



The COFAR VOICE

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

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HOPES REALIZED--A small contingent of the estimated 150 attendees of Judge Tauro's February 8 hearing gathered outside the federal courthouse in Boston prior to the hearing. During the hearing, Tauro ordered an indefinite halt to further transfers of residents from the Fernald Developmental Center, and appointed U.S. Attorney Michael Sullivan to investigate the transfer process.

Federal probe begins of Fernald transfers *Will reportedly examine 'all issues' involving DMR care*

United States Attorney Michael Sullivan has begun what some observers are characterizing as an aggressive and far-reaching investigation of the state's system of care for persons with mental retardation.

"It appears to be a good beginning," said COFAR Executive Director Colleen Lutkevich, who was briefed on a February 17 conference call among attorneys involved in litigation over the Romney administration's plans to close the Fernald Developmental Center. On February 8, Sullivan was appointed as Court Monitor in the Ricci v. Okin case by U.S. District Court Judge Joseph Tauro.

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Editorial

Michael Sullivan's opportunity

The debate over care for persons with mental retardation stands at a critical juncture in Massachusetts and around the country.

The debate is bigger than any one state facility and it is about more than the desires of the families of residents of one facility to keep them there—a desire we strongly support. It is about the quality of care for all persons with mental retardation.

The current and future outlook for that care is dire and only growing more so. As a brief filed with U.S. District Court Judge Joseph Tauro by the Wrentham Association for the Retarded plaintiffs makes clear (see story at left), the community-based system of care in Massachusetts is in disarray, with growing numbers of residents cared for by underpaid staff and facing increasing threats of physical and sexual abuse. What is making those prospects even more bleak is the decision by Congress in February to cut federal Medicaid funding to the states by billions of dollars over the next five years—a situation that threatens to revive waiting lists for community care and further cut funding to a system that is already tragically under-funded (see Medicaid story on page 4).

In the midst of this desperate situation, the Romney administration has been pressing ahead with plans to close the Fernald Developmental Center and other state-of-the-art

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Governor's DMR budget includes some increases

Governor Mitt Romney has proposed a 3.6 percent increase in spending on DMR line items in his Fiscal Year 2007 budget proposal, which was released on January 25.

The community residential account would receive a \$24.4

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Federal probe begins

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Pending the completion of Sullivan's review, Tauro ordered a halt to all further transfers from Fernald to other locations.

The Romney administration announced in February 2003 that it intended to shut down Fernald and the five other remaining state facilities and to relocate those residents ultimately to community-based residences.

COFAR and other advocates for persons with mental retardation have opposed the administration's facility closure plans, arguing that Ricci v. Okin brought about state-of-the-art care in the facilities, which cannot be duplicated in the community system.

Benjamin Ricci, the original plaintiff in Ricci v. Okin, dies. Obituary on Page 5

In February, plaintiffs of the Wrentham Association for the Retarded joined the Fernald plaintiffs in urging Tauro to reopen the Ricci case, from which he had formally disengaged in 1993. The plaintiffs argued that the administration's facility closure plans, coupled with recent budget cuts in the DMR system had made it unlikely that DMR could comply with Tauro's disengagement order that any residents transferred from the facilities receive equal or better care elsewhere.

Lutkevich said the U.S. Attorney's Office apparently has a six-month timetable for its investigation, but she said the timetable has been described as loose and one that could be extended. She said that as of February 17, staff from the U.S. Attorney's Office had already visited Fernald and planned to visit all of the state facilities as well as several community-based homes. They also planned to talk every two weeks with attorneys for the plaintiffs.

"All issues will be looked at," Lutkevich said.

The Fernald plaintiffs's report

Tauro's February 8 hearing was initially scheduled to discuss a report by Fernald Plaintiff Attorney Beryl Cohen detailing numerous alleged deficiencies in the transfer process thus far. Cohen alleged in his report that DMR had failed to document that 43 persons transferred from Fernald since the administration slated the facility for closure in 2003 were receiving equal or better care in their new locations.

