



The COFAR VOICE

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

April 2012

Volume 12/Number 2

DDS failing to follow up on vendor deficiencies

A review by COFAR of quality-of-care documents for two vendors to the Department of Developmental Services appears to show DDS failed to follow up in several cases on cited deficiencies.

The DDS documents failed to show any follow-up actions were taken by DDS to several findings in survey reports showing potentially serious deficiencies by Behavioral Associates of Massachusetts, Inc., and the Center for Human Development, Inc.

"These new documents add to our concern that the group home system in Massachusetts isn't monitored as thoroughly as are the developmental centers," said Colleen Lutkevich, COFAR executive director. "If DDS didn't follow up on serious licensing deficiencies for these two vendors, we can't assume they were corrected."

The administration says it has no record of the total cost of services in a group home program (Page 4)

While developmental centers are surveyed by state Department of Public Health based on federal standards, community-based group homes are surveyed by staff of the DDS Office of Quality Enhancement.

Behavioral Associates of Massachusetts

Documents show DDS granted a 2-year license in May 2010 to Behavioral Associates after a critical survey report in April 2009 had cited numerous deficiencies in the vendor's operations. In April 2009, DDS had approved only a one-year, conditional license for the vendor. The May 2010 licensure and certification letter stated that Behavioral Associates was now being certified with distinction in all areas evaluated and that no further follow-up was needed.

However, while there were indications in DDS follow-up review letters and reports to the April 2009 report that some of the cited problems had been corrected, there were no mentions of other deficiencies found in the original report. In some cases, the May 2010 report simply repeated the same citations of problems previously cited in April 2009.

In response to a written request for comment, DDS

Please see LICENSURE, Page 2



DDS AWARD – John Sullivan, a longtime champion of care for the intellectually disabled and a founding member of both COFAR and the Arc of Massachusetts, steps to a podium in the Great Hall at the State House to receive a lifetime achievement award March 28 from the Department of Developmental Services. Also receiving an award was longtime COFAR member Carolyn Milley and her late husband Fred. Story on page 3.

Intellectual disability definition change sought

A legislative committee has approved a bill that would loosen the state's restrictive definition of intellectual disability in order to allow more people to qualify for care from the Department of Developmental Services.

The bill (H. 3527) is one of several measures approved in late February by the Children, Families, and Persons with Disabilities Committee in order to help people struggling to receive DDS services.

The bill would change the current DDS definition of intellectual disability in order to ensure services to people whose IQ scores fall just above the current cutoff level of 70. During a November 15 hearing before the committee, there was emotional testimony from a number of guardians

Please see ID CHANGE, Page 3

DDS lacks vendor follow-up

LICENSURE, *continued from page 1*

provided responses to some, but not all, of the issues noted in COFAR's review of the Behavioral Associates documents. Those issues include the following:

- The April 2009 licensure report on Behavioral Associates stated that members of the vendor's Human Rights Committee needed to comply with state conflict-of-interest provisions. The June 2009 follow-up letter stated that the chair of the committee had a financial interest in the company and would need to step down. The May 2010 report stated only that the vendor had "consulted with the Ethics Commission in Massachusetts to address potential conflicts of interest within its membership." There was no indication whether the member did in fact step down.

The DDS response did not comment on this matter.

- The name of the Human Rights Committee chair was not disclosed in the licensure reports. A federal tax filing for Behavioral Associates for the year ending June 30, 2010, disclosed that both the executive director and president of the company were married and received combined compensation totaling more than \$410,000, and that several unpaid Board members were related to paid executives of the company.

- The April 2009 licensure report stated that the vendor staff was using a "prone restraint" technique on residents that was not approved by DDS. The June 2009 follow-up report stated only that this problem had been "partially corrected," but did not provide any details about what corrections were made. The May 2010 report did not mention the issue. Prone restraint has been found in a number of cases to cause deaths or serious injury due to asphyxiation.

The DDS response did not comment on this matter.

