



# The COFAR Voice

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

September 2018

Volume 18, No. 2

## State rules DPPC records can remain secret

A bid by COFAR to gain access to an investigative report and other records in the death of a client of the Department of Developmental Services last year has fallen short in the wake of separate rulings by the state's Public Records Supervisor.

The state Disabled Persons Protection Commission (DPPC) has repeatedly denied requests by COFAR for the records following the death last November of Karen McGowen. McGowen reportedly fell from a wheelchair lift while getting out of a van at her Pittsfield-based day program funded by the Department of Developmental Services.

A final decision in early August by Rebecca Murray, the Public Records supervisor, to deny the second of two appeals filed by COFAR for the records effectively means that the commission's investigations of allegations of abuse and neglect in the DDS system can be kept secret.

In July, the New England First Amendment Coalition [published a COFAR blog post](#) about the case. COFAR has

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STATEHOUSE MEETING — Barbara Govoni (right) poses with state Senator Joan Lovely on August 14 after a discussion about Govoni's legislative proposal for work opportunities for developmentally disabled persons, and other DDS issues. (See stories below.)

**COFAR sends written recommendations addressing DDS system to Children and Families Committee** (Story on Page 4).

## Work opportunities seen as lacking for DDS clients

State legislators and policy makers appear to be in agreement that many developmentally disabled persons in Massachusetts have been left without meaningful work opportunities since sheltered workshop programs were eliminated in the state in 2016. (See story on employment data on Page 2.)

But there is not only a lack of consensus over solutions to the problem, there appears to be confusion as well over the types of work programs that comply with current federal rules.

Possibly as a result of that confusion, the Legislature's Children, Families, and Persons with Disabilities Committee killed a bill in June that would have ensured work opportunities for

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## Committee inquiry on DDS slow and unclear

More than seven months after holding an informational hearing on abuse and neglect in the Department of Developmental Services system, a legislative committee had yet to schedule an opportunity as of late August for members of the public to testify before the panel on the issue.

The Children, Families, and Persons with Disabilities Committee was planning to hold the second of two informational hearings on DDS this fall, but no decision had yet been made as to whether the public could testify. The hearings are part of an ongoing review by the committee of the DDS system, but the full scope of that review has still not been made

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## ***Integrated employment hopes fizzling***

Although the Baker and previous Patrick administrations closed all sheltered workshop programs in the state with the intent of placing the participants in the mainstream workforce, that hope of mainstream work does not appear to have panned out.

Data provided to COFAR from the Department of Developmental Services in July show that the number of new DDS clients placed in so-called “integrated employment” settings declined each year between Fiscal Years 2016 and 2018. All sheltered workshops in the state were closed as of the fall of 2016.

During Fiscal 2016, a high of 509 clients in the DDS system newly began working in mainstream jobs. That number dropped to 127 clients entering integrated employment during Fiscal 2017, and to a net increase of only 98 clients during Fiscal 2018. The data appear to show that the administration has been unable to find jobs for people who want them.

Fiscal 2015 and 2016 were apparently the years in which most of the population of the sheltered workshops left those programs and in which most of the increases in integrated employment programs took place. Overall, the DDS day program population increased by 81% from Fiscal 2014 through 2018 while integrated job placements increased by only 19%.

As of Fiscal 2018, the total day program population in the DDS system had caught up with and even surpassed the total number of departmental clients in integrated employment, according to the DDS data.

## ***Family separation case remains unresolved***

More than 2 1/2 years after a developmentally disabled woman was placed in virtual isolation by DDS, her father and sister were still being denied any contact with her as of late August.

Ashley Barr, the sister of the woman, said a guardian employed by DDS was continuing to keep the woman’s location secret from her and her father, David. COFAR has urged DDS to allow visits.

## **Work scarce for DDS clients**

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clients in DDS-funded, community-based day programs. That bill had been proposed by Barbara Govoni, the mother of Danny Morin, a DDS client who formerly participated in a sheltered workshop in Agawam. After the workshop program was changed to a day program, Danny found himself with few work opportunities and was bored and frustrated.

Govoni’s bill, which was filed on her behalf by Rep. Brian Ashe of Longmeadow, would have required optional work activities in DDS-funded day programs for up to four hours a day.

The bill was referred to the Children and Families Committee, which effectively killed the measure in June by sending it to a study. In mid-August, Govoni and COFAR Voice editor David Kassel met with state Senator Joan Lovely, the committee’s Senate chair, to discuss the bill among other DDS issues. (See photo on Page 1.)

