



The COFAR VOICE

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Special Issue on the State-run MR facilities

Exploding the myths

Facility supporters: Amid change, care must be a constant

[Second of two parts on the quality of life in state facilities.]

No one disputes that in the future, the Fernald Developmental Center campus in Waltham will be very different than it is today.

The large, open fields that have characterized Fernald, as they do many other state facilities for the mentally retarded in Massachusetts, may well be dotted with businesses and housing one day. What is in dispute, however, is whether the Fernald site will continue to include a place in that mix for persons with mental retardation. Those who advocate the continued existence of state care for the retarded at Fernald have a vision in which their portion of the campus exists in harmony with all the other users. They refer to their vision as a "Village at Fernald."

COFAR members and other facility advocates say their focus isn't on preserving the land or buildings on the facility campuses. They recognize that those things will always be subject to change. But they are focused on preserving the state-provided *care* that the residents receive at those sites. The Village at Fernald, for example, is both a proposal to preserve care and a call for an inclusive planning effort for the future disposal of the campus land, with the goal of establishing a "community" among all users of the site.

Lately Fernald has been the most visible of the six state facilities for the mentally retarded because the Romney administration has targeted it for closure first and because it has become the focus of an effort in federal court to stop the administration's closure plans. The Village plans are at the
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Diane Derosier in her room at the Glavin Regional Center

Exploding the myths

Glavin resident connects with community

Diane Derosier has lived at the Glavin Regional Center in Shrewsbury for the past 15 years.

"It's okay," she says of her life at the central Massachusetts facility. It soon becomes clear, though, that Derosier enjoys understatement. Her eyes light up when she enumerates the many activities she's involved in now, such as cooking meals for other residents, including Shepherd's Pie, in the small kitchen down the hall from her room.

Once a week, on Mondays, Derosier works as a housekeeper at Shrewsbury Community Services. She worked in the past at Edward's Supermarket, which, she is quick to remind everyone, was recently bought by Stop & Shop. On Wednesdays, she goes dancing with some other Glavin
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Glavin resident connects

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residents at Sh-Booms, a night club in Worcester. “It’s my kind of place. It has a TV screen on the wall,” she says. But best of all, it has Disco music. “I like the 70s sound,” she adds.

Al Bacotti, Glavin’s Director, says Derosier is a good example of a Glavin resident who has been able to integrate her life with the surrounding community and continue to thrive in a facility environment. Adds Roland Charpentier, President of the Glavin Parents Association, “She’s a big sister for a lot of people here. She will watch out for others.”

Derosier has a room all to herself at Glavin, and it has the home-like feel of an apartment bedroom. There are stuffed animals on her bed, and pictures on the walls. But as Bacotti notes, what Derosier enjoys most is making connections with the world outside her room.

Derosier likes to go with other residents and staff on vacations. Last summer, Glavin staff members took her and other residents in her unit to Woods Hole. “Richard (Roland Charpentier’s brother) came to Woods Hole with me,” she says, sounding like any globetrotting vacationer who likes to drop names of the exotic places they’ve been. “I also went to New York—Manhattan—with Gina. I went to Maine and Florida.” Derosier particularly liked the Universal Studios theme park in Florida.

In Woods Hole, they took in the souvenir stores and then took the ferry to Martha’s Vineyard. On Sundays, she goes home to visit her mother and father and nieces and nephews. Her father, she notes proudly, is a minister. “She’s very involved in her church,” Charpentier says.

Fernald plaintiffs to get access to key resident records

The attorney for the Fernald Developmental Center plaintiffs in the landmark Ricci v. Okin lawsuit will receive unprecedented access to Fernald resident records in order to probe a question that has been at the heart of the controversy over the planned closing of the state facility for the past two years.

The question is: are the residents who are leaving Fernald getting equal or better care and services in their new locations?

In a January 20 status conference with attorneys, U.S. District Court Judge Joseph Tauro ordered the Department of Mental Retardation to provide Beryl Cohen, the Fernald plaintiffs’ attorney, with records relating to the Individual

Support Plans for all Fernald residents, including those who are transferred elsewhere. Those records, which hold information about care and services available and planned for DMR clients, had previously been unavailable to the plaintiffs. Comparing the ISPs of Fernald residents before and after they are transferred from the facility could shed light on whether the care and services diminish once the residents are located elsewhere.

