

The COFAR Voice

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COFAR defends Pacheco Law as cost-effective

COFAR made use of social media in mid-July to criticize the conservative Pioneer Institute for seeking to weaken oversight of privatization of state services.

In blog posts and on Twitter, COFAR defended the Pacheco Law, which requires a demonstrated cost savings before services can be privatized. In the wake of a report from the Pioneer Institute that attacked the Pacheco Law, the state Legislature on July 8 enacted a 3-year suspension of the application of the law to the MBTA, which manages greater Boston's bus, subway and commuter rail systems.

COFAR's blog posts attracted the attention of State Auditor Suzanne Bump and her staff, who invited COFAR President Thomas J. Frain and COFAR Voice editor David Kassel to meet with them in late August and early September to discuss concerns over privatization of state services.

While the legislative freeze on the Pacheco law applies only to the MBTA, Frain said he is concerned that the Baker administration will push next to prevent state services for the developmentally disabled from being subjected to Pacheco Law oversight. The law requires state agencies to submit analyses to the state auditor showing that proposed privatization plans will both result in lower costs and maintain quality of services.

"This (suspension of the Pacheco Law) is surely coming to DDS," Frain said. "If they (the administration) can get it approved for the MBTA, it should be no problem for them to target

In a report issued just prior to the legislative suspension of the Pacheco Law, the Pioneer Institute claimed that the law had prevented the MBTA from privatizing bus operations, starting in 1997. The report claimed that the failure to

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GUARDIANSHIP BILL HEARING — State Senator William Brownsberger (left), co-chair of the Legislature's Judiciary Committee, confers with Representative John Fernandes (center), House co-chair, and Keith MacFarland, chief of staff to Fernandes, prior to the start of a June 24 committee hearing on guardianship bills. COFAR is supporting one of those bills that would give greater guardianship rights to family members of persons with disabilities. Story on Page 2.

Few given option of state-run group homes

State-run care for people with developmental disabilities is under attack by the Baker administration and the state Legislature; and state-run group homes appear to be targets of that policy.

New data provided by the Department of Developmental Services show that few, if any, intellectually disabled people waiting for services have gained admission to state-run group homes since fiscal 2008. That

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DDS urged to apply for federal funds

Months after passage of legislation authorizing national background checks of persons hired to care for developmentally disabled persons in Massachusetts, the Department of Developmental Services was still "considering" whether to apply for federal funds to help it implement the program.

COFAR has been urging DDS for the past two years to apply for the grant funding, which has been available to states since 2010 under the Affordable Care Act or ObamaCare.

As of May 31, the Department still had not applied for the funding even though the state legislation authorizing the background check program was signed a year ago in August.

An online DDS document stated that the Department would need a minimum of \$510,000 to hire and train staff to be ready for the January 2016 implementation date for the first phase of the program. Up to \$3 million in federal grant funds have been available to individual states to implement the program.

COFAR seeks end to DOJ closure suits

COFAR is the backing a call to limit federal lawsuits filed to close state-run developmental centers around the country.

In a post on the COFAR blogsite in May, COFAR noted that the Department of Justice has continued to pursue class -action litigation to close developmental centers and other facilities even though those lawsuits are generally opposed by the families of the residents.

In congressional testimony submitted in April, the national VOR asked that federal budget language be adopted requiring the DOJ to first consult with families prior to filing lawsuits requiring the closure of state facilities.

While the DOJ has not filed such a suit against Massachusetts, COFAR Executive Director Colleen Lutkevich noted that with two developmental centers and some state-run programs remaining, the state could well become a target for a lawsuit at any time."

Guardianship bill momentum may have slipped

After years of going nowhere in the Legislature, a bill that would boost the guardianship rights of family members of persons with developmental disabilities seemed to have suddenly gathered momentum earlier this summer.

By mid-August, however, the momentum seemed to be slowing. The bill still had not been approved by the Judiciary Committee, which has held the measure since the legislative session began last January.

The proposed legislation (H. 1459) states that probate court judges should presume a spouse or parent is the proper person to be the guardian of an incapacitated person.