Lovely said Govoni’s bill had been filed late in the two-year legislative session, and that because there was little time to analyze the implications of the bill, the committee decided to send it to a study.

Lovely added, however, that the committee is concerned about the work opportunity issue, and that the panel had been in touch with DDS about it. One proposal being discussed was to hire an ombudsman in the Department who would help individuals and families locate existing day programs that offer work opportunities. Another proposal under consideration was to establish new work opportunities programs in existing day programs without making such work opportunities a legislative requirement of DDS.

### **Confusion over employment rules**

But a staff member for Ashe said she was told by DDS officials that the Department is essentially hamstrung by federal rules that prevent DDS day programs from offering any work activities because such activities can only be offered in “integrated” work settings.

Despite that claim that the federal government forbids work activities in day programs, COFAR is aware of some cases in which such arrangements have been made. It is also unclear whether federal rules strictly forbid work activities in day programs.

In an informational bulletin issued in 2011, the federal Centers for Medicare and Medicaid Services (CMS) stated that work activities referred to as “pre-vocational services” are allowed in “fixed-site facilities,” which would appear to include DDS day programs, although this was also not clear.

COFAR has reported that in March of 2017, the day program for Mark Garrity, another former sheltered workshop participant, found paper shredding work for him that DDS had determined was in compliance with federal rules.

DDS told Ashe’s aide that in order to allow Mark to do the paper shredding work under the new federal rules, the provider agency running his day program actually placed him on its staff and was paying him minimum wage. As a result, Mark was then considered to be working in an integrated setting. Ashe’s aide told COFAR that Mark’s work arrangement is considered a “unique circumstance.”

The confusion over the employment rules appears to be the result of a federal and state anti-congregate care ideology in recent years that led to the shutdown of the sheltered workshop programs. Written federal and state policies erroneously contend that all disabled persons are capable of mainstream employment.

## **Donald Vitkus laid to rest in burial plot of state school**

Beneath a ring of towering pine trees, Donald Vitkus, a survivor of the former Belchertown State School in the 1950s, was laid to rest in June in the institution's burial plot for its residents.

It was Vitkus's wish that he be buried alongside his fellow residents of the then notorious institution. He died in January at the age of 74.

Vitkus's childhood at Belchertown and his subsequent life story were chronicled in "You'll Like it Here," a book published in 2016 by Ed Orzechowski, a COFAR Board member and president of the former Advocacy Network, an affiliated organization. Throughout his adult life, Vitkus attempted to come to terms with his traumatic experience at the state institution. He was at Belchertown prior to the filing of a federal lawsuit in the 1970s that upgraded conditions in the system. In his later years, he earned an associate degree in human services and became a passionate advocate for the developmentally disabled.

In remarks at the June 23 memorial service for Vitkus at the Warner Pine Grove Memorial Cemetery, his grandson, William, said, "There is no more sacred spot for my grandfather to rest. We are powerless to consecrate this ground. The people laid to rest here have all consecrated it."

## **State: DPPC records are secret**

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inquired about possible legal assistance from the New England First Amendment Coalition in appealing the Public Supervisor's determination to state Superior Court.

Murray, who works within the office of Secretary of the Commonwealth Bill Galvin, did not give a reason in her August 1 ruling upholding the DPPC's denial other than to state that the commission had "met its burden of proof" for keeping the records secret.

After losing an initial appeal to Murray for the records in April, COFAR refiled the appeal in July, citing a decision by Superior Court Judge Douglas H. Wilkins in December 2017, which [upheld an appeal for separate records by The Boston Globe](#). The *Globe* has been seeking mug shots and incident reports of police and other public officials who have been arrested on various criminal charges. COFAR argued that the *Globe's* argument that the records it is seeking are public applies equally to the DPPC report and related records in the case of Karen McGowen.

In her April 20 determination in COFAR's case, Murray focused on the DPPC's regulations, which explicitly state that the commission's records are not public. However, in an argument based on the *Globe* case, COFAR pointed out that the DPPC's enabling statute implies that the DPPC's records are public, and that the statute is therefore inconsistent with the regulations.

## **FY '19 DDS budget goes according to script**

The Fiscal Year 2019 state budget, which was officially signed into law by Governor Baker on July 26, continues to boost funding for corporate, provider-run programs and to short-change state-run programs in the Department of Developmental Services system.

