



# The COFAR Voice

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

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**CONTACT DISALLOWED** — A DDS guardian has indefinitely banned all contact with Chelsea Barr (left), by her father, David (center), and sister, Ashley (right). COFAR is working to restore family contact in the case. (See story on Page 2.)

## DDS proposes vaguer rules governing restraints

The Department of Developmental Services has proposed major changes to regulations governing restraints and behavior modification techniques that are used on persons with developmental disabilities.

In August, COFAR submitted comments to the Department, raising concerns that the proposed changes would make those regulations more vague and would open the door to more abuse and neglect in the care of people with developmental disabilities.

DDS claims its proposed regulatory changes will enable disabled individuals “to grow and reach their maximum potential,” and will limit or eliminate the use of certain types of controversial restraints, which are used during behavioral

See RESTRAINTS, page 5

## FY ‘18 outlook bleak for DDS budget

Faced with a state budget shortfall projected for the current fiscal year, it appears unlikely next year’s funding for the Department of Developmental Services will mark an improvement over the current year.

In October, the administration announced a projected budget shortfall in Fiscal 2017 of \$294 million and proposed unilateral cuts and an early retirement program for state employees. As of early December, close to 200 DDS employees had accepted the early retirement offer, including 41 staff members of the Wrentham Developmental Center. (See story on Page 3.)

Governor Baker’s budget cuts in Decem-

## Gritty new book on a survivor of the Belchertown State School in the 1950’s (Story on Page 4)

ber totaled \$98 million. While those mid-year cuts did not affect DDS line items, they signaled trouble for the Department’s Fiscal 2018 budget outlook.

The DDS current-year budget has already been described as “dismal,” with many line items ending up under-funded. (See July 2016 *COFAR Voice*.)

Last spring, the state Legislature declined to adequately fund a budgetary line item that was supposed to ensure that developmentally disabled persons being moved out of sheltered workshops would ultimately be placed in mainstream jobs. The workshops have largely been closed by the administration.

The Legislature rejected a \$4.6 funding increase proposed by Baker for Fiscal 2017 for the new line item intended to fund job development staff and programs. Both the

See BUDGET, Page 5

## **Guardianship opponents backing SDM**

Many advocates for the developmentally disabled agree that the probate court system in this and other states is dysfunctional.

The case of Chelsea Barr (see story at right) appears to be a prime example of that. But there is disagreement over how to reform the probate court system.

One reform proposal that has come up in Massachusetts is to significantly limit or do away with guardianships altogether and replace them with what is known as Supported Decision Making (SDM).

COFAR has raised concerns about SDM, however, contending that it is being pushed by some of the same groups around the country that have promoted runaway privatization of services for the developmentally disabled.

Under SDM, individual guardians are replaced by teams or “network supporters,” who enter into written agreements with disabled individuals to “help them make decisions” about their care, finances, living arrangements and other areas. The network supporters can include family members, friends, and corporate service providers, according to the Center for Public Representation, which is pushing for SDM in Massachusetts.

COFAR contends that SDM advocates paint guardianship with a broad, negative brush and don't appear to acknowledge the value that family members, in particular, bring as guardians to the lives of their loved ones. Many of those SDM advocates appear to be from the same groups that have long opposed congregate-care options for the developmentally disabled, and their language in support of SDM is similar to their longstanding ideological language in opposition to congregate care.

COFAR counsels parents of developmentally disabled children to consider obtaining guardianship rights when their child reaches the age of 18. Rather than eliminating guardianship, COFAR advocates working to improve the system. One reform is passage of a bill that presumes family members to be the most suitable guardians for their loved ones. (See story on Page 5.)

## **Father and sister fight for right to visit Chelsea Barr**

For more than a year, a guardian employed by the Department of Developmental Services has prohibited the father and sister of a developmentally disabled woman from visiting her or contacting her in any way.

The ban has been in effect since Thanksgiving of 2015 on all communication between the disabled woman, Chelsea Barr, and her father, David, and her sister, Ashley.

COFAR has been advocating for the restoration of family contact in the case and contacted the offices of David Barr's local legislators in an effort to resolve the matter.

