



The COFAR VOICE

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State Representative Antonio Cabral, D-New Bedford, and members of the State Legislature's Human Services and Elderly Affairs Committee speak with COFAR and Fernald League members after their tour of the Fernald Developmental Center on March 1. Visible from left to right are Erin Boles, research analyst with the Committee, COFAR Board member George Mavridis (back to camera), Representative John Scibak, D-South Hadley, COFAR member Dorothy Rouleau, COFAR member Joan Doherty, and Cabral.

Legislators visit Fernald

Cabral says he is 'open' to 'Village' concept

Even as the Romney administration maintains efforts to transfer residents out of the Fernald Developmental Center in Waltham, a key state lawmaker said he is open to a compromise proposal to preserve a portion of the 190-acre campus as a permanent site
(Please See Cabral on page 2)

COFAR testifies against DMR budget cuts

Volunteers bring message to State House once again

COFAR volunteers continued their advocacy on Beacon Hill on behalf of the mentally retarded on February 27, visiting the State House and delivering testimony opposing budget cuts in programs for the retarded to a joint session of the Legislature's budget writing committees.

The testimony, which was delivered to the House and Senate Ways and Means committees, stated that the budget cuts, if enacted, would affect more than 2,000 people, many of whom are seriously disabled and are currently not receiving Medicaid-based services from the Department of Mental Retardation. Close to 800 of these people are cared for at home or live on their own and receive no residential services from DMR.

Some 20 COFAR volunteers, one resident and four staff members of the Fernald Developmental Center in Waltham also spent part of the day on February 27 visiting the offices of all 200 legislators. COFAR is pressing for support both for the "Village at Fernald" proposal (see related story on this page) and for long-sought legislation to provide for independent investigations of abuse and neglect in the DMR system. (See photo of COFAR volunteers at the State House, on page 4).

COFAR's testimony was delivered in response to cuts proposed in Governor Romney's budget bill for the upcoming 2005 fiscal year, starting in July. COFAR urges restoration of the following specific funding cuts proposed in House 1:

- **Transportation (line item 5911-2000):** \$4.3 million cut—798 mentally retarded people would lose transportation to their day programs.
- **Day Programming (line item 5920-2025):** \$12.1 million cut—these same 798 mentally retarded people would lose their day

(Please see Testimony on page 3)

Cabral committee visits Fernald

(Cabral, continued from page 1)

for current residents of the embattled facility.

“At some point we have to look at the whole campus and use it in a more efficient way that is more conducive to the residents still living here,” State Rep. Antonio Cabral, D-New Bedford, House chairman of the Human Services and Elderly Affairs Committee, said at the conclusion of a March 1 tour of Fernald that he took with four other members of his committee. “I think there are options from total closure to something that would maintain a portion of the campus (for current residents) in an efficient way. I’m neutral on this, but open to those options.”

Members of the Human Services Committee who accompanied Cabral on the tour included Representatives Mary Grant, D-Beverly; Kay Khan, D-Newton; John Scibak, D-South Hadley; and Anne Paulsen, D-Belmont. Rep. Thomas Stanley, D-Waltham, continued his legislative leadership to save Fernald from closure, by hosting his colleagues on the tour.

Fernald Statistics

Total Population: 283

Male: 167

Female: 130

Mobile: 160

Non-ambulatory: 137

Age Range: 30-94

Deaf: 13

MR Status:

Hearing impaired: 60

Mild (IQ of 50-55 to 70):

12

Blind: 62

Moderate: (IQ of 35-40 to

50-55): 30

Vision impaired: 73

Severe: (IQ of 20-25 to

35-40): 56

Tube fed: 33

Profound (IQ below 20 or

25): 199

On ventilators: 9

Source: DMR

The legislators’ visit to Fernald follows several meetings last year between Cabral and COFAR legislative liaison Larry Harding. Last October, Harding, COFAR President Thomas J. Frain, and COFAR member and Fernald League President Diane Booher presented Cabral with a report contending that the administration is accelerating a trend toward a decentralized, privately operated system of care for the retarded that is lacking in oversight and accountability.

COFAR has been working with the Fernald League, the Waltham Council of Neighborhood Advocates, League of Women Voters and other organizations to develop the “Village at Fernald” concept, which calls for using “smart growth” principals to create affordable housing on the site, preserve open space, and encourage small scale- economic development and other activities. Both COFAR and the Fernald League are calling for preserving at least 60 of Fernald’s 190 acres as a site for current residents.

