



The COFAR VOICE

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Karen Olson (right) poses with her son Patrick (left) and Patrick's niece Josie on Patrick's 29th birthday. Karen Olson learned some hard lessons in getting Patrick out of an inappropriate DDS placement. Story on Page 4.

Right-to-return issue in question

Howe acknowledges no written DDS policy

Is the Patrick administration completely or just partially shredding the Intermediate Care facility system in Massachusetts?

As it moves ahead with plans to close four of six remaining developmental centers for people with intellectual disabilities in Massachusetts, the administration has left many questions unanswered about the future of the ICF system.

COFAR has made several attempts to pin Department of Developmental Services Commissioner Elin Howe down specifically on the administration's plans for the Wrentham and Hogan Centers, which are slated to remain after the Fernald, Monson, Glavin, and Templeton Centers have been closed.

Here are our two key questions that we posed to Howe:

1. Will there be beds available at Wrentham and Hogan for all residents of the Monson, Templeton, and Glavin Centers

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COFAR calls for independent study of state facility closure costs

A cost analysis submitted to the Legislature by the Patrick administration to justify its planned closures of the Monson, Templeton, and Glavin developmental centers is both incomplete and fundamentally flawed, a COFAR review shows.

As a result, COFAR is urging key state legislators to support an independent cost study, which would be subject to legislative approval, before any state Intermediate Care Facilities for persons with intellectual disabilities could be closed.

The state of Connecticut has projected increased costs in the hypothetical closing of the remaining developmental center in that state. (Story on Page 3.)

"As it now stands, this so-called cost analysis is meaningless," said COFAR Executive Director Colleen Lutkevich. "It serves the agenda of the administration, but it doesn't serve either the clients of the DDS system or the state's taxpayers. The Legislature should demand better."

The administration's cost analysis, which was submitted in July to the Legislature's House and Senate Ways and Means Committees and the Joint Committee on Children, Families, and Persons with Disabilities, concluded that closing the three developmental centers would save the state \$20 million a year as of Fiscal Year 2013.

In a letter sent on November 29 to the chairs of the three committees, COFAR Executive Director Colleen Lutkevich and President Thomas Frain maintained that the administration's analysis appears to inappropriately compare the cost of the average client of the community-based system with the per-client cost of developmental center care in

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who choose to remain in ICF-level care?

2. Will there be beds available at Wrentham and Hogan for any former facility resident who is transferred to the community system and for whom the community placement proves unsuccessful?

In a July 2010 report to the Legislature, which COFAR has reviewed (see story on Page 1), the administration projected that 59 of a total of 311 remaining residents of the Monson, Templeton, and Glavin Centers will choose to be placed in either the Wrentham or Hogan facilities. Thus far, some 60 former Fernald residents have already been transferred to Wrentham, which needed \$3.2 million in renovations to accommodate them.

In a November 18 letter in response to our questions, Howe contended that beds at the Wrentham Center “will remain open indefinitely to serve individuals in the closing facilities who choose to remain in an Intermediate Care Facility (ICF) setting.” Howe also stated that beds will also be available at the Hogan Regional Center.

But Howe also stated that there are no plans for any additional renovations at Wrentham. It is unclear how the Wrentham Center, in particular, could accommodate a significant number of additional residents without additional renovations. Meanwhile, Howe acknowledged in her letter that the future of Hogan remains uncertain. A decision on its future remains deferred, she said.

Moreover, notes Colleen Lutkevich, COFAR executive director, DDS’s projection that only 59 of 311 remaining residents at Monson, Templeton, and Glavin will choose ICF-level care appears to be overly conservative. A majority of remaining residents at Fernald chose to be moved to Wrentham. “If Fernald is any guide, the overwhelming majority of residents at Monson, Templeton, and Glavin will want to keep the same level of care they’ve been receiving all along,” she said.

Lutkevich said she finds it difficult to believe that there will be room at the Wrentham Center for everyone who chooses it. And the promise of Hogan’s availability should be of no comfort to families, she said, because it may well be next on DDS’s closure list.

