



The COFAR VOICE

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

January 2007

Volume 9/ Number 1



DISABILITY RALLY—In a scene from the gubernatorial campaign trail in October, then candidate Deval Patrick and Massachusetts Senator John Kerry take questions at a rally of persons with disabilities at the Perkins School for the Blind in Watertown.

‘Brighter day’ seen for disabled under Patrick

Deval Patrick’s victory in the Massachusetts gubernatorial election on November 7 has raised hopes of better care and a brighter future for persons with mental retardation in the commonwealth.

“We see a brighter day coming,” said COFAR President David J. Hart. “After years of fighting with the Romney-Healey administration and previous administrations over everything from the closure of (the) Fernald (Developmental Center in Waltham) to inadequate funding and staffing of critical DMR programs, we think relief may be finally at hand.”

The high hopes for Gov. Patrick come in part from the style of his campaign and statements he has made in the course of it.

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COFAR seeks changes in DMR management style

In the wake of a series of incidents of abuse and neglect within the system overseen by the Department of Mental Retardation, COFAR is seeking a meeting with DMR Commissioner Gerald Morrissey to press for changes in the Department’s management style and practices.

“We are concerned about DMR’s response and attitude toward families and others who who express concerns,” said COFAR Executive Director Colleen M. Lutkevich. “When issues are brought to management that need to be addressed, the response in some cases has been intimidation or threats of a loss of services.”

Lutkevich said COFAR’s concern was heightened by DMR’s initial response to an accident last spring involving Lisa Burke, a resident of a group home in Medford. (See Burke story below).

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Morrissey meets with parents over Lisa Burke accident

Faced with criticism over his reaction to a serious accident in May involving Lisa Burke, a resident of a group home in Medford, Department of Mental Retardation Commissioner Gerald Morrissey has assigned a top administrative aide to look into concerns about inadequate staffing, supervision and other issues at the state-run residence.

Morrissey also reversed his earlier position and agreed to meet with Burke’s parents, David and Linda, to discuss the accident and listen to their concerns about care at the group home. The meeting was held November 15 in the office of state House Minority Leader Bradley H. Jones, Jr., who represents the Burkes’ district.

The Burkes said Morrissey designated Larry Tummino, assistant DMR commissioner for operations, to look into their concerns about the home.

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Changes sought in DMR management style

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Lutkevich and COFAR President David J. Hart sent a letter to Morrissey on December 11, stating that COFAR has become concerned that “the Department has failed to adequately address instances of abuse and neglect, medication errors and other serious problems that have afflicted clients throughout the Department’s system of care.” The letter added that COFAR believes the incidents have resulted from a combination of factors, including a lack of adequate pay, training, and supervision of direct-care staff, and from general management deficiencies in the programs involved and insufficient oversight and proper procedures at the administrative level of DMR.

The letter added that in recent months, COFAR has received a number of reports and indications that “some provider and departmental staff have reacted to family complaints in a defensive manner and have attempted to intimidate or punish those persons who have brought the problems to their attention or who have voiced criticism of the Department’s management.”

Lutkevich’s and Hart’s letter requested a meeting with Morrissey and his staff in order to discuss solutions to those problems and to help COFAR formulate recommendations regarding the Department’s future.

The letter noted that DMR’s regulations specifically prohibit the Department from retaliating against persons who bring forward allegations of mismanagement or abuse or from terminating or threatening to terminate services for punitive reasons.

Morrissey meets with Burkes

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David Burke, Lisa Burke’s father, also reported that the independent Disabled Persons Protection Commission has resumed the investigation of the accident, at Morrissey’s request. The DPPC had initially transferred the investigation to DMR.

The COFAR Voice first reported in the September 2006 issue that Lisa Burke, 39, had been run over by a staff-driven van while she sat outside her group home in a wheelchair. The article noted that Morrissey had initially refused after the accident to meet with the Burkes and that a regional DMR director had threatened to close the group home after the Burkes and other parents of residents of the group home raised concerns about the accident and the staffing issues.

On October 27, after a column about the case appeared in *The Boston Globe*, the Burkes said they were called by Morrissey, who told them he had changed his mind and would meet with them.

David Burke said he and the other parents told Morrissey and other DMR officials, who attended the meeting, that they would like to see greater responsiveness by DMR to concerns raised by parents and advocates about staffing and other issues. He said that Tummino acknowledged that need for greater responsiveness and that Tummino visited the Medford group home on November 30 and met with the staff there. On December 7, Tummino also attended a regular monthly meeting the group home families have been holding with officials from DMR and Northeast Residential Services, the state entity within DMR that operates Lisa’s group home.