The momentum for the bill seemed to be building earlier in the year when the measure received support for the first time from the Massachusetts Developmental Disabilities Council (MDDC), a staterun organization that identifies priorities for care for people with those disabilities, and from the Arc of Massachusetts. The MDDC listed the bill as one of its legislative priorities for 2015-2016.

In mid-June, the Judiciary Committee held a public hearing on the bill and a number of other bills on guardianship issues. Included in that list was a measure dubbed "Justina's Law," which would prohibit state or other authorities from charging a parent or legal guardian with abuse or neglect, based on the type of medical care the parent or guardian chose for an individual in their care.

Passage of Justina's law was being sought by the family of Justina Peletier, a teenager who spent nearly a year in a locked ward in Boston Children's Hospital after doctors there disagreed with the family's belief that Justina was suffering from mitochondrial disease.

In testimony provided to the Judiciary Committee, COFAR noted that in order to participate in the care of a developmentally disabled person, it is necessary to obtain guardianship of that person when they reach the age of 18. Guardians have legal rights to participate in individual support planning, a key element in the care of developmentally disabled persons, and to make other decisions that affect their wards' services and well-being.

In some cases, parents and siblings of incapacitated individuals are passed over by probate court judges in considering guardianships, and, in some cases, judges have removed family members as guardians. In many of those cases, judges appoint either attorneys or corporate human services providers as guardians, and those attorneys or providers may have no connection to the persons who need their representation. Some of those court-appointed guardians have large numbers of wards.

H. 1459 was initially proposed by Stan McDonald, the father of an intellectually disabled man, who has been unable to regain his guardianship of his son. Stan contends his son, Andy, has received inadequate care under a series of court-appointed guardians, and that his emotional needs have been ignored or neglected. Andy McDonald's current court-appointed guardian has had as many as 100 wards at one time.

H. 1459 would also potentially apply to a case in which a probate court judge dismissed several members of the Duzan family as unsuitable to continue as guardians of Sara Duzan, a young woman with a developmental disability.

Records unit to review report on hospital death

The state's Public Records Division has ordered the Department of Public Health to provide it with a copy of an investigative report sought by COFAR in order to determine whether the report can be publicly released.

COFAR has sought since February to obtain a copy of the report on the case of a developmentally disabled man who died while en route to Lowell General Hospital in February 2012 after having been turned away from the hospital twice without any significant treatment.

In an August 20 letter to the DPH, Shawn Williams, the supervisor of public records, stated that his office planned to conduct an "in-camera" review of an un-redacted copy of the report.

Despite COFAR's assurance that it would not reveal the identity of the disabled man, the DPH refused to release the report, citing privacy restrictions. COFAR appealed the denial to the Public Records Division, arguing that COFAR was seeking to determine whether the hospital had been cited for inadequate procedures or training of staff in treating persons with developmental disabilities.

In April, the state Public Records supervisor ordered DPH to release the report to CO-FAR, but did not specify that the Department must release the full report. DPH then released a report that appeared to clear the hospital of wrongdoing, but was so heavily redacted that almost none of the findings or the supporting discussion were readable. Most of the report, which was at least five pages long, was blanked out entirely.

On May 14, COFAR renewed its appeal to the Public Records Division, contending that the DPH had not met its burden of demonstrating that the wholesale redactions of the report were either necessary or complied with the (public) records law's exemption for medically sensitive information.

The disabled man, a former resident of the Fernald Developmental Center, had been living in a group home when he was first taken to the hospital. He had reportedly been having difficulty breathing. The hospital released the man shortly after his arrival. The following morning, the man was sent to the hospital again, and was immediately released again. He died while being taken to the hospital for the third time.

COFAR defends Pacheco Law

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privatize the bus services resulted in the loss of \$450 million in savings for the agency between 1997 and 2015.

In a post on the COFAR blogsite (see site URL below), COFAR contended that the Pioneer report's lost savings claim was based on an improper comparison of actual inhouse costs at the MBTA with hypothetical costs based on bids from contractors submitted in 1997.

In a follow-up post, COFAR reported that the percentage increase in actual MBTA costs for in-house bus operations was less than the increase in the actual cost of contracting for commuter rail services between 2000 and 2015.