COFAR has been waging a battle with the Romney administration for more than a year over the future of Fernald and five other remaining state-run institutions for the mentally retarded. The administration has targeted Fernald for closure and would like to transfer the 283 remaining facility residents either to other facilities or to community-based care. COFAR maintains that Fernald and the other state-run facilities care for some of the most severely and profoundly retarded residents of the Commonwealth, and that the community-based system currently does not provide care that is comparable to the state facilities.

Despite COFAR’s longstanding attempts to negotiate a compromise with the administration, the DMR appears to be moving steadily to persuade families to relocate current residents. Some families are concerned that DMR may allow services and conditions to decline at Fernald, and move residents around on campus, which would encourage families to have their relatives transferred. Cabral and the other members of his committee visited a number of campus sites, including the Marquardt Skilled Nursing Facility, the Greene residential building, and one residential cottage. They talked to facility staff and were driven around the campus by Fernald and DMR officials. About a dozen COFAR and Fernald League family members accompanied the lawmakers on the tour. (See additional story about the tour on page 5.)

As he stood in front of the administration building after the tour, Cabral said he was struck by the large size of the campus and the number of closed buildings. There are 71 buildings on the campus, approximately 30 of which are closed. “Certainly, keeping the campus as is, is not a useful way to proceed,” he said.

George Mavridis, COFAR Board member and Fernald League past president, told Cabral that he had sent him a letter with drawings proposing the development of the eastern half of the campus and the retention of part of the western half for current residents. “I’ll look at it,” Cabral said to Mavridis.

The concept of a “Village at Fernald,” which would formalize a sense of community among all users and residents of the 190-acre Fernald campus, is being developed with input from members of COFAR, the Fernald League, and other Waltham groups and individuals.

Started in 1848, Fernald is the oldest publicly funded institute and residence for mentally retarded in the nation. It is currently also home to the 29-bed Marquardt Skilled Nursing Facility, the Commonwealth’s only specialized skilled nursing

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facility for adult and elderly mentally retarded patients. Additional tenants include the Eunice Kennedy Shriver Research facility, the Greene Therapeutic swimming center and gym, the Tufts Dental Clinic for people with mental retardation and developmental disabilities, the Fernald League Opportunity Workshop, Inc., and a special needs wheel chair and adaptive technology manufacturing and service facility. Three homeless shelters are leased to, and operated by, a not-for-profit agency. The agency provides temporary housing for sixty mothers and over 200 children.

The Legislature has stepped in to slow the closing of Fernald and asked for documentation of \$4 million in annual savings initially claimed by the administration. The DMR has not released documentation of any projected saving and now claims closure is to benefit the quality of life of the residents.

The Village at Fernald

The proposed Village would consist of continued and perpetual state ownership of at least 60 acres of the 190-acre Fernald Center site as the home for current and future generations of severely and profoundly retarded individuals. As vacancies occur because of death and other circumstance, the Village would be open to new residents based on their individual housing and service plan needs and the preferences of residents, parents and guardians.

Day services at the Village would be shared with mentally retarded persons living in group homes, nursing homes and in the community. Land use, facilities, operational and financial plans would be developed for the entire 190-acre site with involvement of and oversight by Waltham City officials, knowledgeable professionals, Fernald parents and guardians, elected and appointed State government officials, neighbors, planners and community advocates.

Advocates of the Village idea note that thousands of retarded people are waiting for DMR services, some with severe disabilities that would benefit from a setting such as the Village. These include members of the group turning 22 years old who are leaving the services of their public schools, and those on waiting lists for services in the community. They contend that services for many of these people could be provided at Fernald in conjunction with the nursing facility, the dental clinic and residential space in the Village. "It makes more sense," said COFAR President Thomas J. Frain, "to bring appropriate people from the community to Fernald rather than to evict people from Fernald and place them in the already overburdened community system."

"We look forward to a dynamic working relationship with members of the greater Waltham community who agree that evicting the current residents of Fernald from their community of peers and staff is life-threatening and unacceptable," added Colleen Lutkevich, COFAR Executive Director. "We know the Village at Fernald provides a model of coordinated, intensive care for people with mental retardation, and we

welcome its integration into a dynamic, planned community that also benefits the residents of surrounding neighborhoods."

