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DETAILS ARE BELOW

VOR 2010 ANNUAL CONFERENCE and INITIATIVE
June 4 - 9, 2010
The Liaison Capitol Hill
Washington, D.C.

VOR Weekly E-Mail Update
March 26, 2010

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LAST CHANCE!
EARLY BIRD REGISTRATION -
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1. VOR Members: Register today to take advantage of discounted registration fee.

FOCUS ON MASSACHUSETTS:
An Excellent Example of Choice Advocacy in Action

2. A "stroll" with a strong message
3. Opponents of closing institutions take case to Statehouse
4. Tufts Dental: Shuttering of Fernald facility will force thousands to seek care elsewhere

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Online Registration, Conference Flyer, Hotel Information, and Sponsorship Opportunities can all be found at: <http://www.vor.net/events/>. Here, you can also download a printer friendly flyer, which includes all

details and a registration form to use and share with your advocacy peers (see, "2010 VOR Annual Conference and Washington Initiative" link).

Conference Highlights:

Friday, June 4, 2010: State Reports

Saturday, June 5, 2010: Annual Conference:

This year participants will hear presentations from Tom York, an attorney specializing in disability litigation; a representative from the Administration (pending); Paul Heckt, an estate planning attorney; and a representative from Capitol Hill who will provide an update on federal disability policy. Conference registration fees begin at \$40 for members who register early. Registration fees include a continental breakfast and plated lunch.

Sunday, June 6, 2010: Membership Forum and Legislative Briefing

Monday, June 7, 2010: Congressional Visits Begin

Tuesday, June 8, 2010: Capitol Hill Reception featuring special guest Congresswoman Debbie Wasserman Schultz (D-FL).

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**FOCUS ON MASSACHUSETTS:
An Excellent Example of Choice Advocacy in Action**

2. A "stroll" with a strong message

Summary: More information about the "State House Stroll", COFAR's State Legislative Initiative, see, www.cofar.org.

**By Julia Spitz
The Hopkinton Crier
March 20, 2010**

Tomorrow, Tom Frain hopes to be more than "a faint sob in the night."

So far, that's about all he thinks legislators have heard when he and his fellow members of the Massachusetts Coalition of Families and Advocates speak out against closing state Department of Developmental Services facilities such as the Glavin Center in Shrewsbury, Fernald in Waltham, Monson in Palmer and the Templeton Center in Baldwinville.

For those with profound disabilities, such as his 47-year-old brother, Paul, "it's cheap, cost-effective, and it's humane" to keep such centers open, said COFAR's president.

"Mentally retarded people are ignored," he said, and "the budget is being balanced on their backs."

Which is why Frain, fellow COFAR members and friends plan to take their annual "State House Stroll" tomorrow morning, stopping to meet with senators and representatives, then rallying at noon in Nurses Hall.

"I hope that the legislators will understand the need to keep the (Glavin) Center open," said Framingham resident Martha Douty-Perez, whose autistic sister is a resident at the Shrewsbury facility. At Glavin, medical care is available 24 hours a day, she said. In group homes, that's often not the case.

"The Legislature, in the last budget, called for a study of the closures of these facilities to make sure that the interests of the residents are placed first, and foremost, in any decision with regard to closure," said state Sen. Richard Moore, D-Uxbridge, who serves on the Senate Ways and Means Committee and is the chairman of the Committee on Health Care Financing. The state's policy has been "toward de-institutionalization and trying to place individuals with disabilities in community settings as much as possible," said Moore, but "I would want to be assured that there are adequately supported community-based services and housing in place before any facilities closed.

"It does not appear that there are alternatives in the community to properly serve many of these residents," said Moore.

That's a message COFAR Executive Director Colleen Lutkevich hopes other legislators, and particularly Gov. Deval Patrick, hear and take to heart.

"Just as in medicine, you need Mass General as well as the CVS Minute Clinic, in DDS, there are as many types of care necessary as there are people who receive services," said Lutkevich, whose sister is a Wrentham Development Center resident.

Patrick has said closing the four facilities is necessary to save money, but "the cost issue is a red herring," said Lutkevich. "The facilities receive 50 percent federal Medicaid reimbursement and are a well-oiled machine, with care and costs in an all-inclusive model - programming, residential, clinical care, medical, dental, etc."

The dental care is of particular concern to COFAR and the Fernald League for the Retarded. Fernald's Tufts dental clinic, which serves more than 2,000 special-needs patients in the region, is slated to close on June 30.