In her November 18 letter, Howe also stated that DDS has no written policy on the related question of whether developmental center beds will be made available for individuals who have been transferred to community-based settings, which then turn out to be unsuccessful.

At the same time, however, as Howe stated in a follow-up letter to COFAR, DDS will provide a so-called “right-of-return-to-a-facility” letter to guardians who request them. But this unwritten policy of providing such letters appears to come with its own drawbacks and questions.

One such “right-of-return” letter, which COFAR obtained, states only that DDS will work with the guardian to identify another available ICF or state-operated group home for a

client for whom a community placement was unsuccessful. Thus, the right to return to a developmental center, such as Wrentham, does not appear to be ironclad. The letter is also made available only to guardians who request it. Many guardians simply don’t know they can request such a letter, Lutkevich pointed out.

Those uncertainties are unacceptable to Bonnie Valade, vice president of COFAR’s Board of Directors.

“If there indeed is no written DDS plan for clients who cannot make it in the community, then how can the administration proclaim they are providing equal or better care?” Valade asked. “DDS needs to be held accountable for their decisions that impact the lives of the clients. They need to have a written plan in place before the client is placed and that should be that the client will return to the facility they came from where it was working for them. The return and only the return assures them of ‘equal or better’ care.”

George Mavridis, treasurer of COFAR’s Board, noted that the right to return to a facility was first proposed by former DMR Commissioner Gerald Morrissey as part of a plan to close the Fernald Center in 2004. Morrissey’s proposal, however, did not include a right to return specifically to Fernald, and the proposal was therefore rejected by the Fernald plaintiffs who were involved in litigation over the planned closure.

It is unclear how the Wrentham Center could accommodate additional residents without additional renovations.

During a 2007 hearing as part of that litigation, U.S. District Court Judge Joseph Tauro requested that DDS include a right-to-return letter with each Fernald resident’s plan for care as a means of “leaving the light on” at the Center for residents who had been transferred elsewhere. DDS agreed to include such letters in residents’ plans for care, but apparently did not interpret Tauro to mean that the letters had to specify Fernald as the facility to which they had a right to return.

Valade maintained that “Wrentham and Hogan are great facilities for certain clients, but not for all.” She contended her son continues to need “the structure of Templeton, simply because of its location.” The proximity of Wrentham and Hogan to residential neighborhoods “will create all the old problems he had before going to Templeton,” Valade said. “Each facility is unique in its services and that is why we need them all to remain open,” she said.

Despite the preference of a majority of former Fernald residents to be moved to the Wrentham center, the administration’s July report to the Legislature contained the statement that there was “virtually no new demand for facility beds.” Lutkevich maintained that the administration’s statement was “a continuation of its disinformation campaign about the developmental centers.”

COSTS, *continued from page 1*

Massachusetts. The study does not appear to adjust for the fact that developmental center residents are more intellectually disabled and have more severe medical problems on average than do residents of the community system.

COFAR has long opposed the administration's plans to close four of six remaining ICFs in Massachusetts, arguing that these facilities provide a comprehensive level of care that is unduplicated in the community-based system of care in Massachusetts.

In response to COFAR's charge that the administration's cost analysis inappropriately used an average cost of community-based care in calculating a savings in closing three of the four targeted ICFs, a spokesperson for the Executive Office of Health and Human Services told reporters of two news organizations that the administration used the cost of a group home in Bedford, housing former residents of the Fernald Developmental Center, as a "baseline" in calculating the cost of community-based care.

Lutkevich countered that nowhere in the cost analysis submitted by the administration to the three legislative committees was the Bedford group home or any other specific residence mentioned as having been used as a baseline in calculating community-based costs.

The administration's claimed costs of operating the Monson, Glavin, and Templeton Centers were, in addition, calculated by dividing the total budgets of the facilities by their total census. This calculation tended to inflate the cost-per-resident of the developmental centers, Lutkevich and Frain wrote in their November 29 letter to the legislative committee chairs, because it didn't account for certain costs associated with community-based residents who use medical, dental, recreational and other facilities in the centers.

