



The COFAR VOICE

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COFAR and VOR members rip Medicaid cuts in Washington

Uphill battle seen in saving funding

Advocates for people with mental retardation are facing an “uphill battle” this month in opposing congressional efforts to cut federal Medicaid funding to the states, the Massachusetts-based president of the National Voice of the Retarded contends.

In an interview, Mary McTernan, who is also a past president of COFAR, maintained that a VOR advocacy effort on Capitol Hill in June, in which several COFAR members participated, was effective. But, she said, more needs to be done. “They’re (Congress) looking to severely constrain Medicaid expenditures and limit eligibility,” McTernan said. “Dire is a good word to describe it.”

McTernan noted that a Medicaid Commission appointed by President Bush voted in August to require \$10 billion in Medicaid cuts over the next five years. That is the same amount in cuts that Congress itself has been considering.

McTernan said that while much of the planned Medicaid cuts will come from shifting spending on prescription drugs for the elderly to Medicare and from tightening Medicaid eligibility of elderly persons, services to people with mental retardation are likely to be affected as well. “The intent is to further reduce the numbers of people receiving ICF/MR care (services in state-operated intermediate care facilities), and substantially limit eligibility for any kind of long-term facility care,” McTernan said. “The primary focus is on the elderly population, but I do think the mentally retarded are going to get caught up in it.”

McTernan said she believes Congress may well vote on the cuts before the federal fiscal year ends on October 1. She noted that President Bush is backing the Medicaid cuts in his “New Freedom Initiative” legislation submitted to Congress

Please see MEDICAID, Page 5



William Gear and his daughter, Gena, after digging out from the Blizzard of '78.

Father gets help in struggle over daughter's care

Says joining COFAR gave him 'new hope'

[First in a series of articles on new COFAR members]

William Gear has struggled on his own for years to care for his daughter, Gena, and has suffered a heart attack in the process.

It has been a continuing battle that at times never seems to end. One of his biggest challenges has been healing the

Please see GEAR, Page 3

Vetoes of facility study, salary reserve overridden

The State Legislature acted this summer to maintain its oversight of the transfers to the community of residents of the Fernald Developmental Center in Waltham and potentially other state facilities.

Lawmakers voted in July to override a veto by Governor Mitt Romney of state budget language that requires the Department of Mental Retardation to submit an annual plan to lawmakers that details the planned transfers.

In another budget development, the Legislature overrode a gubernatorial reduction of funding for a reserve account to boost the salaries of direct-care human services workers. For the second year in a row, the Legislature has appropriated \$20 million into a direct-care salary reserve account.

“Both of these overrides are good news for people with mental retardation,” said COFAR Executive Director Colleen Lutkevich. “The Legislature has shown that it truly cares about the problems ordinary families are facing in the DMR system.”

The override in support of the Fiscal Year 2006 budget language on transfers of Fernald residents was one of a number of instances in which the Legislature maintained its oversight prerogative over Romney’s objections.

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The budget language (in **DMR Facilities line item 5930-1000**) requires DMR to submit the plan regarding community transitions from state facilities by January 1, 2006, to the House and Senate Ways and Means Committees for approval. The plan must detail the transition of clients from Fernald to “appropriate settings” and must include consideration of the transition of Fernald direct-care and other staff into community settings with their clients in order “to ensure continuity of service wherever possible.”

The line item also states that Fernald must not be closed before October, 2005 “to ensure adequate community, client, and family member input into the closure planning process.”

Since 2003, COFAR and the Fernald League have fought plans by the administration to close the state facilities, starting with Fernald. The advocates maintain that DMR has failed to provide an adequate plan for the transfers of the facility residents and that community-based settings do not currently provide the same comprehensive level of care as the state facilities do.

