



The COFAR VOICE

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STANDING ROOM ONLY – State Representative Thomas Stanley (seated at desk in center) testifies before the Legislature’s Children, Families, and Persons with Disabilities Committee on July 16 in favor of a bill that would transfer state funding from the closures of state developmental centers to provider-operated programs. COFAR is concerned this bill and another measure, the ‘Real Lives’ bill, would erode funding for state-operated care. (Story on Page 5.)

National background check not seen as a state priority

Neither the Patrick administration nor the Legislature appear to have made it a priority to require national criminal background checks for persons hired to work with individuals with intellectual disabilities in Massachusetts.

Despite what appears to be widespread agreement that national background checks are a critically important means of protecting these individuals from abuse and neglect, proposed legislation to require such checks for workers in the Department of Developmental Services system (H. 1674) has remained stalled in the Legislature’s Judiciary Committee.

The administration, meanwhile, did not submit testimony in favor of national background checks during a public hearing on the legislation in July. And the administration has failed for the past three years to apply for federal funding available to design a national background check program in Massachusetts.

Please see CHECK, Page 2

ICF-level centers disappearing from state

The Patrick administration is moving closer toward its goal of closing four of six developmental centers in Massachusetts, moving the state closer to the elimination of all federally regulated Intermediate Care Facilities (ICFs) for individuals with intellectual disabilities.

Since December 2008, the state has closed two ICFs – the Glavin Regional Center and the Monson Developmental Center – and has significantly phased down operations in two others – the Fernald and Templeton Centers.

In the process, hundreds of residents of these facilities have been moved to state and provider-operated group homes and to the Wrentham Developmental Center whose residential population has been increased to more than 300. Neither Wrentham nor the Hogan Regional Center, both of them ICFs, are open, however, to new residents other than those from centers targeted for closure. As a result, those two latter facilities will eventually close as well.

COFAR advocate George Mavridis pens a compelling memoir about his cousin, Joanna. (Page 3)

Guardians of two former Glavin Center residents said in late August that they were very satisfied with the care the residents were receiving in new state-operated group homes to which they were moved in early June. And the mother of a Templeton resident said she has been told staffing levels will remain the same when the Templeton facility is eventually converted to state-operated group homes.

But COFAR Executive Director Colleen Lutkevich noted that all group homes in Massachusetts operate under a waiver of the federal ICF regulations, which require minimum staffing levels and specify other strict care and treatment requirements for DDS clients. “My concern is with the overall picture – the gradual and subtle downgrading of services when ICF levels are not maintained,” Lutkevich said. “There is nothing to stop staff or services from being cut once the oversight required at the ICF level is no longer there.”

Lutkevich said she was concerned that under-funding of
Please see ICF, Page 4

National background check not a priority

CHECK, *continued from page 1*

"It's inexplicable that the state has done so little to implement the basic safety measure in Massachusetts of national background checks," said COFAR President Tom Frain. "It's clear that closing state facilities for care is priority No. 1 for the administration and the Legislature. But protecting the clients is somehow not considered important."

National background checks involve matching a job applicant's fingerprints against a federal database maintained by the FBI. Massachusetts currently requires only in-state background checks of people hired to work in the DDS system. Those checks do not identify criminal convictions a person might have from another state.

Since 2010, 23 states and Puerto Rico have been awarded a total of \$53.4 million in federal grants available under the Affordable Care Act to help them design national background check programs. Massachusetts, however, has not applied for those grants, which have been as high as \$3 million per state.

In an August 14 email, Victor Hernandez, a deputy assistant DDS commissioner, said the administration had not applied for the grant funds because the federal program requires the state to guarantee state funding in order to receive the matching federal funding. Hernandez stated that because Massachusetts had not yet guaranteed that funding or enacted the legislation to authorize national background checks (H.1674), "an application to participate in the (CMS) program would be premature."