During the January 20 conference, Tauro denied Cohen’s motion to reopen the historic Ricci case. However, the judge stated that he was prepared to step back into the case—which he oversaw for 20 years, from 1972 to 1992—if Cohen were to demonstrate that care and services to transferred individuals were being cut.

Cohen would first have to seek to get the situation corrected by the DMR Commissioner, and could then go to Tauro as a last resort. In his 1993 disengagement order, Tauro stipulated that any resident transferred from a state facility must receive equal or better services elsewhere.

In July 2004, Cohen filed a motion to reopen the Ricci case, arguing that the DMR has been systemically violating Tauro’s 1993 disengagement order by simultaneously cutting staffing and services at Fernald and attempting to shut the facility down without having certified that equal or better care is available elsewhere. Some 246 residents remain at Fernald out of a total of about 1,100 residents who remain in the six state facilities.

Of 43 persons who have left Fernald, 37 have opted to live in other state facilities, even though those facilities could be next to close, Cohen said.

During the January 20 conference, Cohen stated that 43 Fernald residents had volunteered to transfer out of the facility since the Romney administration announced its plans to close the facility in February 2003. However, only 6 of the 43 opted to live in community-based residences, Cohen said. Thirty-seven asked to be transferred to other state facilities, even though those facilities could be next on the list for closure.

“We think the answer to the question whether services in the community are equal to or better than in the state facilities can be found right there in the decisions of 86 percent of the Fernald residents who left to go to live in other state facilities rather than the community,” said Thomas Frain, COFAR President. “However, these ISP records should give Attorney Cohen the information to examine that issue in a thorough and perhaps definitive way.”

Frain said he believed that if and when the administration takes steps to shut down other state facilities, Tauro would grant similar access to the ISP records at those facilities to attorneys representing the residents’ families and guardians.

Care: a constant amid change at facilities

(Facilities, continued from page 1)

moment, unique to Fernald. But while there haven't been similar village-style plans in the works among the other facilities and community groups, there appears to be a similar commitment among those other campuses in maintaining close connections with their surrounding communities and in sharing their facilities with those communities as well.

"I think this is a wonderful complex of buildings," says Al Bacotti, Director of the Glavin Regional Center, which is home to 63 residents in Shrewsbury. "This is the newest of any facility in Massachusetts, and it's well maintained, with a modern physical plant. But it's not just the bricks and mortar. It's a community that's part of a community. It's all about the people who work here."

Today, roughly 1,100 residents remain in the six facilities, which include Fernald, Glavin, the Wrentham Developmental Center, the Hogan Regional Center in Danvers, the Monson Developmental Center in Palmer, and the Templeton Developmental Center in Baldwinville. The facilities provide state-of-the-art care and services to the residents, a majority of whom are among the most severely and profoundly retarded residents of the commonwealth. The administration, however, has targeted all six of the facilities for closure—a move that has led facility advocates both to the Legislature and to federal court to preserve the care that the facilities currently offer.

"What we are concerned about is what is going to happen if people are summarily evicted from that land and those buildings," says Colleen Lutkevich, Executive Director of COFAR. "Are they going to be receiving care in the community that is equal or better? We think the answer is no. What we're hoping is that that these facilities can continue to provide excellent care to those who need it most, while at the same time people from all sides can come together to plan for change that benefits everybody."

First and second waves of change

The landmark Ricci v. Okin lawsuit, which was brought in 1972 to rectify serious deficiencies at the facilities, can be seen as having ushered in a first wave of change in the facilities. Those facilities underwent sweeping renovations and significant upgrades in staffing and services in the 1980s. With the facilities now facing possible closure, proposals like the Village at Fernald may represent a second wave of change. That second wave is still far off for most facilities, even though some changes are starting to occur.

The Wrentham Developmental Center, for instance, deeded 80 acres of its 480-acre campus to the Town of Wrentham a few years ago to develop a recreation complex, according to Nick D'Aluisio, facility Director. "They [the Town] have a

grand plan on the drawing board that will cost around \$7 million dollars and will further integrate our setting with the community," he said.

At Wrentham, the first wave of change, stemming from Ricci v. Okin, has resulted in quite a bit of diversity among the living arrangements on the Wrentham campus. D'Aluisio said there are 18 residential buildings there that range from cottages to apartment buildings. A number of small cottages, housing five to eight people each, were converted from staff houses several years ago. Larger homes on the campus house up to 11 people each. There are also five apartment-style buildings, the largest of which is a 2-story apartment complex with eight self-contained apartments that house from 5 to 11 residents. Four of the larger apartment complexes are 24-hour nursing buildings meaning there is always a nurse on duty in the residences.

