



The COFAR VOICE

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

August 2012

Volume 12/Number 3



MUSIC THERAPY – Kathleen Downey (with ukulele at left), a musical therapist, joins Paul Frain (center), a resident of a DDS group home in Clinton, in a folk song, while Paul's mother Maryalice looks on. Downey has been playing and singing to residents in public and privately run residential facilities for 15 years. You can read more about her work on the COFAR Blogsite at <http://cofarblog.wordpress.com/2012/06/29/music-therapy-transforms-an-evening-at-a-group-home/>.

Families prepared to fight to save Glavin Center

Family members and guardians of residents of the Glavin Regional Center in Shrewsbury are moving closer to joining their counterparts at the Fernald Center in appealing the Patrick administration's moves to close those two facilities.

After being thwarted for the second year in a row in their attempts to introduce a state budget amendment in the Legislature for an independent study prior to Glavin's closure, several families said in July that they will take advantage of an administrative hearing process in a state law that could promise to keep Glavin open for the foreseeable future.

The Patrick administration has targeted the Glavin, Fernald, Templeton and Monson developmental Centers in Massachusetts for closure. However, Fernald, which had been slated to close in July 2010, has remained open

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Appeals court invalidates DDS IQ cut-off

In a decision that could lead to widespread re-applications for services from the Department of Developmental Services, the Massachusetts Court of Appeals has invalidated state regulations cutting off eligibility if a person scores above a 70 on an IQ test.

The three-judge appeals court panel overturned a Superior Court ruling, which had upheld the regulations.

The case against the regulations, which DDS adopted in 2006, was argued by Thomas Frain, an attorney who is also president of COFAR.

In its July 23 decision, the appeals court ordered DDS to redraft the regulations to conform to a state law that requires the department's definition of intellectual disability to be based on "clinical authorities" and not solely on an arbitrary IQ score measurement.

A DDS caretaker is acquitted of allegedly abusing a group home resident (Page 3)

An undetermined number of people have been denied DDS services since 2006 as a result of the absolute cut-off above a 70 IQ score. Frain said he believes the ruling "could trigger a flood of re-applications for benefits." He maintained that since 2006, "the message from DDS has been 'don't bother to apply if you score above a 70.'"

The appeals court ruling has been hailed by a range of advocacy groups for the disabled, including the Disability Law Center and the Arc of Massachusetts. Those organizations along with COFAR opposed the 2006 regulations before they took effect, arguing that they would give the department wide latitude to deny eligibility to persons who were clearly in need of services.

It was still unclear as of early August whether the Patrick administration intended to appeal the ruling to the state's Supreme Judicial Court.

The case before the appeals court concerned a woman who scored a 71 on an IQ test when she was 18, and who was subsequently denied services by DDS on that basis.

Frain described his client, who is now 45, as "a very

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DDS IQ rule invalidated

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disabled person" who lives with her mother and depends on her for many basic living functions.

The woman's mother, who is 72, said she has to cook for her daughter, take her to medical appointments, handle her finances, and supervise her medication. "She doesn't function as an adult," she said of her daughter.

The appeals court ruling stated that there was also evidence the woman "may have placed herself at risk in her dealings with strangers," and that she has "an ill-defined sense of sexual boundaries."

The Boston Globe, reporting on the case, stated that state officials maintain that their evaluation criteria go "far beyond IQ test results" to include how well individuals function in society. The newspaper said the woman in this case had graduated from high school and had attended Middlesex Community College.

The woman's mother told *The COFAR Voice*, however, that her daughter graduated from a small parochial school after having been "pushed through" by the administration there, and that she took only a clerical course for people with intellectual disabilities at Middlesex Community College.

The woman scored 71 on an IQ test at age 18, 69 at age 40, and 71 at age 42. The appeals court stated that DDS determined that the woman's score at age 18 was "determinative" and that a standard error of measurement of plus or minus 5 points should not be applied "in view of (the woman's) education and work history." Moreover, DDS determined that it was not necessary to consider the woman's adaptive functioning because she had scored above the cutoff of score of 70.

