



The COFAR VOICE

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(COFAR)

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COFAR takes fight for Fernald to Governor

COFAR volunteers have taken their battle to save the Fernald Development Center and other state facilities for the mentally retarded all the way to the Governor's Office.

In the wake of a statewide petition drive by COFAR as well as lobbying visits and a legislative and press

briefing at the State House, both the House and Senate have passed budget legislation with provisions that would protect the state facilities from arbitrary and summary closure. By early June, the petition drive had netted more than 13,000 signatures from people across the state who oppose the facility closures.

The legislative protection measure, however, was facing a likely veto by Governor Romney, meaning that as of late June, COFAR's campaign was far from over.



GROUP EFFORT—State lawmakers and COFAR members pose for a group photo after COFAR's May 21 legislative and press briefing in the State House Senate Reading Room on facility versus community cost study. From left to right are Reps. Carol Donovan, Thomas Stanley, Mary Grant, Brad Hill, and Paul Donato; COFAR Board members Larry Harding and Thomas Frain; Reps. Angelo Scaccia and Barbara L'Italien, and COFAR member Mark Booher. (See story on page 2)

COFAR's campaign on behalf of residents in the facilities began shortly after Governor Romney announced in February that he was targeting Fernald and the other institutions for closure as a potential budget cutting measure. **COFAR opposes the closures, contending they will put the entire continuum of care for the retarded in Massachusetts at risk, without saving the state money.**

Language in both the House and Senate budget plans for Fiscal Year 2004 would require that a cost-benefit analysis be done before either Fernald or the other remaining state-operated facilities could be shut down. That language would also require that any residents transferred from those facilities be provided with equal or better care in any community-setting to which they are sent.

Playing a key role in the House in getting the budget language inserted was Representative Thomas Stanley (D-Waltham). Senator Susan Fargo (D-Lincoln) was instrumental in getting the language into the Senate budget.

On June 20, a House-Senate conference committee adopted language in the Senate version of the budget bill, which offered additional protections. Those provisions would require or authorize that:

- The Department of Mental Retardation (DMR) issue a report stating, in part, the steps being taken to minimize increases in travel distances for family members visiting residents who have been transferred from one facility to another.
- Fernald not be closed prior to October 2004 in order to ensure community, client, and family member input into the closure planning process.
- The DMR allocate up to \$5 million from the line item for residential and day services for residents formerly receiving care in state-operated facilities.

In a letter to the conference committee, COFAR noted that the language in the House and Senate versions of the budget erroneously stated that the DMR would take steps to consolidate or close state facilities in order to comply with the Olmstead (U.S. Supreme Court) decision. This decision, however, did not require the closure or consolidation of all state facilities. In fact, the Olmstead decision specifically stated what the U.S. Department of Health and Human Services had recognized: that "nothing in the (Americans with Disabilities Act) condones termination of institutional

settings for persons unable to handle or benefit from community settings."

Fernald workers march on Governor's house

More than 100 caretakers at the Fernald Center marched under a light rain on June 11 to the Belmont home of Governor Mitt Romney, calling on the administration to keep the facility open.

Dressed in neon-green T-shirts and holding placards, the coalition of unionized workers led a 2-mile-long march from Belmont's Beaver Brook Park to protest the governor's plan to close the facility, *The Boston Globe* reported. No plans have been made for the center's 800 workers. The governor was not at home during the protest, which organizers from the AFSCME Local 402 said was the first of three planned demonstrations.

COFAR highlights study on cost of care

BOSTON--A key weapon in COFAR's arsenal in its battle to save the state facilities this spring has been a newly published review of scholarly literature that challenges the widely held view that community-based care for the retarded is less expensive than institutional care.

On May 21, COFAR members briefed state lawmakers and members of the press on the article, in the Senate Reading Room at the State House. Published in the April 2003 edition of the journal *Mental Retardation*, the article reviewed more than 250 studies done over the past quarter century.

Dr. Mark Booher, psychologist and COFAR member, highlighted the review's finding that the 250 studies "do not support the unqualified position that community settings are less expensive than are institutions." The review noted that studies claiming budgetary savings in community-based care failed to control for a wide range of variables, including geography, staffing levels, and the severity of the mental retardation of the groups being compared. Studies that did control more accurately for those variables did not report savings in the cost of care in the community.

“Year after year, all we hear is that it’s more expensive to keep people in the state facilities,” said Larry Harding, a COFAR Board member. “This cost study punches a hole in that myth.”

COFAR President Thomas Frain said he felt the cost review confirmed his long-held view that the cost of care rises and falls with the level of disability of the person in question. “In the final analysis, it’s not about the money spent,” Frain said. “It’s about whose pocket the money falls into.” Frain maintained that politically connected vendors of mental retardation services were looking to profit financially from the transfer of potentially hundreds of residents of the state facilities into community-based programs.

