



The COFAR Voice

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DDS lifts restrictions on visits as COVID rates drop

With COVID-19 infection rates continuing to drop in the Department of Developmental Services (DDS) system, the Department has finally lifted family visitation restrictions in group homes.

DDS Commissioner Jane Ryder stated in a message on the Department's website on June 14 that DDS had "asked our residential settings to return to their pre-pandemic visitation policies and practices."

Exceptions listed to the new policy included homes in which one or more residents tested positive for COVID.

In late May, COFAR had emailed Ryder and Health and Human Services Secretary Marylou Sudders expressing concern that DDS and its residential providers were imposing strict and sometimes arbitrary restrictions on visitation even in cases in which both the family members and the residents had been vaccinated. Neither Sudders nor Ryder responded to the email.

The decision to lift visitation restrictions came as COVID testing data [published online](#), on June 15, showed that

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RETIREMENT — Colleen M. Lutkevich (right), who served as COFAR's volunteer executive director for more than 20 years, officially retired in June from the organization. She is pictured here with her sister, Jean Sullivan, who has been a resident of the Wrentham Developmental Center since 1959. Story on Page 3.

DDS data show drop in integrated employment

The total number of individuals with developmental disabilities working in "integrated employment" settings in Massachusetts dropped after October 2019, according to DDS data published in April.

The April "Progress Report" from DDS for Fiscal Year 2021 revealed a drop in "group and individual supported employment" between October 2019 and March of this year.

The DDS data raise further questions about the state's claims in closing all sheltered workshops as of 2016 that DDS clients would find better and more fulfilling work opportunities in the mainstream workforce.

According to the 2021 Progress Report,

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Stan McDonald and Fred Doherty, long-time COFAR advocates, are dead (Page 4)

Legislature upholds cuts for state-run group homes, ICFs

COFAR advocated this past spring for maintaining funding for a number of DDS programs targeted by Governor Baker for cuts in the upcoming Fiscal Year 2022 state budget.

Legislative leaders, however, largely approved Baker's funding cuts to state-operated group homes, developmental centers, and DDS day programs.

At COFAR's request, amendments were filed during the state Senate's budget debate in late May to add \$898,632 to the governor's budget request for state-operated group homes.

COFAR also requested adding \$2,142,591 back to the line item for developmental centers, also known as Intermediate

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DDS lifts visitation restrictions

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positive cases had reached new lows in the DDS system. For the first time since COVID testing data has been kept, there were zero positive cases among residents in provider-run DDS group homes, and less than 5 residents testing positive in state-run group homes.

It remains to be seen whether the lower positive rates as of June 15 will continue. The answer to that question will apparently not be known publicly until July 13, when the next results will be published.

It is still unclear how many staff in provider-run group homes in the DDS system are continuing to test positive for COVID. That information has never been included in the DDS facilities reports. The latest report as of June 15 showed less than 5 COVID-positive staff in the state-operated group homes, and zero positive staff and zero positive residents in the Wrentham and Hogan developmental centers.

Staff vaccination rates still unclear

COVID vaccination rates among staff and residents in the DDS system are also not published online. Based on information provided by the Executive Office of Health and Human Services (EOHHS) in response to Public Records Requests from COFAR, we last reported that as of April 9, less than 50% of staff in state-operated group homes were fully vaccinated. In provider-run group homes, only 51% of staff were fully vaccinated as of April 12.

Seventy-five percent and 90% of residents in provider-run and state-run group homes respectively had been vaccinated as of April 12. In response to a renewed Public Records request, which we filed on June 28, EOHHS stated that it had stopped tracking vaccinations of staff and residents as of April 23, and therefore had no further information on those vaccination rates.

Administration won't comment on vaccinations or test results

Since February, Baker administration officials have repeatedly declined requests from COFAR for comment on vaccinations in the DDS system. In February, we emailed both Sudders and Ryder, asking for comment on whether the vaccines were responsible for the declining numbers of infected persons in the system even at that early period in the vaccination effort. Neither Sudders nor Ryder ever responded. In addition to the lack of up-to-date vaccination data, both EOHHS and DDS said they did not have any records on numbers of staff or residents refusing vaccinations.

Top administration officials disagreed over mandatory testing of DDS staff for COVID

Top administrators in the Baker administration appeared to strongly disagree in the summer of 2020 over whether to require testing of staff for COVID-19 in group homes and other residential facilities for persons with developmental disabilities, according to emails provided to COFAR under a state Public Records Law request.

