



# The COFAR VOICE

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

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*Special Fernald Update Issue*

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***Inside: A Fernald parent faces a stark choice as she faces her son's future alone, story on page 4.***



The Marquardt Skilled Nursing Facility shown here at the Fernald Center would be one of the buildings closed under the DMR 13-point plan, and its 27 beds transferred to a new unit at the Greene building.

## **Plaintiffs reject DMR Fernald plan**

The Department of Mental Retardation has presented a 13-point closure plan for the Fernald Developmental Center that would allow up to 97 of the 266 existing residents to remain on campus indefinitely, but the proposal has been rejected by the Fernald plaintiffs, represented by Attorney Beryl Cohen, who may seek to reopen a landmark legal case against the administration.

The plan was presented orally in a final negotiating session between the plaintiffs' attorneys and DMR on June 8. The plaintiffs, who include members of family advocacy

organizations that belong to COFAR, including representatives from Fernald, and Wrentham, as well as Monson, Belchertown and Dever family groups and the Association of Retarded Citizens of Massachusetts (Arc). "We have gone into these negotiations in good faith," said COFAR Executive Director Colleen Lutkevich. "But the DMR's plan regarding Fernald has simply been inadequate. Their plan for Fernald does not address the pain and disruption that will occur to the vast majority of Fernald's residents and their families if Fernald were to close.

**(Please see DMR Plan on page 2)**

## **Facilities cutback remains after DMR budget restorations**

While several DMR line items in the state's 2005 Fiscal Year budget were given modest boosts by the Legislature in the budget process this spring, the Fernald Developmental Center and the other state-run facilities for the mentally retarded are not sharing in the largesse.

Both the House and Senate have maintained a \$5 million cut in the DMR account for state-run facilities, including Fernald.

Also faring relatively poorly among the DMR accounts was funding for DMR service coordinators. The Legislature restored only \$88,000 of a \$1 million cut in the Governor's budget proposal in funding for service coordinators in the DMR system.

Meanwhile, COFAR was urging the House and Senate to override the Governor's veto in late June of \$20 million in the budget to fund a salary reserve to boost the salaries of direct care workers in the DMR community system and other human service fields.

## Plaintiffs reject DMR plan

(DMR Plan, continued from page 1)

Among the key provisions of the DMR plan are that 65 Fernald residents would be given the opportunity to transfer to other remaining, large, state facilities and that the Malone Park cottages on the Fernald campus would be converted to state-operated group homes for 24 to 32 existing Fernald residents.

In addition, the plan calls for 25 existing vacancies in state-operated group homes to be made available to Fernald residents, and the Greene Building on campus to be converted to a skilled nursing facility with 65 beds. The plan further states that the DMR would build or renovate 40 state-operated beds in group homes in the greater Waltham area and 40 more such beds in the northeast region of the state.

In a June 21 letter to DMR Commissioner Gerald Morrissey, plaintiffs' attorney Beryl Cohen stated that no written copy of the DMR's plan had yet been provided the plaintiffs and that the plan was not funded and had not been approved by either the Romney administration or by legislative leaders. Cohen's letter also contended that the plan "ignores the ISP active treatment needs of nearly 200 residents at Fernald."

Among Cohen's key objections was that the proposed transfers of Fernald residents to other state facilities would be disruptive and could potentially involve multiple relocations. [See story on page 3] The letter also noted that the community lacks adequate resources to accommodate the additional facility residents and will therefore be unlikely to provide equal or better care to them.

"We reject the notion that all people with mental retardation are better served in small community residences from which they negotiate all services and supports within the wider community," Cohen's letter stated.

In 1972, separate lawsuits were initially filed on behalf of the residents of five state facilities, including Fernald, charging that the facilities were understaffed and that conditions in them were inhumane. In the following 20 years, the DMR instituted capital and staffing improvements to the facilities under Tauro's oversight. When Tauro disengaged from the case in 1993, he characterized the system of facility care in Massachusetts as "second to none anywhere in the world."

In April, the plaintiffs' attorneys sent letters to DMR Commissioner Morrissey, charging a series of violations of Tauro's final 1993 order. Attorney Beryl Cohen's letter cited the administration's planned closure of Fernald in conjunction with "unprecedented" personnel reductions and budget cuts throughout the DMR system in the past several years as "systematic violations" of Tauro's disengagement order.

As stipulated by Tauro's final order, DMR and the plaintiffs' attorneys have held three negotiating sessions—on May 28 and on June 7 and 8—in an effort to resolve the case before seeking Tauro's renewed engagement.