Prior to 2006, DDS regulations stated that determinations of intellectual disability had to be consistent with the clinical authority of the American Association on Intellectual and Developmental Disability (AAIDD). The AAIDD definition of intellectual disability does not establish an absolute cut-off at an IQ of 70.

The appeals court ruled that DDS's prior regulations were consistent with a state law, which defines intellectual disability as something that is "determined by clinical authorities." The court stated that the 2006 regulations, however, "fail to describe the clinical authorities upon which the clinical judgments regarding intelligence are made."

A bill had been pending in the Legislature that would tie the definition of intellectual disability in Massachusetts to the AAIDD's definition. The measure (H. 4252) was passed by the House in its final formal session of the year on July 31, but was not taken up by the Senate.

The Disability Law Center was planning to urge Senate leaders to pass the bill in an upcoming informal session, which would not necessitate a vote by the full body.

During a hearing on the bill last year, a number of people provided emotional testimony about having been denied DDS services for their children who tested just above the 70

cut-off. One woman, Linda Boucher, whose son had scored a 75 and who was consequently denied services, said it was as if he was under house arrest.

"Where do I go? I need help," Boucher told state lawmakers.

Frain said he hoped that the appeals court ruling combined with the pending legislation would ensure that DDS provides services in the near future to intellectually disabled people such as his client and Boucher's son.

DDS drops limits to services and guardians' rights

In the wake of critical comments from COFAR and the Wrentham Association, the Department of Developmental Services agreed to drop planned changes to its regulations that would potentially limit services and guardians' rights in clients' care plans.

The decision to drop the proposed changes came after DDS met on June 21 with plaintiffs and counsel in the Ricci v. Okin consent decree case, which upgraded care for the intellectually disabled in Massachusetts. Among those attending was Colleen Lutkevich, COFAR executive director and a representative of the Wrentham Association plaintiffs.

In a letter to the plaintiffs' counsel, dated July 2, DDS General Counsel Marianne Meacham stated that the department would drop the planned elimination of a current requirement that services be listed in each client's Individual Service Plan "without regard to the availability" of such services. Also dropped was a second proposed change to eliminate the current requirement that the ISP contain strategies to address the "unmet support needs" of clients.

Lutkevich said she was happy that the meeting had prevented changes that would have violated the historic 1993 Disengagement Order in Ricci v. Okin.

Meacham also stated that DDS would drop a proposed change to the regulations that gives guardians and family members the right to request a meeting with their service coordinator to have their ISP explained to them. She also stated that DDS would drop the planned exclusion of family members from receiving periodic updates from providers on the implementation of ISPs.

Meacham, citing privacy and other laws, said DDS would not agree to a request to drop a change that will allow guardians to object to the participation of family members in the ISP process. COFAR is concerned this change could allow corporate or court-appointed guardians to exclude family members from participating in the care of loved ones with intellectual disabilities. However, Lutkevich said DDS did agree to invite family members to participate if guardians approve.

Meacham's letter did not address an objection by COFAR to another planned change in the regulations that will allow service coordinators to waive ISP modification meetings without the approval of family members.

Caretaker acquitted in abuse trial

After a two-year quest for justice in the alleged assault of her profoundly intellectually disabled brother, Sheila Paquette could only feel frustration as a jury took less than half an hour on July 30 to acquit the man accused of the crime.

"This investigation may not have been complete enough," Paquette told *The Cape Cod Times* at the conclusion of the trial of John Saunders in Falmouth District Court.

Paquette maintained that there appeared to be a lack of communication throughout the investigative process between key investigative agencies such as the Disabled Persons Protection Commission (DPPC) and the Cape & Islands District Attorney's Office.

Paquette, who is president of the Advocacy Network, a COFAR member organization, had personally filed a charge of assault against Saunders in the wake of the alleged assault.

Saunders allegedly hit Paquette's brother, John Burns, while toileting him in a vacation home during an outing in Falmouth in June 2010, causing two black eyes and other injuries. Saunders was at the time a caretaker in a West Springfield group home operated by the Center for Human Development, in which Burns still lives.