Hernandez acknowledged, however, that even without the authorizing legislation or guaranteed state funding, the grant program rules allow states to "work with CMS" to obtain at least partial funding under the program. He said the administration had rejected that option, but offered no reason for that rejection.

Hernandez also said that the administration was "actively working with others in support of the bill (H. 1674)." But he acknowledged that the Department had not submitted any testimony in support of the bill to the Judiciary Committee, which held the only public hearing on it thus far this year.

The federal Centers for Medicare and Medicaid Services, which administers the national background check grant program, has recognized abuse, neglect, and misappropriation of funds as "a widespread problem for millions of Americans receiving LTC (long-term care) services."

VOR, the national affiliate of COFAR, has cited an "alarming number" of deaths and cases of abuse of individuals with intellectual disabilities. In August, VOR urged a federal commission on long-term care to support national background checks and "uniform staffing standards," for community-based residential care settings around the country.

We need your help!

Please take this opportunity to keep COFAR up and running by contributing what you can.

There is still time to take advantage of a generous offer by George Mavridis, COFAR past president, to match your donation.

Your help will enable us to continue producing this newsletter, blogging, testifying on Beacon Hill, and advocating for your family members on an individual basis.

Your donations can be mailed to COFAR, Inc. 3 Hodges Street, Mansfield, MA 02048. You can also donate online by going to our website at www.cofar.org.

Thanks!

DDS eligibility expansion bill remains stalled

More than six months after a bill that would expand care and services in Massachusetts to all people with developmental disabilities was filed, key state legislators do not yet appear to have reached agreement with the administration and key proponents on the scope of the measure.

In late August, a staff member of the Legislature's Children, Families, and Persons with Disabilities Committee, stated that the committee was "assiduously continuing our work" on the bill (H. 78).

An advocate with the Disability Law Center, a major proponent of H. 78, said he had no additional information on the status of the discussions over the measure.

COFAR President Thomas Frain said he would like to see action soon on the bill. Frain was involved in litigation last year that expanded eligibility for care under Department of Developmental Services to persons with borderline intellectual disabilities.

H. 78 would expand DDS eligibility further to include people who are not considered intellectually disabled by DDS, but who have autism or other developmental disabilities that impair their ability to cope in society.

In the wake of a lawsuit brought last year by Frain on behalf of a DDS client, a new state law and regulations were enacted that eliminated a cutoff IQ score of 70 that DDS had used in determining eligibility for services. Nevertheless, Massachusetts reportedly remains the only state in the nation that requires that there be a finding of "intellectual disability" as measured by an IQ score before it will provide services. As a result, an unknown number of people in Massachusetts with autism and other developmental disabilities do not currently qualify for services from DDS.

On May 21, a parade of parents and guardians urged the Children and Families Committee to approve H. 78, saying passage of that and similar measures were the only way their family members would be able to get needed services.

A new book about a special woman

George Mavridis, a longtime advocate for the intellectually disabled, has published a personal memoir of his and his family's experience in caring and advocating for his late cousin, Joanna Bezubka.

"Joanna, God's Special Child" (Outskirts Press) is a moving tribute to a woman whom Mavridis describes as "a surrogate sister and then daughter" to him.

Joanna, who lived for 39 years at the Fernald Developmental Center and for the next seven years in a group home in Lynnfield, died in January 2012 at the age of 60. She had Down syndrome and was profoundly intellectually disabled.

Mavridis, a former president of COFAR and the Fernald League, describes in the book how his experience in caring for Joanna led him into life-long advocacy work on behalf of all persons with intellectual disabilities. He continues to travel to Washington, DC, each June as a legislative committee member of VOR, a national advocacy organization and COFAR affiliate.

Told with warmth and humor, Mavridis's memoir is a meticulous chronicle of Joanna's life. The story ranges from her major scoliosis operation to correct curvature of her spine to a sexual assault, allegedly by group home staff, and Mavridis's pursuit of the investigation. From her life-long love of playing with Lego toys to her specific preferences in clothing and the arrangement of George's apartment, Joanna emerges as a charming and loving person with an independent spirit.