Tauro's hearing also came the day after the Wrentham Association filed a brief and a motion to join the Fernald plaintiffs in seeking to reopen the case and resume Tauro's oversight of the DMR.

Tauro appeared to have accepted at least two of the recommendations in Cohen's report for the Fernald plaintiffs: that the U.S. Justice Department review all transfers from Fernald and that Tauro discontinue all further transfers until it

is established that DMR is in compliance with state and federal law in carrying out the transfer process.

Cohen, aided by past Fernald League Presidents George Mavridis and Diane Booher, examined a limited number of records made available by DMR of the 43 persons transferred out of Fernald between February 2003 and June 2005. Of the total, 34 were transferred to state facilities and nine to community-based residences.

Among the findings in Cohen's report were:

- DMR didn't follow its regulations requiring that the guardians of the 43 transferred residents be given complete information about the risks of transfers, nor were they given assurances that the new locations would be equal or better.
- DMR failed to document that residents would receive equal or better services in their new locations and that all services required by the ISP were available.
- Guardians of the nine residents transferred to community locations may have forfeited the ICF care model without full knowledge of the state's waiver system for community care, which was never explained.
- DMR targeted Fernald residents with corporate and out-of-state guardians for transfer.
- There were documented instances in which residents' services were reduced prior to transfer, in order to induce guardians and family members to consent to the transfers. Those services were then reduced further after transfer to other locations. Examples of this included failures to provide wheelchairs, recreational services, 24-hour nursing care, speech and occupational therapy. In addition, active treatment objectives were reduced after transfers, to generic, nonspecific statements about treatment.
- Six residents have died and others have experienced medical, emotional, and behavioral changes just prior to, and after transfer.
- Familiar staff were not moved with the transferees and many individuals lost contact with significant caregivers important to their safety and well-being.
- DMR failed to provide a "right of return" letter to transferees, as required by the Court.

The Wrentham Association brief

Using examples of abuse and neglect in community-based settings, taken from state records, the Wrentham Association brief concluded that DMR's plan to relocate the roughly 1,100 Ricci Class Members from the facilities to the community would not result in compliance with Tauro's 1993 disengagement order. According to the brief, many residents who were transferred from the Wrentham Developmental Center are not currently receiving equal or better treatment in community-based care.

In contrast to improvements in care throughout the DMR system that occurred during the 1980s and 1990s under

Tauro's oversight, budget cuts and a growing reliance by DMR on the private contracting system have brought about a worsening of conditions for former Wrentham Developmental Center residents, the brief stated. "This time...the majority of (Ricci) Class residents are not 'warehoused' in large facilities," according to the brief. "Instead, Class members who are the victims of medication errors, sexual abuse, physical assaults and outright neglect are three times more likely to be living in the community."

The brief noted that "with the system for providing direct care to Class members in community homes strained to the breaking point," DMR's facility closure policy "will move hundreds more Class members to vendor-operated homes that are already under-staffed and are providing a sub-standard level of care..."

The brief stated that 2,156 individuals were living in state settings (992 in DMR-operated group homes and 1,164 in facilities), and that 8,612 individuals were cared for by private vendors in 2003. Based on the fact that there were 7.4 times as many individuals in community settings as in state settings, the brief concluded that the 121 substantiated abuse incidents in vendor-operated homes in FY 2003 was 50% higher than would be expected. There were 11 incidents in state settings.

Examples of abuse and neglect include the case of Rachel Deline, a Wrentham Class Member, who was given an overdose of lithium prescribed to control mood swings. She developed diarrhea, a symptom of lithium poisoning that went unnoticed. Her parents visited her in her group home on May 11, 2002, and said the staff were all watching television when they arrived. Her father found her moaning and crying, with her body partially on a couch and partially on the floor. The Disabled Persons Protection Commission investigator subsequently determined that she had been in that condition for 90 minutes. She died, on May 13, 2002, of dehydration and kidney damage.

