



The COFAR VOICE

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

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Special Issue on the State-run MR facilities



Donna Beck, a direct-care worker, and Kim Pariseau, Assistant Unit Director, at the Wrentham Developmental Center.

Exploding the myths

State MR facilities seen as caring and diverse

[First of 2 parts on the quality of life in state facilities today.]

For Donna Beck, a Mental Retardation Worker II at the Wrentham Developmental Center, the job doesn't end at the end of her shift.

Beck works 40 hours a week in charge of the first shift in a group home on the Wrentham campus that houses five mentally retarded women aged 43 to 68. Like many other staffers at the state facility, Beck literally devotes much of her life to caring for the women. Every summer, for instance, she takes them on vacation with her to Cape Cod, where they stay in an apartment rented by another Wrentham staffer.

(Please see Facilities on page 3)

Editorial

Setting the record straight

The current and upcoming edition of *The COFAR Voice* are, and will be, largely devoted to telling a story that sadly has been little understood by the public. That story concerns the rich and diverse nature of the living arrangements, services, and care provided in the state-run facilities for the mentally retarded in Massachusetts.

It is one of the unfortunate side effects of the history of care in America for those with disabilities that the image of institutions has become identified in the public's mind with warehouses and other symbols of neglect. There's no doubt that at one time not so long ago, persons with mental retardation, mental illness, and chronic diseases were shunted away in warehouse-like "hospitals," where they were neglected and, in many instances, abused.

These facilities were overcrowded and filthy, and the people placed in them received little or nothing in the way of treatment. This image has been reinforced in many books and movies to the point where it is the predominant image that the public has about places like the Fernald Developmental Center and the other facilities. The fact is, though, that it is completely untrue today.

Due, in large part, to the intervention of the courts in the last quarter century (*Ricci v. Okin* in the case of the facilities in Massachusetts for the mentally retarded), care and conditions in places like Fernald are today among the best in the world. They tend to house only the most severely disabled persons, and families and guardians of these residents overwhelmingly want them to remain in them.

But in recent decades, institutions across the country have become victim to a tide of privatization. Much of this tide has been the result of an often misinformed ideology that the private sector can do everything

(Please see Editorial on page 2)

Setting the record straight

(Editorial, continued from page 1)

better than government can. Some of it results from a desire, also often misinformed, to save money. And some of it has resulted from intense lobbying by private firms, eager to make money by taking over the work and care formerly provided by the government.

It's particularly unfortunate for those who benefit from institutional care that many of these adherents of privatization have found it expedient to encourage public misperceptions about facilities in order to further their cause of closing them all down. It's a cynical game that pits people with disabilities against each other, and which, in the long run, no one can win.

In publishing these two special issues on MR facilities, we hope to take a step toward changing public perceptions by exploding the myths about them.

Romney acknowledges alternatives to closing Fernald

But no change seen in closure policy

As plaintiffs and defendants in the legal battle over the fate of the Fernald Developmental Center continued to meet, Governor Mitt Romney acknowledged for the first time that there are alternatives to closing the state facility.

"I know that I 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," Romney told reporters in December, according to the *Waltham Daily News Tribune*.

Meanwhile, Romney also bowed to pressure placed on him by Fernald supporters, and took a surprise 7:30 a.m. tour of Fernald on December 14. Romney, who was joined on the tour by DMR Commissioner Gerald Morrissey, had been repeatedly invited for a scheduled tour of Fernald with family members of Fernald residents and representatives of the Fernald League for the Retarded.

The Governor's words and gestures stopped short, however, of signaling an about-face in the administration's facility closure plans.

"Right now, we're a bit discouraged that the DMR doesn't seem to be heeding the clear statements from Judge Tauro that they shouldn't be rushing to close Fernald and the other facilities," said Colleen Lutkevich, COFAR executive director.