Among the lawmakers attending the May 21 event were Senator Bruce Tarr (R-Gloucester); and Representatives Brad Hill (R-Boxford), who hosted the event, Angelo Scaccia (D-Boston), Thomas Stanley (D-Waltham), Carol Donovan (D-Reading), Mary Grant (D-Beverly), Barbara L’Italien (D-Andover), and Paul Donato (D-Malden).

Representative Stanley, who led the effort in the House to insert the facility-protection language in the budget bill, maintained that the administration has committed a “rush to judgment” in targeting the state facilities for closure. Not only had the administration’s savings projections in closing Fernald been cut in half in recent weeks, but the administration had yet to provide any financial details backing up those projections, Stanley said. He said he was continuing to request those details from the Department of Mental Retardation.

Representative Donovan told the group that while she believes community-based care is the best alternative for those whose mental retardation is not severe, she also believes the majority of the residents of the state facilities would not be likely to receive adequate service in the community. “I will do whatever I can to keep these institutions open,” she said.

Representative Scaccia urged the 40 COFAR volunteers in attendance to keep up their lobbying pressure at the State House. “You folks have been victorious because you have a passion for your family members (who live in the state facilities),” Scaccia said. “You’ll win this one too. But you have to stay in there. You have to work at it.”

Senator Tarr thanked the COFAR volunteers for attending the event. “We will have to make some difficult decisions,” he said. “Your being here will make a difference.”

The COFAR members spent the remainder of the afternoon on Wednesday delivering copies of the

literature review on institutional versus community-based cost to lawmakers’ offices and talking to the legislators or their aides in support of the facility-protection language in the budget.

COFAR members testify before Joint Committee on Human Services and Elderly Affairs

BOSTON--A week after COFAR’s briefing on the studies of the cost of institutional versus community-based care for the retarded (see story on page 2), COFAR members visited the State House once again to testify in favor of a bill that would establish a legislative commission to examine those same costs.

During a May 28 hearing before the Committee on Human Services and Elderly Affairs, Larry Harding, COFAR’s legislative liaison, delivered testimony in support of House Bill 1671. Filed by Representative Christine E. Canavan (D-Brockton), this bill would establish a 15-member study commission, consisting of legislators from the Human Services and Elderly Affairs Committee and the House and Senate Ways and Means committees.

Harding testified that COFAR supported the establishment of the commission, but recommended that the commission contract with an independent accounting firm to assist it in the compilation of the cost-comparison data.

COFAR’s research has shown that the DMR’s own analyses of the costs of the state-run and community-based systems have been unfairly biased in the past in order to portray the state-run system as more expensive to operate than the community system. This has been done by including in the state facility expenses such costs as the use of the facilities by non-residents, and the salaries and benefits of regional and area staff with offices at the state facilities. Also, DMR’s latest cost analysis was done prior to layoffs and retirements in January 2002 that eliminated approximately 272 positions across the state facilities.

Also delivering testimony during the May 28 hearing were COFAR members Diane Booher, who has two brothers living at Fernald; and Diane Kovacev, who has a sister there. Booher, whose brothers are both blind, have cerebral palsy and seizure disorders, testified that it would not cost less to serve her brothers in the community. She also expressed concern that they would

suffer if they lost the direct care and professional staff (especially nurses) who know them.

Kovacev noted that there are approximately 1,300 people still residing in the six state-operated facilities targeted for closure. "The closing of Fernald and other DMR facilities would call for the creation of multiple new facilities to house these clients," Kovacev testified. "This will take time and cost extensive amounts of money."

In addition to requiring a study of the costs of institutional versus community care, House Bill 1671 would survey mentally retarded individuals eligible for care in the Massachusetts state facilities (and their guardians). The survey would quantify how many would choose to live in state facility such as Fernald if given accurate and current information and a "fair and objective" tour of the facilities. The proposed legislation would also require a review of a preliminary report issued by a DMR Strategic Planning Working Group on the future of DMR facilities.

Meanwhile, a separate budget amendment (443) was approved by the Senate to create a special commission to study the costs and benefits of closing state facilities and using community-based system for those services. The Senate amendment called for a commission of nine members, three of whom would be appointed by the governor, two by the House speaker, two by the Senate president, and one each by the House and Senate minority leaders.

During the May 28 legislative hearing, DMR Commissioner Gerald Morrissey told the committee he had all intentions of moving forward with closing Fernald and several other DMR facilities, according to Kovacev. She said Morrissey also stated that he wanted to be sensitive to the clients needs and their families concerns, and that quality of care was his highest priority. He referred several times, she said, to the closing of the Dever school in Taunton in the early 1990s, and how long that took.

Kovacev also said Representative Antonio Cabral (D-New Bedford), House chairman of the committee, asked Morrissey about the minimum number of clients who might remain in state-run facilities. Morrissey said he had no clear answer, but that the DMR would be considering this as it went through the process of closing facilities.