Based on notes compiled by COFAR and Fernald League members, the following are the 13 elements of the DMR plan:

1. Fernald families may participate in any provider-directed program in the community, including shared living and family partnerships.
2. DMR will build or renovate 40 state-operated beds in group homes in the greater Waltham area and 40 more such beds in the northeast region of the state.
3. Approximately 25 existing vacancies in state-operated group homes in communities around the state will be made available to our Fernald family members.
4. There will be opportunities for 65 Fernald residents to transfer to other large DMR facilities, such as the Wrentham, Hogan, Templeton, Glavin, and Monson developmental centers.
5. The 27 beds at the Marquardt Skilled Nursing Facility will be transferred to the Greene Building on the Fernald campus. The Greene building will be converted to a Skilled Nursing Facility level with a total of 65 beds. Ed note: Not all current Greene residents may qualify to remain in a SNF.
6. The UMass/Shriver center will relocate somewhere on the Fernald campus and house outpatient services, research, the Tufts Dental Clinic and the Therapeutic Equipment Center.
7. The Malone Park ICFs/MR will be converted to state operated group homes for 24 to 32 Fernald residents. Ed note: those residents will most likely receive services in the community.
8. DMR will participate in planning other uses for the Fernald property.
9. Fernald residents transferring into the community will have a written letter guaranteeing their return to a DMR facility if all agree the placement has failed.
10. DMR will rededicate itself to achieving maximum family involvement through the Individual Service Plans and Individual Transition Planning Teams.
11. DMR will maintain full compliance with all DMR regulations, the Court Order and legislative directives.
12. There is no timetable for closing Fernald. It may take until FY06 or FY07 to complete an orderly transfer of all residents.
13. DMR will reach out to families through possible family forums. The stakeholders' meetings will continue, including COFAR, the Fernald League, Arc., the Governor's Commission on MR, the Center for Social Development and Education and other organizations.

(Please see DMR Plan on page 4)

## We reject the plan to close Fernald Center because:

[The following are the objections to DMR's Fernald closure plan, listed in plaintiff attorney Beryl Cohen's June 21 letter to DMR Commissioner Gerald Morrissey, see story starting on page 1.]

- There is no clinical basis for transferring individuals whose families and guardians want them to continue living at Fernald. "These individuals have not suddenly progressed to being ready to live in the community."
- The closure plan requires relocation of Marquardt skilled nursing facility residents for administrative reasons that are unacceptable.
- DMR has not shown there will be savings to taxpayers as a result of creating new or rehabilitated housing in the community for those residents who need more medical and nursing care.
- DMR has not presented any valid cost comparison between the community and Fernald for equivalent services for comparable groups of retarded people. The Legislature mandated such a study as well as assurance that proposed care be equal or better to care at Fernald for any resident being transferred out.
- DMR's own May 2002 study projects a need for 671 to 912 state facility beds through Fiscal Year 2011. DMR has reported that no renovations are underway in other facilities to receive Fernald residents and that no facility staff are being added. Some Ricci class members presently living in other DMR facilities will therefore have to be relocated to offer ICF/MR care for Fernald residents. This displacement of Ricci class members into the community system would affect other retarded adults waiting for community services.
- DMR has not explained why Fernald is the first ICF/MR to be closed or presented any analysis to explain the order and rationale for further closings at Glavin, Hogan, Monson, Templeton, and Wrentham.
- Offering 65 transfer opportunities to other DMR facilities scheduled to be closed is in fact offering Fernald family members multiple relocations with attendant stress and hardship.
- DMR has not afforded all retarded people or other families the choice to live at Fernald. Neither DMR nor the Legislature know if Fernald could achieve a stable census with open admissions and whether a stable census would enable more efficient operations.
- The community system has not yet been adequately supported to develop a stable, trained workforce to provide a lifetime of consistent, quality care for all retarded people who live in settings outside DMR facilities.
- The closure plan places higher importance on ideology and policy than on the needs of individual

people with mental retardation as represented by their guardians. Fernald residents have a higher urgency of need for services than the average person in the community by virtue of their dependence on others for life-sustaining care.

