



The COFAR Voice

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DDS provider system has continuing abuse problem

But state-run services appear safer

An analysis by COFAR last fall of data from the state Disabled Persons Protection Commission (DPPC) confirmed that many providers to the Department of Developmental Services (DDS) have serious abuse problems.

Additional data provided in December by DDS also indicated, however, that on a per-client basis, DDS's state-run residential care settings are safer on average than corporate -run provider residences.

Between Fiscal Year 2010 and 2019, more than 14,000 abuse complaints were filed involving DDS clients in both provider-run and state-run facilities. On a per-client basis, COFAR's analysis showed that state-run group homes and developmental centers were well below average in their numbers of substantiated cases of abuse.

While the average number of substantiated complaints per client among providers of all types was about 0.13, the average number of substantiated complaints per client in state-operated group homes was 0.07.

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DEDICATED ADVOCATES — Gail Orzechowski, a COFAR member and advocate for persons with intellectual disabilities, poses in June with Attorney Beryl Cohen at a memorial service for the late U.S. District Court Judge Joseph L. Tauro, who oversaw Ricci v. Okin, a landmark class-action lawsuit. The case led to greatly improved conditions in facilities for persons with developmental disabilities. Tauro died in 2018.

Cohen was the original attorney for the plaintiffs in the Ricci case, which began in the 1970s. Orzechowski's husband, Ed, received the state's Annual Benjamin Ricci Commemorative Award in March (See story on Page 4). — Photo courtesy of Ed Orzechowski

COFAR urges work activities in day programs

COFAR has asked a key state legislator to endorse the introduction of voluntary work activities in community-based day programs for persons with developmental disabilities.

In a meeting on November 6 with state Representative Josh Cutler and a member of his staff, COFAR members pointed out problems caused by the elimination in Massachusetts of sheltered workshops.

Cutler is chairing a subcommittee of the Legislature's Children, Families, and Persons with Disabilities Committee. In October, COFAR members testified before Cutler's "Workability Subcommittee," and urged support for H.88. The bill would require that work

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COFAR examines the state's "circuitous" process for investigating abuse (Page 3)

DDS terminates provider contract in wake of neglect charges

In the wake of continuing allegations that a corporate residential provider was providing substandard care, the Department of Developmental Services has abruptly terminated the provider's contract to run two group homes in western Massachusetts.

In 2018, Mary Phaneuf, the mother of Timothy Cheeks, a resident of one of the homes, began raising concerns that the Springfield-based provider, the Center for Human Development (CHD), was failing to provide proper medical care for Tim. Phaneuf found that CHD was unable to document visits for Tim to a primary care physician or dentist for seven years. She also said there were no documented visits to a

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Mother pushes for medical training bill

COFAR is supporting proposed legislation that would help ensure that caretakers of persons with developmental disabilities are properly trained in using medical equipment.

The bill, S.73, was proposed by Maureen Shea whose developmentally disabled son, Tommy, died after a visit to a hospital. Tommy, who was 33, was subject to epileptic seizures while asleep. His bedroom in his staffed apartment was equipped with an audio and visual monitor that could alert the staff to make sure during a seizure that Tommy didn't roll over face-down — a position that can prevent breathing.

Tommy had just returned on June 7, 2017, from a two-week stay in a hospital to his apartment. The following day, he was found dead, face-down on his bed. The batteries in the monitor were later found to be dead.

S.73 specifies that when a disabled individual is discharged from a hospital to a residential group home, a licensed medical professional from the group home must review and acknowledge the full requirements of the hospital discharge plan with respect to life support equipment. The medical professional must then advise the group home staff about those requirements.

In June, the bill was reported out favorably by the Children, Families, and Persons with Disabilities Committee and was referred to the Committee on Health Care Financing. As of the end of December, the bill remained in that latter committee.

Provider funding hike did not help workers

The state auditor reported in May that a major boost in state funding in recent years resulted in surplus revenues for human services providers in Massachusetts, but that those additional revenues resulted only in minimal increases in wages for direct-care workers.

While surplus revenues were raised by almost 237% between Fiscal 2010 and 2017, the state auditor found, the average hourly rates paid direct-care workers increased by only 24% in total, to \$14.76.

DDS terminates provider contract

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cardiologist for six years despite Tim's having been born with a congenital heart defect.

In late December, Phaneuf said she was informed by DDS that the department had terminated CHD's contract to operate Tim's residence in East Longmeadow, and that he and the other residents would have to move to another home operated by a different provider in January. As of the end of December, DDS had not responded to a request by COFAR for comment on CHD's contract status.