- The April 2009 report cited numerous issues involving inadequate control of financial transaction records in group homes, including the removal and alteration of records from confidential files and instances in which staff took cash from the homes and didn't record it. The June 2009 follow-up report stated that these problems had been corrected and that the vendor had "significantly strengthened its systems to document and monitor financial transactions." But few details were provided in the follow-up report in response to the specific findings in the April 2009 report.

The DDS response stated that the June 2009 follow-up report provided "some details on corrective actions," including a finding that "receipts are now used to document any cash transactions."

- The April 2009 report stated that the vendor staff was administering sedative medications to residents without guardian consent in some cases and without a plan to reduce or eliminate the medications. The June 2009 follow-up report stated only that the problem had been "partially corrected" and provided no details about the corrections. The May 2010 report stated only that a plan

was not in place to reduce or eliminate sedative medications.

The DDS response did not comment on this matter.

- The April 2009 report cited the vendor for providing residents with only "limited support" to connect with communities. Many community trips for residents were for errands or other "mandated activities." The June 2009 follow-up report did not mention the problem. The May 2010 report stated that residents were "supported" to participate in community activities such as social groups and dance lessons, but that these activities were not consistently documented by the staff. The report indicated that community connectedness was still a problem.

The DDS response stated that the May 2010 report "noted details of the agency's improvement in this outcome, with a recommendation to continue its efforts to support individual's involvement in their communities."

- The April 2009 report cited the vendor for inappropriately operating a day program in the basement of a group home. The June 2009 follow-up report stated that the day program had been relocated to "a safer, more appropriate location." However, the May 2010 report stated that the new location was still too small and that the vendor was "assessing" yet another location for the program. The DDS response stated that the agency subsequently relocated to another, larger location.

The Center for Human Development

A November 2010 DDS survey report for the Center for Human Development stated that one of the DDS's certification standards weren't met because three "reportable incidents" of abuse or neglect had not been reported to the Disabled Persons Protection Commission as required.

A follow-up report dated December 20, 2010, stated that the Center for Human Development had corrected seven out of seven licensure indicators. The follow-up review also noted improvements adopted in the vendor's Human Rights Committee procedures, behavior planning, and medication treatment plans.

However, there was no mention in the follow-up report of the previous certification failure to report the three incidents to the DPPC. Also, neither the original November 2010 survey report nor the follow-up report contained detailed explanations of the deficiencies that had been found.

DDS did not respond to a written request for comment on the Center for Human Development licensure documents.

In October, COFAR reported that a review of 30 selected online licensure and certification reports by DDS of vendors raised questions about the thoroughness and frequency of the state's surveys of the care and conditions in group homes. Among the findings of the COFAR review were that most of the reports appeared to focus on whether providers were achieving broad and often vaguely worded goals.

In the wake of the COFAR review, COFAR requested detailed licensure documents on the Center for Human Development and Behavioral Associates of Massachusetts.

Sullivan, Milleys get DDS awards

John Sullivan, a founding member of both COFAR and the Arc of Massachusetts and a force on many fronts in improving care for the intellectually disabled, was presented with a lifetime achievement award March 28 by the Department of Developmental Services. (See photo on Page 1.)

Sullivan, 91, whose daughter Jean has been a resident of the Wrentham Developmental Center since 1959, was also a plaintiff in the landmark Ricci v. Okin lawsuit, which brought about improvements in care and conditions in both the state's developmental centers and community system.

Another of Sullivan's daughters, Colleen Lutkevich, has served as COFAR's volunteer executive director for many years.

Also receiving an award March 28 was Carolyn Milley and her late husband Fred, long-time COFAR members who advocated for many years for the residents of the Hogan Regional Center in Danvers. The Milley's daughter, Beth, has been a resident at Hogan since the center opened in 1967.

As he accepted his award, Sullivan said he wanted to "pay tribute to the wonderful people that work day in and day out (on behalf of the intellectually disabled). They are the saints on earth."

Present at the March 28 awards ceremony were Sullivan's wife Gladys and many other family members. Gladys and John both helped found a preschool for disabled children when Jean was a toddler.