The override of the governor’s veto of the **Salary Reserve line item (1599-6901)** for direct care workers employed by private human services contractors prevented a cut in the appropriation this year from \$20 million to \$10 million. Romney’s reduction would have cut in half the earmarked amount of \$14 million for workers earning under \$25,000 a year. The governor’s reduction would also have cut in half the earmarked amount of \$6 million for workers earning between \$25,000 and \$40,000.

The Legislature also overrode vetoed language in the **Turning 22 line item (5920-5000)**, which requires DMR to report to the House and Senate Ways and Means Committees no later than January 2, 2006 on the number of clients served in each region and the types of services purchased in each region.

The Legislature let a number of vetoes stand, including vetoed language in the **DMR Regional Administration line item (5920-1000)** that would have required the DMR to issue semi-annual reports to the House and Senate Ways and Means Committees detailing the total number of service coordinators within the department, the number of clients served by the coordinators, and the amount of time spent per month per client. The Service Employees International Union, Local 509, has been seeking detailed information from DMR on service coordinators after its own survey earlier this year found that the caseload of DMR service coordinators had risen to over 50, resulting in delays in completion of Individual Support Plans.

In a conference call in May with COFAR Executive Director Colleen Lutkevich, DMR Commissioner Gerald Morrissey said no service coordinator positions would be cut in the current fiscal year, and in fact positions would be added.

Membership renewal reminder

If you haven’t yet renewed your membership in COFAR for the current calendar year, we urge you to do so and to tell a friend about joining COFAR.

Your tax-deductible, \$25 check can be sent, payable to COFAR at 3 Hodges Street, Mansfield, MA 02048. Or you can join or renew your membership online on our website at www.COFAR-Mass.org.

Remember, your continued support enables us to continue to advocate on behalf of your wards and family members in the DMR system for comprehensive and high-quality care. Your donations also support activities such as the creation of our new online Advocacy Guide (please visit our website to discover how it can help you), and the production of our newsletter, *The COFAR Voice*. Your \$25 donation also entitles you to continue receiving monthly issues of the newsletter, which will help keep you up to date on key events and issues involving the care of your wards and family members.

COFAR offers ‘hope’ to father in caring for daughter

GEAR, *continued from Page 1*

psychic wounds that Gena, who has mental retardation, suffered in a vendor-run group home in Northboro in which physical and sexual abuse were found to be rampant. Now he’s worried that he will be forced out as his daughter’s caretaker and that she will be returned to another group home setting where similar problems might occur.

In addition, Gear says the Department of Mental Retardation has never implemented an Individual Support Plan for care and services for Gena that was approved by a hearing officer in 2002. As a result, his daughter has not had a primary care physician for the last nine years, and for the first five years since she left the group home, she had no dental services. “There seems to be no accountability to deliver mandated services,” Gear maintains.

But since becoming a member of COFAR, Gear, 65, says he no longer feels that he’s alone in the battle. What’s more, since joining the organization about a year ago, there have been some dramatic changes in the case that have given him new hope—changes that he attributes to COFAR’s influence.

The retired office copier repairman says that U.S. District Court Judge Joseph Tauro, who is entertaining motions to resume his historic oversight of the DMR, has taken official notice of his daughter’s situation. In addition, Beryl Cohen, an attorney for many of the plaintiffs in the case before Tauro, has agreed to represent him. “Colleen (Lutkevich, COFAR’s Executive Director) has a great relationship with the Court,” Gear said. “She gets her point across without offending. There’s no doubt in my mind that my joining COFAR has had a positive influence on Gena’s case.”

Gear says he hadn’t heard of COFAR until a friend of his “recommended that if I wanted to move ahead with Gena’s case I should join them because they are a powerful group that is fighting to keep the Fernald (Developmental Center in Waltham) open.” Gena, he noted, lived at Fernald and is a class member of Ricci v. Okin, the case that Tauro has overseen for three decades.

“I liked what I saw at the first (COFAR Board) meeting,” Gear said. “I saw some pretty devoted, long-suffering people who weren’t about to quit. I felt I wasn’t alone anymore.”

