The COFAR Voice

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Nicholas Alemesis and his mother, Cindy, are among the DDS families dealing with separation requirements during the COVID crisis. Cindy is also fighting to keep her guardianship. Story on Page 3.

The Year of COVID in the DDS system

Special Newsletter Issue

We look back in this issue of *The COFAR Voice* on the impact of the coronavirus on the DDS system, and how the Baker administration has responded. We also look ahead to the end of the pandemic and its potentially lasting impacts.

COVID-19 vaccine coming, but timing questions remain

Residents of Department of Developmental Services facilities are reportedly expected to get vaccinated by the end of January of 2021, but DDS has not put out any official information on the matter.

In late December, COFAR received apparently erroneous unofficial reports that residents of the Hogan Regional Center had been vaccinated. There were later unofficial reports that some staff at the Wrentham Developmental Center had gotten the vaccine.

It remains unclear, however, exactly when in January DDS group home residents will get the vaccine, and where those residents fall within Phase 1 of the state's COVID-19 Vaccine distribution plan.

It appears all residents of DDS group homes and developmental centers are included in Phase 1 of the plan, which stretches from December through February. But DDS has not said whether group home clients are closer to the top or the bottom of the Phase 1 priority order.

The state's COVID-19 Vaccine Plan Phase 1 order is:

1. Clinical and non-clinical healthcare workers doing "direct

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Questions linger over DDS response to crisis

The COVID-19 pandemic may forever change they way services are delivered in the DDS system, and it remains to be seen whether DDS is prepared for that future.

Up to now, the Baker administration has reacted slowly and after the fact to the pandemic's impact on DDS clients.

As we note in this special issue of *The COFAR Voice,* the administration didn't appear to have an overall plan for testing, isolating, and otherwise protecting residents and staff in its system.

In early April, news organizations began reporting on what appeared to be a rapidly increasing rate of viral infection in DDS group

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An account of our battles with the administration for records on the crisis. Page 5

DDS reluctant to give providers guidance on visitation

With family members enduring months of separation from their loved ones in DDS facilities due to the COVID-19 crisis, visitation has become a key source of anxiety and confusion for many of those families.

A primary cause of the problem appears to have been that the Department has declined to update its written guidance to providers on when and how to allow visits. This has resulted in inconsistencies and contradictions among visitation policies among different providers, and potentially overly restrictive policies on testing and quarantines in some cases.

DDS, however, has defended the discretion it gives to providers to restrict visits by families to residents in the system,

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Timing unclear on vaccines

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COVID-facing care."

2. Long-term care facilities, rest homes, and assisted living facilities
3. Police, fire, and emergency medical services
4. **Congregate care settings** (including corrections and shelters)
5. Home-based healthcare workers
6. Healthcare workers "doing non-COVID-facing care."

It appears the primary thrust of the federal CDC is to ensure the early vaccination of residents and staff of nursing homes and other long-term care facilities for the elderly. Frontline essential workers such as police, firefighters and teachers are also high on the CDC priority list.

Protecting residents of nursing homes from COVID-19 has been a priority of the Baker administration as well, given the large number of those residents who have died from the virus. COFAR has sought to make sure the DDS system is included in those distribution plans, and that it is clear that both group homes and developmental centers in the DDS system fall into the category of either long-term or congregate care facilities.

As of December 18, vaccines began arriving in Massachusetts, according to the administration. The first vaccine recipients - hospital health care workers - began to receive COVID-19 vaccinations as of that date.

DDS mobile testing program never hit stride

In early April, DDS announced it had hired Fallon Ambulance Service to provide mobile COVID testing services to residents and staff in all group homes and two developmental centers.

The program made only limited progress and was ultimately discontinued in August when the administration required all providers to arrange for their own testing.

While Fallon was reported to be able to do 1,000 tests a day, the company's testing rate by early May was only about half that. By June, Fallon's testing rate had declined almost to a standstill. Officials declined comment on why the company was selected, and did not comply with our request for records on payments to the company.

Confusion persists over DDS visitation policies

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and has declined to update its September 23 visitation guidance in order to provide standards for visitation restrictions.

In late November, we raised a concern with DDS Commissioner Jane Ryder that the Department was giving too much discretion to the providers, resulting in some cases in contradictory and overly restrictive visitation policies.