However, both Ashley and David Barr said they felt abandoned by the two legislators, state Senator Kathleen O'Connor Ives and Representative Linda Dean Campbell. Ives and Campbell declined a request by COFAR that they send a letter to DDS Commissioner Elin Howe, asking for a restoration of David and Ashley's contact with Chelsea.

COFAR has reported that a DDS guardian imposed the ban on all contact with Chelsea primarily because David and Ashley were reportedly viewed by clinicians as too emotional when they were allowed to visit her in at least one hospital setting. Since the beginning of 2015, DDS had not even informed David or Ashley as to where Chelsea was living.

In a November 17 email to COFAR Executive Director Colleen M. Lutkevich, DDS General Counsel Marianne Meacham stated that a departmental review had concluded that the restrictions on the Barrs' contact with Chelsea and the Department's handling of the matter were appropriate. However, Ashley and David said they were never contacted by DDS as part of that review.

Ives' staff member said Ives did not think a letter to Howe was necessary or would accomplish anything, while Campbell's staff member said Campbell's legal counsel raised a concern that sending such a letter could violate Chelsea's privacy rights.

Lutkevich and David Kassel, *COFAR Voice* editor, sent emails to Ives' and O'Connor's staffs, arguing that a letter from Commissioner Howe would potentially be helpful and would not violate Chelsea's privacy.

As COFAR reported on our blogsite, a DDS attorney and Chelsea's DDS guardian and service coordinator all made what appeared to be prejudicial and damaging statements about David and Ashley during an August 2015 probate court hearing in which David had sought to be named Chelsea's guardian. None of those statements was challenged during the hearing. The prejudicial statements include a claim by the DDS attorney that erroneously implied that David provided inadequate care for Chelsea when she previously resided with him, and a separate speculative statement that David and Ashley wanted to visit Chelsea out of “a sense of guilt.”

“As far as I'm concerned, Chelsea's been kidnapped,” David Barr said in an interview. COFAR has reported on a number of other cases in which DDS-paid guardians have imposed severe restrictions on family contact with individuals in the DDS system or have attempted to remove family members as guardians because they were seen as meddling or uncooperative with the agency or providers. (See “When family rights are trumped in care of the disabled,” April 2014 *COFAR Voice*.)

## ***Wrentham, Hogan staff take early retirement***

Close to 200 employees of state-run Department of Developmental Services facilities have accepted an early retirement incentive offered by the Baker administration.

The early retirement program was offered last fall in the wake of a projected state budget shortfall in the current fiscal year (See story on Page 1).

According to DDS, early retirement was taken between mid-October and mid-November by 41 staff at the Wrentham Developmental Center, 11 staff at the Hogan Regional Center, and 140 staff in state-operated group homes. The total number of staff taking early retirement was approximately 3.9 percent of the total staff in those facilities as of the start of the fiscal year last July 1.

COFAR filed a Public Records Law request to DDS on December 2 for information on the early retirement program. In a December 21 response, DDS stated that that the Department did not anticipate any impact on care or services in those facilities.

COFAR has followed up with an additional request for a breakdown of the positions of the staff accepting early retirement as well as of the number of staff DDS planned to rehire in those positions.

## ***Now abandoned, Fernald chapel remembered***

The Chapel of the Holy Innocents at the former Fernald Developmental Center used to be a bustling center of prayer and community-based activity at the now closed, state-run facility.

Today, the chapel stands abandoned, overgrown with vines and weeds. A September 2016 article in the Catholic publication, *The Boston Pilot*, describes the impression the chapel made on Helen Cushman, a volunteer at the chapel and the sister of a Fernald resident. "The cacophony in that building was just incredible," she said.

The article contended that the chapel, sanctioned by Boston's Cardinal Cushing in 1960, "stands as a marker of changing beliefs about how best to care for the developmentally disabled in America." COFAR Executive Director Colleen M. Lutkevich maintained that many advocates, including COFAR, do not share the belief that the replacement of facilities like Fernald with privatized group homes has improved that care for everyone, particularly for the most developmentally disabled.



**MEETING WITH GOVERNOR'S STAFF** — Members of COFAR met with key staff of Governor Charlie Baker on December 29 to discuss rights of developmentally disabled persons and their families to adequate choice in care and the preservation of funding for state-run group homes and developmental centers.

Also discussed was COFAR's support of H. 1459 in the previous legislative session — a bill that would help ensure that family members are appointed as guardians of their loved ones.