The Burkes, meanwhile, said medical bills for Lisa could reach \$100,000. Lisa, who was dragged under the van for 40 to 50 feet in the accident while she was strapped into her wheelchair, suffered a broken right hip, broken bones in her left ankle, two broken ribs, several small broken bones in her back, a deep gash on her left calf and several cuts on her head requiring stitches. She underwent surgery at Massachusetts General Hospital and spent a month at Spaulding Rehabilitation Hospital.

The Burkes said medical bills for Lisa could reach \$100,000.

The Burkes said they personally had to straighten out a complicated process for having Lisa’s medical bills approved by her health insurance. MassHealth initially refused to authorize payment for an electric hospital bed and self-adjusting mattress, which were needed for Lisa’s recovery, despite the doctor’s orders that these items were necessary, they said. MassHealth ultimately did authorize the hospital bed, but only a much lower-cost air mattress, which the Burkes said was useless and had to be replaced by other cushioning mattress materials provided by the Burkes themselves.

David Burke said DMR did do a number of things right following the May accident, including assisting them in getting a replacement electric wheelchair for Lisa. DMR also made provisions for direct care staff to attend Lisa every day throughout her stays in the hospitals and arranged for direct care, supervisory and nursing staff to be trained to handle Lisa’s ongoing recovery at her group home. DMR also agreed to pay for a special recliner chair for use during Lisa’s recovery, he said.

We welcome your comments on our blogsite

COFAR welcomes comments to entries on our blogsite at <http://cofar-mass.org/cblog/>. Just click on “comments” at the top of each entry and fill in the field. You don’t have to list your email address and you can list your name as “anonymous.”

Patrick restores budget cuts

Gov. Deval Patrick has restored all of the cuts made late last year by former Governor Mitt Romney, most of them in human services programs for persons with mental retardation and other disabilities.

In one of his first acts after taking office on January 4, Patrick restored the remaining \$384 million that Romney had cut from the current year state budget under his "9C" powers.

Facing a barrage of criticism, Romney in late December restored \$41.4 million of the total of \$425 million he had cut, including restoring a \$2 million increase that had been approved this year to the Turning 22 program. Patrick has indicated that he will draw down state reserves if revenue growth fails to cover a shortfall in the current year budget.

COFAR volunteers were among the hundreds of human services advocates who called their state representatives and senators in late November to urge them to rescind the devastating mid-year cuts.

Those advocates have continued to call on lawmakers to address all of the human services cuts, which the governor initiated under his "9C" powers to close what he maintained was a projected budget gap in the current fiscal year. Of the total of \$425 million in initial 9C cuts, Romney had cut \$9.75 million from DMR accounts. Of that \$9.75 million, Romney had agreed to restore \$8.4 million, including the following:

- \$2 million from the Turning-22 program. This was an amount Romney had steadfastly refused to provide the program this year. Turning 22 provides transitional funding to persons with mental retardation when they reach the age of 22 and are no longer eligible for special education services provided by local school systems. Despite a rising caseload, the Turning 22 program had not received an increase in several years. This year, the Legislature approved the \$2 million increase, Romney vetoed it, and the Legislature last summer overrode the veto.
- \$4 million in residential and day program services for persons with mental retardation.
- \$1 million under the settlement of the Boulet lawsuit, which provides funding for people with mental retardation who are on a waiting list for care in the community system.
- \$1.37 million in community day and work programs for persons with mental retardation.

Patrick restored the following cuts in DMR line items, which Romney had not restored:

- \$618,000 in respite and family services.
- \$664,850 in DMR regional administrative funding.
- \$34,933 from DMR's new Autistm Division.

Patrick also restored \$28 million, approved last summer by the Legislature over Romney's veto, to increase the compensation for underpaid direct-care, human services workers. Hundreds of recipients of human services programs and advocates demonstrated against the cuts at the State House on December 6.

"These are not pork barrel projects," noted COFAR Executive Director Colleen M. Lutkevich. "They are longstanding programs that serve critical needs. We're glad that this funding has been restored. People might have lost their housing, their day programs, meaningful work, and, in some cases, their eligibility to receive any services at all."