State-run facility care gets cut in state budget

Service coordinators and state-run facilities for the developmentally disabled all received less funding than the administration had initially proposed in the state budget approved by the Legislature for the current fiscal year.

The Fiscal Year 2014 budget, which was signed into law by Governor Deval Patrick in early July, contains some better news for corporate provider-run facilities and programs in the Department of Developmental Services system.

Among provider line items, the Legislature approved a \$2.8 million increase over the governor's budget for adult family supports, a \$1 million increase in autism services, and a \$500,000 increase in Turning 22. The Legislature accepted the governor's proposed budget amounts for both community transportation and day programs.

The Legislature, however, cut the community residential line item by \$13 million from the governor's budget proposal. That still represents a \$59 million increase over the just-ended fiscal year, but it was apparently less than the administration and DDS providers had sought under a

statutory program to boost provider rates (see story on 'Real Lives' and Stanley bills, page 5).

The DDS administrative line item, which funds service coordinators, received \$700,000 less in funding in the current fiscal year than the governor had recommended.

The service coordinators are DDS employees who ensure that DDS clients receive adequate and appropriate services in the community-based system. Their caseloads have grown steadily even as their funding has been cut in recent years.

The Legislature boosted funding for state-operated group homes by \$9.1 million for the current fiscal year, but the amount was \$1.5 million less than what the governor had recommended. The state-operated group homes have become a major destination of residents from developmental centers that have been marked for closure (see story on page 1).

The developmental center line item, meanwhile, was cut by \$10.7 million from the previous fiscal year, under the budget as approved by the Legislature – a cut some \$400,000 larger than what the governor had recommended.

State eyeing phase-out of sheltered workshops

The Patrick administration has begun discussions with corporate providers on possible changes to day and employment programs that could result in the phase-out of sheltered workshops for persons with intellectual disabilities.

The Arc of Massachusetts stated that the discussions stem from a recent settlement of a legal case in Rhode Island in which a service provider was accused of improperly "segregating" developmentally disabled persons in a sheltered workshop and paying them sub-minimum wages.

The Rhode Island case reflects a widening effort at the federal and state levels and among some advocacy organizations to phase out sheltered workshops, which provide work activities primarily for intellectually disabled individuals. Opponents of sheltered workshops contend that they unnecessarily segregate disabled persons from their non-disabled peers in the community. Supporters argue that the workshops often provide meaningful and rewarding activities for people who otherwise would be left on their own with little to do.

In a strategic plan document for Fiscal Years 2012 through 2014, DDS did not use the term "sheltered workshops," but stated that the Department planned to "aggressively pursue the development of real jobs for individuals we support with an emphasis on sustaining career paths for those who are turning age 22..."

The Massachusetts Arc stated that DDS Deputy Commissioner Larry Tummino had been asked to form a work group to recommend new policies on employment programs for the developmentally disabled. DDS has so far invited the Arc and the Association of Developmental Disabilities Providers to participate in the work group.

ICF-level care disappearing

ICF, continued from page 1

the state-operated group home line item in the DDS budget could contribute to the downgrading of those services (see story on the impact of pending legislation on state-operated group home funding, page 5).

Lutkevich noted that the phase-downs and closures of the four developmental centers have apparently not benefited other developmentally disabled people in the DDS system because the former facility residents have been placed in their new community residences ahead of others on a waiting list for such placements.

In 2008, there were 476 residents living at Fernald, Glavin, Templeton, and Monson, the four centers targeted at the time for closure. As of late August, 13 residents remained at Fernald, located in Waltham, and 42 at Templeton. Fernald, which had been scheduled to be closed completely in July 2010, is now entering its fourth year of litigation, started by the families of the 13 remaining residents there. Those families initiated administrative appeals of the residents' transfers, and those appeals have since moved to the state court system.

