



# The COFAR VOICE

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

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## Managed care proposal for disabled draws fire

COFAR and other advocates for the disabled are voicing concerns about a Patrick administration proposal that would dramatically alter the management of Medicaid and Medicare-funded services for persons with disabilities in Massachusetts.

Under the proposal by the Executive Office of Health and Human Services, private vendors, known as Integrated Care Organizations (or ICOs) would be hired to manage services to thousands of persons in Massachusetts who are dually eligible for both Medicaid and Medicare coverage. In addition, payments to providers would be switched from the current fee-for-service system to a "capitated payment" system under which a fixed fee is paid per client to each provider.

### COFAR seeks further review of group home licensure process (Page 3)

At a packed public hearing in Boston on January 4, dozens of dually eligible, disabled clients testified that they are concerned about a loss in choice and access to services and medical equipment under a managed-care system. COFAR presented testimony at the hearing that the proposal "appears to be another step in this administration's quest to privatize key services to the state's most vulnerable people and to remove government from its responsibilities in that area."

Stu Dickson, a representative of SEIU Local 509, a state employee union, testified that while the union "agrees with the need to address needless costs of medical procedures, tests abuse, billing and administrative redundancies, etc., this is profoundly different than the care of human beings." Dickson added that "cost-effective case management for human beings requires far more of a skill set than wearing head phones and gauging what is within the bottom line and what isn't."

Among those who voiced concerns at the hearing about access to services and equipment was Hang Lee, who suffers from cerebral palsy and scoliosis, progressively

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Health and Human Services Secretary JudyAnn Bigby (seated at left) waits with top members of her secretariat for the start of a December 9 state budget hearing in Boston.

## Budget cuts continue to plague DDS programs

Despite repeated promises from the Patrick administration that the phase-down of four state developmental centers would pump tens of millions of dollars in savings into the community-based system of care, providers are decrying continuing cuts in community accounts.

At a December 9 hearing, held at the Agganis Arena at Boston University, Health and Human Services Secretary JudyAnn Bigby heard from a parade of advocates and providers who urged Bigby to spare their programs from further cuts.

COFAR testified at the hearing, asking Bigby for an explanation for the apparent failure of the promise of additional community-based funding stemming from the facility closures.

Meanwhile, COFAR joined with SEIU Local 509, a state employee union, in urging the restoration of funding for service coordinators, who arrange for services for clients in the community system.

A COFAR blog post noted that the Association of

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## EOHHS plan draws fire

MANAGED CARE, *continued from page 1*

worsening diseases of the nervous system and spine. Hang said he is concerned the EOHHS proposal may lead to cuts in funding for such things as a body brace, which he believes he will need in a few years.

One woman testified that she is currently able to see doctors outside of her Medicaid and Medicare networks, but fears that may not be possible under the proposed managed care system. "If this dual eligibility plan meant I were no longer a primary decision-maker in my treatment, I wouldn't have a life," the woman said.

Other speakers from a range of disability-based advocacy organizations called on EOHHS to propose the inclusion of independent or consumer-based entities in the proposed system that would be capable of overseeing the ICOs.

Medicaid helps fund residential, employment, and other services for persons with intellectual and other disabilities, while Medicare funds medical care and prescription drugs for many of those same people. The EOHHS maintains that the proposed system would cut costs of care by eliminating overlap, redundancies, and a lack of coordination between Medicaid and Medicare. Medicare and Medicaid were projected to spend a projected \$3.85 billion in 2011 on health care for dual eligible adults ages 21-64 in Massachusetts, according to EOHHS.

**"If...I were no longer a primary decision-maker in my treatment, I wouldn't have a life." -- testimony at EOHHS hearing**

The EOHHS proposal appears to call for a single managed care system for residential, day program, transportation, and other services in addition to medical care for intellectually and other disabled persons. It could potentially eliminate thousands of both public and private-sector service jobs while providing profits to the private ICOs, according to the SEIU.

