



The COFAR VOICE

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

September 2003 Issue:

Volume 5/ Number 3



ON MESSAGE—COFAR members hold banner during the organization's June 26 visit to the State House to lobby against an expected veto of budget language protecting state facilities for the retarded. Banner reads: "Save Fernald + Lives."

See story p. 5. (Photo courtesy of Senator Susan Fargo's Office)

Battle to save Fernald, state facilities, goes on

Advocates for the mentally retarded waged a successful effort this spring to garner a state budget provision protecting the Fernald Developmental Center and other state

facilities for the mentally retarded from summary closure, but the campaign is far from over.

"The war is by no means won," COFAR President Thomas J. Frain said this summer. "The administration is continuing to move ahead to close these facilities and evict their residents, with no adequate alternatives in sight. We're not going to let that happen."

Frain said COFAR will schedule additional visits to the Legislature this fall and next spring and will continue its petition efforts in hopes of ensuring that the hundreds of

residents of the state facilities continue to receive statutorily mandated services.

COFAR's spring campaign bore fruit in early July when the House and Senate successfully overrode vetoes by Governor Mitt Romney of legislation protecting the state-operated facilities from immediate closure.

The House and Senate also overrode the governor's vetoes of nearly \$700,000 in funding for the state facilities and more than \$4 million in funding for community-based care for the retarded.

The Legislature's actions save the Fernald Center in Waltham from closure prior to October 2004 and ensure that a committee will be established to study the reuse of the Fernald site in order to keep at least a portion of it as a continuing home for its 300 residents. However, the legislative measures have not swayed the administration from its ultimate goal of closing the state facilities and moving their residents to privately run, community-based residences. As a result, the effort to preserve the comprehensive services provided by the facilities will continue in the legislature and may be shifting to a legal front as well (See interview with Beryl Cohen, p. 4).

Proponents of the facility services maintain that their fight has only become more critical as questions continue to mount over recent deaths and cases of abuse and neglect in the community (See story on p. 3).

"Now is certainly not the time to rest on our laurels," said COFAR Executive Director Colleen Lutkevich. "The system is continuing to be dismantled."

COFAR and other advocates for the retarded began lobbying in April against the governor's plans to close the state facilities, which provide state-of-the-art care for the retarded. COFAR maintains that given a continuing lack of adequate funding and oversight of community-based care in Massachusetts, the proposed state facility shutdowns would place the well-being and even lives of the state's retarded citizens at risk.

The governor first announced in February that he was targeting Fernald and potentially the five other remaining state facilities for the retarded in Massachusetts for closure as a budget-cutting measure. The administration, however, never provided backup figures for what have turned out to be declining savings projections in closing Fernald. The administration first projected a \$4 million savings in closing Fernald, and later revised that projection to \$2.3 million. COFAR contends the closures will put the entire continuum of care for the retarded at risk without saving money.

The community-based system is currently unable, due to inadequate funding and oversight, to provide the same level of comprehensive care currently provided to residents of the state facilities, Lutkevich said. A significant portion of the approximately 1,300 residents of Fernald and the other state facilities are among the most severely and profoundly retarded in the state, many are elderly, and many have acute medical needs.

In June, the House and Senate approved state budget language, which would require that a cost-benefit analysis be

done before either Fernald or five other remaining state facilities could be shut down. That language, which was introduced by state Senator Susan Fargo (D-Lincoln) and state Representative Thomas Stanley (D-Waltham), would also require that the Department of Mental Retardation predetermine, prior to transfer, that any residents transferred from those facilities would receive equal or better care in any proposed community-based setting.

The governor vetoed the facility protection language in the Fiscal Year 2004 state budget, and vetoed an outside section of the budget, which called for the establishment of a reuse committee to consider alternative uses for Fernald's 187 acres of land, while maintaining the site as a continuing home for its current residents.

In addition to his vetoes of the state-facility-protection measures, Romney vetoed more than \$4 million in funding for a range of programs for community-based care for the retarded. According to Frain, the governor's vetoes of community-based funding would have meant the closure of 25 group homes in Massachusetts "at the very least."

The governor's vetoes came less than a week after COFAR delivered a final set of petitions to Romney's office containing signatures collected from more than 14,000 people across the state who oppose the facility closures. (See story p. 5.) Romney never responded to several invitations from COFAR and from legislators to visit Fernald before making a final decision on its closure.