Moreover, according to Beth Gray-Nix, former director of occupational therapy at the Fernald Center, primary care doctors there, for instance, were paid under the Fernald budget. Yet, in the community system, doctors for DDS clients appear to be paid under MassHealth, which is separate from the DDS budget. Thus, said Gray-Nix, the administration's cost analysis appears to include doctors' fees and possibly other medical costs in its overall cost of care for the developmental centers, but not for the community system.

The administration was required in language inserted in the Fiscal Year 2010 state budget to submit a report as of last July with a cost analysis of closing the centers. Left out of the study, over the objections of COFAR and affiliated organizations, was a requirement that a cost analysis be submitted of the closure of the Fernald Developmental Center, the first of the four such centers that the administration has targeted for closure.

On December 3, COFAR submitted a Public Records Law request to the administration, asking for backup documents supporting the savings claim in closing the three developmental centers.

Other problems with the cost analysis

An additional problem with the administration's cost analysis, according to COFAR's letter to the three legislative committees, is that it failed to include potential costs of developing group homes and other state and community-based facilities to accommodate the residents of the developmental centers that are slated for closure.

The administration's cost analysis did make projections of capital expenditures that would be necessary if the Monson, Templeton, and Glavin Centers were to remain open.

The COFAR letter pointed out that some capital costs have already been incurred in the closure of the Fernald Center, including the \$3.2 million cost of renovating two buildings at the Wrentham Developmental Center, and the development and lease of community-based group homes at a cost to DDS of up to \$2 million per home over a 20-year period.

CT projects no savings in closing Southbury facility

In contrast to the Patrick administration's savings projections in closing developmental centers, state officials in Connecticut have projected potential cost increases in the hypothetical closure of that state's remaining developmental center.

Cost analyses done by the Connecticut Department of Developmental Services in 2002 and 2010 state that there would be no savings in closing the Southbury Training School because of the potentially high cost of developing new community-based housing for that developmental center's 441 current residents.

That potential community-based infrastructure cost is one of a number of costs that the Patrick administration does not appear to have taken into account in its projection last year that this state would save \$40 million a year in closing the Fernald, Monson, Templeton, and Glavin developmental centers in Massachusetts (See story starting on Page 1).

In the 2002 cost study, the Connecticut DDS stated that transferring residents from "a large-state operated setting" to the community system would have to be "a multi-year effort due to lack of available community-based services." The study projected that costs "during the multi-year effort will increase -- in this case by 200-300 percent."

The Connecticut DDS's updated study in November 2010 projected some lower per-diem costs in moving Southbury Training School residents to privately run group homes due to lower paid staff in the private system. But the study ruled out the likelihood of short-term savings and did not project any long-term savings in closing Southbury because of "substantial cost implications associated with developing an infrastructure to accommodate a parallel service system in the community."

A mother's tough lesson in getting care for her son

Karen Olson says that when her son, Patrick, turned 22, she had no idea of the vast differences that exist in the quality of residential programs available in Massachusetts for persons with intellectual disabilities.

She learned her lessons about the system the hard way – in particular, how difficult it can be to extract a loved one from an inappropriate placement.

Patrick, who has a mild intellectual disability and has had some severe medical and behavioral issues, had been in special education residential programs since age 15, first at the Cardinal Cushing School in Hanover, and then at the Judge Rotenberg Center in Canton for 18 months prior to his 22nd birthday. The JRC placement was highly successful in helping him regain his health, both emotional and physical, following kidney failure at age 20, Olson says.

Although JRC has had its share of controversy because of its use of aversive therapy techniques such as electric shocks, Olson said those techniques were not used on her son. The program was heavily structured, however, which was good for Patrick, who flourished there.