In 2008, there had been 162 residents remaining at Fernald. More than 60 of those residents were moved to the Wrentham Center, and most of the remaining residents moved to state-operated group homes.

The Monson Center in Palmer was officially closed last year. In 2008, there were 136 residents remaining in the facility.

“Templeton was a real community, Valade said. “When I drive through there now, it’s like a ghost town.”

The last residents moved from the Glavin Center in Shrewsbury in late May and early June, said Roland Charpentier, the brother of Richard, who was one of the final two Glavin residents to leave. In 2008, 55 residents were still living at Glavin.

The move from Glavin was a contentious one for Charpentier and the family members of about a dozen other residents, who had organized rallies and protests at the State House in the past two years in an effort to keep the facility open. The protests dwindled out, however, when it became clear that key state legislators would not support a proposed independent study of the cost of the Glavin closure and other aspects of the DDS system. (See March 2013 *COFAR Voice*).

Charpentier said he agreed to move his brother in early June to one of three state-operated group homes across the street from the center after extracting written promises from DDS of 24-hour nursing in the group home and other staffing guarantees. “The only thing DDS refused to budge on was our request to make the group home an ICF-level facility,” Charpentier said. “Otherwise, we got what we

wanted and the care is wonderful. I don’t know of any placements that haven’t worked out,” he added.

Charpentier said, however, that he had not heard from families of any residents other than those transferred to state-operated facilities. Will and Rosemary Dumont, whose son Stephen had been a Glavin resident, for about five years, had voiced concerns that a move from Glavin would cause their son to resume severely injurious head-banging behavior that he had exhibited in community-based residences before he was accepted at Glavin. Stephen was transferred in early June to a state-operated facility in Spencer, and thus far there have been no head-banging incidents in his new home, Will Dumont said.

Dumont said staffing at the new residence is similar to what it was at Glavin. While Stephen received clinical and medical care on site at Glavin, he now goes for medical tests and procedures to UMass Memorial Hospital in Worcester. Dumont said it has worked out so far, and that Stephen has a new team of doctors who are doing “a lot of testing” of Stephen for respiratory and other problems.

Templeton now a “ghost town”

As of late August, DDS planned to close some of the existing buildings at Templeton and build three state-operated group homes on the campus, according to Bonnie Valade, a COFAR Board member and mother of Tony Welcome, a Templeton resident. The group homes will continue to serve residents with behavioral problems and medical concerns. While some clinical and 24-hour nursing staff will remain in the group residences at the Templeton site, those new facilities will no longer operate under ICF-level requirements once the new facilities are built and in operation, Valade said.

Valade said there is a proposal to lease some of the property at Templeton to local farmers and to continue to allow facility residents to work at the dairy barn under the Department of Agriculture. She said day programs and a recycling program will continue to operate on the facility grounds.

Valade said many of the services and much of the staffing at Templeton have been steadily reduced in recent years, even under the facility’s ICF designation. Activities ranging from horseback riding to swimming to tending gardens have largely been eliminated, she said.

“I remember when I visited Templeton what a perfect place it was,” Valade said. “It was a real community for the residents. When I drive through there now, it’s like a ghost town.”

COFAR seeking DDS records

On June 28, COFAR sent a Public Records Law request to DDS, seeking documents showing the number of residents who had been transferred from the developmental centers marked for closure to both state and provider-operated group homes. The records request also sought information on the number of state and provider-operated group homes that have been developed in Massachusetts since 2008 and that were projected to be developed. While DDS indicated in early July that departmental staff were compiling the requested documents, no documents had been provided as of September.

'Real lives' bill and Stanley bill could hurt state care

COFAR has raised concerns about two pending bills in the state Legislature that would potentially divert funding from state-operated care for the developmentally disabled into residential and other programs run by corporate providers to the Department of Developmental Services.

Both bills (H. 151 and H. 156) call for using so-called savings in closing state developmental centers to fund provider-based programs.