Since the previous fiscal year, total state funding for three key state-run DDS programs dropped by \$7 million when adjusted for inflation, whereas total funding for three corporate provider-run programs tracked by COFAR rose by \$6.4 million. COFAR analyzed state budget information available on the online Massachusetts Budget and Policy Center [Budget Browser](#) site.

That \$7 million reduction in funding for the state-run programs represents a larger proportional loss for those programs than would otherwise be the case because total funding for the three provider-run programs is nearly four times higher in the current fiscal year than funding for the state-run programs.

The state-run program line items tracked by COFAR include state-operated group homes, developmental centers, and the DDS administrative account, which funds service coordinators. The corporate provider-run line items include privatized group homes, day programs, and transportation services.

That difference in state funding for state and provider programs continues a long-term trend. Since Fiscal 2012, total annual funding for the state-run programs has dropped by \$38 million, while total funding for the provider-run programs has risen by \$432.3 million.

The largest dollar increase has gone to the provider-run group home line item, which received a \$783,500 increase over the previous fiscal year. While that represents less than a 1% increase in the provider residential account when adjusted for inflation, it nevertheless stands in sharp contrast to reductions in funding for state-operated group homes, developmental centers, and service coordinators.

Since the previous fiscal year, the state-operated group home account received a \$1.2 million cut in funding when adjusted for inflation. The developmental center line item received a \$3.5 million cut, while the administrative account received a \$2.3 million cut. "Unfortunately, this shows that the administration and Legislature are continuing to put a priority on privatized care at the expense of state-run programs," said COFAR Executive Director Colleen Lutkevich. "It continues the erosion of the choices and quality of care and services available to clients of the DDS system."

## DDS review unclear

INQUIRY continued from Page 1 clear.

In response to an email from COFAR on August 22 inquiring about the scope of the review and urging that the public be invited to testify at the second hearing, Representative Kay Khan, House chair of the committee, stated that the committee was “carefully reviewing your (COFAR’s) requests and concerns” and was continuing to plan for the hearing “with your points in mind.” Khan’s email response did not address the question about the scope of the committee’s review.

COFAR has long sought a legislative investigation of the DDS-funded group home system, which is subject to continuing reports of abuse and neglect and inadequate financial oversight.

In January, the Children and Families Committee held an initial informational hearing on DDS, but the committee invited only DDS Commissioner Jane Ryder and Nancy Alterio, executive director of the Disabled Persons Protection Commission, to testify publicly. Members of the public, who attended the hearing, were allowed only to submit written testimony on problems they have encountered with the system.

A legislative aide to Khan said in late August that the committee planned to hold the second hearing in the fall and that the hearing would specifically concern sexual abuse in the system.

In its August 22 email to the committee, COFAR urged the panel to expand the scope of the hearing itself to include all types of abuse and neglect in the DDS system as well as care and conditions in general.

## COFAR provides committee with recommendations on DDS

COFAR has sent the co-chairs of the Legislature’s Children, Families, and Persons with Disabilities Committee a set of written recommendations for addressing serious problems with care and conditions in the Department of Developmental Services system.

In an August 22 email sent to Senator Joan Lovely and Representative Kay Khan, the Senate and House chairs of the committee respectively, COFAR urged the committee to consider the recommendations as part of its ongoing review of the DDS system.

The recommendations address problems that include inadequate oversight of DDS-funded group homes operated by corporate providers, a pattern of retaliation by DDS against family members who raise concerns about conditions in group homes, and a lack of adequate resources for the agency investigating abuse and neglect in the system. The recommendations include the following:

- ◆ Increased funding for state-operated programs.
- ◆ Increased resources for the Disabled Persons Protection Commission, and investment of the agency with sole authority to investigate abuse and neglect.
- ◆ Increased financial oversight of the corporate provider system and the DDS and probate guardianship systems.
- ◆ Establishment of a registry disclosing the names of individuals who have had serious abuse or neglect charges substantiated against them. Also, establishment of a registry of DDS provider agencies with more than a threshold number of employees who have had serious abuse or neglect charges substantiated against them.
- ◆ Passage of legislation requiring probate court judges to presume that family members are suitable guardians of persons with intellectual and developmental disabilities.
- ◆ The provision of free legal assistance to family members and guardians who been barred from contact with their loved ones in the DDS system or who have otherwise faced retaliation from the agency or from providers.
- ◆ The provision of free legal assistance to family members whose guardianships are challenged by DDS.
- ◆ Passage of legislation requiring that meaningful work activities be provided to DDS clients in community-based day programs.
- ◆ Improvements in the inspection and licensing process of corporate-operated group homes.
- ◆ A policy statement by DDS recognizing individuals and their families and guardians as the “primary decision makers” regarding services and supports those individuals receive.