On November 10, U.S. District Court Judge Joseph Tauro urged the DMR to reach an agreement with Fernald families and advocates on how to preserve the high level of care at Fernald that resulted from landmark legal action between 1972

and 1993. The case, *Ricci v. Okin*, had been suspended since 1993, when Tauro disengaged from it.

Last July, Beryl Cohen, an attorney for the original Fernald, Belchertown, and Monson plaintiffs in the case, filed a motion to reopen the lawsuit, alleging that the administration's facility closure plans coupled with budget cuts and staffing reductions at Fernald and other facilities constituted "systemic violations" of Tauro's 1993 disengagement order. Cohen also charged that the administration has been illegally altering Fernald residents' Individual Support Plans in order to clear the way for the closure of the facility.

Attorneys for other original plaintiffs in the case, including Wrentham and Dever plaintiffs, were expected to join in Cohen's motion to reopen the case.

Since the November 10 hearing before Tauro, the two sides have made some progress in working out disputes over the ISPs. A stipulated agreement between the plaintiffs and defendants, dated December 29, states that the DMR will not discuss alternative placements during the meeting between clinicians and guardians to develop a facility resident's annual ISP. The annual ISP meeting will be limited to identifying and recording the individual's current needs and supports. According to the stipulation, the DMR will discuss alternative placements at a separate ISP modification meeting, which will be held only after a specific placement site is identified.

Since the November 10 hearing before Judge Tauro, the two sides have made some progress in disputes over ISPs.

But despite the ISP agreement, Cohen filed a notice with Tauro on December 29 listing 17 "unresolved outstanding issues" between the plaintiffs and defendants. Those outstanding issues include Cohen's previously alleged violations by DMR of Tauro's 1993 disengagement order.

In addition, Cohen noted as unresolved the plaintiffs' request for a prohibition against multiple transfers of current Fernald residents among other facilities.

In a related development, on December 21, 2004 an attorney for the Concerned Citizens for the Mentally Retarded, Inc., the advocacy group for residents of the Hogan Regional Center, sent a letter to DMR asking for an "affirmative confirmation" from the Department that all Ricci Class Members and non-class members at Hogan would be provided the same level of support and services and would be treated the same with respect to potential transfers into or out of the Danvers facility.

Approximately 128, or 81 percent, of the Hogan population are non-class members. Should the DMR not agree to equal treatment, the CCMR reserved the right to ask Tauro to expand the Ricci Class to include all Hogan residents, the letter stated. According to the CCMR letter, a distinction between Ricci Class members and others in state facilities is not consistent with either Massachusetts law or the U.S.

Constitution's Equal Protection Clause, which requires that all people similarly situated should be treated alike.

Bill Gauthier dies

Bill Gauthier, a founding member of COFAR and a long-time advocate for the mentally retarded, died suddenly on January 3 following complications from surgery.

Gauthier, who had a daughter at the Monson Developmental Center, was a founder of the parents' group there.

Gauthier was also a member of the Governor's Commission on Mental Retardation for many years as well as an original plaintiff in the landmark Ricci v. Okin lawsuit. He is survived by two daughters and his wife, Dustie.

Facilities are caring places

(Facilities, continued from page 1)

Throughout the year, she takes them out to eat and takes them shopping. She gets some compensatory time or payment for the extra hours, but it doesn't come close to the actual time she spends caring for the women.

"I'll never leave here 'till they kick me out," Beck adds. "I'm here for the ladies I work with."

Beck is not alone in that view among the staff at Wrentham and the five other state-run facilities for the mentally retarded in Massachusetts. In fact, a close look at the living arrangements, care and services at those facilities reveals a system that belies many popular conceptions about the institutions, particularly that they are outmoded, uncaring, and isolated.

"Many people think that the state facilities are huge old warehouses, where mentally retarded people are hidden away, neglected or worse by uncaring staff," says COFAR Executive Director Colleen Lutkevich. "In fact, nothing could be further from the truth."