Rep. Wolf defends Village

Among the highlights of the February 27 legislative budget hearing at the State House (see story starting on page 1) was an exchange between state Rep. Alice Wolf, D-Cambridge, and an advocate for the disabled. The advocate was testifying before the joint House and Senate Ways and Means committees and inaccurately claimed that residents of Fernald and the other state schools were "warehoused" there.

At that point, Rep. Wolf interrupted him. She referred to the Village at Fernald concept and said various groups are trying to work out a solution for residents there who "would have difficulty transitioning to the community." She added that this compromise proposal was something that needs very careful attention." COFAR members in the audience applauded Rep. Wolf's statements.

COFAR testifies on budget cuts

(Testimony, from page 1)

programming. The DMR has commented that without day programs, these individuals may require more costly residential supports.

- **Regional DMR Administration (line item 5920-1000):** \$1 million cut—this would eliminate 20 service coordinators out of 477 across the state, forcing the reallocation of 1,000 mentally retarded persons to new service coordinators.
- **Clinical Team Services (line item 5920-2000):** \$1.2 million cut—2,400 mentally retarded persons could lose 50 percent of their clinical supports.
- **Facilities (line item 5930-1000):** \$5 million cut, divided among all facilities. The DMR has proposed partially mitigating this cut by pursuing additional federal Medicaid funding. This may be problematic, however, because the Bush administration is reportedly cracking down on the practice among states of seeking federal funds to make up for cuts in state Medicaid funding.

During their visit to the State House, the COFAR volunteers delivered packets of information to the offices of every House and Senate member. They also urged support of HB 2066, which would transfer investigative resources from the Department of Mental Retardation and from other state human
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services agencies to the Disabled Persons Protection Commission (DPPC).

COFAR has also asked the House and Senate Ways and Means Committees to support a restoration of funds in the Governor's budget to the DPPC. The Governor's FY05 budget bill proposes restoring \$132,419 to the DPPC to enable the agency to add three new oversight and investigations positions (line item 1107-2501). (See the January 2004 COFAR Voice about the impact of budget cuts on the DPPC).

House passes whistleblower bill

The Massachusetts House of Representatives has approved a bill, which would impose a civil penalty on anyone who retaliates against persons who report abuse of the disabled.

HB 3241 is currently before the Senate Ways and Means Committee. A statement issued by the Disabled Persons Protection Commission in support of the measure noted that state law already provides only for a criminal penalty against those who retaliate against whistleblowers in abuse cases. A civil remedy providing for treble damages is needed to make victims of retaliation whole, the DPPC stated.

COFAR has also called for support of HB 2066, which would transfer investigative resources to the DPPC. The DPPC is the only statewide organization in Massachusetts that conducts independent investigations of abuse and neglect of disabled adults.



COFAR members (in second row) listen to testimony during February 27 state budget hearing before the joint House and Senate Ways and Means committees.

COFAR launches fund drive

COFAR has received renewals from about half of the organization's current membership as well as new memberships from 46 people as a result of membership renewal and fund drive letters that were sent out in February.

COFAR Executive Director Colleen Lutkevich urged members to take the time to renew their memberships (see last page of newsletter for COFAR contact information). The fund drive letters noted some of the highlights of COFAR's activities over the past year and the results achieved:

- **April 2003:** COFAR began a series of public advocacy actions kicked off by an April 17 rally at Fernald. COFAR volunteers urged passage of language in the Fiscal Year 2004 state budget to prevent the closing of the state facilities until both a cost-benefit analysis is done showing a real savings and there is a guarantee of equal or better care to current residents.
- **May 2003:** COFAR members briefed state lawmakers and members of the press on an article published in the prestigious journal *Mental Retardation*, which challenges the widely held view that community-based care for the retarded is less expensive than institutional care.
- **June 2003:** COFAR volunteers delivered petitions containing more than 14,000 signatures opposing the facility closures to the offices of Governor Mitt Romney, House Speaker Thomas Finneran and Senate President Robert Travaglini.
- **June-July 2003:** The House and Senate approved budget language protecting the state facilities from immediate closure and then overrode a veto of the language by Governor Romney.
- **August-October 2003:** COFAR volunteers held a series of meetings with State Representative Antonio Cabral, D-New Bedford, House chairman of the Human Services and Elderly Affairs Committee, to continue to press the case for comprehensive care for the mentally retarded. In October, COFAR presented Cabral with a report concluding that summary closures of the facilities will only disrupt the entire DMR system.

