



The COFAR VOICE

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Hogan Stabilization Unit, First in a Series on DMR's "Greatest Hits," page 3

FY09 Budget, Governor's Veto,
Layoffs, and now...

More Cuts for DMR!

Severe and Profoundly Retarded Hardest Hit

Despite overall gains in the DMR FY09 budget now already in its fifth month, residential services for the most disabled people served by DMR took hard cuts in the FY09 budget. Then came mid-year cuts announced Oct. 15, which *again* axed facility funding.

The six developmental centers and the approximately 100 state-operated group homes were funded below DMR's request throughout the state budget process, then forced to absorb 2008 fuel bills, slammed by Governor Patrick's veto of \$750,000 from facilities, and ended up about \$5 million short, more if the price of oil and gasoline stay high. As a result, up to 200 layoffs at five of the six developmental centers began in September, with voluntary retirement incentives.

Then came the worse news: Another \$3 million slashed out of the facilities line Oct. 15 as declining state revenues forced another round of cutbacks. As this issue goes to press, DMR has not described how it can accomplish another cut to the facilities line without falling below Medicaid staffing mandates, endangering

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Three generations of the family of the late Dick Krant came to the Wrentham Development Center's 100th Anniversary Oct. 5 to see the administration building named for the longtime advocate, a former president of COFAR and of the Wrentham Parents Group. From left: Richard Krant, Jr. Muriel Krant, Mariel Wade, Meredith Wade, Bryan Krant.

Happy 100th, Wrentham

The 100th anniversary event at the Wrentham Developmental Center, Sunday October 5, drew hundreds of families, staff, former staff, present and former residents, and DMR leadership. There was a cookout under tents, exhibits of current programs (theater, sailing, fitness center, kayaking, bocce, swimming pool, horseback riding, art), and a program in the gym, featuring the dedication of the Administration Building to the late Richard W. Krant.

"Looking forward, we know that the Wrentham Developmental Center will have a long-lasting legacy in the Department of Mental Retardation," said DMR Commissioner Elin. M. Howe.

At a quieter gathering after the formal program, a plaque was unveiled on the administration building described Krant as "a champion for over 48 years for the rights of individuals with developmental disabilities."

Groton 43 Take to the Streets, 100 “March and Roll” for safety

Residents of the Seven Hills Pediatric Center at Groton, family members, and supporters – 100 strong – marched from the Center down Groton’s Main Street and back home October 19 to protest DMR’s inclusion of 31 residents on a Rolland Settlement community placement list. Residents of the pediatric nursing home have profound mental retardation and complex medical problems, and many use feeding tubes. The Rolland class-action lawsuit is intended to move people with MR/DD from nursing homes into community placements, or get them “active treatment” where they are. But Groton families protest that the Center provides an excellent program for their loved ones, and that moving them to a lower level of medical care would endanger their lives.

Local clergy and elected officials joined the rally, which featured signs such as: “Group Homes are Unsafe for the Medically Fragile,” “Help Our Loved Ones Stay in Their Groton Home – Tell Mass: ‘No Forced Moves,’” and “Sacrifice the Most Helpless?”

Speaking at the rally, parent Louis Putterman asked why Governor Patrick had not responded directly in any way to the situation, and described the agony of family members since they suddenly learned of the Rolland Community Placement List last May: “When someone phones us from this facility where our children are cared for, some of them for 20 years or longer, the caregivers have been trained to begin the call by saying: ‘Don’t worry, your child is o.k.’ and then proceed with their information. We have lived with the anguish of our child’s or sibling’s condition for many years, and that pain is never completely absent.

“But the situation that the Commonwealth of Massachusetts has put us into through its actions in the Rolland Suit goes beyond anything that we’ve experienced since we received the painful news of our children’s conditions two or more decades ago. Each of us feels that we are living in a nightmare day and night since we learned of this situation this past May. We wake in the morning worrying about it; we go to sleep at night worrying about it; and we spend the day worrying what we can do that we have not yet done to try to protect our loved one from this danger.”