The House and Senate overwhelmingly overrode the governor's vetoes in early July. In addition to saving the Fernald Center, the Legislature's overrides mean reprieves for a number of other facilities on the Fernald grounds, including a skilled nursing facility for 27 people with mental retardation, two state-operated group homes housing 12 people, and a shelter for homeless women.

COFAR readies for Annual Dinner

COFAR's Annual Dinner, scheduled for Wednesday, October 29th, at the Newton Marriott, promises to be a time of both celebration and reflection, according to Colleen Lutkevich, the organization's Executive Director.

"This year's dinner is particularly poignant because of the danger the Governor has placed the families of the state facilities in," Lutkevich said. "But there will also be time for celebration and gratitude to those who helped us succeed in overriding the Governor's vetoes of budget language protecting the facilities."

Providing the musical entertainment will be the renowned Blue Horizon Jazz Band. Awards will be given to four legislators who have been instrumental in helping save the state facilities thus far: Senators Susan Fargo and Richard Tisei, and Representatives Thomas Stanley and Brad Hill. Tickets are \$40.00.

Care in the community comes under increasing scrutiny

As the Romney administration presses ahead with plans to close state-operated facilities for the mentally retarded in Massachusetts, oversight of the community-based system has come under increasing scrutiny and criticism at both the state and federal levels.

The *Boston Globe* reported on August 5 that abuse cases in community-based group homes in Massachusetts have risen since 2000 as the homes absorb mentally retarded residents from the state facilities. The rising abuse cases and three deaths in group homes since May 2002 that have resulted from staff negligence are signs of a system that is under pressure from rapid expansion, high staff turnover, and lack of adequate supervision.

The Globe's lead editorial on August 8 called on Governor Romney to shelve plans to close the Fernald Developmental Center and the other state facilities "until the Legislature approves salaries for direct care workers in contract facilities sufficient to attract a qualified work force."

Meanwhile, the U.S. General Accounting Office has reported that the Bush administration has allowed states to waive Medicaid regulations in order to expand community care, but hasn't held the states accountable for the quality of care being provided in the community.

In examining waivers covering services to more than 260,000 elderly people in 15 states, the GAO found that in many cases, Medicaid beneficiaries did not receive required services, *The New York Times* reported.

"Massachusetts is one of several states facing a crisis in care being provided in the community," said COFAR President Thomas J. Frain. "Care is slipping there even as the salaries of the executive running the vendor agencies providing that care are rising. And the Governor wants to put further strain on the system by closing the state facilities. It makes no sense."

In Massachusetts, community-based care for the mentally retarded is provided under a waiver of Medicaid regulations, which contain a set of requirements for individually tailored care in institutions. The waiver program was instituted by Congress in 1981 as an alternative to institutional care. In the past decade, the number of Medicaid beneficiaries receiving such care under federal waivers has risen dramatically.

Massachusetts now serves over 8,000 persons through its community-based waiver program and has federal approval to serve over 12,000. However, two federal lawsuits filed in recent years in Massachusetts have alleged that mentally retarded and other disabled persons have not been receiving community-based services to which they are entitled under the waiver system.

A lawsuit filed in 1999 (*Boulet v. Cellucci*) alleged that more than 3,000 mentally retarded people were being kept on

a waiting list, in some cases for years, for community-based care. In a second suit (*Rolland v. Cellucci*), the plaintiffs argued that more than 1,600 mentally retarded and otherwise developmentally disabled persons were being inappropriately confined in nursing homes rather than provided with the community-based care specified in the waiver. Thousands more were at risk of inappropriate nursing home confinement.

In December 2000, the DMR committed to requesting appropriations of \$85 million in new funding over the next five years for new residential placements and interim services for the plaintiffs of *Boulet v. Cellucci*. While this effort has reduced the numbers of class members on the waiting list for community care, it has not addressed the needs of potentially hundreds of other families who are believed to be waiting for services in Massachusetts, but who were not part of the original waiting list.

Similarly, while *Rolland v. Cellucci* was also settled, DMR has continued to place clients in nursing homes due to a lack of available space in the community, and has failed in many cases to provide specialized services to which those clients are entitled under the Medicaid law, according to information from the Disability Law Center.

