



The COFAR Voice

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SEEKING SOMEONE TO LISTEN -- David Buckley (left) with his younger brother, Richard, when David was about 10 years old. Some 30 years later, David was scalded to death in a DDS group home. Richard is now hoping legislators and others will finally listen to him about the case, and will listen to other families about similar cases. (Story on Page 5.)

Oversight hearing on DDS shuts out families

Amid a growing number of reports of abuse and neglect in group homes, a state legislative committee held a rare oversight hearing in January on the Department of Developmental Services system in Massachusetts.

But the joint Children, Families and Persons with Disabilities Committee did not allow families to provide verbal testimony at the January 17 hearing. Among those hoping to testify was Richard Buckley, whose brother, David, was scalded to death in 2001 in a DDS group home. (See photo above.)

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Family rights bill still can't get traction in committee

The Legislature's Judiciary Committee has continued to allow a key bill to languish that would boost the rights of developmentally disabled individuals and their families.

The bill (H.887) was sent to the Judiciary Committee in January 2017 and has remained there without any vote or action by the committee. As of late last year, Representative Claire Cronin, the House chair of the committee, said the measure remained under consideration.

The bill, which would require probate court judges to presume the parents of developmentally disabled persons to be the proper guardians for them, has been continually filed in the Legislature since 1999, but has never gotten out of the committee. The measure has no public opposition, leaving it unclear whether there has been private opposition to the bill from within the Legislature or from some other quarter.

Meanwhile, a second bill that would establish an independent agency called a "Public Guardian" has also been stuck in the Judiciary Committee since January. COFAR opposes that bill (H. 3027) because it specifies that the public guardian would be a nonprofit and not a public agency.

The state's reasons for banning David and Ashley Barr from visiting David's disabled daughter keep changing. (Story on Page 4.)

Gov.'s FY '19 budget short-changes state-run programs

Governor Charlie Baker's budget for Fiscal Year 2019, which he submitted to the Legislature in January, continues a long-term trend of starving state-run programs for the developmentally disabled of needed funding.

Faced with a potential budget shortfall in the coming fiscal year, the governor's proposed funding increases are modest even for corporate, provider run programs overseen by the Department of Developmental Services. But as has been the case for the past several years, the governor's Fiscal 2019 budget is much more generous to provider-based line items

See BUDGET, Page 2

Donald Vitkus dies, was Belchertown survivor

Donald Vitkus, 75, a survivor of the Belchertown State School in the 1950s, whose life became the subject of a book by his friend, Ed Orzechowski, died on January 24.

Orzechowski's book, "You'll like it here," chronicled Vitkus's childhood at Belchertown and his life afterwards in which he dealt with the emotional effects of his experiences in the institution. After an initial failed marriage and a literal search with his son for his past among Belchertown records, Vitkus found his calling in recent years as an advocate for persons with developmental disabilities.

Vitkus was sent by a foster family to Belchertown in 1949, when he was six years old. He had a tested IQ of 41 and was labeled "a moron" in the state school records; yet he went on after leaving Belchertown at the age of 17 to earn a high school diploma, and, later in life, an associate degree in human services from Holyoke Community College.

Orzechowski said he was "both privileged and honored to have shared his (Vitkus's) life story, and to have become a very close friend. We had quite a journey together."

State-ops continue to lose residents

Data from the Department of Developmental Services show a continuing decline in the census in both state-operated group homes and developmental centers.

The number of residents of state-operated group homes declined from a peak of 1,153 in Fiscal 2016 to 1,119 in the current fiscal year.

The number of residents of the Wrentham and Hogan developmental centers declined from 437 in Fiscal 2016 to 408 in the current fiscal year.

Given the presumably growing number of people waiting for residential care in the state, these latest numbers appear to add confirmation to COFAR's concern that DDS is not making state-run facilities available as a residential option to those people.

Gov.'s DDS FY '19 budget continues to promote privatization

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than to state-based line items.

The governor's average proposed increase for Fiscal 2019 for three major provider-based DDS line items was 2.26% when adjusted for inflation. However, Baker proposed an average **decrease** of 1.42% for three key state-run program line items. The following are the governor's proposals for those line items:

Provider-based line items: (Governor's proposed increase or decrease from Fiscal 2018, adjusted for inflation):

Community Residential Line item 5920-2000: Proposed increase of \$783,480 or .07%. (This line item will have been increased by 41.4% since Fiscal 2012.)