For more information, pictures, stories, and the full text of Louis Putterman’s speech, see: <http://www.AvertRollandTragedy.org>



Groton 43 march, photo by Judy Diamondstone

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the residents and risking a new round of scandals in the much-improved former “state schools.” Although a federal appeals panel Oct. 1 reversed Judge Tauro’s 2007 order and appeared to clear the way for closing the Fernald Center (see “Tauro Reversed,” page 4), state officials had emphasized an orderly and legal process, which would have little impact in FY09.

“In any case,” said COFAR Executive Director Colleen Lutkevich, “Other state cutbacks will make it very hard to move anyone in the DMR system. State-operated group homes have less money than last year, and the community residential budget is also slightly reduced. With the logjam in residential services, we felt we had to recommend deferring the governor’s ‘Community First Initiative’ – to get elderly and disabled people out of nursing homes and back home or into active treatment, even though we generally support that goal. And the Governor agreed, but that dries up another funding source to make a few more DMR residential beds.

“Meanwhile, there is another \$7 million in new cuts across the DMR system, so it’s harder for people in all settings, harder to get help from DMR administrators to navigate the minefield, and we are even losing Medicaid matching funds in the Autism waiver.”

The forum at www.cofar.org is a good place to post observations on where the DMR cutbacks are most obvious to you.

Prizewinning Hogan Stabilization Unit Turns Lives Around with CSI +TLC

(First of a multi-part series on the very best facility-based DMR programs, and how they combine secure treatment and concentrated resources with community integration.)

“Alex” (not his real name) was 23, and despite mental retardation had always lived at home. Now he was coming into the DMR system, but his prospects for employment were limited by the fact that he weighed 510 pounds and was insulin-dependent. Alex’s mother, with younger children in the home, knew it was wrong, but the only way she could cope with some behaviors was to feed her son even more. The mother was unsure about sending him to the Hogan Evaluation and Stabilization Unit. A locked ward, in “an institution,” where Alex would be with older and troubled DMR clients. Was it the right move?

Two years later Alex came home, 215 pounds lighter, off insulin, with a new interest in basketball, relationships, with a life. His mother, with new ways to communicate with her son besides food, now can get out to buy clothes for the other children, and has returned to school herself.

“Lisa,” an older woman, had hip surgery. The surgery went well, but with mental retardation, she wasn’t able to focus on her rehabilitation, and the medical rehab center had no one trained to work with her. After four months, Lisa had more complications than progress. At the Hogan ESU, the facility’s physical therapist set up her program, and staff experienced in working with her disability were able to support her. Lisa was eventually able to return to her group home.

“Mike” had an apparently explosive temper, and was a “biter.” He came to the ESU wearing a mask. He had often been in 24-hour restraint. “It was very negative,” understates Hogan Facility Director Rosemary A. Bevins. “It took six months to get Mike out of restraints, but over the course of two years, we could build trust, first with a stuffed animal, then with certain staff, asking his permission to sit down.”

Mike has been able to return to his group home, restraint-free, with a paper route. He also, thanks to the Hogan psychiatrist, gets some relief from an off-label use of blood pressure medication for anxiety.

“Julie,” a young woman with autism, was pinching people around her. The ESU staff, up on the latest findings with this puzzling disease, analyzed the situation as difficulty with communications. Julie could not speak well, and might be pinching to get attention.

By working with her emphasizing a sensory focus, they were able to reduce the pinching, develop other signals that worked for her, and stopped a problem that might have progressed to more aggressive behaviors.

The 9-bed Evaluation and Stabilization Unit at the Hogan Regional Center is designed to take people in crisis, most often in psychiatric hospitalization, and return them to community settings. Not counting the present residents, it has treated 54 people, succeeding with almost 95 percent -- only two discharges to a mental health facility. Facility Director Rosemary A. Bevins received the 2007 Manuel Carballo Governor’s Award for Excellence in Public Service for fostering the ESU, an award in which she modestly includes her entire staff. The nomination put it this way: “...we have worked with Rosemary on a number of very challenging cases, cases where, without Rosemary and the Stabilization and Evaluation Unit, these people could not be kept safe in the community. Now... these individuals are stable, contributing members of the community.”