A third post by COFAR reported that a recommendation by a special panel on the MBTA in April to remove the MBTA from the Pacheco Law's requirements contained virtually no rationale in support of that recommendation. The special MBTA panel was appointed by Governor Baker in the wake of major breakdowns in MBTA service last winter.

COFAR's initial blog post, which was cross-posted on Blue Mass Group, a political blogsite, was acknowledged by *CommonWealth* magazine in its own online blog on July 15. The *CommonWealth* post stated that COFAR had "poked a few large holes in the Pioneer report, including raising questions about the dubious premise of the MBTA missing out on nearly half a billion dollars in savings."

COFAR opposes changes in group home license rules

As of mid-August, the Department of Developmental Services was continuing to review planned changes in its licensing regulations.

COFAR contends the proposed changes in the regulations appear to reduce oversight of corporate providers of services to the developmentally disabled. The proposed regulatory changes also appear to further reduce family involvement and choice in care and services.

One of the proposed changes to the regulations would appear to give DDS providers at least partial authority in determining whether their licenses to operate residential and other programs should be renewed. Proposed new language in the regulation (115 CMR 8.00) would codify a process that allows providers to assess their own compliance with state licensing and certification standards as part of the licensure renewal process.

COFAR submitted comments to DDS in December, opposing the regulatory changes to DDS. COFAR stated in a letter to DDS that that allowing providers to assess their own services sanctioned a conflict of interest.

DDS normally grants licenses to corporate providers every two years to operate residential and other programs, following a survey or inspection of their facilities.

Autism regs exclude residential services

While a new law was enacted last year that expands eligibility for state services to people with autism and two other developmental disabilities, the Department of Developmental Services has proposed regulations based on the new law that appear to preclude those people from receiving services in group homes.

The proposed regulations, which were posted on the DDS website in July, state that persons with autism and two other conditions known as Smith-Magenis and Prader-Willi Syndrome will be eligible for community-based services only if they are living in their own or their family's home.

The new statute itself does not appear to exclude persons with those conditions from receiving expanded residential services. One advocate said his organization was troubled that the proposed DDS regulations "appear to create distinctions that appear to have no foundation in the statute."

The Legislature approved a new DDS line item with \$12.7 million for tiscal 2016 to fund the increased services (see budget story on Page 5).

The new eligibility law specifies that in addition to people with intellectual disabilities, people with autism and conditions known as Prader-Willi Syndrome and Smith-Magenis Syndrome will be eligible for DDS services.

Until passage of the law, state law restricted eligibility for DDS services to people with "intellectual disabilities," as measured by a score of approximately 70 or below on an IQ test.

Requirements reduced for DDS 'Real Lives' law contractor

Key requirements set in 2008 for firms to manage "self-directed services" for the Department of Developmental Services were dropped from the actual contract signed that year with the winning bidder, according to documents provided by the Department.

Public Partnerships, LLC (PPL), which was selected for the contract based on a competitive Request for Response (RFR) process in 2008, is paid up to \$1 million a year by DDS. But PPL is not required under the contract to carry out certain services specified in the RFR, including hiring care workers under the self-directed service programs or managing "support broker" services. Support brokers are employed by participants in self-directed services to help in managing their care.

Self-directed services are billed as an alternative to DDS's traditional method of providing services to clients either directly or via contracts with providers. Under self-directed services, program participants reportedly plan their own services, manage their "individual budgets" for care, and hire support workers of their choosing.

COFAR has reported that PPL's contract essentially requires the firm to perform what appear to be check-processing and basic accounting services in connection with three self-directed services programs.

It is not clear whether the reductions in requirements in the PPL contract are in compliance with state procurement regulations. Those regulations state that any negotiations with a contractor selected in response to an RFR must not change "the language of the Contract or Contract performance identified within the scope of the original RFR and the Bidder's or Contractor's Response" (801 CMR. 21.07).

In a May 4 letter to COFAR, Marianne Meacham, DDS general counsel, maintained that PPL's requirements "far exceed" basic accounting functions, and that "the functions performed by PPL have expanded, not been reduced, since 2008."

However, the actual contract with PPL contains an addendum explicitly deleting requirements in the 2008 RFR. The deleted requirements include "requirements related to support brokerage" services, which are intended to help program participants manage their individual budget accounts. Also dropped was a requirement that PPL directly hire "support workers" under the programs.