## ***Please Contribute!***

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.

Thank You!

## Direct-care workers win fights for equity

Two recent cases in Massachusetts appear to demonstrate the difficulty direct care workers in the Department of Developmental Services system face in getting adequate wages and working conditions.

But in both cases, the workers won at last partial victories with help from SEIU Local 509, a union representing human service workers in both DDS state-run and provider run facilities.

After a battle with management over the right to organize, the workers at Triangle, Inc., a Malden-based DDS provider, [voted overwhelmingly](#) in mid-August to join the SEIU local.

Earlier this year, the National Labor Relations Board had [filed a complaint](#) against Triangle over allegations that the provider had harassed and fired some of its workers for trying to organize the union vote.

Triangle management ultimately agreed to a settlement of the NLRB case under which a union vote was scheduled and the fired workers were either reinstated or provided with financial compensation.

In July, workers at CLASS, Inc., a second DDS-funded day program provider based in Lawrence, [reached a settlement](#) with management to raise the workers' wages by 60 cents an hour. The CLASS, Inc. workers had engaged in [a five-day strike at the facility](#) in July for a living wage. The workers were getting paid about \$13 an hour and wanted a \$1 increase. The company was initially offering an increase of only 40 cents.

Robert Harris, the president of CLASS was paid \$187,500 in Fiscal 2017, according to the state's online Uniform Financial Reports database. The agency CFO received \$132,900 that year.

Coleman Nee, the CEO of Triangle, Inc. received \$223,270 in Fiscal 2017, according to the UFR database. The CFO received \$182,151.

In June, Governor Charlie Baker signed a bill into law that would establish a \$15 an hour living wage as of 2023.

## COFAR questions Supported Decision Making claims in webinar

COFAR is questioning a growing movement among disability advocates and attorneys to reduce or even eliminate guardianships of persons with developmental disabilities.

The movement, which is being promoted in Massachusetts and other states, calls for replacement of guardians with more informal "Supported Decision Making" (SDM) teams.

In an August 22 webinar, in which COFAR participated, advocates discussed three instances in which they helped bring about the termination of guardianships of individuals. It wasn't clear whether the guardianships were replaced in each case by SDM arrangements. The webcast was sponsored by the [National Center on Law & Elder Rights](#).

Webinar participants were allowed to pose written questions only, during the event. COFAR submitted a comment and a question, but COFAR's question was not among those that received an answer from the webinar panel.

COFAR noted in its comment that SDM could marginalize family members who often make the best guardians for persons with developmental disabilities. COFAR also noted that developmental disability-related and elderly guardianship issues are different from each other, and that severe and profound developmental disabilities present different issues than moderate disabilities. Yet, it did not appear that the webinar panel was taking those differences into consideration.

COFAR's question was whether any protections exist under SDM to ensure that a family member is not "outvoted" on an SDM team by providers, clinicians or others who may not have the same degree of interest in the wellbeing of the disabled individual.

## Abuse registry bill left in limbo

Proposed legislation to establish a registry of caregivers in the Department of Developmental Services system who have been found to have abused DDS clients was left in limbo as formal legislative business ended on July 31 in the state Legislature.

S. 2606, known as "Nicky's Law," would ban caregivers from employment in the DDS system if they have been found by the Disabled Persons Protection Commission or DDS to have committed acts of abuse or neglect. The bill was passed unanimously by the Senate in mid-July, but was then sent to the House Ways and Means Committee, which did not act on it as of July 31.

COFAR has voiced support for the legislation as a first step in reducing levels of abuse and neglect in the DDS system and particularly in provider-run group homes. COFAR has also called for a legislative investigation of abuse, neglect, financial mismanagement, and other problems in the privatized DDS system. (See story on Page 1.)

COFAR has urged legislators to forge a comprehensive solution to the problem of abuse and neglect of developmentally disabled persons. Other needed measures include increased financial oversight of corporate DDS providers and legislation requiring family members to be presumed by probate court judges to be suitable guardians. (See COFAR recommendations on Page 4.)

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