Transportation 5911-2000: Increase of \$1.19 million or 5.29%. (This line item will have been increased by 83.6% since Fiscal 2012.)

Community day and work 5920-2025: Increase of \$2.9 million or 1.4%. (This line item will have been increased by 51.4% since Fiscal 2012.)

State-run program line items: (Governor's proposed increase or decrease from Fiscal 2018, adjusted for inflation):

Developmental centers 5930-1000: **Decrease** of \$3.49 million or 3.29%. (This line item will have been **decreased** by 39.6% since Fiscal 2012.)

State-operated Residential 5920-2010: **Decrease** of \$915,600 or .43%. (Despite the decrease for Fiscal 2019, this line item will have been increased by 15.4% since Fiscal 2012.)

DDS administration 5911-1003: **Decrease** of \$405,427 or .56%. (This line item will have been increased by only 1.88% since Fiscal 2012.)

The DDS administration account is used to fund agency service coordinators whose caseloads have been rising steadily in recent years. A decrease in the account when adjusted for inflation is likely to be further bad news for service coordinators whose job is ensure that clients throughout the DDS system receive the services to which they are entitled.

COFAR, meanwhile, has queried the administration about the apparent lack of spending under a separate reserve account that is slated to be used, in part, to increase the wages of underpaid direct-care workers in provider-run group homes. Historical spending numbers on the state's mass.gov website show lower amounts being spent out of the reserve account than the amounts appropriated. Only \$9.38 million was spent from the account in Fiscal 2017, and \$9.78 million was projected to be spent in the current fiscal year. In contrast to those spending amounts, the mass.gov site shows \$36.2 million was appropriated for the reserve account for Fiscal 2017, and \$39.7 million was appropriated for the current fiscal year.

Edward Stefaniak, founding member of COFAR, dies at 90

Edward Stefaniak, a founding member of COFAR, died on December 21 at the age of 90.

Stefaniak, who served as a member of COFAR's executive board since 1982, also volunteered for many years as COFAR treasurer. He passed the treasurer's job along to his son Bill, who currently serves in that position.

Stefaniak and his wife Loretta were actively involved parents when their son Danny was a resident of the Fernald Developmental Center. Their advocacy continued as Danny later moved to a state-operated group home.

Stefaniak was a signer of the consent decrees in the Ricci v. Okin class action lawsuit in the 1970s, and volunteered his expertise as an engineer to help review plans for renovations at Fernald. "He was highly intelligent, kind, and self-effacing, with a wry sense of humor," said Colleen Lutkevich, COFAR executive director. "He never lost sight of what life could be for his son and for so many others."

Families shut out of hearing

HEARING, continued from Page 1

The committee heard only from Jane Ryder, now commissioner of DDS, and Nancy Alternio, executive director of the Disabled Persons Protection Commission.

The hearing was scheduled in the wake of a DDS investigative report last September that found seven employees of Bass River, Inc., a DDS provider, at fault in a case in which Ioannis "Yianni" Baglaneas, a 29-year-old man with Down Syndrome, contracted severe pneumonia in his group home after aspirating on a piece of cake. The DDS cited the staff for failing to ensure that Yianni regularly used a portable breathing mask at night called a CPAP, and the report stated that a high-level Bass River employee removed key records from the home and had instructed the staff not to cooperate with the DDS investigation.

While the Children and Families committee's description of the planned hearing was vague, it did appear that the scope would be larger than a review of the Baglaneas case alone. Rep. Kay Khan, House chair of the committee, said during the January 17 hearing that the committee would be guided in its review by a recently issued report by the Inspector General for the U.S. Department of Health and Human Services, which found failures in Massachusetts and other New England states in reporting instances of abuse and neglect.

COFAR has urged legislators to undertake a more comprehensive legislative investigation of the group home system than the limited report by the HHS IG. To date, no such investigation has been undertaken by the Legislature since the late 1990s when the Legislature's House Post Audit and Oversight Committee examined the group home system and found systemic problems with abuse, neglect, and financial irregularities.

DDS staff training requirements may need revisiting

The apparent lack of training of staff in a group home in preventing and responding to aspiration symptoms of Yianni Baglaneas (see story at left) raises questions about training of staff in recognizing and responding to medical issues.