Among other changes, the proposed system would potentially eliminate the role of state service coordinators, who help DDS clients choose from among available services in the community system and ensure that the correct services are provided. Management of those services would be done instead by the private ICOs.

Also expressing concerns about the EOHHS proposal are the Association of Developmental Disabilities Providers and the Arc of Massachusetts. In a December 16 email to members, the ADDP stated that "the Arc and ADDP do not believe there is current research available that validates significant cost savings attained by turning over large parts of State Medicaid programs to managed care companies."

The SEIU questioned whether the state Legislature has been consulted or is fully aware of the "severely limiting effect this proposal would have with their flexibility regarding hundreds of millions of Medicaid dollars that previously went into the General Fund." The union added

that a capitated service system "will end up 'decapitating' people whose needs have changed. People who develop medical, aging or behavioral issues will be told 'too bad, this is all you get,' with no other recourse within state or federal government."

## Cuts plague DDS programs

BUDGET CUTS, *continued from page 1*

Developmental Disabilities Providers, while decrying community-based budget cuts, has actually suggested to the administration that it cut the service coordinators further. In the last line of a November 23 email to members, the ADDP stated that it "will urge any **spending reductions to be focused on the state's own administrative and service system** and to protect the more cost effective and inclusive community delivery systems" (our emphasis).

While the ADDP statement is unclear, it is well known that service coordinators are funded under the Department of Developmental Services' administrative line item in the state budget. Thus, any spending cuts in the DDS administrative line item would automatically mean cuts in funding for service coordinators.

In contrast, the SEIU asked that the administration *restore* \$5 million to the DDS administrative line item. The SEIU contended that between 2007 and 2010, 82 service coordinator positions were cut, placing Massachusetts in the bottom 10 percent of the country for monitoring and overseeing the provider contracting system and the care it provides.

In testimony delivered at the December 9 hearing, COFAR also noted that Bigby had promised in 2008 that \$45 million per year in savings from closing the Fernald, Monson, Glavin, and Templeton developmental centers would be used to boost funding for community-based programs. However, while \$45 million was in fact cut from the developmental centers line item in the state budget between Fiscal Year 2009 and the current fiscal year, most community-based line items were cut during that period as well.

COFAR pointed out that community-based cuts since Fiscal Year 2009 include reductions to adult family supports (26.9 percent cut), community transportation (17.6 percent), community day and work (3.8 percent), and Turning 22 (35 percent). The only community line items that were boosted were the community residential and state-operated group home line items, at least partly to accommodate hundreds of residents transferred from the developmental centers targeted for closure.

As a result of the transfers of those former developmental center residents, the waiting list for care in community-based facilities has only grown longer, COFAR noted. "It is dismaying that this administration has pursued a single-minded policy of laying off highly experienced and trained workers and clinicians and eradicating the stringent and effective Intermediate Care Facility model" used in the developmental centers, COFAR's testimony added.

## COFAR seeks further review of group home survey process

COFAR has asked the Department of Developmental Services for detailed records concerning its licensing process for three selected group home providers.

The December 19 Public Records request was made following a review of a random sample of 30 licensure and survey reports on the DDS website, which raised concerns about the thoroughness and frequency of the state's surveys of care and conditions in group homes. (See October 2011 *COFAR Voice*)

"We're continuing to take a close look at the DDS licensing process because we think changes are needed," said Colleen Lutkevich, COFAR executive director. "We hope the Legislature will look further into this as well."

On December 15, state Representative Kay Khan, House chair of the Legislature's Children, Families and Persons with Disabilities Committee, met with DDS Commissioner Elin Howe and top departmental licensing officials to discuss licensing issues raised by COFAR in an October 28 letter to the Committee. Khan, however, said following the meeting that she didn't plan to hold any hearings on the issue.

"I'd like to thank COFAR for bringing these issues to my attention," Khan said in a telephone interview following her meeting with Howe. "I appreciate your role as a watchdog. It's important that we understand what the quality (in these homes) is like." A request by COFAR to Khan's staff to attend the December 15 meeting was declined.