Brain damage from an anti-bacterial drug

As an infant, Gena Gear, now 41 years old, was given Hexachlorophene—a drug used then to treat bacterial infections, but later found to cause brain damage. The drug had been administered to her by hospital staff. Gena can speak and is healthy, Gear says. But she needs round-the-clock care. With prompting, she can dress and shower. But she can’t function in a work environment. Gear says, though,

that she’s very active, likes to take walks, and helps him with gardening and furniture making.

“We found out [about the effects of Hexachlorophene] years later when we spoke with a doctor,” Gear says. “We knew she had developmental delays when she was approaching two years old. Later, we couldn’t get her into any schools.”

Then a second blow came when Gear’s wife and Gena’s mother, Evelyn, died of cancer on Christmas Day 1970, when Gena was six. Gena continued to live at home with her father until she was eight. At that point, Gear was forced to find an out-of-home placement for her because it had become too difficult for him alone to both meet her needs and earn a living. For the next 24 years, Gena lived in several congregate care settings, including Fernald. For seven years—between 1989 and 1996—she lived at the Northboro group home, which was managed by New England Residential Services, Inc., and licensed by DMR.

While Gena was in the Northboro residence, the Disabled Persons Protection Commission investigated allegations of rampant abuse in the group home. In a 300-page report issued in 1996, the DPPC found “a climate of secrecy existed at the [New England Residential Services] program in which abuse was accepted, perpetrated, and hidden.” The report concluded that none of the residents of the program escaped this abuse, and that rather than suspending or revoking the provider’s license to operate the residence, DMR initially re-licensed the program in 1993.

“I liked what I saw at the first (COFAR) Board meeting,” Gear said. “I saw some pretty devoted, long-suffering people who weren’t about to quit.”

The DPPC report noted that it was only after the DPPC investigation began that DMR began its own investigation and placed restrictions on the license. New England Residential Services ultimately withdrew as the manager of the residence in December 1993. Several DMR officials were singled out in the DPPC report for failing to adequately monitor the home and to respond adequately to the allegations of abuse.

Gear said that while Gena was living in the Northboro residence, she was also given large doses of psychotropic drugs without his required consent. “I went through the roof,” he says. He took Gena back to live with him in April 1996, after the DPPC report was issued.

Once home, Gena was difficult to manage because she now displayed aggressive and compulsive behavior and was prone to frequent panic attacks in which she recounted acts of abuse and sexual violation. She was afraid for years to take a shower, Gear said.

Continued on next page

Continued from previous page

Over the next year, Gear worked with a physician to reduce Gena's dependence on Haldol and other psychotropic drugs. He said her panic attacks have now been reduced by more than 80 percent. She is currently not on medications other than a low dose of Paxil, a mood stabilizer.

Hard times continue

But though Gena was now out of harm's way, life was far from easy for either her or her father. Gear said that during this time, he was renting a house in Lynnfield and that he was receiving a stipend from DMR to serve as Gena's sole caretaker. In 2001, however, DMR declared the stipend illegal and stopped it. Forced to work outside the home and continue caring for his daughter, Gear suffered both a hernia and a heart attack.

"I was told I needed a heart bypass, but I believe that had I done so and been laid up that long, I would have lost Gena," he says. He says his heart condition has now stabilized.

Then Gear learned that a residence in Roslindale, Massachusetts, was available through the Polus Center. DMR offered to make staffing services available through the Shriver Clinical Services. Gear accepted the offer.

Gear worked for a year with a physician to reduce Gena's dependence on Haldol and other psychotropic drugs.

Still, their troubles were far from over. In 2002, Gear appealed Gena's ISP in order to ensure that he continued to supervise her care and that she wasn't returned to a setting similar to the one in Northboro. Although he prevailed at the Fair Hearing, he claims DMR nevertheless rewrote the hearing officer's plan without his consent. Gear contends the rewritten document would have opened the door to the adoption of a behavior plan for Gena that might have excluded him from further involvement in her care. He appealed the rewritten ISP in October 2004, and is still waiting for a date for a Fair Hearing on that second appeal.