In another case in 2001, a resident of a group home had left the residence without being noticed and was found the next day, lying in the mud in a field behind the residence. The person was disoriented and suffering from hypothermia.

In one case in 2003, a resident of a group home was brought to the Lahey clinic due to an overdose of Levoxyl. She had taken approximately 35 pills. At the clinic, the resident stated that another resident had hit her and another had kicked her. It was unknown how the person had gained access to the pills.

In yet another case in 2002, the alleged abuser raped a resident over a 4-year period, holding her down and using physical restraint to stop her from fighting him off, and threatening her that he would kill her if she told anyone.

The brief tied the problems in the community system in part to a failure by DMR to provide adequately trained staff in group homes due to inadequate salaries and benefits. The brief cited the situation faced by Tracy Adams, which was described in the November 2004 issue of *The COFAR Voice*. Adams, a 22-year-old assistant manager at a group home in Newton was barely earning \$12 an hour, yet she faced

physically demanding work with responsibility over the lives of several residents.

The Wrentham brief also discussed the problem of under-funding of the DPPC, which investigates abuse and neglect complaints. And the brief noted that DMR staff cuts have decreased services to Ricci Class Members as well. There are currently fewer than 50 full-time-equivalent psychologists available to support the entire population of some 10,000 individuals, and only approximately 18 of the psychologists are PhD-level professionals.

The brief also noted that DMR's oversight of the community system is inadequate. Consumer satisfaction surveys, which DMR relies on for its information on the system, fail to collect data on basic issues, such as whether Individual Service Plans are being followed. In addition, some 20 vendors could not demonstrate that they had run criminal background checks on 200 direct-care workers, according to the brief.

Michael Sullivan's opportunity

EDITORIAL, *continued from Page 1*

facilities that care for more than 1,100 of the state's most severely and profoundly retarded residents. As the Wrentham plaintiffs' brief points out, this is only going to further exacerbate the problems in the community system and extend the waiting lists for care there as residents are evicted from the facilities.

The Department of Mental Retardation and its state-funded providers argue that this course of closing facilities must be pursued no matter what. Yes, they agree, the community system is under-funded and under-staffed; and that, they say, is precisely why we need to close the facilities—so that the money now being spent on them can be diverted to the community system.

But this is a misreading of the problem, and it certainly will not solve it, although it may enrich many of the private vendors, who see big dollar signs in the closing of Fernald.

The problem is bigger than the facilities, or any one portion of the DMR system. A coherent plan must be developed to fix, and ultimately save, the entire DMR system. Sacrificing one part of that system to temporarily shore up another part will not work.

And this is where U.S. Attorney Michael Sullivan's opportunity lies. As our Page 1 story notes, Sullivan has been appointed by U.S. District Judge Joseph Tauro to serve as Court Monitor in the ongoing litigation over the planned closure of Fernald. We hope Attorney Sullivan will make use of this service to work out a compromise over Fernald as part of a larger plan to save the entire system.

Fernald advocates have already presented their basis for such a compromise—a "postage stamp" proposal, under which Fernald's current residents would occupy a portion of the campus, leaving the remainder of the grounds available for

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appropriate development. We think this approach can serve as a blueprint for the other remaining state facilities as well.

DMR and the vendors argue that that Fernald is a large, old, centralized institution and therefore prohibitively expensive to run. Any attempt to modernize it, they say, would involve pumping millions of state dollars into decrepit buildings, as one media account recently put it. (Never mind that the Commonwealth has spent more than \$200 million on refurbishing Fernald and the other facilities between 1974 and 1993, under Judge Tauro's supervision.)

Under the postage-stamp proposal, if there are still any decrepit, inefficient buildings left at Fernald, they can and should be torn down and efficient, cost-effective housing should be built in their place. The fact is that if Fernald and the other facilities are closed, this housing will have to be built somewhere else.