Pictured from left are Kaitlyn Sprague, Baker's legislative director; Ryan Coleman, Baker's deputy chief secretary; Thomas Frain, COFAR president; Colleen Lutkevich, COFAR executive director; and David Kassel, *COFAR Voice* editor.

The meeting was arranged by Marty Corry of Corry Associates, a leading lobbying firm on Beacon Hill. Corry has advocated on a voluntary basis on behalf of COFAR for many years. (Photo courtesy of Marty Corry.)

## **State audit raps two DDS vendors**

State Auditor Suzanne Bump issued reports in December that found financial irregularities involving two corporate providers to the Department of Developmental Services.

In one of the reports, Bump contended that Human Service Options, a Weymouth-based for-profit DDS provider, purchased more than \$200,000 in furnishings and other items on credit cards rather than using a competitive procurement process. The company also inappropriately allowed employees to purchase more than \$8,000 in personal items on a corporate credit card.

In a second report, Bump found that Nonotuck Resource Associates of Northampton, a nonprofit provider, did not have contracts with two of five consultants to which it paid more than \$200,000 for a variety of legal, computer and other services. Nonotuck has been involved with the Center for Public Representation in advocating for restricting or eliminating guardianships of developmentally disabled persons. (See story on Page 2.)

## State mixes message on congregate care

In a revised draft plan on community-based care and in responses to comments, the Baker administration seems to be sending out a mixed message.

The Department of Developmental Services has acknowledged in response to comments on its initial draft Statewide Transition Plan that not all congregate care should be prohibited.

Yet in the revised draft plan submitted last summer to the federal government, DDS still indicated that it would restrict most new group homes from housing more than five residents; and it would apparently restrict funding for most other congregate settings such as farm-based residential programs.

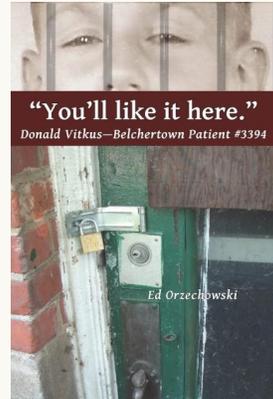
The Statewide Transition Plan is a requirement of the federal Centers for Medicare and Medicaid Services (CMS), which issued a new regulation in 2014 governing community-based care receiving Medicaid funding. The CMS regulation is intended to reduce reliance on congregate care, but Massachusetts originally appeared to go even further than the CMS regulation in banning congregate care almost entirely.

It appears that DDS received a large volume of comments to its original draft plan on community-based care in 2014. Like COFAR, many of the commenters felt that DDS was going too far in seeking to ban virtually all forms of congregate care in the state. In follow-up comments submitted to DDS in August, COFAR noted that despite the concession that not all congregate care should be prohibited, the updated Statewide Transition Plan does not appear to reflect any change in the state's restrictive policy on congregate care.

## How a man survived childhood in the Belchertown State School

When Donald Vitkus and his fellow juvenile inmates at the then Belchertown State School found the occasional cigarette butt on the floor, they had to use their wits to figure out how to light it.

Matches were forbidden, so Vitkus climbed up on his friends' shoulders and carefully inserted a single strand of steel wool into an empty overhead light socket in the boys bathroom. Many of the other challenges and trials of living in the now-closed institution for the developmentally disabled were not as easy to deal with.



"You'll Like it Here," which was published in November by Leveller's Press of Amherst, MA ([www.levellerspress.com](http://www.levellerspress.com)), is the ironically titled story of Vitkus's life, as told to Ed Orzechowski, a COFAR Board member and president of the Advocacy Network, an affiliated organization.

Vitkus was sent by a foster family to Belchertown in 1943, when he was six years old. He had a tested IQ of 41 and was labeled "a moron" in the state school records. But as you read this account, you realize just how faulty IQ tests can be.

What Vitkus and so many others went through at Belchertown in the 1950's was the result of an attitude at that time that people with intellectual disabilities were not only sub-human, but that horrendous things could be done to them without fear of retribution. The residents were abused and treated as prison inmates by many of the staff. The place was overcrowded and unsanitary.