The September 23 DDS guidance, for instance, permits in-house visits by family members. But an undetermined number of providers issued bans in late November on in-house visits in light of rising COVID rates in the DDS system.

Also, different providers have adopted widely varying and sometimes onerous policies on testing and quarantining residents after the residents have left group homes even for short visits to their family homes.

In our email to Ryder, we stated that the biggest COVID risk to residents in the DDS system does not appear to come from family members who visit under controlled conditions, but from staff who face few restrictions in going in and out of group homes.

One provider had not allowed any indoor visits by families since March, according to a family member. The provider had also sharply limited outdoor visits by families, and banned visits by residents out of the group home to their families as of December 1. Another provider allowed off-site visits, but required that residents taken off site receive a negative COVID test less than 48 hours before returning to a group home or other DDS-funded setting.

Yet another provider required a resident taken for an off-site visit to remain at the family home for 14 days before even getting tested. Even if the test was negative, the provider's directive stated that the resident must remain in isolation in the group home for an additional 72 hours and then needed a second COVID test.

Christopher Klaskin, a DDS spokesman, stated in a December 2 email to COFAR that the September 23 guidance "permits flexibility for providers to address COVID-related health and safety concerns specific to their residential sites."

In a response to Klaskin, we noted that while we understand the need for flexibility and some discretion on the part of the providers in these situations, the problem is that there is no overriding guidance as to when and under what circumstances that flexibility should be exercised.

At what point does in-home visitation become unsafe, for instance? Each provider is left to make their own assessment of that threshold.

Excessive discretion on visits was a similar problem last spring

As we reported last spring, DDS first partially lifted its then almost-complete COVID lockdown in group homes in early June by permitting limited outdoor visits. No in-house visits were yet allowed.

Under those then new visitation rules in June, providers were given discretion to set the terms for the visits and to ban families for perceived violations. We soon began getting reports that some of the restrictions placed on those visits by certain providers were onerous and others inconsistently applied.

Mother who saved son's life fights to retain her co-guardianship

Cindy Alemesis saved the life of her son, Nicholas, in December 2018, after staff in his group home in Dracut failed to take him for a scheduled morning ultrasound appointment. An ultrasound would have shown that his brain shunt was leaking spinal fluid.

Yet, since that time, Cindy has been sharply restricted by the group home provider in her contact with Nick, and DDS petitioned the probate court in the fall of 2020 to remove her as his co-guardian. DDS has given no specific reasons for its move other than a statement that she has made decisions that were not in Nick's best interest. Cindy has been critical of the group home for continuing to miss doctor's appointments for Nick, and had moved to remove DDS's paid co-guardian for failing to participate actively in his care.

The group home, run by Incompass, a DDS provider, initially posed restrictions on Cindy's contact with Nick due to the COVID crisis. But Cindy said those restrictions continued after DDS began to allow in-house visitation as of October.

Mother urged hospital care for son

Just hours after the scheduled time for the ultrasound appointment on December 19, 2018, Cindy first noticed how ill Nick appeared. Cindy was with Nick following an evening church service, and made sure he was taken to a hospital. There, doctors found that the shunt was leaking spinal fluid into his body, and that the fluid had begun to build up in his stomach. Cindy didn't know at the time that the ultrasound appointment had been missed.

Nick got sepsis from the leaked fluid, and was in Mass. General Hospital for eight months, during which he underwent multiple brain operations and other procedures. Cindy was at his bedside for much of that time.

Nick, who is 28, has a mild intellectual disability, and was born with hydrocephalus, a condition in which there is excess spinal fluid in his brain. He has a shunt in his brain that drains the fluid.

Since Nick's recovery and release from the hospital in July 2019, Cindy has regularly complained that staff in the group home have continued to miss medical and dental appointments for him. Cindy said DDS has done little or nothing to address the concerns she has raised about Nick's care.

Cindy said the other co-guardian for Nick, who is paid by DDS, appears to live in Florida, and has been uninvolved in Nick's care. Cindy sought unsuccessfully to remove that co-guardian last year in probate court.

Records provided by DDS under a Public Records Law request, show that other co-guardian has been paid over $36,000 by DDS since Fiscal Year 2016. The records don't indicate whether Nick has been that co-guardian's only ward, or whether the payments were for services to other wards as well.

It isn't clear whether the current move by DDS to remove Cindy as co-guardian is in retaliation for her attempt to remove the other co-guardian. It is also unclear whether DDS wants to make that other individual Nick's sole guardian.