"The governor, in his wisdom, has terminated the health care for 2,400 individuals," said Frain.

"Fernald is our line in the sand."

Even those whose loved ones are well-served by smaller group homes have reason to be concerned, said Pauline Stathis, a Stow resident whose daughter has cerebral palsy and lives in a group home.

"There are many individuals who are so seriously impaired, mentally and physically, that being in the community would be detrimental to their health," said Stathis. "They have been (in the state facilities) for decades and appear to have their needs met in those facilities with nursing and recreational facilities at their fingertips.

"When advocates feel that their children or siblings are better off in a more confined residential setting, I feel as though that option should be available to them. There should be a choice. No one setting is good for all."

And if the dental clinics and swimming pools at the state facilities "are closed down with no replacement elsewhere...that means those already in the community lose it also," she said.

"The facilities are important for the people who live there, but they are every bit as important for the system itself," said Lutkevich. "If we close them down and sell off the land, and lose the years of clinical, direct care, nursing and other experienced staff, we will be very sorry indeed."

As a legislator, "I am concerned that the policy needs to be sound and fully vetted, and that it is a cost-effective, not just cost-saving, solution," said Moore.

3. Opponents of closing institutions take case to Statehouse

By John J. Monahan

TELEGRAM & GAZETTE STAFF

BOSTON - The long-running debate over deinstitutionalization continues to hang over plans to close four of the state's six intermediate care facilities for the developmentally disabled, including the Glavin Center in Shrewsbury, the Templeton Development Center in Templeton and the Monson Development Center in Palmer.

Critics of the closings, set to take place over four years, with the Fernald Developmental Center in Waltham shutting its doors this summer, made their case at the Statehouse yesterday. They said residents being evicted from the facilities will get inadequate and unsafe treatment in privately operated and state-run group homes.

Several Central Massachusetts lawmakers, unionized staff from the facilities, and family members of residents at the facilities complained that the closings are unfair, take away the choice of people to remain where they have lived for many years, and could jeopardize their well-being.

While the critics said state officials and others working on the closure plans are pressuring residents and their families to move residents to group homes, officials said residents of the four facilities being closed are being given the choice of relocating to one of two other institutions that will remain open.

Jean McGuire, assistant secretary for the Executive Office of Health and Human Services, argued that group homes will provide residents of the long-term institutions, many of whom are severely disabled, with "equal or better treatment."

Ms. McGuire said thousands of other residents have moved successfully from institutions to group homes in the larger community.

"Change is difficult, and certainly family members are accustomed to a place where their loved one has always been," she said. But she insisted that all of the relocations are going to provide quality services for the residents.

"There is nobody in the institutions that is different from those who are out in the community," she said. Ms. McGuire referred to court-ordered standards and said the state has consistently demonstrated that group homes provide equal or better living arrangements.

But not everyone agrees. Thomas Frain, president of the Massachusetts Coalition of Families, said the closures should be halted until ongoing studies are completed to show whether the relocations will be safe and cost-effective. He said the change is being driven by the financial interests of private companies that operate group homes and support services.

Referring to the slogan adopted the state for its "Community First" program, Mr. Frain said when people hear that slogan they should think, "vendor first."

Several people at the meeting said institutional settings provide a more open and accountable setting to prevent abuse and ill treatment.

The Chairman of the Templeton Board of Selectman, Gerald Skelton, said the residents of the Templeton institution are considered part of that town's community. The residents vote and are often seen in local restaurants.

"All I can say to the governor is don't take our residents and put them somewhere else. We like our residents where they are," he said. "What is going on here is horrible."

Bonnie Valade has a son who has lived at the Templeton facility for 23 years. Residents at the institution, she said, are "easy prey when it comes to cutting their crucial services and evicting them from their homes.

"They can't make demands. They don't protest. They don't riot. They can be moved and removed from their homes against their will without objection," she said. Ms. Valade noted that the developmentally disabled do not even get the legal representation given inmates at state prisons.

Community living, "does not work for everyone," she said. "Most residents were placed in these facilities because they could not and will not survive in the community."

She argued that residents moving to group homes will not get on-site clinical care with nurses to monitor their medicine and the services of social workers and psychologists and will lose the security and jobs available at the institutional grounds.

Ms. Valade criticized Gov. Deval L. Patrick's plans saying, "It's inhumane. It's uncompassionate, and shame on him."