The case against Saunders largely depended on the testimony of David Vecchiarelli, Burns' roommate in the group home, who was outside the bathroom in the vacation home at the time of the alleged incident.

Vecchiarelli had originally signed a written statement submitted to the court that he had looked through the open door of the bathroom and had seen Saunders strike Burns on the bridge of the nose. However, when he took the witness stand at the trial, Vecchiarelli stated that he only saw Saunders place one hand over Burns' mouth and the other behind his head as Burns sat on the toilet. He said this time that he did not see Saunders hit Burns.

That change in Vecchiarelli's account appeared to be a major factor in the jury's decision to acquit Saunders.

COFAR and the Advocacy Network have raised a number of questions about the investigation of the case, including the question why the District Attorney's office didn't subpoena investigators from the DPPC or its State Police Unit to testify during the trial. The only investigative witness called to the stand was an East Falmouth Police Department officer, who had filed a preliminary report on the incident and never interviewed Vecchiarelli.

The DPPC, however, did issue a comprehensive report on the incident in February 2011, which was based on interviews with Vecchiarelli as well as with other staff in Burns' group home and his day program. That report concluded that there was sufficient evidence to conclude that Burns was "seriously injured" by Saunders.

Assistant District Attorney Kerry Whalen, who tried the case, maintained to *The COFAR Voice* that any testimony given by the DPPC or State Police in the case would have

been considered hearsay because those investigators did not interview Saunders, the defendant in the case.

The DPPC report, however, indicated that a DPPC investigator interviewed Saunders by telephone on July 24, 2010.

Tom Frain, an attorney and COFAR's president, contended that the District Attorney's office should have introduced the DPPC report and testimony to build a fuller case.

Similarly, none of the staff of the group home, other than Saunders and a second caretaker who had been on the Cape Cod trip, testified at the trial. The DPPC report on the incident stated that when Burns and Saunders returned to West Springfield from the weekend trip on the evening of June 28, 2010, Burns was "acting out a bit, yelling more than usual," and that Saunders was "acting aggravated and derogatory toward the other staff," and that he had spoken "in a derogatory manner about (Burns) in (Burns') presence..."

Paquette experienced frustrations with the investigation of the case almost from the start. In an article written for the fall 2010 issue of the Advocacy Network newsletter, Paquette wrote that she personally filed the assault charge against Saunders some three weeks after she had first reported the incident to the DPPC. It was only after she filed the assault charge that the DPPC sent a state trooper to her house to investigate, she stated. "Until I had filed charges myself, I wasn't taken seriously," she wrote.

In addition to concluding that there was reasonable cause to believe Saunders had assaulted Burns, the DPPC report recommended that Saunders no longer work with individuals served by DDS. The report also recommended retraining of the staff at Burns' group home "regarding notification of administration regarding injuries and general quality of care issues." Saunders was fired by CHD following the alleged incident.

National background check bill dies again

The House Ways and Means Committee has once again failed to take action to pass a bill that would give the state the authority to conduct national background checks on persons hired to work with clients of the Department of Developmental Services.

The measure, perennially sponsored by state Representative Martin Walsh of Boston, has been strongly supported by COFAR and other advocacy groups for the intellectually disabled.

Currently, DDS authorizes Criminal Offender Record Information (CORI) checks on new hires, but CORI records do not disclose criminal convictions a job applicant may have received in another state.

Walsh told *The COFAR Voice* that he is hopeful his bill will be taken up in an informal session of the Legislature. He contended that the Patrick administration has the authority to write regulations establishing a national background check system in Massachusetts, but hasn't done so.

Glavin families prepare for fight for center

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pending the outcomes of the administrative and court appeals filed by guardians of 14 remaining residents there.

The Glavin families, however, have not given up on the hope of getting help from the Legislature for that facility. They were scheduled to meet on August 14 with state Representative Patricia Haddad of Taunton, a member of the House leadership, who spearheaded an effort in July in the House to save Taunton State Hospital from being closed.