Bevins emphasizes that the unit could not operate outside the context of a developmental center, with its specialists, intensive staffing, secure treatment, and gradual step-down opportunities. These beds aren’t cheap, but they are more economical than respite, psychiatric wards, or long-term hospitalization. Because the patients remain in “active treatment,” Medicaid shares costs, and the unit draws from all over the state. “A little bit of investment pays off.” Bevins says. With secure treatment, the ESU can take a person off medications to check the original diagnosis, and rule out side-effect issues. Staff “love the idea that they’re the people who can take a person others have been unable to help.” Every case is different, but one common thread is working closely with family members and guardians, who have frequent conferences, may participate in training, and call the nurses’ station on a 24-hour basis.

While the unit is part of a brick facility building, and decorations are bolted securely to the walls, intensive staffing allows it to be much more home-like than a psychiatric ward, and still very safe. The kitchen is larger but equipped much like the kitchen at any modern group home. And with the surrounding facility, clients can ease into community situations, and begin making friends and resuming activities as they recover. Three people have been admitted to Hogan, but one person made two close friends in the facility, and the trio moved out to a community-based group home together.

New COFAR website

Faster News, Easier Letters to Legislators Forums, Blog for Exchange of Ideas

COFAR's new website rolled out last month. New features for members and visitors include a streamlined link for writing instantly to legislators on key issues, a forum for exchanging thoughts and opinions (brief registration required), an events calendar (never misplace an invitation or email again!), and sign-ups for newsletters or membership.



Homepage shows fun in the Fernald Pool!

Behind the scenes, the new publishing system enables us to link to breaking news, key documents, and COFAR commentary in minutes. Go take a look, at www.COFAR.org. Bookmark the site, and return often!

Updates from www.COFAR.org

HR3995, Barney Frank's bill to provide warnings and opt-outs when federally-funded lawyers start class-action suits against ICFs/MR, is up to 41 Congressional sponsors, 17 Republicans and 24 Democrats.

The **federal GAO** in a May report on DMR deaths in 14 states praised Massachusetts for a relatively good reporting system (implemented after the 1997 House Post-Audit report criticizing Mass. DMR), but suggests new and higher standards for all states.

A **Boston Globe** expose August 30 revealed that \$30 million in "Client Trust Funds" set up by DMR 25-30 years ago for facility residents going into community residences are seldom spent for the benefit of their beneficiaries, but are slowly drained by fees to banks and Court-appointed trustees.

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Tauro Reversed on Appeal

Narrow Ruling Leaves Ricci Class Rights Intact

A three-judge Federal Appeals Court panel ruled October 1 that Federal District Court Judge Joseph Tauro did not have jurisdiction to reopen the Ricci vs. Okin case over transfers from Fernald during the Romney administration, and therefore that his order of August, 2007, is not in force. That order had required that the Fernald Center be included as a placement option in the annual Individual Service Plan for each Fernald resident, since August, 2007.

DMR and advocates of closing the Fernald Center had appealed the order as preventing the state from its normal administration of services, and impeding the process of moving people into the community. COFAR's amicus brief argued that the order was a necessary interpretation of the Supreme Court's Olmstead decision requiring individually appropriate treatment in appropriate settings.

The Appeals Court refused to rule on these larger issues, taking the position that since the court monitor had found the 2003-5 transfers to be legal, there was no basis to reopen the 30-year-old case.

The decision includes cautions on how it is to be read: "We do not decide the issue of what path best serves the interests of the residents of Fernald and the other parties who have a stake in this matter. People of good faith can and do passionately differ about the Commonwealth's intention to close the Fernald Center. We hold only that the district court lacked authority to reopen the consent decree in this case and that it lacked jurisdiction on that or any other basis to reopen and to enter the orders it did." An "amended judgment" issued November 18 clarified that the 1993 disengagement order remains in force. Thus Fernald residents who were there in the early 1970s retain a right to "equal or better treatment" and to another ICF/MR placement.