COFAR has since asked DDS for detailed licensing records for the Center for Human Development, Inc., Behavioral Associates of Massachusetts, Inc., and the Arc of Greater Boston, Inc. COFAR is asking for all licensing reports and corrective and enforcement actions taken with regard to the providers.

The Center for Human Development employed a staff worker who allegedly assaulted an intellectually disabled resident in June 2010. (See related story on this page.) COFAR reported in October that the Center for Human Development received a two-year license to operate in November 2010 even though there had been three instances in the previous two-year licensing period in which reportable incidents of abuse or neglect in its residences had not been reported to the Disabled Persons Protection Commission as required.

Behavioral Associates of Massachusetts received a conditional license for one year and was certified even though only two out of six required "quality of life areas" had been achieved, according to an April 2009 licensure report, the most recent report available on the DDS website.

The Arc of Greater Boston was listed as of January 8 on the national Arc website as "disaffiliated" from the national organization. The organization ran into controversy in February of 2008 when it approved the transfer of Anna Tross, a 91-year-old woman, from the Fernald Developmental Center to a newly built group home in

Bedford, reportedly over Tross's objections. At the time, the Greater Boston Arc was Tross's corporate guardian.

Among the concerns raised in COFAR's October 28 letter to Khan were the following:

- Only 25 percent of a provider's group home sites are inspected or surveyed by DDS licensing staff during each two-year licensing period.
- While two out of 30 licensure survey reports randomly sampled contained detailed findings of deficiencies in care and procedures in providers' group homes, the majority of the reports appeared to focus on achieving broad and vaguely worded goals such as "maximizing independence." In contrast, a 2008 survey report on the state-run Fernald Developmental Center, which was done by the Department of Public Health, contained 56 pages of detailed findings about treatment and care, based on direct observation as well as resident records.
- Of 30 online DDS licensure and certification reports reviewed, one third were out of date on the DDS website, some by as much as two years.

Khan said she asked DDS officials about the issues raised in the October 28 letter, including the fact that only 25 percent of a provider's group homes get inspected. She said DDS officials responded that there are "many layers to the licensing process," and that surveyors examine "the total quality of the provider," including how they train their staff and their safety system. Khan said, however, that "I don't think we got into specifics" during the meeting about staff training.

Khan said DDS officials appeared open to addressing a concern raised by COFAR that there were few if any indications on the DDS website of the outcomes of management issues raised in the licensure reports. "They need more detail (than what is now available on the DDS website)," she added.

Asked about COFAR's concern that there were no indications in the DDS licensure reports of findings based on direct observation of group home residents, Khan responded, "I don't believe that came up."

### ***Alleged assaulter is no show for trial***

John Saunders, a former staff worker at a West Springfield group home operated by the Center for Human Development, failed to show up for his scheduled trial in Falmouth District Court on January 9 on charges of assaulting a resident of the home.

Saunders allegedly hit John Burns in the face while toileting him during an outing on Cape Cod in June 2010, causing black eyes and other injuries.

The alleged victim is the brother of Sheila Paquette, president of the Advocacy Network, a COFAR member organization. Paquette personally filed assault charges in the case against Saunders. She has started a legal fund to raise money to pursue her brother's case and to help others pursue similar prosecutions of assaults against people with disabilities.

## COFAR urges approval of DDS eligibility bills

COFAR is urging the state Legislature's Children, Families, and Persons with Disabilities Committee to approve several bills this month intended to help people who are struggling to get services.

One of the bills (H3527) would change the current Department of Developmental Services definition of intellectual disability in order to ensure services to people whose IQ scores fall just above the current cutoff level of 70.

The bill would bring DDS in line with the American Association on Intellectual and Developmental Disabilities, in establishing eligibility for DDS services for IQ scores of "approximately" 70 or below. This would prevent the rigid cutoff now used by DDS in excluding people from services.