The emails, provided in February by the Department of Public Health (DPH), appeared to imply that as late as last July 2020, Health and Human Services Secretary Marylou Sudders strongly opposed mandatory testing of staff in residential facilities in the DDS system. At the same time, the emails indicated that then DPH Commissioner Monica Bharel and members of her office supported mandatory testing. Bharel left the job on June 18 of this year.

By mid-August 2020, EOHHS finally issued a directive requiring testing of staff throughout the human services system. However, this was some five months after the pandemic had become a full-blown crisis in the state. The apparent opposition by Sudders could help explain the lengthy delay in implementing the mandatory testing of residential staff in the system.

Stimulus funds sought for ICFs

COFAR joined with the AFSCME state employee union in June in seeking to ensure that at least some funding under President Biden's \$2 billion jobs and infrastructure plan will go toward Intermediate Care Facilities (ICFs) for persons with developmental disabilities.

As part of his plan, Biden has proposed a \$400 billion expansion of home and community-based services (HCBS) for people with disabilities and the elderly. But none of that funding is specified for state-run ICFs, which provide critical care for residents with some of the most severe and profound intellectual disabilities.

The two remaining state-run ICFs in Massachusetts are the Wrentham Developmental Center and the Hogan Regional Center in Danvers.

In a joint letter sent in June to Massachusetts Senator Elizabeth Warren, Thomas J. Frain, COFAR Board president, and AFSCME Council 93 Executive Director Mark Bernard stated that steering increased funding only toward community care would create a strong incentive for Massachusetts to close the Wrentham and Hogan facilities.

In addition to stripping the DDS system of a badly-needed component of the continuum of care for the developmentally disabled, the closure of the ICFs would jeopardize the jobs of approximately 1,400 union workers represented by AFSCME alone.

The joint letter noted that choice in care is only meaningful if individuals are given access to the services that they need and prefer. But DDS does not routinely inform either individuals or their families who are waiting for residential placements even of the existence of either ICFs or state-operated group homes. The only "choices" offered are corporate provider-run group homes.

Colleen Lutkevich retires from COFAR

Colleen M. Lutkevich, COFAR's longtime volunteer executive director, officially retired from the organization in June after having served in that role for more than two decades. She had been associated with COFAR for some 35 years. (See photo on Page 1.)

"I feel good about this decision (to retire) and I know that no one is irreplaceable!" Lutkevich wrote in a message to the COFAR Board on June 2. "I remain willing to offer help and advice as needed and I wish all of you the very best in continuing your work with COFAR." She is continuing to serve as president of the Wrentham Family Association, an affiliated organization to COFAR.

Lutkevich's announcement was met with well-wishes and accolades from the Board and from commenters on a post on COFAR's blogsite about her decision. "You will be missed greatly indeed," wrote Lynn Royal, a COFAR member whose son, like Lutkevich's sister, Jean, is a resident at the Wrentham Developmental Center. "Your open heart and soul speak volumes about you and your parents and the many families who have been crucial to continuing COFAR for so many years."

"How do you thank someone that had given so selflessly to so many? There are no words that can express the gratitude for all you have achieved," wrote COFAR member Marion Julian.

When Lutkevich was 25 years old and pregnant with her first child in 1985, she first went to work part-time as a secretary for COFAR, which had only been established a couple of years earlier. She was following in the footsteps of her father, John Sullivan, and her mother, Gladys, in advocating for better care for Colleen's sister Jean, who has been a Wrentham Center resident since 1959. John Sullivan, who was one of the founders of COFAR, was among the plaintiffs in Ricci v. Okin, the landmark federal lawsuit in the 1970s that led to major upgrades in care in the state facilities. John died in 2017 and Gladys died in 2016.

Lutkevich said her father, in particular, served as an inspiration to her in her advocacy. "My dad worked and fought his whole life to make the system work for the least fortunate among us," she said. "His advice was always, 'never be afraid.'" In 1983, Sullivan and other pro-facility plaintiffs in the Ricci case formed COFAR. But the organization began experiencing financial problems and was unable to pay Lutkevich's nominal secretarial salary of about \$7,500 a year. She continued to work without pay in the same position until 1995.

Although Lutkevich ostensibly quit COFAR in 1995, she came back to fill the then vacant executive director position in 1998. Once again, she accepted the position without pay, and continued to work as a volunteer executive director ever since. She recalled that among the highlights of her work for COFAR were successful advocacy drives to prevent involuntary placements of persons with intellectual disabilities in mental health facilities and nursing homes in the late 1980s and early 1990s. In the past 10 to 15 years, Lutkevich said, she found that COFAR's relationship with DDS and successive administrations changed. That change, from a relatively cooperative relationship to a more adversarial one, came as those administrations began closing the Fernald Center and other Intermediate Care Facilities. But through it all, it was clear her personal desire to help families remained unchanged.