After Jean was admitted to Wrentham, Sullivan became a member and later president of the Wrentham Parent's Association. He later fought for the passage of Chapter 766, the state's special education funding law, and visited local school committees to petition for special education services within area towns.

Sullivan was instrumental in founding the Charles River Arc, the Charles River Workshop, and later, three group homes. He also was a founding and executive board member of the Massachusetts Arc and organized one of the organization's first state conventions. However, when the Arc began to advocate for closure of the developmental centers, Sullivan dropped his membership in that organization and helped found COFAR.

An article about Beth Milley in *The COFAR Voice* in December 2003 discussed Fred and Carolyn's anxiety over budget and staffing cuts at Hogan and the then Romney administration's plan to close Hogan as well as the other developmental centers in Massachusetts. "So much of our lives have gone into advocating for her (Jean), and yet there never seems to be an end to the uncertainty," Fred said at the time.

During the March 28 awards ceremony, the annual Gunnar Dybwad Leadership Award was presented posthumously to Louis Nisenbaum, a co-founder of The Coalition for Community Living, a self advocacy group. The Allen Crocker Health Services Award was presented to

Brian Skotko, a physician and leading advocate and national spokesperson on Down Syndrome.

ID definition bill advances

ID CHANGE, *continued from page 1*

who were unable to obtain DDS services for intellectually disabled wards who scored slightly above the current IQ cutoff level.

The Children and Families Committee also approved the following bills in late February:

- S45, which would establish a state task force to study the average compensation, level of training, and turnover of direct-care workers in the DDS system.
- H975, which would provide easy public access to a wide range of information about direct-care worker turnover and compensation as well as the compensation of vendor executives. The information would be published on the DDS website. The bill is opposed by the Arc of Massachusetts, many of whose affiliated organizations are contractors to DDS.
- H2683, which would establish an independent office of quality assurance to monitor the care of clients throughout the DDS residential care system.

Meanwhile, the House Ways and Means Committee has failed since October to take action on H523, which would require national criminal background checks on persons hired to work with Department of Developmental Services clients.

This bill, which is strongly supported by COFAR and other advocacy organizations for the intellectually disabled, has been repeatedly filed by Rep. Martin Walsh of Boston. In an interview on March 20, Walsh attributed the continuing inaction on the bill to the press of business before the committee. He said he continued to know of no specific opposition in the committee to the bill. The same bill, however, died last year after the Ways and Means Committee failed to take action on it. The Committee has until July to act on the bill before the end of the current legislative session.

Trial in assault case postponed

After two postponements, the trial of John Saunders, a former group home staff worker who has been charged with assaulting a resident of the home, has been scheduled for June 4.

Saunders had initially been scheduled for trial on January 9, but failed to appear in Falmouth District Court. The trial was next scheduled for March 27, but the judge continued the case until June 4 because a defense witness had failed to appear.

Saunders is accused of hitting John Burns in the face during an outing on Cape Cod in June 2010. Burns is the brother of Sheila Paquette, president of the Advocacy Network, a COFAR member organization. Paquette personally filed assault charges in the case.

State says it has no record on total group home costs

In response to a request last July by COFAR for documents on the cost of providing medical, clinical, and therapeutic care in a community-based group home program, a Patrick administration official now contends it has no such record.

In an April 5 email, sent more than eight months after the documents request was first made, Jon Seiff, a records custodian in the Executive Office of Health and Human Services, said that agency did not have “an existing record showing (costs of) the particular services provided to the particular individuals in question. In fact, the identity of these individuals is not known to us.”

In October, the DDS, to which COFAR had also sought the records in July, claimed that it had no such documents other than individual client records, which are private. COFAR ultimately appealed to the state Public Records Division to obtain the records, suggesting that any identifying information in them be redacted.

COFAR originally filed the records requests with both EOHHS and DDS after examining a \$1.2 million state group home contract with the May Institute. The contract did not specify any funding for clinical, medical, or therapeutic services.

The administration has claimed that the cost of care in community-based programs such as the May Institute program is less expensive than care in state developmental centers. The administration’s cost analysis was based on a comparison of the budgets of the Monson, Templeton, and Glavin developmental centers in Massachusetts with the costs of contracts such as the May Institute contract.