Ironically, Gear says, DMR has spent close to \$180,000 on rent and services for Gena in the past year—far more than would be needed to implement the ISP. Further, Gear contends that due to recent problems in getting funding from DMR, Shriver Clinical Services has announced that it will withdraw services for her. Another provider, the Polus Center, which owns the rent-subsidized apartment in which Gena lives in Roslindale, has announced that it is selling the property.

"It never seems to end," Gear says. "But they [DMR] probably know by now that I will never give up. I owe that much to Gina." Moreover, he believes that with his well-

known attorney in his corner and Judge Tauro now interested in the case, things may finally be resolved in Gena's favor.

William Burke, Esq., dies: wrote key COFAR/VOR legal brief

William Burke, a long-time attorney for people with disabilities, who drafted a key legal brief for COFAR and the Voice of the Retarded in ongoing litigation before U.S. District Court Judge Joseph Tauro, died in June.

Burke, who lived on Long Island and practiced law in New York City, worked for the VOR on cases in many states concerning the welfare of severely impaired people. He is best known for writing and presenting VOR's *Amicus Curiae* brief to the U.S. Supreme Court in *Olmstead v. L.C.*, a 1999 landmark decision dealing with institutional and community-based care for the disabled.

In the brief, Burke argued that institutional care is appropriate for persons in cases in which treatment professionals determine that it is necessary. In its decision, the high Court quoted from a statement in Burke's brief that: "Each disabled person is entitled to treatment in the most integrated setting possible for that person—recognizing that, on a case-by-case basis, that setting may be an institution."

In November of 2004, Burke worked with Thomas J. Frain, COFAR President, who is an attorney, and with Mary McTernan, VOR President, to draft an amicus brief on behalf of the plaintiffs in *Ricci v. Okin*, the case before Judge Tauro.

Burke and Frain appeared before Judge Tauro to present the brief, which argued that, contrary to statements made by the Romney administration, the Supreme Court decision in *Olmstead* is consistent with efforts to keep the Fernald Developmental Center and other state facilities in Massachusetts open. "As long as there are Massachusetts citizens with profound mental retardation, there will be a need for institutional care," Burke's brief stated. "If Governor Romney's promise to close all institutions is taken literally, it cannot pass muster under *Olmstead*. Some form of in-state, institutional placement is required to comply with *Olmstead*."

In the November 2004 hearing, Tauro agreed with Burke's position, saying his brief "accurately cites the *Olmstead* case. It's nothing I [Tauro] haven't said for the last 20 years."

Burke's family requested that memorial donations be sent to VOR. The VOR Board of Directors has established the William Burke Legal Fund to be used for future legal challenges across the country. Memorial donations should be sent to VOR at 5005 Newport Drive, Suite 108 Rolling Meadows, IL 60008.

George Mavridis, a past president of the Fernald League and COFAR, said Burke's death on June 9 "drained the spirit but not the resolve of the VOR members" who attended the organization's annual meeting in Washington two days later [see story on COFAR/VOR Washington initiative starting on page 1.]

"It is safe to say," Mavridis added, "that only a handful of individuals with mental retardation ever met Bill Burke. But all the individuals with mental retardation lost a champion advocate in the judicial system. Bill Burke worked tirelessly to improve their quality of care."

COFAR/VOR attend Washington advocacy effort

MEDICAID, *continued from Page 1*

that limits Medicaid growth and which "will ultimately result in cuts in facilities for the mentally retarded and move more people out."

Under Medicaid, the federal government reimburses the states approximately fifty-percent of the cost to operate intermediate care facilities and community-based group homes.

