



The COFAR Voice

The Official Newsletter of COFAR, Inc., The Massachusetts Coalition of Families and Advocates

October 2014

Volume 14, No. 3



Then state Representative Martin Walsh, now mayor of Boston, testifies in July 2013 in favor of his national background check bill for DDS workers and providers. Although the bill was finally signed into law this year, DDS corporate providers were involved in negotiating delays in the law's requirements. (Youtube screenshot).

DDS providers lobbied for background check delays

Corporate providers to the Department of Developmental Services appear to have negotiated major delays in the requirements of a new national background check law for workers in the DDS system.

That was one of several pieces of legislation on which state-funded, corporate providers have played key lobbying roles on Beacon Hill this year. But in two of those cases, involving sheltered workshops and the so-called Real Lives bill, COFAR was successful in opposing efforts by the providers to further privatize DDS services.

In the case of the national background check bill, provisions inserted by the Legislature's Judiciary Committee will allow the law's requirements to be phased in through January 2019 for current employees of both DDS and provider agencies. In addition, the law's background check requirements will not take effect for new employees until January 2016.

COFAR has questioned the need for the delayed im-

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Fernald land sale terms leave out the disabled

A new state law that authorizes the long-anticipated sale of land at the Fernald Developmental Center to the City of Waltham contains no provisions for continuing care or services at the site to people with developmental disabilities.

The legislation was the product of negotiations among representatives of the Patrick administration, Waltham officials, and key legislators. Earlier this year, the Fernald Working Group, a coalition of Waltham-based organizations, had recommended that a portion of the Fernald campus remain the site of residential care and services for the intellectually disabled. Similar proposals have been made over the years by COFAR and the former Fernald League.

But the legislation, which was signed into law by Governor Patrick on August 6, does not specify that any of the land or existing facilities will be set aside for the disabled. Under the law, the state will sell the campus to the city for \$3.7

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New DDS policy goes beyond federal rule in limiting home size

A new Patrick administration policy on community-based care of the developmentally disabled limits the number of people living in new group homes to five or fewer and bans other new residential and day programs that involve congregate care.

Even farm-based programs are banned under the policy as being too institutional and as isolating participants from the "broader community." Individuals who continue to live in "non-compliant" residences could be dis-enrolled from the state's Medicaid-funded Home and Community Based waiver program, the policy states.

COFAR has criticized the new state policy,

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Corporate guardian leads DDS list

The Arc of Bristol County was the highest paid appointed guardian for Department of Developmental Services clients in both Fiscal Years 2013 and 2014, according to data provided by DDS under a Public Records Law request.

The DDS data showed that the Arc of Bristol County, which is also a DDS residential provider, was paid a total of \$129,080 in FY 2013 and \$70,772 as of the third quarter of FY 2014 for guardianship services. COFAR sought the guardianship data as part of an ongoing review of the administration's guardianship policies in light of a number of controversial cases involving guardian and family rights. (See April 2014 COFAR Voice, "When family rights are trumped in care of disabled.")

In responding to the records request, DDS did not disclose the number of wards belonging to each guardian, nor did it disclose the amount of hours put in by each guardian on behalf of their wards. Of the 70 guardians paid in FY 13, six appeared to be corporate guardians. DDS payments to the 70 guardians in FY 13 totaled \$612,437, and payments to the 46 guardians listed in FY 14 totaled \$265,248 through March 2014.

State expands congregate care for mentally ill

Although the Patrick administration is closing most of its larger, state-run centers in Massachusetts for the intellectually disabled, the administration appears more open to congregate care for the mentally ill.

The Boston Globe reported in June that Governor Patrick has proposed both a major increase in staff at Bridgewater State Hospital and a new facility there where potentially violent patients with mental illness could receive care. The administration also opened a new \$300 million hospital for the mentally ill in Worcester in 2012. COFAR has questioned the apparent "double standard" in care for both groups of people.

Fernald land sale leaves out disabled

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million, which comes to \$18,500 per acre — a price that has been described as "dirt cheap." It appears there is also a requirement that the city pay the state up to half the proceeds from the re-sale of any of that land to developers. The Department of Developmental Services reportedly plans only to keep a therapeutic swimming pool open at the Fernald site and to maintain a 29-bed nursing home on the campus.