But when Patrick's special education funding ended, Olson says the Department of Developmental Services told her he would have to move to a less expensive, group home setting. In 2003, the Department suggested Patrick be placed in a home run by Delta Projects, Inc., a DDS-funded human services vendor. The program turned out to be inappropriate for him.

"I relied heavily on the staff of DDS, and believed completely all the information I was given by Delta Projects' staff regarding their ability to support my son with comparable services to JRC," Olson said. "That was one of the biggest mistakes of my life."

Unlike JRC, there was no nurse or nutritionist on staff at Delta Projects for support and medical backup for Patrick, who was still maintaining his fragile kidney function with self catheterization, Olson says. Patrick was also no longer taken to a day program once in the Delta residence. The promised structured program was "basically Pat staying at home with staff and a list of daily 'chores,'" she said.

Without the level of structure, exercise or nutrition provided at JRC, Patrick's need for anxiety medication returned within months, and his weight ballooned from 185 to 260 pounds. JRC had helped him come off all medications, other than his kidney medications, Olsen says. In addition to the kidney concerns, Patrick is a childhood leukemia survivor, and at risk for potential life-long health complications.

Then one day in early 2009, Olson stopped by the group home and noticed that Patrick had scratches on his face. She learned, from Patrick, that the staff had placed her son in restraints two days previously without informing her. She says this happened twice more, within weeks and without notice,

while she continued to petition DDS for a new placement for Patrick.

"I didn't know how to maneuver in the system to make sure he got what he needed," Olson says. She filed a complaint with the Disabled Persons Protection Commission, alleging a lack of proper medical care for Patrick and a lack of cleanliness and proper communication in the group home. The DPPC forwarded the investigation to the DDS, which issued a number of recommendations to the group home to address substantiated issues, Olson says.

In 2009, Olson found COFAR's website and contacted the organization. She was advised by Thomas Frain, an attorney and COFAR's president, to try to get her son into a state-operated group home.

"The most striking thing about our first conversation was that he (Frain) kept using the terminology, 'vendor' and 'state-operated' homes," Olson says. "It took me a while to figure out that there were two systems here."

At first, Olson said, DDS resisted her efforts to move her son out of his Delta Projects residence. DDS also denied her request that her son be placed in a state developmental center.

At that point, Olson said, she contacted State Representative Christine Canavan, who contacted DDS on her behalf. Canavan was successful in persuading DDS to consider a placement for Patrick at a state-operated group home. Olson had to wait about a year for a placement to open up at Southeast Residential Services, a state-operated residential system located south of Boston.

"I...believed completely all the information I was given...That was one of the biggest mistakes of my life."

Patrick moved in to the SRS residence last summer. "Long story short," says Olson, "he (Patrick) is a new person. His home is immaculate, the staff is compassionate and really seem to love what they do, and his medical needs are handled completely by SRS, and he is loving life."

Olson says Patrick's housemates all have dietary issues and are all on a diabetic menu. Patrick also exercises at a local YMCA several times a week. "They treat him with dignity," says Olson. "It's beyond anything I could have imagined. He has found a home."

Olson says that while Patrick is still on anti-anxiety medications, he has had no behavioral issues since moving to SRS and has lost at least 15 pounds, and the hope is to reduce Patrick's medications within a year.

COFAR Executive Director Colleen Lutkevich terms Karen and Patrick's experience a "success story, but one that has come at a cost of much time and effort." Before accepting any placement in the community system, Lutkevich advises, guardians should learn as much as they can about the care and staffing provided there. "Don't rely on promises," she said. "Go and see it for yourself, and don't be afraid to ask a lot of questions."

'Tis always the season: Contributions tell story on Hill

There is a culture of giving on Beacon Hill in Boston, but the giving isn't necessarily to the truly needy.

COFAR examined the online records of campaign contributions by just a dozen executives and lobbyists in the human services provider industry in Massachusetts. Altogether, those individuals contributed more than \$44,600 to close to 60 state representatives and senators and to Governor Deval Patrick and other politicians between 2005 and 2010.