D'Aluisio further notes that as is the case in almost all the facilities, all Wrentham residents live in residences with single and double bedrooms. All of the living areas have their own living room, dining room and kitchen. Some of the smaller cottages do some meal preparation from scratch, he says, but most of the food is prepared centrally and delivered in individual trays specific to the diet and food texture needs of the person receiving the meal. There are 316 residents at Wrentham.

A focus on community

At the Glavin Center, a significant portion of the 75-acre campus was also recently sold; and, as was the case with Wrentham, the process there was a cooperative one. The DMR sold a 20-acre parcel along Route 9 to a developer with the consent of the Glavin Parents' Association, according to Roland Charpentier, President of the parents' group.

That spirit of cooperation has extended to efforts to build two new group homes on the Glavin Center property that will house four residents each. Charpentier said the Parents Association worked with the Shrewsbury Housing Authority to gain funding for the project, which will qualify as affordable housing in Shrewsbury.

"We're very much a part of the surrounding community," says Bacotti, the Glavin Center Director. "We're close to the center of Shrewsbury. People walk down to Borders [bookstore on nearby Route 9]. We have residents who volunteer at the local food bank, and some have jobs in the community."

Bacotti maintains that that sense of community exists among the staff as well. During a blizzard in January, he said, many staff members came into work up to six hours early to make sure they would be available when their shifts started. Others picked up coworkers and drove them to work. And many staffers stayed for hours after their shifts ended to make sure that residents weren't left alone before members of the next shift arrived. "I never asked them to do any of those things," adds Bacotti.

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Bacotti also notes that the administration at the Glavin Center “includes families in what we do here. We involve them in how the facility looks and runs.” Charpentier concurs, adding that the Parents Association has been “intimately involved” in the design and building of the two new houses on campus.

Bacotti adds that the Glavin Center has also admitted several persons who had been living in community-based settings in recent years. All admissions with one exception have come from family homes or community programs, he said.

While most of the 60 residents of the Glavin Center live in an apartment style building, which is connected by an enclosed walkway to an administration building, five residents live in a separate house on campus. The administration building houses both Glavin Center and DMR offices and rooms for day programs. The residential building has two units, with roughly 30 clients living in each.

With COFAR’s help, the Parents Association helped thwart an effort by the Weld administration to shut down the Glavin Center in 1994.

The Village at Fernald

The efforts among facility advocates and community groups to develop a plan for the development of the Fernald campus have recently caught the attention of Governor Mitt Romney. In an interview in December, Romney told reporters that he had heard “some suggestions that they perhaps shrink the footprint of the Fernald School to a smaller portion of the campus there, and that they develop other portions that they sell for development.”

The Fernald League, which represents families and guardians of Fernald residents, has called for the “continued and perpetual state ownership” of at least sixty acres of the 190-acre Fernald site as “the home for current and future generations of severely and profoundly adult and elderly mentally retarded individuals.” The Fernald League has been involved in the development plans with a number of groups, including COFAR, the Waltham Land Trust, the Waltham League of Women Voters, and the Waltham Alliance to Create Housing.

Under the Fernald League plan, as vacancies occurred due to deaths or other circumstances, the Village would admit new residents based on their individual housing and service plan needs and preference of prospective residents, parents and guardians. The Village would be intimately connected with the surrounding community, sharing its day programs with persons living in group homes, nursing homes, and elsewhere. A Fernald League position paper on the Village concept notes that affordable housing could be provided on the grounds for staff, thus providing jobs and housing without adding commuters to the traffic on local Waltham roads.

The Fernald League position paper also notes that many people with mental retardation have continued to wait for DMR services, including those turning 22 years old who are leaving the services of their public schools, and those on waiting lists from the community. Hospice and respite care for those people could be provided along with other services at the Marquardt nursing facility, the Tufts Dental Clinic, and in residential units on campus, the paper states.



George Mavridis, shown in front of one of the Malone Park residential units at the Fernald Center, has been working to develop specific proposals for the future of the campus.

George Mavridis, Massachusetts coordinator of the National Voice of the Retarded and a former COFAR president, has worked with the Fernald League to develop specific proposals for the locations of residences and other facilities as part of the Village plan. In what he terms the “postage-stamp” proposal, Mavridis suggests clustering all of the existing residential, clinical, and recreational facilities for the mentally retarded down the hill, on the west side of the Fernald campus. The construction of a heating plant in that location would allow the facilities to be self-sufficient, he proposes. Many of the buildings on the east side of the campus could be demolished and the area developed. Mavridis terms this “a win-win result.”