In December, Phaneuf forwarded to COFAR a summary document from DDS concerning investigations of CHD by its licensure office and its financial investigation unit.

The investigations were undertaken in the wake of blog posts by COFAR in July and August and coverage of the case by *The Springfield Republican*. The DDS summary document appeared to debunk previous statements by CHD that the problems Phaneuf cited were largely the result of mismanagement by a single staff member — a former house manager of Tim's group home.

The summary of the review by the DDS Bureau of Program Integrity, which appeared to date from September, specifically stated that "while some of the issues (raised by Phaneuf) can be attributed to the former house manager, the lack of oversight and control procedures are indicators of potential systemic issues across CHD homes." In addition, the DDS document stated that while there was no direct evidence of fraud by CHD, the agency must provide complete restitution of the personal funds "for which they cannot provide validation of appropriate expenditure."

After COFAR first contacted CHD about the matter in July, James Goodwin, the provider's CEO and president acknowledged "failures to follow protocols," among other problems and said the organization was taking a range of corrective actions.

Goodwin issued a statement to COFAR in August listing a number of corrective actions that he said CHD has taken since January, including cataloging all medical visits in a database, requiring more rigorous supervision of program leaders, and developing a system to automatically inform family members and guardians of medical appointments and their outcomes.

Despite those corrective policies, Phaneuf said that in September, she noticed Tim had gained a considerable amount of weight in a short period. She said she met with Tim's primary care doctor on September 10th and learned only then that in late July, Tim had been found to have gained 20 pounds and that medical lab tests had been ordered. The lab tests showed Tim was prediabetic and had hypothyroidism, and that he needed to be placed on a low-carbohydrate diet with daily exercise immediately.

Phaneuf said CHD subsequently failed to provide her with a proposed food or exercise plan. And at Tim's Individual Support Plan (ISP) meeting in October, Phaneuf said she was informed that as of that date, no trainings had been scheduled for the staff regarding a low-carb diet or exercise plan for Tim. In a follow-up statement issued on January 3, Ben Craft, CHD vice president of community engagement, stated that the provider was "fully engaged in comprehensive changes in policy and operations to return and sustain the quality of our DDS services to the high standards that we have upheld across our organization for nearly fifty years."

Abuse, ongoing problem for providers

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The Wrentham Developmental Center had a rate of 0.0037 substantiated complaints per client, while the Hogan Regional Center had a rate of 0.0074 substantiated complaints per client.

COFAR has forwarded its findings to staff in several agencies with which COFAR met last year, including the offices of the state attorney general, inspector general, and the state auditor. COFAR also contacted the chairs of the Legislature's Children, Families, and Persons with Disabilities Committee regarding the findings.

COFAR survey of abuse data

COFAR examined data from DPPC concerning 79 residential providers, 75 for which DDS subsequently provided data on the number of clients served.

The data from both agencies show that the total network of state-operated group homes, with 1,118 clients, had more abuse allegations in total than other individual providers between Fiscal 2010 and 2019. But that would normally be expected given the state-operated network is nearly three times larger than the largest single corporate provider, Seven Hills, with 397 clients.

The DPPC data showed a total of 2,045 abuse complaints had been filed during the 10-year period involving the state-operated homes, which was nearly three times higher than for Vinfen, the individual provider with the next largest number of complaints — 758.

But when ranked by total number of substantiated abuse allegations *per client* after investigations either by DPPC or DDS, the state-operated group home network fell to 48th on the list. When ranked by the number of allegations per client referred to district attorneys for criminal investigation, the DDS state-operated group home system fell even further, to a ranking of 50 out of the 75 providers.

Also, the Wrentham and Hogan developmental centers were at or near the bottom of the list of total providers in every abuse measure. In Fiscal 2018, both developmental centers still had well above the average number of clients or residents, among all providers. Wrentham and Hogan are the state's only two remaining developmental centers that meet federal standards for Intermediate Care Facility (ICF) services.

COFAR maintains that this type of provider-based data should be made easily available and accessible online by DDS and DPPC. COFAR has continued to urge the Legislature's Children and Families Committee to approve a bill (H.93), which would require DDS to post online information about provider-based abuse data and performance (See story on Page 5). COFAR also maintains that this data underscores the need for state-run residential care for persons with intellectual and developmental disabilities.

Abuse allegation referral problem goes in circles

When it comes to investigating allegations of abuse of persons with developmental disabilities in Massachusetts, the process is frustratingly circular in a majority of the cases, COFAR has found.

Based on a review of responses last year from three state agencies to Public Records Law requests, COFAR found that in an apparent majority of the cases, the referral and investigation process starts and ends with the Department of Developmental Services (DDS).