In early July, several Glavin family members met with the editorial board of *The Worcester Telegram & Gazette* to urge the newspaper's support of the preservation of the Glavin facility. The families were joined by COFAR representatives and by Al Bacotti, a former director of the Glavin Center, who has spoken frequently about Glavin's cost effectiveness.

The newspaper published an editorial on July 11, calling for both the Glavin Center and Taunton State Hospital to remain open. The editorial stated that both facilities "are places where hope pours in daily from family members and others who cherish their special someone who lives there."

The editorial also stated that group homes are not necessarily appropriate for all persons with intellectual disabilities. "The reality is that developmental disability will never adapt to a one-size-fits-all solution," the editorial stated. "Medium and larger facilities where patients are more closely guarded have a vital role."

The Massachusetts Association of Developmental Disabilities Providers, reacted to the editorial with a negative op-ed in the *Telegram & Gazette* about Glavin. The ADDP and the Massachusetts Arc, both of which represent state-funded group home operators, have long sought to close all developmental centers in Massachusetts and move their residents to community-based group homes.

The ADDP op-ed repeated claims, which COFAR has long disputed, that Glavin and other developmental centers are prohibitively expensive to operate and that better care is available in community-based settings.

COFAR wrote an op-ed in response to the ADDP's article, referring to Glavin as a "vital asset to the state." COFAR's op-ed also stated that it appeared to "make no fiscal or logistical sense" that the Patrick administration was closing all of the existing developmental centers west of Route 128 around Boston and maintaining only two such centers, one in Danvers and one in Wrentham.

The Wrentham center in southeastern Massachusetts is being offered as a site for residents now living at Glavin and the other centers targeted for closure. That facility already houses more than 300 residents and may well become larger, the COFAR op-ed stated, adding that it would make more sense to keep the Glavin, Monson, Templeton and

Fernald centers open in their current strategic locations with smaller numbers of people in them.

'Real Lives' bill dies at end of session

Proposed legislation to encourage a concept known as self-directed services for the intellectually disabled in Massachusetts was approved by the House but died at the end of the legislative session on July 31, when the Senate declined to take it up.

COFAR has raised a number of concerns about the proposed legislation, dubbed the "Real Lives" bill, including its designation of unspecified private companies known as service brokers to manage the initiative.

The bill was supported by the Massachusetts Association of Developmental Disabilities Providers (ADDP) and the Arc of Massachusetts, which were seeking in early August to get the measure approved in an informal legislative session.

"What this bill appears likely to do is encourage runaway privatization of public services," said COFAR President Tom Frain. "That could lead to less transparency and more waste in the way those services are delivered."

Frain said one of his chief concerns is that the bill would provide that the ADDP and the Arc, both of which represent state-funded service contractors, would set policy in establishing self-directed services. He said he was also concerned that the so-called service brokers would duplicate or possibly displace service coordinators, who currently coordinate care and services for clients of the Department of Developmental Services.

The measure's principal sponsor, state Representative Tom Sannicandro, told *The COFAR Voice* that the intent of the bill is to "put the individual at the center of the decision process."

Frain maintained, however, that the individual is currently at the center of a decision process in the drafting of his or her plan of individual care, known as Individual Service Plan (ISP).

Studies give mixed grades to community care

Contrary to the claims of many proponents of community-based care of the intellectually disabled, academic studies on deinstitutionalization have not given the community system uniformly good grades.

A review by COFAR of scholarly studies on the quality and length of life of people who have been moved from developmental centers to community-based care indicates that there is no academic consensus that either system is best for all intellectually disabled individuals.

"Our survey supports the claim we've long made that while the community system is beneficial for many

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intellectually disabled people, a percentage of them continue to need facility-based care,” said Colleen Lutkevich, COFAR executive director.

Many opponents of state-run developmental centers maintain that research has consistently shown that community-based care is beneficial to most or even all intellectually disabled individuals.

COFAR reviewed 17 academic studies, reviews, and commentaries on deinstitutionalization of intellectually disabled persons. The studies concluded that many people who were deinstitutionalized did indeed experience improvements in the quality of their lives and adaptive skills after being transferred to community-based group homes.