The 2008 RFR required the contractor to develop contracts with service providers and to help participants "manage their individual budgets." The RFR also required the contractor to hire direct support workers. And the RFR required the contractor to "manage a network of Support Brokers to assist program participants.

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Through our newsletter and our blog posts, we provide information you won't find anywhere else about care of persons with developmental disabilities in Massachusetts. We also advocate for your loved ones every day. Please contribute to us keep us going. See our back page for details.

Thank You!

Final FY '16 budget restricts state care

Governor Charlie Baker signed a state fiscal year 2016 budget bill into law in mid-July that boosts funding for privatized group homes by close to \$80 million, but provides either much smaller increases or makes cuts in state-run services.

The corporate residential line item in the budget (5920-2000) has been increased in fiscal 2016 by \$78.3 million from the amount originally appropriated for the previous fiscal year. That line item now contains close to \$1.1 billion in funding.

State-operated group homes (line item 5920-2010) have received an increase in funding of \$8.4 million over the original appropriation last year. Total funding for the state-operated residences is less than 20 percent of the amount appropriated for provider-run residences. (See story at right about the lack of new admissions to state-run group homes.)

The fiscal 2016 budget provides for a \$3.5 million increase in funding for remaining state-run developmental centers over the amount appropriated last year. However, because last year's appropriation was not sufficient to keep the centers running, a mid-year, supplemental budget appropriation was needed. Compared with total spending on the centers last year, the fiscal 2016 funding represents a \$1.5 million cut.

The fiscal 2016 budget includes a new autism line item, funded at \$12.7 million, to provide services to persons with autism and Smith-Magenis and Prader-Willi syndromes (see story on Page 4).

The autism line item funding includes \$300,000 for a state autism commission.

The DDS administrative line item, which funds service coordinators, was increased by about 6 percent from the previous fiscal year. Respite and family supports was increased by less than 2 percent form the amount appropriated for last year.

Few getting into state-run group homes

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was the year that the then Patrick administration announced plans to close four of six remaining state-run developmental centers in Massachusetts. The latest DDS data, provided under a Public Records Law request, appear to show that virtually all of the people who have been admitted to state-run group homes since 2008 have come from the developmental centers that were targeted for closure

According to the data, the number of people living in state-operated group homes in Massachusetts increased by a total of 144 between fiscal 2008 and 2015. Previously, DDS had provided data showing a total of 156 persons had been transferred from the developmental centers to state-operated group homes between fiscal 2008 and 2014. The numbers suggest that up to 12 of those transferred residents had either died or been transferred for a second time since 2008, from the state-run residences to another location.

COFAR has noted that DDS routinely fails to inform people seeking residential care of the option of state-run services. Families and individuals appear to be directed almost exclusively to group homes run by corporate providers to DDS. Despite that, direct-care workers in provider-run residences receive lower pay and benefits and have higher turnover and less training on average than workers in state-operated group homes. Moreover, the provider-operated system has insufficient capacity to accommodate all of the people who are waiting for residential care in the DDS system.

While DDS does not officially acknowledge a waiting list for care and services, the Massachusetts Developmental Disabilities Council has cited a 2010 survey, indicating that some 600 people were waiting for residential services in the state, and up to 3,000 people were waiting for family support services. The new DDS data also show a total of 266 state-operated homes in Massachusetts as of April 2015. While that amounted to a net increase of 40 homes over the total number in 2008, 28 homes were closed in that time.

Federal IG doing review of privatized group home system

The Inspector General for the federal Department of Health and Human Services has been undertaking a limited review of data on abuse and neglect in privatized group homes in Massachusetts and two other states, according to a letter obtained by COFAR.

COFAR reported in May that HHS Inspector General Daniel Levinson's office had begun to examine data on admissions of persons from group homes and "nursing facilities" to hospital emergency rooms in Massachusetts, Connecticut and New York.

Levinson's review was undertaken at the request of U.S. Senator Chris Murphy of Connecticut in the wake of a series of articles in *The Hartford Courant* in 2013, which documented dozens of deaths, injuries, and other problems stemming from inadequate care and supervision in group homes in Connecticut. It was not clear when the IG's apparently limited review would be completed.

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