DDS is required by state regulations to report all abuse allegations to the Disabled Persons Protection Commission (DPPC), the state's only independent agency for investigating abuse of disabled adults.

But DPPC lacks jurisdiction to investigate financial abuse and other cases that don't result in serious injury, according to the agency's assistant general counsel, so it refers those cases back to DDS to investigate. DPPC also lacks resources to investigate a majority of the cases for which it does have jurisdiction, and refers those cases back to DDS as well, COFAR found.

In addition, DPPC lacks jurisdiction to investigate abuse of the elderly, so it refers allegations of all types of abuse involving persons over the age of 59 to the Executive Office of Elder Affairs (EOEA). But EOEA then also refers those same allegations back to DDS to investigate if they involve persons living in DDS facilities, according to EOEA officials and to a 25-year-old memo received by COFAR from EOEA.

In the May 6, 1994 memo, then Secretary of Elder Affairs Franklin Olivierre said his agency and DPPC recognized "that this system is circuitous," but that attempts to change the process through legislation had not been successful in the previous two years.

A bill filed by DPPC at that time would have allowed the DPPC to investigate all reports of abuse of persons in DDS and Department of Mental Health facilities. That bill never passed, and the circuitous referral process continues to exist to this day.

No centralized record keeping or tracking

It was not easy to track the circularity of the abuse referral and investigation process because there appears to be no central record keeping or tracking system for abuse complaints and investigations, whether financial or other forms of abuse. COFAR found that among DDS, DPPC and EOEA, each agency keeps some of the records regarding the abuse investigation process, but no single agency appears to have them all.

COFAR urges work activities in day sites

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activities be provided in community-based day programs to all clients who want that choice.

In the November meeting with Cutler, COFAR members noted that there are some persons who do not have the capability to succeed in the mainstream workforce, and that there is a shortage of jobs in the workforce even for those who are capable of doing them.

In 2014, the administration of then Governor Deval Patrick began closing sheltered workshops for persons with developmental disabilities throughout the state. The workshops were settings in which DDS clients did small assembly jobs and other piecework activities provided by area businesses. The participants usually received a nominal wage.

Many family members and guardians strongly supported the workshops; but the Patrick and then Baker administrations held to an ideology that the workshops “segregated” the participants from non-disabled workers, and that the participants would all be better off in mainstream, “integrated” job settings. However, as of 2018, it was clear that the promise of the replacement of sheltered workshops in Massachusetts with mainstream integrated employment was not being realized. An unknown number of former sheltered workshop participants were being left without work of any kind in their DDS-funded day programs.

It was unclear whether Cutler’s subcommittee will ultimately support H. 88 and the continued payment of nominal or subminimum wages to DDS clients in order to enable them to get work opportunities either in mainstream or DDS settings.

Among the COFAR members who met with Cutler in November was Patty Garrity, whose brother Mark has largely been left without work opportunities since his sheltered workshop program was terminated. Garrity maintained that Mark and many of his peers are not minimum wage candidates. “There is still a huge void in Mark’s day and it is not going well,” Garrity wrote in an email to COFAR. “It’s going on four years now that I have been waiting for them to improve upon this and it is not happening. Mark is happy to be with his peers, but all he is doing is shredding paper and he is bored.”

COFAR urges Warren, Markey to oppose DIA

COFAR contacted the offices of U.S. Senator Elizabeth Warren and Ed Markey in May and June to urge them to reconsider their support for the federal Disability Integration Act of 2019 (HR.555 and S.117). The bill would threaten the Wrentham Developmental and Hogan Regional centers, the state’s only two remaining residential facilities that meet federal Intermediate Care Facility standards. The bill calls explicitly for the “transition of individuals with **all types of disabilities at all ages** out of institutions.” But the bill states that a facility is community-based only if it has four or fewer residents.

Ed Orzechowski receives Ricci honor

Ed Orzechowski, a former COFAR vice president, accepted the 2019 Dr. Benjamin Ricci Commemorative Award in March 2019, and called for the establishment of a “lasting memorial” at the former Belchertown State School.

The annual Ricci award celebration recognizes the accomplishments of individuals served by the Department of Developmental Services, and the dedication of caregivers and advocates.

Orzechowski authored “You’ll Like it Here,” a gripping book published in 2016 about the life of Donald Vitkus, a one-time resident of the former Belchertown State School.

Orzechowski’s book chronicled Vitkus’s childhood in the 1950s at Belchertown, which was then notorious for its inhumane and unsanitary conditions. The book also described Vitkus’s battle throughout the rest of his life to come to terms with his past at Belchertown.