A Department of Developmental Services "action plan" in response to the Baglaneas case, required the provider in that case to provide retraining to group home staff in areas including reporting of incidents and the application of specialized medical equipment.

COFAR asked the Department of Developmental Services in September for departmental policies and requirements for staff training. DDS responded that key training-related requirements could be found in DDS regulations (115 CMR et seq.) and in group home licensure "indicators," which are used by departmental personnel in inspecting provider residences and other facilities.

COFAR reviewed licensure indicators regarding the training of group home staff in recognizing and responding to illness and other medical issues, but the requirements did not appear to be specific or detailed.

One licensure indicator (L80) states that "support staff are trained to recognize signs and symptoms of illness," while another (L81) states that "support staff know what to do" in a medical emergency. L84 states that staff and care providers "are trained in the correct utilization of health related protections per regulation."

The DDS regulations do not appear to include specific requirements for training staff in the identification of illness or responses to illness. The regulations do specify that prescription medication may not be administered by unlicensed program staff unless they have completed a program known as the Medication Administration Program (115 CMR 5.15).

In Yianni's case, the DDS investigative report noted that MAP certified staff stated that because they were not full-time employees of the group home, they did not feel it was their responsibility to administer his medications or to ensure he was wearing a CPAP portable breathing mask at night as his doctor had directed.

In that case, the DDS investigative report recommended that all provider employees receive MAP training and that certified MAP personnel be informed of their responsibility to provide medications. The action plan gave Bass River 30 days to propose remedial action to address noncooperation by staff with the investigation. At another point, the Action Plan appeared to give Bass River discretion as to whether to take remedial actions.

When professional guardians abuse the elderly and disabled

In a recent article, *The New Yorker* magazine described disturbing instances of financial exploitation and abuse of elderly persons in Nevada by professional guardians (“How the Elderly Lose Their Rights,” October 9.)

The article appeared to echo many of the concerns COFAR has raised in recent years over the treatment of individuals and families by guardians paid by the Department of Developmental Services. COFAR has reported on several cases in which family members of persons with developmental disabilities have been excluded from decisions about their loved ones and have even lost their visitation rights. Similar dynamics were described in the *New Yorker* piece.

As is the case in Massachusetts, the primary problems with the system exposed by the *New Yorker* article appear to lie with abuses by attorneys or other professionals who are appointed as guardians of incapacitated individuals. In many of these cases, family members, who would be better suited to be the guardians, are passed over by the courts.

COFAR has previously reported that the state’s system of paying attorneys to serve as guardians of DDS clients is poorly overseen and that the professional guardians appear to have an incentive to do little work representing individual clients while taking on as many clients as possible (See August 2017 *COFAR Voice*).

According to the *New Yorker*, elderly people in many instances, were removed from their homes by professional guardians who then sold their property and pocketed the money.

Story keeps changing on why Barrs can’t visit daughter

When David Barr and his daughter, Ashley, were banned as of November 2015 from all contact with David’s other daughter, who is developmentally disabled, they were told it was because they became too emotional when they visited her.

As of February 2018, David and Ashley were told by the Department of Developmental Services that they would not be allowed to visit the woman, whose name we are withholding, prior to a trial, which is scheduled to be held on May 15 on criminal charges filed against the woman’s mother and a man who has been described as her boyfriend. The disabled woman was allegedly sexually assaulted by her mother’s boyfriend with her mother’s approval in 2014.

Neither David Barr, who has been divorced from his daughter’s mother since 2003, nor Ashley have been charged with any crimes. But they said they feel as if they have been treated as criminals and that David’s daughter has been further victimized by DDS and by the Essex County District Attorney’s office by being kept in virtual isolation.

A spokesperson for the Essex County D.A. told COFAR in February that the ban on family contact was ordered by the DDS-paid guardian of the disabled woman and that the D.A. was not responsible for it. After initially indicating that DDS was trying to resolve the situation, DDS Commissioner Jane Ryder has not returned calls or messages from COFAR.

Provider turned on family trying to advocate for son

Ryan Tilly, who has Down Syndrome, was allegedly assaulted and neglected in 2016 in his corporate, provider-operated group home in Haverhill. But his parents claim the provider and the Department of Developmental Services ultimately tried to blame them for the problems with his care.