The Fernald Working Group had described "a progressive site at Fernald where open space and greenways can be matched with an equal vision of integration for individuals with disabilities." That vision encompassed both existing residents and disabled persons in the surrounding community.

The Working Group specified that this vision included new housing and the preservation of the therapeutic pool and gym at Fernald as well as the chapel and programs for physical therapy, dental and medical services. As the vision statement noted, "all of these services could become part of the community and economic life of the Fernald redevelopment."

COFAR has long supported a "postage-stamp" proposal for the Fernald campus, which would allow a portion of the land to be used for care for the developmentally disabled while the rest of the campus was developed for commercial or other uses. COFAR has maintained that continuing to provide centralized care at developmental center sites could both allow more people in the surrounding community to receive services and provide those services more cost-effectively than is the case in a system consisting almost entirely of disbursed group homes.

'Real Lives' law compromise still has problems

Despite their strong lobbying presence on Beacon Hill, corporate provider organizations were unsuccessful in introducing a number of provisions into the so-called Real Lives law this year that would have benefited themselves financially.

The measure, which was signed into law by Governor Patrick on August 6, introduces what is called "person-centered planning" in providing care and services to persons with intellectual and developmental disabilities. It allows DDS clients to direct their own services and manage their own "individual budgets" for care.

In the wake of criticism earlier this year from COFAR, legislators removed proposed provisions from the bill, which had named the Association of Developmental Disabilities Providers and the Arc of Massachusetts to a board that will advise DDS in developing the person-centered planning system. But the law still raises a number of concerns, including providing what appears to be only a limited role for guardians and family members in the person-centered planning process. The law also introduces a central role in the process for vaguely defined "financial management services" and other privately run entities.

"The law as written will open the disabled up to financial exploitation," said COFAR President Thomas Frain. "This is still a very flawed piece of legislation."

Former DoJ official admits to problems in ICF closures

A former top official in the federal Department of Justice has acknowledged in a law journal article that the closures of state-run developmental centers in Massachusetts and other states have not resulted in promised increases in funding for community-based care.

But in an article in the *Cardozo Law Review*, Samuel Bagenstos, a former principal deputy assistant attorney general in the DoJ, did not concede that the closures of the centers, also known as Intermediate Care Facilities (ICFs/IID), have also resulted in tragic outcomes for many deinstitutionalized individuals and added to waiting lists for residential care.

The DoJ, while at least partly under Bagenstos's leadership, has filed, joined, or participated in more than 40 lawsuits in at least 25 states to close or limit the functioning of ICFs/IID, according to the VOR, a national advocacy organization for the developmentally disabled.

Both COFAR and the VOR, have criticized Bagenstos and the DoJ for their roles in the ICF/IID closures. "Bagenstos shows no willingness to take responsibility for the tragedies that he and the other advocates caused to these highly vulnerable individuals," the VOR stated on the organization's website (at www.vor.net). "Nor have past failures moved Bagenstos to take a more reasoned approach to deinstitutionalization efforts, one that insists on building quality, community placements and adequate oversight before displacing fragile individuals from ICFs/IID."

Bagenstos' article also included what appeared to be an inaccurate description of the history of the litigation over the closure of the Fernald Developmental Center in Massachusetts. He wrote, without specifying a date, that "Massachusetts responded to fiscal concerns by seeking to close (Fernald)."

Bagenstos further stated that the Fernald parents had sought to reopen a "long-closed" federal court case (*Ricci v. Okin*) based on the argument that Fernald's closure "deprived them of the opportunity to oppose placement in the community." In fact, the Fernald parents sought to reopen the closed *Ricci v. Okin* case in 2004 based on the argument that budget and staff reductions at Fernald were violating the terms of U.S. District Court Judge Joseph Tauro's 1993 disengagement order in the *Okin* case.

New state policy bans new congregate care programs

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arguing that in setting the five-person limit, the policy goes even further than a new Obama administration regulation on Medicaid-funded, community-based care on which the state policy is supposedly based. In comments on a federal website, the federal Centers for Medicare and Medicaid Services (CMS) stated that it had rejected a proposal to specify the number of people who are allowed to live in community-based facilities. Such a limit was neither "useful or appropriate," the federal agency stated.

"The state has embarked on a course that is leading to further privatization and consequently the further isolation of people with developmental disabilities," said COFAR President Thomas Frain.