Vitkus, who died in January 2018, received the Ricci award posthumously that year.

In calling for the establishment of a “lasting memorial” at the former state school, Orzechowski proposed the establishment of a museum on the grounds, and a memorial, a place for archives, and photos and exhibits.

In addition to serving for many years on COFAR’s Board, Orzechowski was president of the Advocacy Network, a former advocacy organization for the developmentally disabled in western Massachusetts. The Ricci award is named for Ben Ricci, the original plaintiff in the landmark federal class action lawsuit, Ricci v. Okin, which brought about upgrades in care at Belchertown and other Massachusetts facilities.

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

COFAR testifies on guardianship bills

COFAR members gave testimony before legislative committees on Beacon Hill in June and September on two bills that could significantly change the guardianship system in Massachusetts involving persons with developmental disabilities.

In one case, COFAR called for safeguards in a bill (H.172) that would potentially restrict guardianship by introducing Supported Decision Making (SDM). Under SDM, individual guardians are replaced by teams or “network supporters” who enter into written agreements with disabled individuals to help them make decisions about their care, finances, living arrangements and other areas.

In June, COFAR members testified before the Children, Families, and Persons with Disabilities Committee that SDM can hold promise for some high-functioning individuals, and that the organization would support its adoption with adequate safeguards, particularly safeguards against the potential marginalization of family members.

In particular, the bill, as currently written, skirts the question whether everyone is really capable of making their own decisions in those very important areas. COFAR also suggested the insertion of language in the bill that would exclude persons with intellectual disabilities from participating in SDM arrangements. COFAR contends that because intellectual disability involves “significantly sub-average intellectual functioning” and “significant limitations in adaptive functioning,” a person with such a disability has an inherent need for a guardian. COFAR also suggested language prohibiting employees of providers of services to individuals from participating in SDM arrangements involving those individuals.

Parental rights bill

In September, COFAR members testified in favor of H.1415, a bill that would require probate court judges to presume that parents of persons with developmental disabilities would be suitable guardians for them.

COFAR pushes for transparency in abuse investigations

COFAR has urged state lawmakers to enact legislation (H.93) that would increase transparency regarding abuse and performance records of providers to the Department of Developmental Services (DDS).

As part of a transparency effort, COFAR has pushed for the elimination of a provision in a separate piece of legislation in the current legislative session (H.117, Section 17) that would declare that investigative records of the Disabled Persons Protection Commission (DPPC) are not public records.

COFAR has continued to ask the state Legislature’s Children, Families, and Persons with Disabilities Committee to approve H.93, a bill that would require DDS to post easily understandable, comparative information on its website about abuse and neglect and provider performance. As of December, the committee had yet to act on the bill.

The DPPC bill, meanwhile, contains a provision that would draw an ever-tighter cloak of secrecy around investigative reports on abuse and neglect of persons with disabilities in Massachusetts. That bill, H.117, appears to have gone relatively unnoticed on Beacon Hill and by the media. Overall, H.117 proposes a number of seemingly innocuous changes to the DPPC’s enabling statute such as replacing the term “disabled person,” with “person with a disability.” That latter term avoids the stigma associated with describing an individual totally in terms of their disability.

However, Section 17 of the bill would effectively exempt all investigative reports and records of DPPC from public disclosure. The section would add language to the DPPC’s enabling statute stating that the agency’s records containing confidential or personal data “**shall not be public records.**” (our emphasis)

In April, COFAR members testified before the Children and Families Committee, noting that the proposed language in Section 17 is not needed to protect the personal privacy of victims of abuse and neglect or others involved in those investigations. The DPPC’s enabling statute currently states that the DPPC should disclose “as little personally identifiable information as possible.” That language gives the DPPC the discretion to protect the privacy of all parties involved.

The presumption of the state’s Public Records law is that all state governmental records are public documents unless they are explicitly exempted from disclosure by statute, or they fall under an exemption to the Public Records law itself.

Mainstream media does not respond to COFAR’s concerns

In March and April, COFAR contacted editors of mainstream media outlets throughout Massachusetts, including *The Boston Globe*, expressing concerns about Section 17 of the DPPC bill.

The New England First Amendment Coalition published COFAR’s email to mainstream media outlets on its blogsite on April 8 (see <http://nefac.org/mass-bill-filed-to-expand-secrecy-of-investigative-records-on-abuse-of-the-disabled/>). But there was little or no response from actual media outlets. *The Boston Globe* in the past has taken strong stances in favor of the public disclosure of state records. In 2015, the paper organized coordinated editorials among several media outlets criticizing the state’s Public Records supervisor for rulings allowing the withholding of records from public disclosure by state agencies.

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