In July, COFAR submitted written testimony to the Legislature's Children, Families, and Persons with Disabilities Committee, contending that the proposed legislation would appear to reduce the discretion of DDS to fund state-operated group homes, in particular.

H. 151, also known as the 'Real Lives' bill, was filed by Representative Thomas Sannicandro. It states that 40 percent of the "savings" in closing at least three developmental centers must be directed to a fund that would support "self-directed services" for DDS clients. The bill appears to specify a major role for the providers in establishing that self-directed services fund. One of the stated purposes of the fund would be to subsidize providers that lose funding when their clients leave their facilities for facilities run by other providers.

H. 156, which was filed by Representative Thomas Stanley, would require that "not less than 50 percent" of developmental center closure "savings" be used to "fund and implement Chapter 257 of the Acts of 2008." That statute is intended to boost state payments to group home providers. Total proposed Chapter 257 funding apparently did not materialize in the final budget for the current fiscal year. The provider residential line item in the final budget, as approved by the Legislature, was \$13.1 million less than what the governor proposed in January.

In an interview, Stanley stated that the developmental center closure "savings" specified in his bill are based on a projection that was made by DDS in a 2008 Facilities Restructuring Plan. That Plan projected a \$40 million savings per year in closing the developmental centers. Stanley's bill would appear to require that the administration direct an additional \$20 million per year (or 50% of the "savings") to fund provider-based line items under Chapter 257.

COFAR is concerned that additional funding for the providers specified in both bills would have to be taken from the state-operated group home line item. Both bills are before the Children and Families Committee, which had not acted on them as of late August.

State ends attempt to evict Seven Hills residents

Parents of 43 residents of the Seven Hills Pediatric Center in Groton breathed a sigh of relief with the formal end in May of a federal lawsuit that had threatened the residents with eviction from their longtime home.

The Rolland v. Patrick lawsuit had originally been brought in 1999 against the inappropriate placement of developmentally disabled persons in nursing homes, which did not provide them with adequate care.

In 2008, the Patrick administration informed the Seven Hills parents that their children were on a list to be moved to community-based group homes as a result of a settlement agreement that year of the lawsuit. In May, a federal judge ended the case after the plaintiffs agreed the administration's efforts to move hundreds of residents out of nursing homes had satisfied the conditions of the suit.

Louis Putterman, the father of a Seven Hills resident, said that the center's parents were informed following the agreement to end the case in May that their children would be allowed to remain at the Seven Hills facility.

The Seven Hills parents had strongly opposed plans to move their children to group homes, arguing that Seven Hills was a specialized facility that is staffed and equipped to care for people with severe and profound levels of developmental disability and complex medical conditions. However, for five years, Putterman said, he and the other Seven Hills families lived with uncertainty over the fates of their loved ones.

'The well-being of our loved ones should always take precedence over ideology...' – Seven Hills families' policy statement.

The Seven Hills parents fought the potential evictions, dogging Governor Patrick at campaign and town meeting events. The families also went to court in May 2008 to decertify the Rolland class and appeal the settlement. Their motions were denied, in part, on the basis that they had waited more than 10 days to try to opt out of the suit. They contend they were not informed of its existence for nine years.

COFAR has long supported the Seven Hills families in the case, many of whom have become COFAR members, arguing that the plaintiffs and the administration failed to acknowledge the difference between specialized nursing facilities, such as Seven Hills, and nursing homes without expertise in caring for the developmentally disabled. The plaintiffs that failed to make that distinction include the Center for Public Representation, a government-funded legal advocacy organization, which brought the Rolland lawsuit.

In June, the Seven Hills families adopted a public policy statement, suggesting that "the well-being of our loved ones (should) always take precedence over ideology when making the life-and-death decisions that affect them."

In an online comment about the role of the administration and the Center for Public Representation in the case, Putterman wrote that: "Not one of those advocates has shown a single iota of concern for the well-being of our children, who are among the neediest individuals in this world...We have never heard the slightest word of apology from them."

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