There have also been ongoing charges of neglect and abuse in the community-based system due to inadequate oversight on both the state and federal levels.

The Globe described the case of Wil Ward, a 26-year-old mentally retarded resident of a group home in Western Massachusetts, who choked to death on a disposable glove after he'd been left unattended in a bathroom. He'd swallowed more than a dozen gloves and a washcloth. His parents had paid \$94,000 a year out-of-pocket to Berkshire Meadows, a facility run by Justice Resource Institute.

Last year, the newspaper stated, investigators determined that 127 other mentally retarded residents of group homes were injured due to documented abuse or neglect by caregivers, and that 55 other allegations were pending, according to the state Disabled Persons Protection Commission. Some 148 companies run group homes under state contracts.

The Globe also detailed the case of Rachel Deline in May 2002, who died of kidney failure resulting from a month-long overdose of lithium that was overlooked by the staff of her Foxborough group home and a local doctor. State investigators faulted Rehabilitative Resources Inc., which ran the home, for allowing an "unsatisfactorily performing" manager to oversee "reportedly unqualified or inept staff."

The newspaper further reported that low pay—averaging less than \$20,000 a year for direct care workers—has led to turnover rates as high as 50 percent a year in group homes, according to the Association of Developmental Disabilities Providers. An association report described the use of temporary staff that includes many people lacking education, experience and training.

In a third death detailed by the newspaper, David Malcolm, 39, who lived in a Weymouth group home run by South Shore Mental Health, died in January after receiving inadequate

dosage of anti-seizure medication. The house manager, who was supervising several houses, delayed filling the prescription, according to the investigator's report. The manager then delayed bringing Malcolm to the hospital after he started to have seizures. He suffered a heart attack at the hospital and died.

Because of budget cuts, the DPPC can investigate only about 5 percent of complaints, *The Globe* reported. The Commission relies on other agencies, including DMR, to investigate the rest. COFAR has long advocated the removal of investigative functions from DMR and their placement in an independent agency.

Morrissey told *The Globe* the state thoroughly inspects all homes every two years and does unannounced spot checks on a monthly basis. He has hired the UMass Medical School to review every death.

[In next month's issue, *The COFAR Voice* will detail the neglect suffered in a group home by Paul Frain, the mentally retarded brother of COFAR President Thomas Frain.]

Interview

Cohen: 'We might go back to Tauro'

Plaintiffs' attorney says conditions may exist to reopen consent decree case

[On July 21, *The COFAR Voice* interviewed Beryl Cohen, long-time attorney for the plaintiffs in the landmark *Ricci v. Okin* case, which led to the improvement of conditions in state facilities for the retarded between 1972 and 1993. U.S. District Court Judge Joseph L. Tauro, who presided over consent decrees stemming from the court case, disengaged from his oversight in 1993, but left open the possibility that he might revisit the case if the stipulations of his disengagement were violated.]

Q: Can you say anything about your legal strategy and the outcome of the plaintiffs' meeting last week [July 17] with DMR?

A: We had a meeting on Thursday [July 17]. I can't say much about that. We have another meeting August 25. There is a lot in progress. We're seeking information about their plans to close (the facilities). DMR is providing information that we've requested—information that must be obtained before people can be asked to make alternative choices. We need good information about these facilities and how they're going to work.

We're waiting right now. We're not going to move any faster than DMR. Until they give us this information, they can't do anything. There can be no transfers. We're not accepting anything.

Q: What is the status of the DMR's efforts right now to get people to change their ISPs [Individual Service Plans] and to transfer them out of the facilities?

A: We're not accepting anything. The annual ISPs are taking place. We're participating to a limited extent.

Q: What is your advice to the families of the residents at Fernald and the other state facilities?

A: Don't commit to anything until you have an ISP. Your rights can't be bargained away. Until the ISP process is completed, there will be no transfers. If people don't want to go, wait until the ISP review is held and every requirement is complied with.

Q: What if people are unsure about whether there is compliance?

A: Call the Fernald League, which is providing assistance. The number is (781) 891-7345.

Q: What was the outcome of the DMR's information fair at the Fernald Center on so-called alternatives to the state facilities?

A: The information fair was held July 13. Less than a dozen family members showed up for it.

Q: Is there a possibility you might go back to Judge Tauro and ask him to reopen the consent decree?