State Reps. Anne M. Gobi, D-Spencer, and Karyn E. Polito, R-Shrewsbury, said the closures will hurt the residents and should be stopped. State Sen. Michael O. Moore, D-Millbury, is also opposed to the plan.

"We know how important it is for these people to stay where they are," Ms. Gobi said, pledging to work in the House to stop the closings. "We will do our best to continue this fight."

But Ms. McGuire insisted that "community-based care works," and said the state has reduced the population in institutional settings to about 800. "We know maintaining a 150-year old institution is neither effective or efficient."

She said the current residents facing closure of their facilities are being given a choice of settings, but that in the future the state will not give developmentally disabled people the choice of living in an institution.

4. Tufts Dental: Shuttering of Fernald facility will force thousands to seek care elsewhere

By Meghan E. Irons
Boston Globe
March 22, 2010

For 34 years Tufts University has provided comprehensive dental care to severely mentally disabled patients who have long been ignored by private practitioners.

Now dental care for 2,100 patients with autism, brain injuries, and mental retardation is in doubt as the Waltham clinic where they are treated prepares to close this June.

The Waltham dental clinic, the largest of its kind in Massachusetts, is located in Fernald Development Center, which the state will close June 30 as a cost-saving measure. The center's closing is forcing Tufts to shutter the dental clinic, and when it goes, advocates say, patients who are difficult to treat will have few places to turn for fillings, crowns, or partial dentures.

"Where will they go?" said Marilyn Meagher, who heads the advocacy group Fernald League for the Retarded Inc. "These are extremely handicapped people. It is going to be very devastating for them."

Most of the patients live in group homes, and their disabilities can be so severe that many can't sit still or follow simple instructions. Some have seizures. Others spit, kick, and thrash about when receiving care.

"The perception of someone approaching you with a toothbrush can be very traumatic," said Darren Drag, who runs the Tufts special needs dental program. "These are people who may not understand that we are trying to help them."

Caregivers, practitioners, and advocates hail the Tufts clinic's expertise in tackling the behavioral and medical problems that arise. Tufts specialists in this field spend an extra three years in dental school learning to deal with developmentally disabled people.

Felicia Xiang, a dentist at the clinic, said the staff members have the space, flexibility, and time to work with such patients.

"We use a lot of patience," said Xiang. "Some patients are sensitive to touch and noise. Anything can scare them."

As news of the closing spread this week, state and Tufts University officials sought to allay concerns, saying they are working to ensure that dental care will be available at other Tufts clinics.

"We are not anticipating an interruption in services," said Jean McGuire, an assistant secretary for the Executive Office of Health and Human Services. But the other clinics - in Palmer, Shrewsbury, Taunton, and other towns - are farther away for many patients and smaller than the Waltham facility. Advocates worry that the system can't absorb the displaced patients.

Joseph Castellana, executive associate dean at Tufts University School of Dental Medicine, said officials are reviewing possibilities for expanding services at the other clinics.

"The state and the school of dental medicine are working every day trying to find ways to ensure that there is no diminishing of service to this population," he said.

Tufts officials are hoping to continue collaborating with the Department of Public Health, and the state plans to keep funding at \$1.2 million in the next fiscal year, the same as last year.

Tufts Dental Facilities was established in 1976 after a lawsuit demanded that Massachusetts improve dental care for people with developmental and acquired disabilities in the institutional system. Tufts and the state formed a partnership, operating seven clinics that serve 9,000 patients, staffed by 25 dentists, 11 hygienists, and 58 practitioners who specialize in treating people with disabilities.

In Waltham last week, the green dental chairs were empty. A few people sat in a waiting room, including one woman in a wheelchair who was wearing a helmet and protective facial gear.

Marit Pyle, an 87-year-old Boxford mother, said the clinic took her daughter, Kristine, 55, who has Down syndrome, when no one else would.

"I'm very sad about this," Pyle said about the closing. "I'm worried about what is going to happen next."

She and others contend that many private dentists won't take MassHealth, the state's insurance system, and there are too few options for the vulnerable.

"I've been in this business for 38 years," said Susan Shalit, a house manager at a group home in Lexington who took Ann Murphy, a 45-year-old woman with Down syndrome, to the clinic for her regular dental cleaning. "I can remember when there was nothing, because no one would take them."

Tamie Hopp, Director of Government Relations & Advocacy

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