Lutkevich maintains that this outdated view of facilities as warehouses of neglect is unfortunately actively promoted by opponents of the facilities who are seeking to shut them all down and move their more than 1,100 residents into privately run, community-based group homes. The Arc of Massachusetts, for instance, refers on its Website to the state facilities as places that "isolate" and "segregate" the facility residents from the surrounding community. The Arc Website also maintains that the care in facilities is based on "a service model of the past."

However, visits to the facilities and interviews with family, staff, and other advocates for the residents show that the institutions continue to provide state-of-the-art care, have staff that are committed to the residents, and have varied and

diverse connections with the communities around them. A number of the facilities, for instance, share their therapeutic and recreational facilities, such as gyms and swimming pools, with community groups, and many open their medical and dental clinics to mentally retarded people who live in the community. Several facilities host major community-oriented activities, such as regional agricultural fairs; and all of the facilities provide day programs to their residents, which frequently involve them in producing goods and services for businesses and other organizations.

"The people [Fernald residents] eat at the Andros Diner [in Waltham] and are taken to the Waltham Mall," says George Mavridis, Massachusetts coordinator of the national Voice of the Retarded and a former COFAR president. "They have more community involvement than if they were in a group home with no staff to take them out."

On the facility campuses, the living arrangements are diverse, with a large segment of the populations of many of the facilities living in small, cottage-style residences, while others live in apartment-style buildings, both small and large. Gone are the days of large, open wards with people sleeping in side-by-side beds. Virtually all of the residents of the facilities currently have either single or double rooms that meet stringent privacy and living standards resulting from the landmark Ricci v. Okin settlement that significantly upgraded care and conditions in the facilities since the 1970s.

"I'll never leave here [the Wrentham Developmental Center] 'till they kick me out," Donna Beck says. "I'm here for the ladies I work with."

The care provided in the facilities is intensive, and also stems from requirements imposed by the Ricci settlement. The facilities by and large house the most severely and profoundly retarded residents of the Commonwealth.

In February 2003, the Romney administration announced that it was targeting all six of the facilities for closure, starting with Fernald. Concerned that the administration has lacked a plan for placement of more than 1,000 remaining facility residents in the community-based system, and concerned that the community-system does not provide care that is equal to or better than the facilities, the families of many facility residents immediately began fighting the administration's closure efforts.

Wrentham a center of day programs and volunteering

Beck's experience at Wrentham appears typical of staff at the facilities. She has worked at Wrentham for 24 years and has cared for one of the women in her on-campus home for at least 20 of those years. The women in her house are moderately retarded, and one is deaf while another has

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cerebral palsy. Some are also dual diagnosed with mental health issues, and some have behavioral issues.

Beck starts her day at 6:45 in the morning, making breakfast for the residents, who are all awake and up by 6 to 6:30. After they've eaten, a nurse visits and gives them needed medications. The staff helps them to brush their teeth and get ready to go to work. Everyone is taken in a van to the Quinn building on campus for day programs, starting at 9:15 a.m. There, during the week, the women are taken to the pool, the gym, adult-education classes, and the Wrentham Industrial Workshop, which provides contracted piecemeal work to businesses.

The adult education classes instruct the Wrentham residents in such things as the days of the week, dates, and the weather. As attendance is taken, the staff members give the residents pictures of each other in the class to identify. Some residents use switches on adapted wheelchairs to communicate. The classes are also used to work on objectives in the residents' Individual Support Plans. One person has an objective to write down his name once a day, said Kim Pariseau, Assistant Unit Director. The staff makes frequent use of sign language and pictures for communication. Beck and other direct-care workers help the habilitation coordinators, who run the classes.

After eating lunch in one of two dining rooms in the Quinn building, the women in Beck's house are taken to a library, where they "chill out" and some take naps. After that, they return to their workshops for an hour and then are taken back to their house where they have a cup of coffee and a snack and some down time. The second shift arrives at 2:45 p.m. That is the end of Beck's official workday, which had started eight and a half hours earlier, at 6:45 a.m.