Cuts in funding upheld for state-run group homes, ICFs, and day programs

BUDGET CUTS continued from Page 1

Care Facilities for persons with intellectual and developmental disabilities (ICFs). Baker's budget proposal would cut the ICF line item by that amount when adjusted for inflation.

In addition, COFAR proposed adding \$13,693,964 back to the Community-Based Day and Work (CBDW) line item to prevent a cut in that line item after adjusting for inflation. The amounts sought by COFAR in restored funding for each of the line items were based on numbers obtained from the Massachusetts Budget and Policy Center's Budget Browser, an online database of state budget information.

While Senate leaders did not accept COFAR's proposed amendments, COFAR was able for the first time to get Senate sponsors for the measures. The amendments to restore funding to the state-operated group homes and ICFs were sponsored by Senator Nick Collins of Boston, while the amendment to restore funding to the day programs was sponsored by Senator Joan Lovely of Beverly.

DDS said the proposed cuts in CBDW funding were related to reduced attendance in day programs during the height of the COVID pandemic in Fiscal Year 2020 and the first half of 2021. The administration shut the day programs down due to safety concerns in March 2020 and reopened them in July of that year. Data provided by DDS show that as of November of 2020, 36% of day program participants were no longer participating on site even though the programs had been reopened by then. Instead, those clients were attending remotely via online platforms such as Zoom.

COFAR has been contacted by a number of families concerned about the impact on their loved ones of the lack of on-site day program activities. The line item cut threatens to further curtail day program activities to transition clients to integrated employment. (See story on employment on Page 1.)

Employment dropped after 2019

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total integrated employment of DDS clients in Massachusetts reached a peak of 7,180 in October 2019, and then declined to 7,090 as of October 2020. As of March of this year, only 6 additional clients had been placed in integrated employment from October 2020, five months previously.

The new DDS Progress Report largely blamed the integrated employment slowdown on the COVID pandemic, even though numbers provided in March to COFAR by DDS indicated that the slowdown began before the pandemic began.

Based on the earlier figures provided by DDS, COFAR calculated that the number of clients in integrated employment actually dropped by 53% between October 2019 and February of 2020, which was prior to the start of the pandemic.

Despite those problems in finding employment for disabled persons, Governor Baker and the Legislature proposed cuts in the Fiscal 2022 state budget for DDS day programs. The day programs are tasked, in part, with helping transition clients to integrated employment. (See story on budget cuts on Page 1.)

The DDS 2021 Progress Report also showed that the number of clients being placed in day programs after the closure of the state's remaining sheltered workshops outpaced the number entering integrated employment.

While the numbers of clients placed in integrated employment rose by 20% from June 2015 to October 2019, the number of clients in DDS day programs increased by 43% over that same period—a percentage more than twice as high—and those numbers continued to increase through March of this year. The 2021 Progress Report acknowledged the state has experienced “difficulty obtaining job opportunities for individuals with significant disabilities,,,”

Fred Doherty, longtime COFAR advocate, dies

Fred Doherty who, along with his wife Joan, was one of COFAR's original Board members, died May 26 at the age of 84.

The Dohertys' son Timmie was a Fernald Center resident for many years. Before COFAR was founded, Fred and Joan were active in advocating for the residents at Fernald. When they joined COFAR, their Fernald advocacy continued, but that advocacy also expanded statewide.

Fred Doherty was described in May by then COFAR Executive Director Colleen Lutkevich as “loyal, reliable, kind, and with a positive attitude and a great heart.” Even though Timmie died in 1998, Fred and Joan participated in efforts that began in 2003 to save the Fernald Center from closure. During one volunteer lobbying event at the State House in April 2003, Fred explained to *The COFAR Voice* why he and Joan were still involved. “We're (now) here for the other kids,” he said.

Stan McDonald, rights advocate, dies

Stanley McDonald, who fought a battle for decades for guardianship of his developmentally disabled son Andy, died on May 6. He was 85.

In addition to seeking the guardianship, McDonald waged a long-term battle for a bill in the state Legislature that would require that probate court judges consider parents as suitable guardians of persons with intellectual and developmental disabilities. COFAR is continuing to advocate for passage of the legislation, now H.1733. COFAR frequently reported on efforts by McDonald and his wife, Ellen, to overturn a lifetime ban imposed in 2006 by a probate court judge on visits by Andy to his hometown in Sherborn. Andy, 53, is intellectually disabled and has lived since 1993 in a group home.

Berkshire-based DDS provider hit by state audit

Personal use by executives of corporate credit cards and frequent flyer airline miles were among the findings in a report by the Massachusetts State Auditor on the Berkshire County Arc.