COFAR emailed a request for comment on this matter on November 10 to DDS Commissioner Jane Ryder and to Barbara Green Whitbeck, DDS assistant general counsel. Whitbeck signed the Department's petition to the probate court to remove Cindy as co-guardian. Neither Ryder nor Whitbeck has responded to the request for comment.

DDS does not appear to have internal written criteria on evaluating or removing guardians

In November, COFAR filed a Public Records Law request, asking DDS for all of its written policies for evaluating and removing guardians. We wanted to know whether there are criteria that a guardian should meet in order to be considered to be doing an acceptable job.

In response, DDS provided an RFP it issues for professional guardianship services and a list of sections from the Uniform Probate Code and DDS's own enabling statute. The Department claimed those items were responsive to our request.

The statutes and rules cited by DDS essentially say that a guardian can be removed only for acts of abuse or neglect, actions that are not in a ward's best interest, or financial misuse. DDS apparently has no separate written policies or procedures for evaluating or seeking to remove guardians. As a result, it appears to us that DDS is basing is rationale for removing Cindy entirely on the broad and vague best-interest standard.

The RFP that DDS provided states that Qualified Bidders shall be expected, at a minimum, to attend all ISP meetings and meet at least quarterly with the individual, among other requirements.

As we have seen in this and other cases, DDS and providers often take punitive and retaliatory actions against family members and guardians when they are seen as troublesome or meddlesome in advocating for adequate care for their loved ones in the system. Guardians, parents, and other family members can suddenly find their contact with their loved ones restricted or banned entirely, and their guardianship placed in jeopardy.

Questions linger over COVID response in system

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homes. The infection rate on April 3, while still under 100 residents in the DDS system, had risen by 50% from the day before.

As the scope of the pandemic was becoming known in the state, we began receiving reports from families and others that many residents in the system were losing services altogether as caregivers were being ordered by providers in some cases not to enter residential facilities or homes. DDS did issue the first of several COVID guidance documents to providers in late March. But confusion over how to respond to the crisis remained among provider staff. We received an internal memo in early April from an employee at one provider agency asking whether guidelines existed "to deal with the situation."

DLC shares our concerns

By late May, the Disability Law Center, a federally funded nonprofit in Massachusetts, was echoing a number of concerns COFAR had raised. Among them, there was still no "firm rule" preventing direct support staff from working for multiple employers in different DDS group home settings. At the same time, nursing and direct care personnel "were performing heroically,'" said Joe Corrigan, a COFAR member, referring to the Wrentham Developmental Center, where his sister lives.

Questions on future of DDS care

It remains to be seen whether the effects of the pandemic will linger in the system even after all residents have been vaccinated and the virus is eradicated. Will many day programs continue to be provided virtually via platforms like Zoom? Will residential facilities be slow to re-adjust to family visitation? Will work opportunities be available for clients in a slowly recovering economy? Will DDS be better prepared if another pandemic comes along?

Confusion caused by release form requirement for day programs

As day programs for DDS clients were reopened in late July due to a slow-down in COVID infections in the state, guardians were nevertheless asked by the administration to sign a release form that would absolve day program providers of legal liability if a client contracted the virus.

Many family members indicated they didn't want to sign such a form, and an undetermined number of residential providers declined to send residents to the day programs. In mid-August, the administration appeared to backtrack on the release form requirement. DDS Commissioner Jane Ryder said guidance on the form was being revised, but confusion has remained over the matter.

Ryder did not respond to questions from COFAR in early August about the form and whether it was still required.

Baker dragged feet on DDS staff testing

It took months of advocacy to get the Baker administration to require testing of staff in the DDS system for COVID-19.

That testing requirement finally came in late August, and it came shortly before a second surge of the virus hit DDS staff harder than it appeared to have hit residents of the facilities. Prior to August, testing had been voluntary for staff, despite concerns raised by COFAR and other advocates that staff were potentially a prime source of introduction of the virus into group homes.

COFAR first began calling for mandatory testing of staff in late April. In a blog post on May 18, we reported that in our view, the failure to make the testing mandatory was flouting state guidelines, which required testing of staff in small facilities in which at least some individuals are symptomatic.

COVID-19 testing guidelines from the Department of Public Health (DPH) state that "all individuals" who have "close contact" with persons showing symptoms "**should be tested**" for COVID-19.