Mavridis’s proposal acknowledges that the approximately 300 residents who are envisioned as residing permanently at Fernald would never need all 187 acres of the land there. Among the points of the proposal are that if the DMR were to declare a portion of the Fernald property as surplus, the Commonwealth should offer the property first to other state agencies. The proposal also suggests that as part of any sale to developers, the developer would pay cash for the land and would provide necessary heating systems to supply heat and hot water to the remaining Fernald Center and the Shriver Center.

[End of series]

Medicaid block grant plan would hurt facilities

Plans by the Bush administration to cut Medicaid and turn it into a block grant program would cause major cuts and disruptions in care for the mentally retarded in Massachusetts and elsewhere, according to advocacy groups for consumers.

According to the National Voice of the Retarded, Congress is currently considering the administration's block grant proposal as well as further cuts to Medicaid.

Medicaid is a joint state and federal program, which pays for long-term care, hospital, and other medical services for more than 900,000 people in Massachusetts. Long-term care, "optional" Medicaid benefits include funding for home and community based services, personal attendant care, case management, and state facilities for the mentally retarded.

COFAR, an affiliate of the VOR, is urging its members to call and write Massachusetts' two senators and members of the state's congressional delegation to oppose the Medicaid block grant proposals.

In a bit of good news regarding Medicaid, the state won't lose nearly \$600 million in federal funds that had been threatened by a potential new interpretation of Medicaid rules, the State House News Service has reported.

Governor Mitt Romney and Senator Edward M. Kennedy had lobbied the Bush administration to continue reimbursing Massachusetts for so-called intergovernmental transfers under Medicaid, which allow the state to be reimbursed for state funds transferred to state MR facilities and hospitals. In the current fiscal year, an intergovernmental transfer helped partially offset a \$5 million cut in funding to the facilities.

Some money flowing back into facilities account

Governor Mitt Romney has proposed a 5 percent increase in funding to the Department of Mental Retardation in the upcoming fiscal year, but the increase to the state facilities account would be less than half of that amount.

In his 2006 budget proposal, which was submitted to the Legislature in January, Romney proposed \$54 million in additional funding for the DMR.

Under the governor's budget plan, which is now before the House Ways and Means Committee, the state facilities account would receive a 2.3 percent increase over projected current-year spending. However, given that the facilities account was cut by a net amount of \$2.5 million in the current fiscal year, the proposed \$3.7 million increase would be only \$1.2 million higher than what was spent in the 2004 fiscal year. In addition, the Governor's budget plan would allow the DMR to transfer money from the facilities account to

community accounts as facility residents leave state facilities for community-based residences.

In his own words

[The following are remarks of U.S. District Court Judge Joseph Tauro, taken from the transcript of his January 20 conference with attorneys in the Ricci v. Okin case (see plaintiffs story on page 2.)]

"I don't know of any developer that would come in and want to buy the [Fernald] land when he has got two hundred people living there under a court order. And until the Court is satisfied that something just as good is available [residential programs exist in the community of equal or better quality], then they are going to stay there [at Fernald]. And, I mean, that is it."

"...[Fernald] is a place where a lot of wonderful people dedicated to treating the retarded and have worked, you know, dedicated and against all odds have done a marvelous job. So to that extent it is a memorial to real public service."

[In discussing Romney's remarks that there are alternatives to closing Fernald] "...he [the Governor] said something two or three years ago [Romney's February 2003 announcement that Fernald and other state facilities would be shut down]. And maybe on reflection and with further experience and advice it wasn't the absolutely great idea he thought it was when he said it. And he is open to other suggestions. And he has got a very flexible approach, which I think is most encouraging."

State drops Special-ed changes

After a storm of disapproval from parents, lawmakers and special education advocates, the state Board of Education has dropped proposed changes in the Chapter 766 Special Education Law regulations, which would have affected programs for children with mental retardation and other disabilities.

The Board of Education had proposed to permit administrators to determine the special education classroom or school for children, outside of the children's IEP Team meeting process. The new regulations would also have allowed a school district to refuse to evaluate or re-evaluate a child who had been referred for an assessment by a parent, teacher, or other professional. In a letter to the DOE Board, COFAR noted that these proposed measures would remove parental rights and give schools too much authority in that regard.

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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