Ryan, 24, is continuing to live in a group home operated by the NEEDS Center, a DDS provider. Ryan’s mother, Deborah, said that in addition to suffering abuse and neglect, Ryan was harassed by another resident of the group home so severely in 2016 that he has continued to isolate himself in his room there. Deborah said that in each of three instances in which she filed complaints with the state in 2016 for abuse and neglect, DDS neglected interview key witnesses in the case, including herself.

The provider also banned Ryan’s father, Brian, from visiting him for months. It was only after the parents hired an attorney that the situation began to improve, they said. The attorney was Tom Frain, who is COFAR’s Board president.

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Through our newsletter and our blog posts, we provide information you won’t find anywhere else about 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!

Man hopes brother's death sparks change

After his older brother was scalded to death in a group home run by the Department of Developmental Services in 2001, Richard Buckley and other members of his family tried everything they could to seek justice in the case, and to get answers to their questions. (See photo on Page 1.)

Among their questions were, how could it have happened that David, who had Down Syndrome, could have received fatal burns while being showered by staff in the West Peabody group home; and how was it possible that no one was found at fault in the state investigation that followed?

But Richard found that people in positions of power in state government did not seem interested in providing the family with that information or even in listening to the family about the case.

On the morning of March 30, 2001, David, who had Down Syndrome, received second and third degree burns to his buttocks, legs, and genital area while being showered by staff in the residence run by the Department of Developmental Services. The temperature of the water in the residence was later measured at over 160 degrees.

David died from complications from the burns some 12 days later, yet no one was ever charged criminally in the case, and the DDS (then Department of Mental Retardation) report on the incident did not substantiate any allegations of abuse or neglect.

David, who was 39 years old when he died, had Down Syndrome and Obsessive Compulsive Disorder.

Richard Buckley attended January's oversight hearing on DDS care, which was held by the Legislature's Children, Families, and Persons with Disabilities Committee. He had put his brother's case aside for nearly 17 years prior to attending the hearing, but was nevertheless not allowed to testify. (See story and photo on Page 1.)

Rep. Ashe drafting bill to ensure work opportunities in DDS day programs

The office of state Representative Brian Ashe is drafting a bill intended to ensure work opportunities for developmentally disabled persons who are unable to cope with mainstream workplace settings.

The legislation will be filed on behalf of Barbara Govoni, the mother of Danny Morin, one of thousands of persons who participated in sheltered workshops in Massachusetts before they were closed in 2016. While the administration's plan was to place those workshop participants in mainstream or "integrated employment" settings, many of the participants are unable to function in those mainstream or community-based settings.

Rep. Ashe's draft legislation would require that the Department of Developmental Services recruit employers to help identify work opportunities that could be incorporated into existing community-based day support services programs for up to four hours a day. All participants would receive a subminimum wage rate under the Fair Labor Standards Act.

COFAR shares concerns with unions about Pacheco Law regs

COFAR has joined with two state employee unions in raising concerns that provisions in new regulations proposed by the state auditor would weaken the longstanding Pacheco Law.

COFAR has long supported the politically controversial law, which requires state agencies seeking to privatize services to demonstrate that contracting out would save money and ensure equal or better service quality. While the law has been in effect since 1993, the Office of the State Auditor, which oversees the statute, proposed regulations only last year to govern it.

A key objection raised by COFAR in comments submitted in September to the Auditor's Office, concerns a provision in the proposed regulations that would appear to give state agencies an incentive to boost the actual cost of their in-house services if a Pacheco Law review determined that those services should stay in house.

In comments submitted to the auditor in October, SEIU Local 509, which represents human services workers in both state-run and privatized facilities, stated that the union agreed with COFAR's concern about the regulatory provision. The provision appeared intended to keep in-house costs down by stating that a state agency could reopen privatization negotiations if in-house costs rose.

But COFAR argued that allowing an agency to reopen privatization negotiations would give the agency an incentive to let the in-house costs rise. The SEIU also agreed with COFAR's recommendation that another provision be dropped that would require the in-house cost estimate to reflect a state agency's "sunk costs" of equipment or other assets.

COFAR, meanwhile, agreed with a number of concerns raised by both SEIU and AFSCME Council 93, including a concern that the proposed regulations would reduce performance measures needed to prove that service quality would be equal or better in privatizing services.

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