Medical, clinical and therapeutic services are included in the developmental center budgets. However, as DDS acknowledged in a March 12 letter to the Public Records Division, medical, clinical, and therapeutic services in community-based settings are provided through private insurance or public health insurance programs such as Medicare and MassHealth (Medicaid).

“The administration is finally now admitting that they have no idea what the total cost is to care for residents in the community,” said Colleen Lutkevich, COFAR executive director. “We think this calls their savings analysis in closing the developmental centers into further question.”

Meanwhile, with time rapidly running out on the Monson, Templeton, and Glavin centers, which have been targeted by the administration for closure, a bill proposed by COFAR that would require an independent study of the costs of closing the centers was approved in late February by the Children, Families, and Persons with Disabilities Committee. The bill (H. 3964) had languished in the committee for more than a year before it was sent to the House Ways and Means Committee where its fate remained highly uncertain.

“Time is of the essence if this study is to have any meaning at all,” Lutkevich said. “There are fewer and fewer people left in these three facilities.”

The budgets and number of residents of the three developmental centers have been diminishing rapidly. As of March 2012, there were 75 residents remaining at Templeton, down from 123 in 2008. The Glavin Center had 30 residents left in March, down from 55; and the Monson center had 45 residents in March, down from 136.

The Fernald Developmental Center, which would not be part of the study, has 14 residents remaining, all of whom have filed appeals of the transfers of their wards. There were 162 residents living at Fernald in 2008. Those numbers don’t count the 29 residents in the Marquardt skilled nursing facility on the Fernald campus, which is slated to remain open and which serves all DDS clients.

Roland Charpentier, the head of the Glavin Center’s family organization, said in March that among the remaining guardians there, “about 20 of us class members are going stand and fight to stay. We’re seeking legal help,” he added.

The independent cost study bill approved by the Children and Families Committee is based on proposed legislation originally introduced in January 2011 by Rep. Anne Gobi of Spencer as both a stand-alone bill and an amendment to the FY 2012 state budget. In April 2011, the House Ways and Means Committee decided in a closed-door meeting to scuttle Gobi’s amendment before it could reach the House floor for debate. A similar fate befell a similar budget amendment last May in the Senate Ways and Means Committee.

Intellectually disabled man turned away from hospital

State officials have asked the Department of Public Health to investigate the case of an intellectually disabled man who died after being sent home twice by Lowell General Hospital in early February, apparently without any significant treatment.

COFAR first reported on the case on the COFAR blogsite on February 27. A staff member of the Disabled Persons Protection Commission said the agency had forwarded the case to the DPH for investigation.

The 51-year-old man, whose name is being withheld by COFAR, had been having difficulty breathing and was sweating profusely when he was taken to the hospital on both February 6 and 7. He was sent back to his residence each time. He died, apparently en route to the hospital, after the group home staff called an ambulance for the third time on the afternoon of February 7. The cause of death was listed on the death certificate on file in the City of Lowell as acute respiratory failure and aspiration pneumonia, which can indicate choking on an object or on saliva. A death report form filed with the DPPC, however, stated that the man died after experiencing cardiac arrest.

Despite the possible discrepancy in the stated causes of death, the Chief Medical Examiner’s Office declined to do an autopsy, and the man’s remains were cremated.

Continued on next page

Continued from previous page

Dorothy O'Rourke, a COFAR member whose son lives in the group home in which the man had lived, was supportive of the staff of the group home, which is managed by Northeast Residential Services, a division of the Department of Developmental Services. "The staff there are wonderful," she maintained. "They did all they could for him, including performing CPR. It's the hospital that kept sending him home. I thought they would have at least kept and monitored him. I don't understand it."

O'Rourke said she had no information about what actually happened in the hospital after the man was taken there on each occasion. But she maintained that many hospitals are ill-equipped to deal with intellectually disabled people, particularly those who are non-verbal, as this man was. "I think hospitals tend to ignore the mentally disabled," she said. "I think they may need a special unit to handle mentally disabled people."