However, many of those same studies reported that many deinstitutionalized people have encountered a lack of adequate medical care in the community system, and quality of life and adaptive skills often did not improve for those who had the most profound levels of disability or who were older.

COFAR also reviewed an academic controversy over a series of studies by David Strauss, Robert Shavelle and other researchers in California who found a higher death rate among people who were deinstitutionalized than what would have been expected in their former facilities.

In a comment to a July 2 COFAR post on the Blue Mass Group political blogsite that mentioned the California studies, Gary Blumenthal, president of the Massachusetts Association of Developmental Disabilities Providers, contended that the studies by Strauss and his colleagues had been “discredited by multiple expert researchers.”

Blumenthal cited four studies that he claimed discredited Strauss’s research. COFAR reviewed the four studies cited by Blumenthal and found that only one was overtly critical of Strauss and his methodology. The principal author of that critical study, James Conroy, has himself come under criticism for the methodology of his studies that have consistently found no increased death rate due to deinstitutionalization.

COFAR’s full account of its academic literature review on deinstitutionalization can be found on the COFAR Blogsite at <http://cofarblog.wordpress.com/2012/08/06/what-do-the-academic-studies-say-about-community-based-care/>

Lawmaker declines review of DDS licensure system

A key state lawmaker stated that she is satisfied that the Department of Developmental Services has fully addressed concerns raised by COFAR about the department’s group home licensure process in general and the licensure of two DDS vendors in particular.

In a July 2 email to COFAR, state Representative Kay Khan, House chair of the Children, Families, and Persons with Disabilities Committee, wrote that COFAR should contact DDS directly with its concerns.

Tom Frain, COFAR president, expressed disappointment in Khan’s response, contending the lawmaker should have scheduled a committee hearing on concerns raised by COFAR over the past year. “We think it is the Legislature’s responsibility to look into this issue, and it’s unfortunate that Rep. Khan has decided not to do that,” Frain said.

In an April 30 letter to Khan, COFAR reported that a review of documents indicated that DDS failed to follow up in several cases on deficiencies found in inspections of group homes operated by both Behavioral Associates of Massachusetts and the Center for Human Development.

Previously, COFAR had written to Kahn, raising a number of questions about the DDS licensure process in general, including a finding that licensure reports appeared to focus on whether providers achieving broad and often vaguely worded goals.

In a June 7 email to COFAR, Lisa Rosenfeld, legislative director for Khan, stated that the lawmaker felt that “DDS has satisfactorily answered the talking points in your (COFAR’s April 30) letter.”

Rosenfeld was referring to a May 22 letter by DDS Commissioner Elin Howe in which Howe defended the department’s licensure process regarding Behavioral Associates and the Center for Human Development.

Howe’s May 22 letter did note that DDS has taken a number of steps to correct some of COFAR’s concerns. She stated that vendor follow-up reports are now posted on the DDS website in addition to an initial licensure report, and that licensure reports will “contain more specific details about specific issues that remain after follow-ups are done.” In addition, Howe stated that “documentation will be added to ‘close the loop’ on remaining issues, specifically dates when the outstanding issues are resolved.”

In its April 30 letter to Khan, COFAR stated that DDS did not appear to have followed up on citations of Behavioral Associates in 2009 for conflict-of-interest issues, the use of unapproved “prone restraints” on group home residents, inadequate control of financial transaction records, and a lack of support to residents in connecting with their communities, among other issues.

The COFAR letter stated that DDS appeared to have also failed to follow up on a citation of the Center for Human Development for failing to report three incidents of abuse and neglect to the Disabled Persons Protection Commission.

In a June 26 letter written in response to Howe’s May 22 letter, COFAR urged Khan to review the issues raised about the DDS licensing process more thoroughly and possibly obtain help from the House or Senate Post Audit and Oversight Committees. The COFAR letter concluded that the concerns it had raised about the DDS licensure process could have ‘implications for the relative safety and well-being of clients throughout the community-based group home system.’

COFAR’s June 26 response to Howe’s letter and COFAR’s previous letters to Khan can be found on the COFAR website at www.cofar.org News and Publications page.

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