'Brighter day' seen with Patrick

PATRICK, continued from Page 1

Patrick talked repeatedly of his desire to build a "community" in dealing with the myriad issues involved in governance. COFAR was invited to attend an October rally of persons with disabilities and advocacy organizations at which Patrick spoke.

At the October 24 rally at the Perkins School for the Blind in Watertown, Patrick and Massachusetts Senator John Kerry held a question-and-answer session with members of the audience and talked in specifics about special education funding, funding for personal care attendants, voting rights for the disabled, the MCAS exam as a graduation requirement, appropriate design standards for buildings to make them accessible to the disabled, and much more. (See photo on page 1.)

Role for state facilities

Lutkevich said she has also been encouraged by Patrick's stated position on the role of facility-based care for persons with mental retardation. In response to a question during the gubernatorial campaign from the Arc of Massachusetts, Partrick said he would appoint a task force on implementing the Olmstead Supreme Court decision, which defined conditions under which both institutional and community-based care are appropriate. He also stated that community-based care is the most appropriate level of care "in most cases," leading to the conclusion that he believes facility-

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based care is needed in some cases. His campaign aides have privately seconded that view in conversations with COFAR staff.

Patrick transition team efforts and COFAR priorities

Patrick's gubernatorial transition team, which was established in late November, organized working groups in several areas, including human services. COFAR approached the transition team, seeking to provide input to the human services working group, which was co-chaired by the Rev. Richard Richardson, President Emeritus of Children's Services of Roxbury, and by Marylou Sudders, president of the Massachusetts Society for the Prevention of Cruelty to Children.

In a position paper delivered to the human services working group, COFAR identified three priorities for the incoming administration. The first concerns a need to address inadequate funding of DMR programs, particularly those that involve community-based care.



Members of the Deval Patrick transition team's human services working group take testimony December 7 from the public at Temple Emmanuel in Worcester.

The COFAR paper pointed out that a lack of adequate oversight coupled with high turnover and lack of training of direct-care workers have contributed to high rates of neglect and abuse throughout the community system. A series of cuts in DMR line items in the state budget in recent years have worsened the situation. Yet, in the face of these problems, the paper noted, the Romney administration has pressed ahead with plans to close the remaining state facilities that provide services and supports to some of the state's most severely and profoundly mentally retarded residents. "We believe this will only increase the strain on the system and lengthen waiting lists for care in the community," the paper stated.

The COFAR position paper called for development of a "rational and comprehensive plan" for the future of care in

the entire DMR system. "We believe that all aspects of that system, from home and community-based care to facility-based care must be utilized in delivering supports and services in the future," the paper added. The paper also called for the independent Disabled Persons Protection Commission to be given authorization and resources to conduct all investigations of abuse and neglect in the system.

Eligibility for Services

The COFAR paper also expressed concern over new DMR regulations and departmental policies that appear to make it more difficult for individuals and families to qualify for supports and services. (See the November 2005 issue of *The COFAR Voice*.) The position paper offered COFAR's input in making changes to these policies and regulations "in order to broaden eligibility as much as possible while, at the same time, making the eligibility requirements clearer."

DMR management

As its third priority, the COFAR paper stated that the organization would like to work with DMR to enhance the accountability and responsiveness of DMR management to the clients and families it serves. The paper cited concerns about a number of instances in which DMR has responded with threats or intimidation of people who have brought management and other concerns to the Department's attention. (See story on DMR management on Page 1.)

COFAR seeks reconsideration of denial of housing records

COFAR will seek reconsideration of a decision by the state's public records supervisor to deny the release of state records on the procurement of community-based housing for residents of the Fernald Developmental Center.

In a January 2 letter, Alan Cote, state Supervisor of Records, ruled that the records, which include proposals for development of the housing, are exempt from disclosure under the state's Public Records Law.

"We find Supervisor Cote's decision to be somewhat inexplicable," said Colleen M. Lutkevich, COFAR Executive Director. "The law clearly states that proposals and bids are public record once they are opened, and these proposals were opened last September. We think this denial, if allowed to stand would set a bad precedent."

Lutkevich said COFAR may consider going to court to obtain the records if Cote doesn't reverse his decision.

In an appeal, filed with the Public Records Division on November 16, COFAR asked that the Division of Capital Asset Management be ordered to release copies of the latest proposals it has received to develop group homes in the metro Boston and northeast regions and lease them to the

Department of Mental Retardation. COFAR initially filed a request with DCAM for the proposals on October 5. DCAM never provided COFAR with any of the requested records or with any written explanation as to why the records were not been provided. In his January 2 letter, Cote stated that DCAM had stated that disclosure of the records could “taint” the procurement process.

