligibility story on page 2].

COFAR gets Fernald Corp. grant for *The Voice*

The Fernald Corporation has approved a \$25,000 grant to COFAR to enable the organization to continue to produce and distribute *The COFAR Voice* in 2006.

Since 2003, the newsletter has chronicled a campaign by the Fernald League, COFAR, VOR and other organizations to prevent the summary closure of the Fernald Developmental Center and other state facilities for persons with severe and profound mental retardation. *The Voice* covers a wide range of issues of concern to persons with mental retardation and their families.

"We regard *The COFAR Voice* as our principal means of communication with our members, members of the Legislature and other policy makers, and the public," said COFAR Executive Director Colleen M. Lutkevich. "We are very grateful to the Fernald Corporation for this very generous donation, which will definitely help us keep the newsletter going."

The Fernald Corporation is a nonprofit corporation established in 1850.

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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The COFAR VOICE
JOIN COFAR IN OUR ADVOCACY EFFORTS TO PROVIDE
COMPREHENSIVE CARE
FOR ALL PERSONS WITH MENTAL RETARDATION

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