A: Yes, we might go back to Tauro. We have to prove the system is in violation of the class members' rights. The closing of all the facilities to meet the Governor's claim of saving money may potentially be grounds for asking the judge to revisit it. These closures have nothing to do with [providing adequate] care. But it's too early to say what we will do right now.

Q: What is your take on the overrides in the Legislature of the Governor's veto of the facility protection language in the budget?

A: The override was 125 to 22 in the House and 30 to 5 in the Senate. It now depends on [Governor] Romney and whether he wakes up to it.

Q: Will the overrides slow down the Governor's efforts to close the facilities?

A: I don't see him slowing down when he vetoes a four-month delay in closing Fernald. [The budget language precludes the shutdown of Fernald prior to October 2004.]

When less than a dozen people show up to their information fair; when they [DMR] do a telephone survey and two thirds of the families refuse to respond; when you have 14,000 signatures from across the state opposing the closures, I don't know if he's getting the message or is just tone deaf.

Q: Is there any sign that they're backing off on the closures?

A: I don't think so. A lot of people are getting paid to close Fernald. They're contracting with Public Consulting Group [a consulting firm that has specialized during the past decade in helping the state close public institutions serving the disabled.] Procedurally, they haven't moved anyone yet [from Fernald]. They must follow the requirements. There is no way there can be transfers without following the regulations. There is a variety of legal requirements. We're going to let them wallow in it. We're not going to point the way for them in closing these facilities.

Fernald advocates make surprise connections at State House

COFAR members made some unexpected connections as they made their final push at the State House in June for enactment of legislation to prevent immediate closure of the Fernald Center.

As they waited outside the Governor's office to deliver a final set of petitions containing more than 14,000 signatures opposing the facility closures, House Speaker Thomas Finneran strode by on his way to an elevator and gave the group encouragement. Earlier, as the COFAR members stood outside the State House, former Governor Michael S. Dukakis stopped, after crossing Beacon Street, and talked with some of the members of the group.

"If I were still there (in the Governor's Office), you wouldn't need to be out here demonstrating," he said.

Facing a possible gubernatorial veto of budget language protecting the state facilities from closure, about 25 COFAR volunteers traveled by bus from the Fernald Center in Waltham to the State House for the June 26 event. It was the final visit by COFAR members to the State House in their spring lobbying campaign.

After getting off the bus, the group unfurled a home-made banner in front of State House, reading: "Save Fernald + Lives." (See photo page 1). At 1 p.m., the group presented the final petitions to an aide to the Governor. From there, they visited both Finneran's and Senate President Robert Travaglini's offices, and then split up to visit individual legislators to thank them for their support.

"The lives of these residents count. People count," said George Mavridis, a COFAR Board member said, in one of a series of prepared statements delivered by all the members of the group, as they presented the petitions to an aide to the Governor.

As they stood waiting outside the Governor's office, Finneran himself stopped briefly and expressed support for the state facilities. "Don't get discouraged," he said, as he made his way past to a waiting elevator. "I've seen these proposals (to shut state facilities) before. They come and they go."

Accompanying the COFAR members on a portion of their rounds in the State House was Senator Susan Fargo (D-Lincoln), who was instrumental in inserting the facility protection language into the budget for the upcoming fiscal year (see front-page story).

Fargo, who introduced the COFAR members to aides in both Finneran's and Travaglini's offices, said she had written a letter to the Governor asking him to visit Fernald personally. "I've always found that in decisions about land use, it really helps to visit the place," she said. Romney did not respond to several invitations from COFAR to visit Fernald.

Fargo's letter to the Governor, which was also signed by Representatives Thomas Stanley (D-Waltham) and Peter Koutoujian (D-Newton), stated that "preserving Fernald is consistent with the principles of efficient, effective government. Closure of Fernald could result in the death of many of its residents, or at best, a dramatic deterioration in their health and quality of life because there are no community residences anywhere in this state at this time that can provide equal or better care."

Also speaking to the COFAR members at the June 26 event was Senator Pamela Resor (D-Marlborough) and Representative Paul Donato (D-Medford) both of whom expressed support for the facility.



House Speaker Thomas Finneran (left) offers encouragement to COFAR members during July 26 State House visit. (Photo courtesy of Senator Susan Fargo's Office)

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, write or call:

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