After the decision was announced, state officials reiterated promises to abide by the disengagement order, and close Fernald in an unhurried and orderly way, respecting rights of the residents. However, layoffs in September and October concentrated on reductions there, and Governor Patrick's announcement of an additional cut in the FY09 facilities line item Oct. 15 specifically referred to a pending facility closure.

At press time, the Fernald League was considering an appeal to the US Supreme Court.

Phil Corrigan Interview, Part I: ARC, Fernald League, COFAR Pioneer Shared Memories

(Philip J. Corrigan, 89, a founding member and past president of COFAR, as well as of the Fernald League, and a one-time regional officer of the ARC, died October 17 after a long illness. The COFAR Voice was fortunate to spend a couple of memorable hours talking with Phil in early September. Although physically frail, he was in good spirits, typing his autobiography into a laptop, sharp as ever, and up to date on recent developments because of calls from old friends.)



Phil Corrigan

“I was working in the East Boston shipyard, and got drafted into the Rainbow Division. I left a wife and two children. The youngest, Patricia, was only a few months old. By the time I came home, it was obvious that Patricia was “delayed.” There were no services; people were hiding them in the closet. A neighbor, a guy I worked with on the side, suggested Kennedy Memorial Hospital [now Franciscan Children’s Hospital]. And I placed Patricia there; she was there until she was 12.

“The Kennedys had not endowed it yet, so it was costing me the equivalent of a college education to keep her there. They were having trouble maintaining the facility even at that rate. So they joined the March of Dimes, and that meant that if you were not physically handicapped, you couldn’t stay there. So again, this neighbor told me about an evaluation program at the Fernald State School. And I had Patricia evaluated realistically for the first time, and at their recommendation, I placed her at Fernald.

“That was a revelation! Because whether you kept them at home, or in an institution, they were being hidden away. Fernald was still an institution; I shouldn’t call it a facility at that point. We eventually formed a parent organization, ‘The Fernald League for Retarded Children.’

“We began to meet Sunday afternoons and discuss how we could improve conditions, and in this period we were telling one another some of the horror stories we had encountered. And that also was a kind of revelation to me. I didn’t realize it then but only later on.

I had felt like it only happens to ordinary people. That people with exceptional ability and education and all that – it wouldn’t happen to them.

“Of course you know, all of a sudden, these Sunday afternoons, people came and, showed up, and were willing to discuss the issues, and I realized that it can happen to anybody.”

“It’s fair to say, I started out for selfish reasons. I had two retarded children. By that time I had a son also, who was slightly more retarded than my daughter. And I had placed him at Fernald also, and on his 16th birthday I had him transferred up to the Templeton colony. But I learned that collectively we could be tremendously effective in upgrading the conditions at Fernald. The conditions in all of Massachusetts, really, and we did. And for that, I am happy.”

(Next Issue: Parent Groups unite and “go political.”)

Updates, Continued from Page 4

Judge Tauro’s Court Monitor, charged since February 27 to report on the situation of “A.T.,” a 91-year-old woman moved from Fernald that month, possibly against her will, has yet to report as this issue went to press. Meanwhile, her corporate guardian, ArcGB, has refused to allow any visitors who knew A.T. at Fernald to see her at the Bedford state-operated group home where she now resides, citing the ongoing court investigation. This is a violation of DMR regulations, and A.T.’s civil right to have visitors.

After almost two years in office, **the Patrick administration** has issued a major policy statement on long term care. The 32-page “Olmstead Plan” roughs in a “Community First” agenda for elderly people and all disability groups. One big omission: family members.

The **Fall River rape case** in which COFAR has been supporting a victim-witness with MR/DD (See “COFAR Advocacy Helps to Jail Abuser” *VOICE*, June 2008) is now scheduled to begin trial December 8. A second defendant, William Senay, was placed on more restrictive bail terms in July with new charges including witness intimidation. COFAR will be organizing court monitors for the trial as a measure of the criminal justice system keeping our loved ones safe in the community.

Also on the site: Blog reviews *DMR*, the novel.

The COFAR Voice December, 2008

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The COFAR VOICE
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COMPREHENSIVE CARE
FOR ALL PERSONS WITH MENTAL RETARDATION

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