Under DDS's own guidelines, group homes appear to be a type of facility in which close contact is unavoidable.

We also noted that guidelines from the federal Centers for Disease Control (CDC) identified "workers in congregate living settings" as a "high priority" for testing if they themselves have symptoms of COVID-19. Other persons in that high-priority class, if they had symptoms, were residents in those facilities and hospitalized patients.

DDS, however, was not requiring group home providers to test staff even if the workers had symptoms.

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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.

Attorney General files charges in COVID deaths

COFAR questions AG focus

Massachusetts Attorney General Maura Healey announced in September that she was filing criminal charges against two top managers of the Soldiers' Home in Holyoke for allegedly mishandling a COVID-19 outbreak at the facility that led to the deaths of 76 veterans.

Healey's announcement made national headlines and newscasts. At the same time, COFAR raised a concern over the overall investigative goals of Healey, Governor Baker and the Legislature with respect to the COVID crisis in the state.

In a blog post, COFAR noted that what happened at the Soldiers' Home was certainly horrific and potentially a case of grossly negligent management. But the Soldiers' Home wasn't the only institutional residential setting in which large numbers of people were infected and have died of the virus.

Our focus has been on the nearly 4,000 staff and residents of residential facilities in the DDS system who contracted COVID-19 since April, and the close to 150 residents and an undetermined number of staff who have died of it.

While criminal charges in the Soldiers' Home case may be warranted, we argued that criminal charges should be among the last actions taken by the attorney general in response to a public health crisis like this one. Those charges should come only after the AG has conducted an investigation of the overall response of the state's congregate care institutions and policies and practices, both public and private.

Those comprehensive investigations are almost never done. Baker, himself, ordered an independent review focused solely on the Soldiers' Home deaths, which resulted in a report in June that was widely covered by the media.

As we argued, we need to examine the underlying problems in the response to the crisis — problems that are usually much wider in scope.

State reluctant to release records on COVID response

COFAR has had numerous battles with the Baker administration to obtain records on testing results and deaths due to COVID-19 in the DDS system.

In many cases, DDS, the Executive Office of Health and Human Services (EOHHS), and Department of Public Health (DPH) either ignored or denied records requests from COFAR, or did not comply with rulings from the state's public records supervisor to provide responses to our requests.

These records denials came in conjunction with often spotty online reporting by the administration of COVID testing results on residents and staff in the DDS system.

On April 6, we first posted that DPH was providing daily online updates on the numbers of deaths and positive cases in Massachusetts among the general and nursing-home populations. But virtually no information was available on the number of persons with intellectual and developmental disabilities who had died or been exposed to the virus.

As of September, we had four outstanding public records requests to the three agencies, and the agencies failed to comply with the supervisor's orders in at least three of those cases. In the fourth case, which involved our request for information on the causes of deaths in the DDS system since January, DDS denied our request, citing patient confidentiality. However, we were asking for aggregated numbers, not information that could identify any individuals.

One of COFAR's outstanding requests was first filed on May 26, when we asked for internal emails and other records from EOHHS, DPH, and DDS regarding mandatory testing of staff in the DDS system for COVID-19. As of early September, more than three months later, we had not received any records from any of those agencies.

By September, however, the controversy over the administration's failure to require testing of staff had become moot because the administration did finally mandate staff testing in late August. (see story on Page 4)

Based on internal emails that we were able to obtain from EOHHS, top human services administrators reached an apparent consensus in June to reduce public reporting of COVID-19 test results in congregate care facilities. That consensus appears to have led to decisions to stop publicly reporting cumulative COVID testing data and not to report test data on provider staff working in DDS group homes.

An October 12 *Boston Globe* editorial echoed our own concerns about the lack of public information from the Baker administration about COVID testing. As the editorial stated:

> …it's worrisome that the Baker administration has provided only partial access to important COVID infection data in nursing homes and other long-term care facilities, even after the governor signed a law to enhance data reporting.

In early November, staff-related testing information was listed for the first time in weekly state facilities reports. But the bad news has been that the testing data listed are for *all* "congregate care" sites operated by state-contracted human services providers. The numbers of provider staff testing positive are not broken down among facilities funded by DDS, the Department of Mental Health, the Department of Youth Services, and possibly other agencies.

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COFAR is a statewide, nonprofit education and advocacy organization funded by families of people with developmental disabilities.

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