Under a congressional budget resolution approved in April, Senate and House authorizing committees are instructed to reduce spending on mandatory (entitlement) programs by \$34.7 billion over the next five years, from fiscal year 2006 - 2010. Included is \$10 billion in proposed cuts to Medicaid, starting in Fiscal Year 2007, according to the VOR. Other entitlement programs such as Supplemental Security Income (SSI), Title XX Social Services, Foster Care and Adoption Assistance are facing significant cuts as well. Domestic discretionary cuts could be \$212 billion over five years. The budget also makes room for substantial tax cuts that primarily benefit wealthy households, according to VOR.

Medicaid advocates won at least one significant victory this summer when the National Conference of State Legislatures voted to encourage the Bush administration to maintain Medicaid as an entitlement program. "That is significant," McTernan said. "We had a major push week to get our members to contact members of the NCSL health committee."

COFAR and VOR visit Capital Hill

Some 75 VOR members visited congressional offices during the week of June 13 to urge the lawmakers and their staffs to preserve Medicaid and to oppose attempts to privatize Social Security. COFAR was represented by Charles and David Hart, McTernan, and George Mavridis, a past president of the Fernald League and of COFAR. In addition Allyson and Daryl Every from the Dever Association and Irene Welch, a former Massachusetts resident, visited congressional offices.

"These (Medicaid-reimbursed state facility and community residential) programs are not optional for the persons served, but the federal reimbursement is an optional Medicaid line item just like prescription medication," Mavridis said. "Those programs will be in jeopardy if the federal portion of the Medicaid program is reduced."

Mavridis maintained that Congress is looking to tighten nursing home admission requirements, lower the cost of prescription drugs for Medicaid participants and tighten the requirements for inter-governmental cost transfers. "Some congressional health aides say they found the \$10 billion [in Medicaid cuts proposed in the budget resolution] within these three items," Mavridis said.

Mavridis said VOR also asked for a Beneficiary Impact Statement from the Social Security Administration on every major Social Security reform proposal. McTernan and VOR Executive Director Tamie Hopp discussed the impact of Social Security Reform in the office of the President's Social Security Commission.

In a related development, COFAR Executive Director Colleen Lutkevich wrote to Governor Romney in July to urge him to oppose proposals at that month's meeting of the National Governor's Association to enact cuts in federal Medicaid funding to the states.

Lutkevich's letter stated that cuts in Medicaid benefits and services would run counter to Romney's efforts to provide health care for all Massachusetts residents. Romney has proposed a plan to provide universal health care coverage in Massachusetts. The governor has noted that more than 100,000 residents who qualify for Medicaid coverage are not currently enrolled. "Clearly, your plan cannot succeed if the participation rate in Medicaid is reduced," Lutkevich's letter stated.

Fernald League urges AG to oppose Fernald closure

The Fernald League has called on Massachusetts Attorney General Thomas Reilly to oppose the Romney administration's efforts to close the Fernald Developmental Center, and invited Romney to visit the Waltham facility, the State House News Services reported.

"You are the first attorney general to choose to side with DMR since the case was brought before the federal court more than 30 years ago," Fernald League President Diane Booher wrote in a letter to Reilly in June. "You have a duty to defend the most dependent people under state care, not a state administration which seems to care less."

COFAR President Thomas J. Frain said COFAR "fully supports" the Fernald League's comments. "We hope that Tom Reilly comes to understand that closing Fernald and the other state facilities will not save money," Frain said, "nor is closure supported by the overwhelming majority of family members and guardians."

Aides to the attorney general said he is fulfilling his duty to defend the policies of state agencies. "Our role is simply to defend the policy of the administration," First Assistant Attorney General Stephanie Lovell told the News Service."

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:**

COFAR
3 Hodges Street
Mansfield, MA 02048
Phone: 508-339-3379
Fax: 508-339-5034

Thomas J. Frain, Esq. President tjf@frainlaw.com
Colleen Lutkevich, Executive Director colleen.lutkevich@verizon.net
David Kassel, Newsletter Editor dkassel@earthlink.net

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COFAR
3 Hodges St.
Mansfield, MA 02048