DMR's current plans to develop housing in the community and lease it back to the state appear almost prohibitively expensive over the long run and have led to uncertainty over siting and design (See procurement story on this page.) Were this housing to be built at Fernald and on the other campuses, it could be subject to the state's public construction bid laws, which require the adoption beforehand of complete designs and specifications. Thus, the uncertainties over siting and design would be eliminated, and, we believe, the ultimate result would be a much better deal for taxpayers.

Moreover, this solution will keep families, residents, and current staff together at Fernald and the other facilities, which is what those families overwhelmingly want. We strongly dispute the vendors' contention that the facilities somehow "segregate" or isolate their residents from the wider community. As experience has shown, this segregation actually occurs more and more often in community-based care, in which residents are often neglected by underpaid, inexperienced staff, and, in many programs, are rarely taken out of their group homes other than to state-funded day programs.

We acknowledge that the postage-stamp idea for the facilities is only one aspect of what must be a comprehensive plan to save the entire system. But should Sullivan embrace it, it would be a start toward a system of improved care, monitoring and accountability. It is perhaps our last, best opportunity as well.

Fernald community housing procurement process delayed

Despite conditionally selecting two private vendors in July 2005 to develop housing for residents of the Fernald Developmental Center, the state had still not signed lease-

purchase contracts with these firms as of February 2006, some seven months later.

In an interview on February 14, Peter Wilson, DCAM's deputy general counsel, said no lease-purchase agreements with any of the proposers had yet been signed.

Meanwhile, in the wake of concerns raised by COFAR about the procurement process, *The Waltham Daily News Tribune* reported on January 26 that DCAM had reportedly put a hold on contract negotiations with one of the vendors—Dedham-based Toward Independent Living and Learning, Inc. (TILL).

"These delays are indicative of the difficulty DMR is having in developing housing in the community at the same time that it is attempting to close large state facilities," said Colleen Lutkevich, COFAR Executive Director. "We think this portends only increases in the future in the waiting lists of people seeking community-based residential services as the facilities are closed."

COFAR has asked the state Inspector General to investigate several apparent flaws in the procurement process, which resulted in the conditional selection of TILL and CIL Realty of Massachusetts, Inc. (CIL) to build and rehabilitate housing containing up to 80 beds in the metro Boston and northeast regions of the state. *The COFAR Voice* has reported that CIL was selected by the Division of Capital Asset Management to build several group homes without having identified any sites for them. TILL was selected after having submitted proposals that appeared to be identical and incomplete for rehabilitating and constructing five homes.

In addition, a January 2002 report by State Auditor Joseph DeNucci stated that TILL had spent more than \$4 million in state funds in "unallowable, undocumented, and questionable business activities." And TILL appeared to lack experience in housing construction.

The only rehabilitation improvement specified in any of the TILL proposals was a statement that TILL was proposing to convert a garage in one house into bedrooms. None of the proposals specified the type and age of the windows and roof of each house as required in DCAM's RFP. No floor plans were provided that were specific to the houses for which renovations were proposed. Further, in none of the proposals did TILL provide required information about financing the rehabilitation and construction projects it was proposing, and none of the proposals identified the contractor expected to complete the rehabilitation improvements or new construction, as the RFP required.

DMR budget hikes proposed BUDGET, *continued from Page 1*

million, or 4.88 percent, increase in its funding, under the governor's proposal.

The governor also proposed an additional \$1.4 million for the state facilities, which represents less than a 1 percent increase over current year funding.

However, some programs, such as the Turning 22 program, which provides transitional assistance to families of persons who turn 22 and are no longer eligible for special education funding, would be level-funded at \$6.47 million. In an update emailed to stakeholders, DMR noted that level-funding of this account would “make it difficult” to serve all new Turning 22 individuals in the coming fiscal year, particularly since the Turning 22 caseload was projected to increase by 150 persons above the historical average.