At a November 15 hearing before the Children and Families Committee, Linda Boucher testified that her son attended special education programs from the time he was 3 until he reached the age of 22. At that age, special education services end, and people needing services must apply to DDS.

Boucher's son scored 75 on an IQ test and was denied DDS services. He had been in a day program, she said, but has been home ever since. Boucher has a full time sales job that often requires her to be away from home for as much as 10 hours at a time, and sometimes requires her to be away from home overnight. It's as if her son is under house arrest, she said.

"Where do I go? I need help," Boucher said, her voice cracking with emotion. Ironically, Boucher worked in the Department of Mental Health during the Dukakis administration and helped develop many of the community-based programs for persons with intellectual disabilities that are now being cut. She said no one from DMH or DDS would now return her phone calls.

Other bills before the Committee, which COFAR supports include:

- H983, which would provide an additional \$23.4 million in funding for DDS community-based programs for persons with special needs who are either turning 22 or have graduated from high school.

The bill would also direct that funds from the sale of developmental center properties be earmarked for community-based programs for persons turning 22. COFAR would support that provision if language was added to support the continued operation of the developmental centers for those who choose to live in them.

- S45, which would establish a state task force to study the average compensation, level of training and turnover of direct-care workers. Lisa Gurgone, Executive Director, of the Mass. Council for Home Care Aide Services, noted that direct-care workers tend to struggle to make ends meet, and termed those workers "a piece of the puzzle left out of health care reform in Massachusetts." She and other speakers maintained

that with the numbers of elderly and disabled people projected to grow rapidly in coming years, the state needs to develop a new workforce strategy to meet the demand. The task force is a first step in that direction, they said.

- H975, which would provide easy public access to a wide range of information about direct-care worker turnover and compensation as well as compensation of top executives of DDS contractors. The bill would require that all of that information be published on the DDS website. The Arc of Massachusetts, which is heavily funded by DDS contractors, opposes the bill.
- H2683, a bill filed by Rep. Angelo Scaccia, which would establish an independent office of quality assurance that would monitor the care of intellectually disabled persons throughout the DDS residential care system. COFAR, which supports the bill, has raised a number of questions in recent months about the current DDS licensure and certification system for community-based group homes (see story on page 3). The Arc opposes this bill as well.

COFAR opposes language in H984, "An Act to encourage responsibility, cost effectiveness and meaningful lives for individuals with disabilities." The bill appears to provide for choice in the purchase of supports and services, but specifically excludes "congregate services" from that choice selection.

## ***Long march continues for national background check bill***

A bill, filed repeatedly in recent years, which would require national criminal background checks on persons hired to work with Department of Developmental Services clients, was approved in October by the Judiciary Committee and sent to the House Ways and Means Committee.

The bill is strongly supported by COFAR and by other advocacy organizations, such as the Arc of Massachusetts and the Massachusetts Down Syndrome Congress. However, the measure has repeatedly run into roadblocks in the Legislature.

State Representative Martin Walsh of Boston, the long-time sponsor of the bill, noted in an interview that the measure has repeatedly gotten grouped with legislation to reform the state's Criminal Offender Record Information (CORI) system, and, as a result, has gotten "pushed aside" in the legislative process.

That happened as recently as last year, Walsh said, when his national background check bill had similarly been approved by the Judiciary Committee and sent to the Ways and Means Committee, where it died. Walsh said he is hopeful that won't happen again this year.

Walsh said he spoke to House Speaker Robert DeLeo about the bill last fall, and said DeLeo told him he is neutral

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on the measure, but did not oppose it. Walsh said he planned to speak with Ways and Means Chair Brian Dempsey about the measure.

COFAR placed a call to Dempsey's staff in December to inquire about the chairman's position on the bill. The call was not returned.