But that is only Beck's official job description. She volunteers to take her house residents on vacations to Wareham on Cape Cod every summer. She takes two women at a time for three-day stints, and stays with them from morning to night. A staff worker on the second shift in the Wrentham house rents a cottage in Wareham for three weeks each summer, and for the past three years has donated a week of that time to the women.

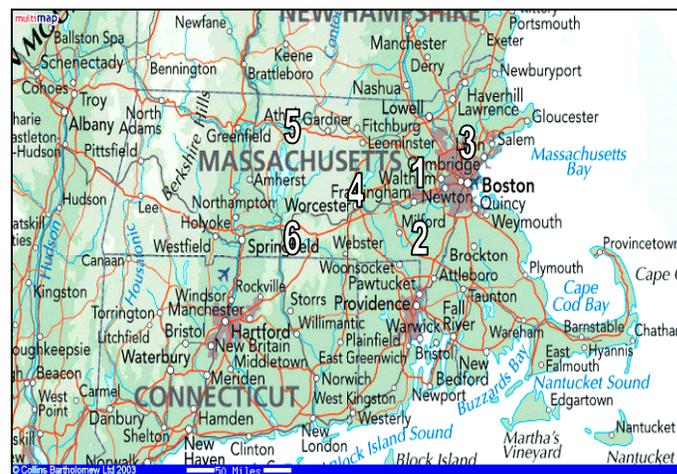
"Some of these women had never been on a vacation their whole lives," says Pariseau. Pariseau says that other staff at Wrentham have taken residents on trips to Bermuda and Disney World. Beck also organizes a family day at the Wrentham house each fall in which families come with pot luck meals. Staff cook Christmas dinners in all the cottages, she said.

Volunteering and community connections are a part of each of the other facilities as well. At the Templeton Developmental Center, located near Gardner in central Massachusetts, the facility's residents are frequently taken in groups of five out to dinner, and are taken out on vacation, says Currie Barss, the mother of 54-year-old Chris Barss, who has resided there for 34 years. A couple of years ago, she

says, the staff took Chris and four other residents to Bar Harbor, Maine, and the group then took a catamaran to Nova Scotia.

Barss says that when her son, who is moderately retarded, was first placed at Templeton at the age of 20, he responded positively and has been happy there ever since. "I remember we got there in the evening," she says, "and from that time, Chris has never looked back. It's his home and workplace. It's wonderful there. He has the protection and freedom he needs."

MR facility locations in Massachusetts



1. Fernald Developmental Center, Waltham
2. Wrentham Developmental Center
3. Hogan Regional Center, Danvers
4. Glavin Regional Center, Shrewsbury
5. Templeton Developmental Center, Baldwinville
6. Monson Developmental Center, Palmer

Community use of the facilities

Despite the segregation charge brought against the facilities, there are numerous examples of both the sharing of facility grounds and services with the surrounding community, and of contact between facility residents and the community.

At Fernald, the Tufts Dental Clinic campus is the best in the world for dental treatment of mentally retarded patients, according to Mavridis. Ninety percent of the Tufts Dental Clinic patients live in community residences, Mavridis says.

The Therapeutic Equipment Center at Fernald designs and builds specialty equipment and modifies wheelchairs both for facility residents and for persons living in the community. The Marquardt Skilled Nursing Facility on campus is available to serve all eligible persons in the DMR system, based on their medical needs. And the Eunice Kennedy Shriver Research

Center does research on mental retardation issues and provides clinical evaluations of people in the community, many of them children, who are diagnosed with mental retardation.

The Hogan Regional Center in Danvers has a clinical "Evaluation and Stabilization Unit," which offers short-term stabilization and intensive supports to persons with mental retardation living in the community. In many cases in which community living options have been exhausted and stays in psychiatric hospitals have not been successful, the Evaluation and Stabilization unit has been successful, says David Hart, a COFAR Board Member and President of Concerned Citizens for the Mentally Retarded, Inc., the Hogan advocacy organization.