- The closure plan and the plan to convert Malone Park to state-operated group homes does not guarantee that current residents will be allowed to remain there, even if they waive the treatment-rich model of ICF/MR services and accept community care that is neither equal nor better.
- The plan to close Fernald Center and build or renovate state-operated group homes exists only on paper and there is no way for individuals and their families to know if these residences will be equal or better.
- The closure plan and the plan to relocate family members to existing vacancies in state-operated group homes are based primarily on whether a particular bed is vacant and only secondarily on the needs of the Fernald residents. The plan also perpetuates injustices within the DMR system because some retarded people have waited for years for such community placements.
- The closure plan fails to provide continuity for any Fernald resident. Even those few who might be allowed to remain at the Greene Building or Malone Park do so with changes in staff, peers, programming and location of services.
- The need for intermediate care facilities is growing as the population of aging baby boomers is growing. This demographic bulge of retarded people will need additional medical, nursing, dental and other skilled care as they age to prevent and/or minimize suffering.

### COFAR gets \$75,000 grant

COFAR has received a \$75,000 grant from The Fernald Corporation, the largest donation the nonprofit corporation has made to COFAR to date.

George Mavridis, a COFAR Board member and Fernald League past president, said the grant will be provided in three installments, each four months apart. Last year, COFAR received \$20,000 from The Fernald Corporation.

"This is a tremendous gift for COFAR," Board President Thomas J. Frain said. He said a portion of the funds would be earmarked to help implement a plan for a series of seminars around the state. The seminars would work to inform families of people with mental retardation about advocating for better care for their loved ones. He said he hoped to hold the initial seminars in Springfield, Worcester, Boston, and Fall River.

## DMR Plan for Fernald

(continued from page 2)

### The Arc position

In a recent newsletter, Arc officials stated that they opposed the DMR plan because it would allow the “continued operation of segregated facilities and the fact that almost 100 people will remain at Fernald.” In the article, ARC also contended that if the Commonwealth were to continue to invest “long-term dollars” in Fernald, mentally retarded persons would be “forced to live there as openings develop.” The article also referenced the Olmstead Supreme Court decision on community-based care, and stated that the Romney administration had not proposed needed investments in community services, including upgrading of frontline managers and staff and clinical services.

The ARC article further contended that public pressure to maintain the “segregated service model” continues to be supported by an “uninformed public.” and that the proposed “postage stamp plan” at Fernald reflects “our failure to properly educate the public and families at the facilities.”

### COFAR response

Responding to the Arc article, Lutkevich stated that it is untrue that keeping people at Fernald would force others into the facilities. “Each guardian has the right to decide where their family member should live,” Lutkevich said. She said that there are many people who might benefit from a facility placement due to the severity of their mental retardation and their physical or behavioral needs. For many years DMR has denied admission to state facilities for such people because of their “closed admissions policy”. “For the Arc to state that people will be forced by DMR to live in openings that may occur in the proposed 24 to 32 state-operated Malone Park placements is inflammatory at best,” she said. “There will be few openings, and as they occur, families will be eager to accept them.” Lutkevich also made the following points:

- A key reason COFAR opposes the closure of Fernald is the instability of the community system, including high staff turnover and less oversight for those with intensive medical and clinical needs.
- The Arc article incorrectly referenced the Olmstead Supreme Court decision in advocating the closure of state facilities. In fact, the Olmstead decision explicitly states that “we emphasize that nothing in the Americans with Disabilities Act or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings.”
- COFAR objects to statements that its families are uninformed. COFAR also objects to the concept that it is

the Arc’s responsibility to “educate” facility families. “The Arc has a very strong interest in closing state facilities,” Lutkevich said. “Given that known bias, there must be better sources of educational information. “

- The Arc is narrow in its definition of “community.” “State facilities are not segregated, but are regional centers that serve both mentally retarded members of the larger community, and facility residents who participate in the community for services and activities,” added Diane Booher, Fernald League President and COFAR member. “DMR facilities are also well-integrated into the community because they are open to visitors, being public institutions. Our legislators can visit. Taxpayers can visit. Group homes, while appropriate for many, can lack the sense of community offered in a stable facility environment, and are also less able to be closely monitored,” she said.

### *Know your rights on transfers*

Fernald League President Diane Booher says that those families who don’t want to consent to the DMR’s plans to move their family members out of state facilities should request treatment plans for their family members under the “Transfer ISP process.”

Transfer ISP regulations require DMR to present a written statement that describes why the proposed transfer is better than the current placement. There are other protections, including a letter of appeal from the guardian listing reasons for believing the proposed transfer does not offer better care for the ward. DMR must then request a hearing through formal channels.

“For DMR to move people who are wholly dependent on them for care, against their will, is to treat them like packages,” Booher said. “The package may be carefully prepared for shipment, and the destination may be prepared to receive it, but it may still be true that the contents are fragile and better off not being moved.”

## *A Fernald parent faces a stark choice*

[One in an occasional series of articles on care in the DMR system]

Jane Gabel is the first to tell you that the story of her son’s care at the Fernald Developmental Center has in many ways been a typical one.