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- **October 2003:** COFAR brought together close to two dozen state lawmakers, scores of volunteers, state employee union members, more than 50 DMR staff, and many others to the organization's Annual Dinner. Honored during the occasion were U.S. Congressman Edward Markey and four state lawmakers for their commitment to the welfare of the mentally retarded. Former New Jersey Governor James Florio gave the keynote address.

Fernald tour an emotional experience for some

Lucy Leyland asked whether the group might visit her brother during the March 1 legislative tour of the Fernald Center campus (see tour story on page 1).

Leyland was one of about a dozen CORAR and Fernald League family members accompanying state legislators on their tour. The legislators and family members had split into two groups in the Greene residential building, and Leyland was with those who were being shown the floor her brother lives on. Diane Enochs, a DMR administrator, who is overseeing efforts to close Fernald, assented to Leyland's request and Leyland led the way to her brother's room. Inside, her brother, Bradford, was sitting cross-legged on a mat on the floor, a child's toy in his lap. Four other residents were sitting or lying on similar mats as two Fernald staff members watched over them.

"Hello, hello," Leyland said softly as she knelt down next to her brother. A smile came over his face and he reached for her hand. His clasped his hand around her wrist.

"Leaving him is always the hardest part," said Leyland, as she sat on the floor next to her brother, her wrist still firmly in his grasp. "He doesn't want me to go. The other day after I left I was in tears. But I feel good about him being here. The nurses are fabulous."

Leyland and other family members are concerned that the level of care their relatives are receiving at Fernald may not be available in the community. Leyland said her brother is very susceptible to infectious diseases and has to be in "a very clean environment." The Greene building is kept so clean, she said, that her brother has avoided infections.

Earlier in the Marquardt Skilled Nursing Facility, Jane Crowley told the lawmakers that her 55-year-old sister, Anne Byrne, has thrived due to the care there. "When she came here, she couldn't even talk," Crowley said. She had been in

several hospitals, she said, and had developed a serious bone disease before coming to Fernald.

Linda Roedder, director of nursing at Marquardt, said that the nursing facility staff "are the experts in mental retardation. The folks do really well here." The nursing facility has 29 beds. Two of those beds were empty, she said, but there were five people waiting for them. She said the facility doesn't have enough space to accommodate the demand for care there, and must refer patients to private facilities.

Family members and Fernald staff were also eager to show the lawmakers the activities rooms and the therapeutic swimming pool in the Greene building. Karen Cole, habilitation coordinator in the Greene building, showed off an elaborately designed workshop in which even severely retarded residents are able to shred newspaper and make the shredded material into fireplace bricks. Cole said clinicians and staff spent years developing the workshop, which has equipment that can be operated by people with severe physical handicaps.

At the swimming pool, Peter Marron, aquatics manager, talked about the therapeutic value of the 90-degree water, particularly for residents who spend most of their time in wheelchairs. "The water really gets them to open up and relax," Marron said. "It's dramatic and vital that they use this place." He said the pool is used by Fernald residents, many special education students and by several community-based programs for the mentally retarded. He said that water sanitation standards are among the highest in the state.

Cleanliness also appeared to be a priority in the Greene building. "There are no bedsores here," said Joseph Breen, acting facility director at Fernald, as he showed lawmakers some of the rooms. Bedridden patients are turned frequently enough, he said, that "there is very little skin breakdown."

The group's final visit was to one of the campus's ten residential cottages, referred to by the staff as the "Pizza Huts," because of their squat, 1970s design. Each single-story cottage houses 16 residents and contains two lounges, two day rooms, a dining room, and a kitchen. Many Fernald advocates see maintaining the cottage complex as central to keeping residents at Fernald because 42 percent of residents currently live there.

VOR Washington Initiative

COFAR's national affiliate, the Voice of the Retarded, will hold its 2004 Annual Meeting on the weekend of June 12. On Saturday, the annual meeting will be held, followed by a networking dinner where people can meet advocates from other states. On Sunday afternoon, briefing folders will be distributed, and on Monday people begin visits to their own state legislators. Debriefings occur each afternoon with sharing of ideas by members. Discount hotel and airline tickets available. Call the COFAR office if you would like to attend and information will be forwarded to you.

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 contact us at:**

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The COFAR VOICE
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COMPREHENSIVE CARE
FOR ALL PERSONS WITH MENTAL RETARDATION

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