While the average level of contributions per donor of \$3,700 over the six-year period isn't shockingly large, it nevertheless confirms that there is a "pay to play culture" on Beacon Hill, says COFAR President Thomas Frain. "These provider executives and their lobbyists clearly have a vested interest in making regular donations to influential politicians at the State House," Frain said. "And it would seem the politicians are gratefully responding in kind."

Frain noted that the Legislature has done little to investigate or provide better oversight of the state's \$1.5 billion human services provider system. Also, efforts to require meaningful cost analyses of initiatives by the Patrick administration to close developmental centers in the state and privatize services have made little headway in the Legislature.

Many of the largest contributors are members of the Arc of Massachusetts and the Association of Developmental Disabilities Providers, which are closely tied to the provider system in the state.

For a list of the dozen contributors, their donations, and the major recipients of those donations, see our online post on Blue Mass Group, a leading political blogsite in Massachusetts,...at

<http://www.bluemassgroup.com/diary/21525/political-contributions-tell-the-story-in-human-services>. A new COFAR blogsite is under construction.

Guardian personally files assault charge

The guardian of an intellectually disabled man living in a West Springfield group home has personally filed an assault charge against a staff worker at the home for allegedly assaulting her ward.

The vicious assault, in which the group home resident was allegedly poked in both eyes, took place last June during a "mini-vacation" on Cape Cod on which the resident and his roommate were taken by the group home staff.

The felony assault charge was filed by Sheila Paquette, who is the president of the Advocacy Network, an affiliate of COFAR. In an account of the incident in the fall 2010 issue of *The Advocacy Network News*, Paquette wrote that she personally filed the charge through the East Falmouth Police

Department last fall, some three weeks after she had first reported the incident to the Disabled Persons Protection Commission. The assault allegedly took place against Paquette's brother Jack, who is non-verbal.

It was only after she had filed the charge against the staff worker that the DPPC sent a Massachusetts state trooper to her house to investigate, Paquette wrote. "Until I had filed charges myself, I wasn't taken seriously," she wrote.

As of the press date of this newsletter in early January, the alleged perpetrator was still at large. Paquette wrote that in November she learned the staff worker had been subpoenaed for an October 12 court appearance in Barnstable County, but failed to show up for the hearing. She stated that she is concerned that until the alleged perpetrator is actually arraigned, nothing will appear if a potential employer runs a CORI (Criminal Offender Record Information) check on him.

While the staff worker was fired after the incident by the Center for Human Development, the state-funded operator of Jack's group home, "who's to say he won't turn up somewhere else, perhaps in a nursing home?" Paquette asked.

Paquette said he alleged assault was witnessed by Jack's roommate. The roommate said that while the staff worker was toileting her brother, he suddenly poked Jack in the eyes and that the assault was entirely unprovoked. Jack was not examined by a doctor until he was returned from the Cape to West Springfield, and Paquette took him to Noble Hospital in Westfield. She said the medical staff there told her that her brother's black eyes "were consistent with somebody taking their fingers and shoving them right into his eyes, with sufficient force to cause blood to pool." It had taken several hours for the bruising to show, Paquette wrote, which was why it wasn't noticed earlier.

Paquette said he later learned that her brother "was up all night, moaning and crying," after the alleged assault.

Your contributions are needed

COFAR has been in the forefront of the battle for choice in care for persons with intellectual disabilities in Massachusetts since 1983. We are the only statewide, nonprofit organization fighting for a comprehensive continuum of high-quality care that ranges from developmental centers to community-based group homes.

But we are facing a major challenge in continuing our work on behalf of our member families and guardians. Unlike many advocacy organizations, we receive no funding from the Department of Developmental Services or any of its provider agencies. We survive entirely on member donations.

If you haven't already, please pay your 2011 dues or make a larger contribution, if possible. You can use the form on the back of this newsletter to pay by check, or you can pay online, on our website, at www.cofar.org.
THANKS!

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