The report, which was released in May, was among the latest in a series of such reports by outgoing Massachusetts State Auditor Suzanne Bump of corporate DDS providers. Some other examples include audits of Brockton Area Multi Services, released in early June; Human Service Options and Nonotuck Resource Associates, in 2016; the May Institute, in 2013; Crystal Springs, in 2012; and Toward Independent Living and Learning, in 2002. Among other problems cited by the audit, Berkshire Arc executives allegedly used Arc credit cards to pay \$124,247 in expenses that were non-reimbursable under the Arc's state contracts.

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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.

Mother fights battle for adequate care for son

COFAR is advocating on behalf of Valerie Loveland, the mother of an intellectually disabled man. Loveland has fought a years-long battle to ensure adequate care for him in the DDS system.

Loveland's son, who is 23, has an intellectual disability, is non-verbal, and needs 24-hour care. He has now been a resident for the past five years in three separate group homes on Cape Cod run by the May Institute.

[A June 29 post](#) on the COFAR Blogsite reported that Loveland found that her decisions regarding her son's care were questioned, not only by the staff in her son's previous group home in Cotuit, but by DDS officials and even the DDS-paid co-guardian for him.

At times she said she feared that her own co-guardianship of her son might be taken away. (Although she wanted her son's story told in the post, she requested that his name not be used.)

In addition to other issues she had to deal with, she said the state's response to alleged sexual abuse of her son in March of this year in the group home has been shrouded in secrecy. Even as co-guardian, Loveland has not been allowed to view the complaint filed in the matter. She has been told only that her son was allegedly sexually abused by a group home staff member, but not what happened.

The good news is that although Loveland was not able to get her son into a state-operated group home, as she had hoped, the May Institute did place him in June in a new residence, also in Cotuit. And she said the new group home staff was making an effort to follow her requests to improve her son's diet, which she said is linked both to his health and his behavior.

COFAR reported in the post that a dozen May Institute executives received more than \$100,000 each in total compensation in 2019. The president and CEO, Lauren Solotar, received almost \$477,000.

COFAR seeks seats on commission on state facilities

COFAR is seeking to ensure that families of current residents of the Wrentham and Hogan developmental centers have seats on a proposed commission on the history of institutions in Massachusetts for persons with developmental disabilities.

In testimony submitted in June to the Legislature's Mental Health, Substance Use, and Recovery Committee, COFAR expressed support in concept for legislation (S.1257 and H. 2090) to establish a commission to study the controversial and often dark history of the state schools.

At the same time, COFAR's testimony stated that we are pushing for changes in that legislation to ensure that the commission recognizes the significant upgrades in care and services that occurred in those facilities in the 1980s. Those changes were primarily due to Ricci v. Okin, a landmark federal consent decree case overseen by the late U.S. District Court Judge Joseph L. Tauro.

The testimony stated that the proposed commission needs to recognize that the Wrentham and Hogan Centers — the state's two remaining developmental centers or Intermediate Care Facilities (ICFs) — provide state-of-the-art care and services today.

Nevertheless, ICFs have remained political lightning rods for advocates of deinstitutionalization and privatization of remaining care and services for the developmentally disabled. For that reason, COFAR's testimony asked that the proposed membership of the commission and its written charge be changed to ensure a balanced review by the commission. COFAR is seeking additional seats on the panel for family members and guardians of current residents of Wrentham and Hogan.

It appears that the makeup of the commission, as currently described in the legislation, would primarily consist of opponents of ICFs, and of supporters of further privatization of DDS services. COFAR also previously contacted Senator Michael Barrett and Representative Sean Garballey, the principal sponsors of the legislation, to express those concerns.

In March, COFAR also raised concerns about a scheduled Zoom panel discussion being sponsored by the Harvard Law School, which appeared to be intended to portray the former Fernald Developmental Center in a negative light. Alex Green, a key participant on that panel, is a proponent of the commission bill.

Green later told Colleen M. Lutkevich, COFAR's then executive director, that he was sympathetic to COFAR's concerns, and would seek to amend the legislation to add two seats for "facility families—whose experiences deserve representation."

COFAR maintained in the testimony that in addition to specifying that there would be current facility family members on the commission, the language in the legislation should be changed to specify that the commission would assess the quality of life of *current* residents of the Wrentham and Hogan Centers. The legislation, as currently worded, only refers to assessing the quality of life of "former residents (of state institutions) now living in the community."

The quality of life of both current and former facility residents needs to be assessed in order to present a balanced view of Wrentham and Hogan today, COFAR's testimony stated.

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