A spokeswoman for Lowell General said the hospital would have no comment on the case due to privacy issues.

A bill filed by state Representative Carolyn Dykema of Holliston would require training for medical and nursing personnel in dealing with persons with intellectual disabilities. The bill, however, was sent to a study in March by the Public Health Committee, meaning it was effectively dead unless revived in some other form.

DDS care exempted from managed care plan

The Patrick administration has agreed to exempt community-based residential and day services for persons with intellectual disabilities from a plan to introduce managed care into Medicaid and Medicare coverage.

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 persons in Massachusetts who are dually eligible for Medicaid and Medicare. The original EOHHS proposal appeared to call for a single managed care system for residential, day program, transportation and other services in addition to medical care for intellectually disabled persons. That proposal could also potentially have eliminated state service coordinators who help DDS clients choose from among available services in the community system.

In early January, COFAR joined with SEIU Local 509, a state employee union, in opposing the EOHHS proposal. In testimony presented at a January 4 hearing in Boston, COFAR maintained that the proposal appeared 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."

The revised EOHHS plan stated that DDS clients in developmental centers and receiving services under a large community-based Medicaid waiver program would not receive services from an ICO, and that other exempted services include Adult Day Health, Adult Foster Care,

Day Habilitation, Group Adult Foster Care, and Personal Care services.

An SEIU official stated that the union is concerned that some people who are served by DDS could still find that their services are managed by an ICO, under the revised EOHHS proposal. These would primarily be DDS clients who are eligible for Medicaid and Medicare, but for whom DDS doesn't bill Medicaid or Medicare for reimbursement.

Ways and Means hearing draws pleas against cuts

People with disabilities, from blindness to intellectual impairments, urged members of the Legislature's budget committees in early March to stop the yearly cycle of budget cuts that continually threaten their services.

"I want to shake you all," one woman, who is both deaf and blind, said through an interpreter. She was referring to the proposed elimination in Governor Patrick's Fiscal Year 2013 budget of \$450,000 for a program to provide her with community-based support services.

"Can you imagine being deaf and blind and trying to go food shopping without any help?" she asked. "If this program is eliminated, I will be suicidal."

Representative Martha Walz of Boston, a member of the Ways and Means panel, responded that "it is the governor who proposes to cut these programs every year and the Legislature that restores it year after year."

COFAR testified at the hearing in favor of a proposed independent study of the costs of closing developmental centers for the intellectually disabled (see story on Page 4).

Chris Emory, a member of the deaf-blind community, maintained that there are roughly 500 people in Massachusetts who are both blind and deaf, and that the program in question is able to provide services for only about 70 of those people.

Vendor CEO pay went up and direct-care pay down

A survey by COFAR of more than 30 state-funded vendors of residential services to the intellectually disabled showed that average compensation of the top executives increased by 16.7 percent from Fiscal Year 2008 to 2011. However, direct-care workers in those same companies saw their average salaries drop by 1.88 percent during that time.

The average CEO compensation rose to \$227,749 in the four-year period, while direct-care wages dropped to \$32,808. Among the sample, nine CEOs received compensation increases in the four year period reviewed while the direct care workers employed by those same vendors actually saw their wages cut. More information about the survey can be found in an article posted on The COFAR blogsite at <http://cofarblog.wordpress.com/2012/02/13/provider-executives-not-sharing-the-pain-of-their-workers/>

COFAR
3 Hodges St.
Mansfield, MA 02048



COFAR is a family supported, education and advocacy organization funded by member families.

Phone: 508-339-3379
Fax: 508-339-5034

Thomas J. Frain, President, Thomas.frain@cofar.org
Colleen Lutkevich, Executive Director, colleen.lutkevich@cofar.org
David Kassel, Newsletter Editor, dkassel@earthlink.net

Please donate or renew your membership to keep COFAR alive and viable, and continue to receive *The COFAR Voice*.

____ Membership \$25

\$____ Other Donation

First Name Initial Last name

Address City State Zip

Telephone () E-Mail Check #

Thank you!