Jimmy Gabel, now 49, has been a resident of Fernald for 34 years. He is profoundly retarded and needs intensive, one-on-one care on a round-the-clock basis. He is subject to panic attacks, which can turn violent, and needs Lithium to stay on an even keel.

“I’m probably not the best person for a story,” she says. Yet, her story is one that she does want to tell the world.

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“My political opinion is that every parent who has to make the difficult decision to place their child in a state facility has to trust that the state will live up to its promises and obligations,” she says.

Like hundreds of other family members, Jane Gabel’s life has been upended by the Romney administration’s decision to close Fernald. And like hundreds of others, she’s found it difficult to cope with the uncertainties and the worries that the DMR seems to have done very little to allay, she says.

For instance, there was the anxiety she experienced in mid June when she received a “Placement Profile” from the Fernald administration, indicating that her son would be placed in a state-operated group home in the community. Several months earlier, she says, she and her husband had made it clear to Fernald administrators that they wanted Jimmy to remain at Fernald and not to be sent to a community residence, even a state-operated one.

“Jimmy has always been difficult to handle,” Gabel says. “I feel there’s absolutely no way he can live in the community.” She says that her basic concern is that his Lithium would not be provided to him on a consistent basis in a community-based group home.

Shortly before her husband died in February, Gabel received a Placement Profile questionnaire from DMR administrators, which asked a number of questions about her son’s care. She filled it out as best she could, she says, and mailed it back with a cover letter, reiterating her stated preference that Jimmy remain at Fernald. It was a shock, therefore, when she received the Placement Profile in June and a form letter from Fernald’s Acting Facility Director, stating that sections of the Profile had been completed for her because she had failed to participate in the process. “I found that unbelievable,” she says.

Gabel wrote a letter in response to the Acting Facility Director, stating that her objections to a placement in a community residence had to do with Jimmy’s “safety, medications, and difficult behavior, which might make such a placement impossible.” Her letter added that: “...the State is now reneging on what we considered a promise to care for him in an institutional setting, thereby gaining for him the advantages of what a place like Fernald offers.”

Shortly after a *COFAR Voice* reporter accompanied her on a visit to her son at Fernald in late June, Gabel received a phone call from the Acting Facility Director’s office. She said she was told that the Placement Profile for her son was being changed to reflect a preference for a state facility, and was asked whether she would be satisfied with having Jimmy transferred to the Wrentham Developmental Center. She responded that she would prefer that Jimmy remain at Fernald. Wrentham, after all, may be next on the list to be closed.

Gabel now faces the uncertain prospects of her son’s future alone. She knows one thing, though, and that’s that she will fight to keep him out of the community for as long as she can, not only because the care in the community is currently not comparable to the care at Fernald and the other state facilities,

but because her son is such a difficult resident to deal with that she’s sure no community-based group home would want to take him.



Jane Gabel and her son, Jimmy

“If he could be taken care of in a community residence with its limited staff, I’d keep him at home,” she says. “He absolutely requires one-on-one staff, 24 hours a day. There is no community home I’ve heard of that offers that kind of care.”

Gabel has always struggled with the “terrible decision” she and her husband first made to place Jimmy in state care, when they were living in Illinois in the 1960s. That first placement was in a private home in Red Oak, Iowa. Jimmy couldn’t be handled there, however, and Gabel and her husband immediately brought him back home when they found out that he’d been tied to his bed there with women’s stockings. Then, the state placed him in another private facility in southern Illinois. At the time, Gabel’s husband, an archeologist, was leaving for Africa to do field work and she was preparing to join him there. She went to visit Jimmy and couldn’t bear to leave him there, so she took him with them to Africa.

But after her third child was born, she says, it became impossible to care for Jimmy at home. He presented a physical danger to their youngest child. The Gabels placed him in a state facility in Illinois. In 1970, after they had moved to Massachusetts and her husband had begun teaching at Boston University, Jimmy was transferred to Fernald.

Things have greatly improved for Jimmy since those early days at Fernald, when there was a population there of close to 2,000 residents. Today, Jimmy seems to recognize certain attendants, who have worked with him and taught him to recognize his parents. He is taken to a workshop every day on the grounds where he spends much of each day in organized activities before returning to his residential cottage in the afternoon.

“All other things being equal, I think we’ve moved forward in keeping Jimmy as part of the family as best we could by visiting him,” Gabel says. “That’s always been the basis of our relationship.”

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](http://www.cofar-mass.org), or write to:**

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

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