The state policy, which was issued on September 2 by the Department of Developmental Services, will be accompanied by a "transition plan" that the agency said is based on the new rule issued by the CMS. The transition plan states that DDS services must be "integrated in and support full access of individuals to the greater community."

But COFAR has long maintained that congregate care settings are just as capable as smaller settings in supporting full access to the community. According to a DDS email sent to advocates on early October, the key provisions of the transition plan and the new policy include the following:

- Residential care settings must be "selected by the individual." [There was no indication in the DDS email, however, that the guardian or family would have the authority to select the setting.]
- Settings must "ensure privacy, dignity, respect and freedom from coercion and restraint." [COFAR has raised concerns about at least one case in which DDS has permitted a provider to use virtually unrestricted restraints on a client. (See December 2013 COFAR Voice, "Family denied contact with daughter.")]
- Documentation must be provided showing that any modifications to the provisions above "are supported by an assessed need..." [The parents in the case noted above have been unable to obtain documentation regarding the restraints used on their daughter.]
- Individuals in provider-controlled settings will need to provide locks on all bedroom doors. [Frain maintained, however, that even though certain staff would be provided with keys, this could result in problems if a resident locked himself in his room and had an emergency.]
- Each individual or their guardian in a provider-controlled setting "will be required to receive a copy of a provider lease for their residence...and both the provider and the individual must sign the document." [It is unclear why this requirement is being imposed on individuals and guardians, given they are not usually parties to the lease agreements.]

DDS eligibility law raises legal concerns

A new state law that allows adults with autism and two other specified conditions to become eligible for the first time for Department of Developmental Services appears to raise potential legal questions.

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

The new law was the product of closed-door negotiations among legislators, administration officials, and selected advocacy organizations. The law's intent is to expand DDS eligibility to people with developmental disabilities, including autism, who have been denied services because they have not met the DDS definition of intellectual disability.

But in specifying three additional conditions that make individuals eligible for DDS services, the new law necessarily leaves out other conditions that often result in many of the same types of functional limitations, such as Williams Syndrome, spina bifida, and cerebral palsy.

The law also establishes a permanent autism commission in the state, which will include most of the parties involved in the negotiations over the bill, including the Arc of Massachusetts. There are no seats on the commission for any advocates of state-run care for the developmentally disabled.

"We think this is an unfortunate oversight in the makeup of the commission," said Colleen Lutkevich, COFAR executive director, maintaining that state-run group homes will be needed to accommodate the influx of new people who will become eligible for care under the new law. "If the state continues to close state-run facilities, it will only make the problem worse."

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DPPC investigative reports are heavily redacted

Reports done by the state Disabled Persons Protection Commission on sudden deaths of two former residents of developmental centers appear to raise more questions than answers about the residents' care and the circumstances of their deaths.

Both reports, which were provided to COFAR by the DPPC, were so heavily redacted by the agency that it was impossible to tell in a number of instances whether concerns and allegations raised about each case were investigated.

It was also unclear why it took nearly two years for the DPPC to provide one of the two reports in response to a request for the report by COFAR in October 2011. That report concerned a former Templeton Center resident who died on July 24, 2011, four days after he was transferred to a state-operated group home in Tewksbury. The cause of death was reportedly a blood clot in his lung. The report, which concluded there was no evidence of abuse or neglect, was dated as having been completed on November 1, 2012.

The second report concerned a former resident of the Fernald Developmental Center, who died on July 6, 2011, after having ingested a plastic bag in a Northeast Residential Services group home in which he was living in Tyngsborough. That report found evidence of neglect.

The two deaths were among three cases brought to COFAR's attention in 2011 and 2012 in which clients of the Department of Developmental Services died suddenly after being transferred from developmental centers to state-run group homes operated by Northeast Residential Services, a division of DDS.

In the third case, a 51-year-old resident of a Northeast Residential Services home in Chelmsford died of acute respiratory failure on February 7, 2012, after having been sent back to his residence twice by Lowell General Hospital. The DPPC indicated that it had referred the case to the Department of Public Health, which has jurisdiction over care provided in hospitals. COFAR has requested the results of the DPH's investigation of the matter.