In addition, Hogan hosts a partnership between Boston University and North Shore Enterprises, an on-campus program that provides vocational supports to both community-based and facility-based persons. Under the partnership, BU students have visited Hogan during the last week of August for the past 14 years and have received hands-on experience in caring for Hogan residents. A similar partnership has been established between North Shore Enterprises at Hogan and the North Shore Vocational Technical School in Middleton.

At the Monson Developmental Center near Springfield, the dental clinic serves people from the community, according to Bill Gauthier, who was president of the Center's parents' group until his death on January 3. (See obituary on page 3). The Center also has a medical clinic, which provides medical respite care for people with mental retardation who can't be treated in the community. In addition, Monson houses the DMR Region 1 and 2 offices, which are staffed by 110 state employees.

The Glavin Regional Center in Shrewsbury has a University of Massachusetts pediatric center on the campus which serves special needs children from the community, says Roland Charpentier, who has a profoundly retarded brother at Glavin.

Community members help the facilities

Nicholas D'Aluisio, Director of the Wrentham Center, says that in addition to the volunteering done by the Wrentham staff, volunteers from the community spend hundreds of hours per week visiting the campus and spending time with the residents, individually and in groups. They participate in special activities and religious services, and they assist in environmental projects such as outdoor clean up, planting, and the painting of buildings inside and out.

Common grounds

The connections between the facilities and the community don't just involve clinical care or persons with mental retardation. In many cases, the facilities are available as centers of recreational and other activities for all persons in the surrounding communities.

At Fernald, the Greene Building gym and the soccer fields are used by community residents who are not mentally retarded. The gym and swimming pool at Wrentham are used regularly by community groups including senior citizens, local AAU basketball teams, day care centers, and a number of community group homes and individual families who have developmentally disabled children, D'Aluisio says.

At Hogan, the pool, auditorium and gym are used by several community-based groups, says Hart. The auditorium is the site of the North Shore Players, an amateur theatrical society, and of the North Shore Children's Theater. At Glavin, Charpentier said there are five soccer fields on the campus as well as a baseball field, which are used by Shrewsbury and surrounding towns. The facility swimming pool is used by the community as well.

The Templeton Developmental Center hosts the annual Fernald Fair on its grounds. It's a major country fair held the last weekend in September, says Patricia Lyons, Director of the Templeton facility. The facility also operates a farm which sells the produce grown there as well as milk to commercial brands such as Gerelick Farms.

At Wrentham, there is a major fairgrounds on campus that is the site of the Annual Crackerbarrel Fair in the fall that brings up to 10,000 people to the campus, says D'Aluisio. That has been going on for the past 25 years. The fairgrounds area is also used for three or four major dog shows that on any given weekend may bring in up to 2,500 dogs, he says.

Relocations from the community

Yet another indication of the importance of the facilities to the DMR system and the community is the fact that the facilities are frequently contacted by parents and guardians who want to place their loved ones there.

Wrentham, for example, has accepted a number of people who haven't been successfully treated in the community because of complex medical or behavioral needs, says Pariseau. Their relocations to Wrentham have been sought by guardians and approved. At least five have come in the last couple of years, Pariseau says. They previously lived in vendor-run homes and came to the medical center at Wrentham, where their medical conditions were stabilized. "Wrentham has the consistency of medical and direct-care attention that is needed by these people," she adds.

Pariseau maintains that the staff at Wrentham has been energized by the new arrivals. "When new people come in, it gives us a feeling that we're growing," she says.

Lutkevich adds that given that enthusiasm for new arrivals at Wrentham and the high quality of care at the facilities in general, "It would be especially tragic if DMR eliminated these facilities that provide so much benefit to so many people."

[Next month: Facilities sport diverse and changing housing options for residents.]

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