## **Facility cost study bill buried DDS continues to stonewall on cost**

For more than a year, COFAR has scrutinized the Patrick administration's claim that closing the Fernald, Monson, Templeton, and Glavin developmental centers in Massachusetts would save the state \$20 million annually in the cost of care of persons with intellectual disabilities.

However, the Department of Developmental Services has been increasingly unwilling to disclose critical cost information to COFAR, and the Legislature has failed to support calls for an independent cost analysis of the facility closures.

As of mid-December, a bill filed by State Representative Anne Gobi, which would require an independent analysis of the cost of closing the facilities, remained in the Children, Families, and Persons with Disabilities Committee, where it was first sent in January 2011. A legislative aide to Rep. Kay Khan, the House chair of the committee, said she had no indication whether the bill would be scheduled for approval by a mid-March deadline.

Meanwhile, COFAR has appealed a denial by DDS in October of records detailing the costs of medical, nursing, clinical, and therapeutic services for individuals in a group home program.

As previously reported (July 2011 *COFAR Voice*), COFAR examined a DDS group home contract with the May Institute, Inc., which specified only minimal nursing services for the residents and no physician, clinical, or therapeutic care. The contract was one of 1,000 such residential services contracts whose average per-client cost was cited by the administration in 2010 as being less than the average per-client cost of operating the Monson, Templeton, and Glavin developmental centers.

In an October 23 letter to COFAR, Marianne Meacham, DDS general counsel, stated that the requested records were exempt from public disclosure due to client confidentiality requirements. In an October 27 appeal to the state Public Records Division, COFAR maintained it has no intention of publicly identifying any individuals in the May Institute program, and suggested that DDS redact any names and any other information that might identify clients.

"What we want to find out is which agency or agencies both fund and provide the medical, nursing, clinical, and therapeutic services under this particular May Institute contract, and how much these services cost state taxpayers in total," COFAR's appeal stated. Should DDS refuse to provide that information, "the public will have no way of

knowing basic details about the provision and funding of these kinds of public services," COFAR's appeal added.

As of January 10, the deadline for producing *The COFAR Voice*, the Public Records Division had not ruled on COFAR's appeal.

## **Rep. Gobi can't get DDS answer on client deaths**

A state lawmaker has reportedly been unable to get any information from the Department of Developmental Services about residents who have been transferred from four developmental centers marked for closure.

In an October 13 letter to DDS Commissioner Elin Howe, State Representative Anne Gobi asked for statistics on the number of residents who had been transferred from the developmental centers to community-based residences in the past two years, how many of those residents had died after the transfers and what the causes of death were.

As of January 10, a legislative aide to Gobi said Gobi still hadn't received a response from DDS to her inquiry. The aide said Gobi was concerned and frustrated that she had not gotten an answer. The Templeton Developmental Center, one of four facilities targeted by the administration for closure as of the end of Fiscal Year 2013, is in Gobi's district.

Gobi's aide said Gobi had sent her inquiry to Howe in the wake of reports from COFAR that two former developmental center residents, both of whom had been in their 50s, had died suddenly after having been transferred to group homes. One of the residents had formerly lived in the Templeton Center and the other had lived in the Fernald Developmental Center.

The former Templeton resident died on July 24 in a state-operated group home in Tewksbury, four days after having been transferred there from Templeton. The cause of death was listed as a blood clot of unknown origin in his lung. The former Fernald resident died on July 6, two weeks after having swallowed a plastic garbage bag in a group home in Tyngsboro. He had been transferred to the group home about a year earlier from Fernald.

COFAR has also submitted a request on October 24 to DDS for information and public records concerning the number of developmental center residents who have been transferred to group homes since 2008 and the number of those residents who have died. COFAR also asked, among other information, for the number of community-based group homes that have been built to house former developmental center residents. As of January 10, DDS had not provided documents in response to COFAR's request.

### **Please contribute**

COFAR continues to need your financial contributions in order to continue our mission of advocacy for DDS clients and families. A donation box appears on the back of this newsletter.

**Thank you!**