COFAR Executive Director Colleen Lutkevich termed the lack of increased funding to the Turning 22 program “dangerous and scary.” She noted that the program serves as a key transition for families of persons with mental retardation who lose special education funding for services when they reach the age of 22.

Although not a DMR line item, the Disabled Persons Protection Commission, which has been significantly cut in the past, would receive nearly a 7 percent increase of \$119,769.

Other DMR line-item proposals by the governor are as follows:

- **Line item 5911-2000:** Transportation: An increase of \$172,000 or 1.24 percent.
- **Line item 5920-1000:** Regional Administration: an increase of \$2.4 million or 4.5 percent.
- **Line item 5920-2006: Residential rate initiative:** funding of \$2 million, a new initiative to address rate disparities in residential contracts.
- **Line item 5920-2010:** Community state-ops: An increase of \$2.65 million or 2.22 percent.
- **Line item 5920-2020:** Boulet settlement: An increase of \$747,375, or 0.87 percent.
- **Line item 5920-2025:** Day programs: an increase of \$4.12 million or 3.64 percent.
- **Line item 5920-3000:** Family supports: An increase of \$1.8 million or 3.52 percent.
- **Line item 5920-3010:** Autism services: level-funded at \$1.2 million.

Medicaid cuts approved

Congress has approved a federal budget bill that will cut Medicaid by at least \$6.9 billion over the next five years—a move that will put significant pressure on states to maintain services to the poor and disabled, including persons with mental retardation.

“It’s unfortunate that our most vulnerable citizens occupy the lowest rung on the priority ladder in Washington,” said COFAR President David Hart. “The poor and disabled can’t make the big campaign contributions needed to promote their agenda in Congress, and as a result, Congress has forgotten them once again.”

However, intense lobbying by advocacy groups for the poor and disabled, including COFAR and the VOR, made the vote

close. The vote in the Senate on passage of the Budget Reconciliation Act of 2005 was tied at 50-50, and needed a tie-breaking approval vote by Vice President Richard Cheney to pass it. The final measure passed by only three votes in the House.

According to *Washington Watch*, a newsletter of the Disability Policy Collaboration, one of the key provisions of the law, which was signed by President Bush on February 8, allows states to cap the number of people to be served under the new home and community services Medicaid option. It allows states to provide these services in limited areas of the state and explicitly allows states to maintain waiting lists for these services.

Ben Ricci dies: was original plaintiff in Ricci v. Okin

Benjamin Ricci, who was the driving force behind the landmark Ricci v. Okin lawsuit that has had lasting and positive repercussions for persons with mental retardation in Massachusetts, died on January 21 at the age of 82.

Ricci filed the lawsuit in 1972, after years of frustration in trying to improve the care and conditions in the former Belchertown State School, where he and his wife had placed his son, Bobby in 1953 at the age of 6.

Boston attorney Beryl Cohen filed the Ricci case as a class action suit that eventually included plaintiffs from several other state facilities for the mentally retarded. The litigation brought about the 20-year oversight and involvement of U.S. District Court Judge Joseph Tauro, who required DMR to make significant upgrades in the staffing and facilities in the state institutions.

“In court, when I saw Ben (Ricci) looking up, I said to myself: ‘Joe, you’d better get this right,’ ” Tauro told *The Boston Globe*.

COFAR Executive Director Colleen Lutkevich said Ricci “will be remembered as a man of action, who took on the Commonwealth on behalf of his own son and many others, and who was responsible for helping thousands of people with disabilities.” Ricci leaves his wife Virginia, and two sons.

A memorial service has been scheduled for March 26 at 2 p.m. at UMass Amherst Memorial Hall. All are invited.

DMR delays implementation of eligibility regulations

In the wake of criticism from COFAR and other advocacy groups, DMR has delayed the implementation of regulations that would make it harder for persons with mental retardation to qualify for care and services.

It was not immediately clear when, or if, the regulations would go into effect [See the January 2006 *COFAR Voice* for a full story on the proposed regulations.]

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