Last year, *The COFAR Voice* disclosed numerous flaws in the housing procurement process after reviewing an initial round proposals solicited by DCAM. COFAR provided a report on its findings (available online at <http://www.cofar-mass.org/Fernald%20procurement%20report.pdf>) to U.S. District Court Judge Joseph Tauro and United States Attorney Michael Sullivan. Tauro appointed Sullivan in February to investigate the Romney administration’s process of closing Fernald and transferring its residents to other state and community-based locations.

Among COFAR’s findings were that the DCAM’s original Request for Proposals, which had been issued in January 2005, didn’t include requirements for selecting the most qualified developers and contractors to develop the community housing. COFAR also criticized DCAM’s selection of two private vendors that responded to the RFP—Toward Independent Living and Learning, Inc. (TILL) and CIL Realty of Massachusetts, Inc. (CIL).

The Voice reported in September that in the wake of COFAR’s criticisms, DCAM issued a new RFP in July for at least a portion of the community housing. In addition, DCAM reportedly dropped plans to award any lease contracts to TILL. In its October 5 request to DCAM for documents, COFAR requested copies of all proposals submitted in response to the new RFP issued in July.

Fernald cost records provided

COFAR has also sought records from DMR on the cost of operating the Fernald Developmental Center in Waltham. In December, DMR provided COFAR with a list, as requested, of all buildings on campus and their uses.

COFAR is seeking the information in order to be able to scrutinize claims made by DMR that it costs as much as \$165,000 per resident to operate the facility. DMR officials have used that figure to justify efforts to close the center.

In July, the Department initially provided a spreadsheet listing line items for several large cost items at Fernald for Fiscal Year 2006, including salaries totaling \$29.2 million, electricity totaling \$1 million, heating fuel totaling \$1.6 million, and other costs.

On October 3, COFAR sought more detail on these costs and specifically requested the list of the buildings on campus for which the heating, electricity and other costs were budgeted. COFAR is currently analyzing the DMR records. A preliminary review indicates that several of the buildings for which heating and other costs are budgeted are currently unoccupied or don’t house Fernald residents.

COFAR responds to attempts to discredit facilities

In a letter sent this month to the incoming Patrick administration, COFAR emphasized the continuing need in Massachusetts for the high level of care provided by state-operated facilities for persons with mental retardation.

The letter, which was signed by COFAR President David J. Hart and Executive Director Colleen M. Lutkevich, was addressed to JudyAnn Bigby, incoming secretary of health and human services.

The letter was in response to a recent renewed call by The Arc of Massachusetts to close the Fernald Developmental Center and the other remaining state facilities and to privatize all DMR services.

“Continued efforts to close these critical facilities will result in the evictions of hundreds of residents with serious medical conditions and the most severe and profound levels of mental retardation in the commonwealth,” Hart’s and Lukevich’s letter stated.

The letter rebutted claims that closing the facilities would save the state money and that the closures are mandated by U.S. Supreme Court in its 1999 Olmstead decision. The letter cited a legal brief filed by COFAR and the national Voice of the Retarded, which noted that the Olmstead decision held that institutional placements are justified when they are medically required, sought by the individual or his or her guardian, and places are available

The letter concluded with a call for development of a comprehensive plan for the future of care in the DMR system and reiterated COFAR’s “postage-stamp” proposal for the Fernald Center, under which the current residents would continue to occupy a portion of the campus, leaving the remainder of the grounds available for appropriate development

Budget transparency needed

A group of state budget experts has concluded that the Massachusetts state budget needs to be made more understandable and accessible to the public.

In a report issued in October, the Massachusetts Budget Transparency Project noted that, among other omissions, the budget doesn’t list all significant new programs or expansions as well as all programs that have been eliminated or cut deeply. The budget also doesn’t provide descriptions of individual programs or list key goals of those programs. The report, which was issued by the nonprofit Massachusetts Budget and Policy Center, called for the provision of that and much other information, such as the publication of actual spending over the previous five years.

COFAR President David J. Hart maintained the reforms proposed by the report “make a lot of sense.”

COFAR is a family support, education and advocacy organization funded by member families. **Become a COFAR member and receive *The COFAR Voice*.** For membership information and information on how to donate and to be on our mailing list, visit our website at www.cofar-mass.org, or write to:

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