In the case of the man who died of a blood clot four days after leaving Templeton, COFAR raised questions at the time whether whether a medication error or other care issue was involved. The former Templeton resident's guardian said the man had had a blood clot in his leg a year before the move from Templeton and had been put on a blood thinner called Coumadin, but that he was taken off that medication without her approval while he was still at Templeton. The un-redacted portions of the DPPC report on the case did not mention the guardian's allegation regarding the Coumadin. Similarly, un-redacted portions of the DPPC report on the death of the man who ingested the plastic bag raised questions about possible changes in his care plan.

Answers sought on DDS funding issues

COFAR is seeking answers from the Patrick administration to questions raised about the adequacy of state funding for key programs for people with developmental disabilities in the current fiscal year.

In emails sent to the Department of Developmental Services and administration budget officials, COFAR has posed questions regarding the following issues:

- The Arc of Massachusetts and the Association of Developmental Disabilities Providers contended in a joint email to their members in September that the administration has failed to fund the new DDS eligibility law. (See story about the new law on the previous page.) The email stated that the law could be funded this year with \$5 million. COFAR is seeking to clarify whether the law is still unfunded.
- The Arc/ADDP said in the same email that the administration has failed to fully fund the Chapter 257 law, which established higher rates for residential providers. The Arc/ADDP email stated the shortfall this year was \$45 million. Earlier this year, however, the Legislature approved an increase of more than \$160 million in the DDS community residential line item in this year's budget, with much of the increase intended to fund Chapter 257.
- It is unclear how Chapter 257, which pays providers set amounts per service, relates to the "individual budgets" set up under the 'Real Lives' law. (See Real Lives law story on Page 2.) Chapter 257 seems to be intended to pay providers for specified services -- not to pay for individual clients' budgets.
- It is unclear who will receive money from two new reserve funds in the state budget to transfer residents out of sheltered workshops.

As of October 17, no response to COFAR's queries had been forthcoming.

Providers lobbied for delays in national background checks

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plementation of the law. "There is no compelling logistical reason we know of to take more than four years to phase in these needed requirements," said Colleen Lutkevich, COFAR executive director. "The providers have said all along that they are for national background checks, yet they seem to want to delay them as long as possible." National background check legislation had long been proposed in the Massachusetts Legislature by then state Representative Martin Walsh, now mayor of Boston. But until this year, the bill had never gotten out of committee.

The new law requires persons hired to work in an unsupervised capacity with developmentally disabled individuals to submit their fingerprints to a federal database maintained by the FBI. The law applies to DDS employees, employees of corporate service providers to the department, and caregivers over the age of 15 of persons living at home.

Prior to the implementation of the new law, persons hired to care for clients in the DDS system have had to submit only to an in-state criminal background check, which identifies only criminal arrests and convictions in Massachusetts. When COFAR contacted the Legislature's Judiciary Committee to ask why the committee had approved the delays in the new law's requirements, a staff member referred COFAR to Johnston Associates, a Beacon Hill lobbying firm.

A member of the firm said both providers and other advocates had pushed for phasing in the fingerprint requirements due to concerns over the time needed to implement them. A member of the Association of Developmental Disabilities Providers (ADDP) and a spokesperson for a special education program provider expressed concern in articles in the *Lawrence Eagle Tribune* in August that the new fingerprint requirements could prove burdensome to smaller provider agencies and special needs employees.

In addition to inserting the provisions phasing in the background check requirements, the Judiciary Committee inserted a provision into the new law that appears to allow persons to be hired before they are cleared through the FBI database. The staff person for Johnston Associates said she was unsure of the purpose of that provision or why it had been inserted. Calls placed by COFAR to the state Department of Criminal Justice Information Services, which is in charge of administering the law, were not returned.

Providers lobbied on other bills

In another instance in which they lobbied on Beacon Hill this year, the providers joined with the Patrick administration in a push to eliminate sheltered workshop programs from the state as of June 2015 and to transfer workshop participants to provider-run day programs. COFAR worked with sheltered workshop proponents in a successful effort to introduce language in the Fiscal Year 2015 state budget to preserve the workshops.

The providers also had lobbied heavily for a version of the Real Lives bill this year that would have allowed them to dominate an advisory board created under the legislation. COFAR opposed that version of the legislation, resulting in the removal of that and other provisions sought by the providers. (See Real Lives bill story on Page 2).

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