Harding said that when he was called to testify, Cabral was the sole member of the committee to hear him. He said that in addition to testifying on the cost commission bill, he told Cabral that residents of state facilities currently have little or no access to community-based

facilities offering services comparable to those at the state facilities. He also maintained that if the most severely retarded of the state facility residents were moved to the to existing community residences, many would die.

Harding added that his son had "received great treatment at (the) Hogan (Developmental Center in Hathorne)," but that he was concerned that that facility would close. He said Cabral asked him the same question he had asked Morrissey about the number of state facilities that should remain open. He said he responded by asking Cabral what he would do if he were to receive a call from a constituent seeking care for a severely handicapped individual. "Wouldn't you want the best of care that can only be obtained in a large facility?" Harding said he asked. He said Cabral asked whether that meant all remaining state facilities should be kept open, and Harding said that was his hope.

Fernald use subcommittee formed

During the COFAR Board's May meeting, the Board approved a proposal of David Kaloupek, a Waltham area businessman with a background in health care consulting, to form a subcommittee to explore the idea of "a Village at Fernald".

Kaloupek agreed to chair the subcommittee, which will explore the possibility using portions of the Fernald site for other uses, while keeping the campus as a home for current residents. Kaloupek agreed to chair the subcommittee. COFAR Board member George Mavridis agreed to serve as vice chair, and Ed Haddad and Mark Booher and John Sullivan joined as representatives of COFAR. Other representatives will come from a variety of places, such as the Waltham City Council and local land/housing developers.

Petition drive continues to grow

On June 7, COFAR volunteers gathered at Shaw's Supermarket in Leominster to collect signatures in opposition to the proposed closure of the Fernald Center. **The effort brought the total number of signatures on petitions opposing the closure of Fernald and the other five state facilities to 13,393!**

American Legion hosts Fernald forum

WALTHAM—Local unions representing the more than 800 Fernald employees staged a forum May 12 at the American Legion Hall, with several family members of Fernald residents also attending, according to *The Waltham Daily News Tribune*.

Among the lawmakers attending were Senators Susan Fargo (D-Lincoln) and Pamela Resor (D-Acton). Also attending were Representatives Thomas Stanley (D-Waltham), Peter Koutoujian (D-Newton), Ann Paulson, (D-Belmont), and Patricia Jehlen, (D-Somerville).

Faces in the facilities and community

Belmont Businesswoman goes all out to save Fernald

BELMONT—Wanda Shepherd is ordering key blanks and shower curtains from a salesman who is visiting her hardware store at Cushing Square in Belmont.

“Do you also have four-inch roller frames?” she asks.

“Sure, got ‘em,” the salesman says, checking off a line on a clipboard.

A customer wanders in looking to have a key made.

“Be sure you sign the petition,” Shepherd says to the customer as she takes the key over to the grinding machine. She asks both the salesman and a reporter to bear with her for a few moments.

It’s a typical day at Winter’s Hardware, a business Shepherd bought several years ago. She’s busy. And yet she has found the time to do quite a bit of work on behalf of the families fighting to save the Fernald Developmental Center in neighboring Waltham.

Shepherd and a friend of hers at the nearby Ben Franklin’s Five & Dime have gathered close to 2,000 signatures on those petitions. Shepherd keeps hers next to the cash register. The petitions oppose the Governor’s efforts to close Fernald and the five other remaining state-operated facilities for the retarded.

Shepherd has also had bumper stickers made, as well as a 10-foot banner, which reads: “Have a Heart. Help the Residents of the Fernald Center Save Some Land for Their Homes and Special Care Needs!”

The banner was used in a march to Governor Romney’s home in Belmont by Fernald advocates and employees on June 11 (see story on page 2). “It makes me so mad that he (the Governor) was at the ballgame the other day, but he can’t find the time to go and see Fernald,” she says, noting that Romney lives only a short distance from the facility.

Shepherd has also had smaller signs made supporting Fernald and placed them at the Trapelo Road entrance to the facility—twice. The signs were removed each time. She said she was finally told that the signs are not allowed on state property.



Wanda Shepherd (left) and her aunt, Gertrude Merlino, who is a resident of the MarQuardt Nursing Center at Fernald.

What’s behind the desire of this proprietor of a small business in town to donate so much of her time and money to the Fernald cause? Part of it is that she has an aunt with mental retardation who is currently residing at the facility. Part of it, she adds, is that she has a background in human services, and understands the suffering that will ensue if the facility is closed. “They (the mentally retarded) need their own piece of land and a caring facility,” she says. “They’re human beings and they respond to human kindness. You don’t want them in a place where someone is just going to roll them over.”

Shepherd acknowledges that the Fernald residents don’t need all 182 acres of land that currently comprises the facility. Much of it can and should be developed for other uses.

“But just don’t take it all,” she insists.

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 to:

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