At one point, Vitkus began refusing to take mind-numbing Thorazine and bit off the finger of an attendant who was trying to jam the pills down his throat. He spent 34 days in solitary confinement as a result. In 1960, he was "paroled" from Belchertown at the age of 17, after graduating from the sixth grade at the school.

Orzechowski's book details Vitkus's life after Belchertown, from his voluntary service in Vietnam to his failed first marriage. That life has borne the indelible imprint of Belchertown.

But the book is also a story of hope and resiliency. Orzechowski relates the reconnection Vitkus made with his son, Dave, a police officer in Northampton. Together, Donald and his son went on a quest to piece together the strands of Donald's lost life.

This is a must-read for anyone who wants a sense of what it took to survive in large institutions before the advent of class-action lawsuits in the 1970s both greatly improved conditions in them and led to the creation of the community-based system of care.

## Please Contribute!

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!

## Legislature left much undone

The state Legislature officially ended its 2-year, 189th session this month, having killed or failed to act on numerous initiatives proposed for people with developmental disabilities.

Those initiatives include a perennial measure to boost the rights of family members in guardianship cases. As we reported, the bill, H. 1459, was sent last March by the co-chairs of the Judiciary Committee to a legislative study, which effectively killed it for the session.

H. 1459 would have required that probate court judges presume a spouse or parent to be the proper person to be the guardian of an incapacitated person. The measure, which is strongly supported by COFAR, also had the support for the first time of the Massachusetts Developmental Disabilities Council and had no known opposition.

Also killed in the session was H. 1932, which would have required that hospital personnel receive training in treating persons with developmental disabilities. Other bills that died include measures to:

- **Expand Turning-22 services** (S. 2223). That bill was referred to the Senate Ways and Means Committee in April 2016. It remained in the committee through the end of the session, which effectively killed it.
- **Expand civil rights protections** (H. 121). The bill was referred in March to the House Ways and Means Committee where it died at the end of the session. The bill would change a number of provisions in the Massachusetts General Laws dealing with non-discrimination or civil rights to include specific reference to the disabled.
- **Create housing for people with disabilities** (S. 2202). The bill died in Senate Ways and Means.
- **Track unmet needs** (H. 127). The bill died in the House Ways and Means Committee.

## Bleak budget outlook seen for DDS

BUDGET, continued from Page 1

Legislature and Baker also approved almost \$10 million less in funding for the DDS community day and work line item than what the corporate providers contended was needed.

Last year, the Legislature further approved a \$1.6 million cut in the developmental centers line item. And the Legislature approved an increase of only \$3.7 million in the line item for state-operated group homes, which amounts to a cut when adjusted for inflation.

## New restraints rules more vague

RESTRAINTS, continued from Page 1

emergencies. A review of the proposed changes by COFAR, however, shows the changes would eliminate a large number of specific requirements and restrictions on behavioral techniques and restraints, and would replace them in most cases with more vaguely worded provisions that would provide less protection against potential abuse.

For instance, DDS was proposing to scrap the regulatory definitions of chemical, mechanical, and physical restraints as well as many of the procedures specified in the current regulations regarding those restraints. These procedures would be replaced by a process called the "Crisis Prevention, Response and Restraint curriculum" (CPRR).

It was not clear in the proposed regulations what the CPRR curriculum was. At the same time, requirements would be deleted that mechanical and physical restraints be authorized by either the provider agency head, an authorized physician, or a designated staff member who has had training in the safe use of those procedures.

Also deleted in the proposed regulations was language stating that any mechanical device used as a restraint must allow for "the physical and emotional comfort of the individual in restraint." In addition, the proposed regulations would delete language in the current regulations prohibiting locked mechanical restraint devices requiring the use of a key for their release.

In its comments, COFAR did support a proposed change in the regulations that appeared to introduce a specific prohibition against dangerous physical restraints that cause pressure on the lungs. Specifically prohibited under this section would be restraint in a prone position in which the individual is lying on their stomach.

In the same set of regulations, DDS was also proposing to scrap the term "behavior modification" and replace it with "positive behavior supports" (PBS). COFAR commented that those proposed changes raised a similar concern in that there appeared to be less specificity in the proposed PBS system than in the current requirements, many of which would similarly be deleted.

The proposed regulations, for instance, would delete all references to "Level I and Level II behavioral interventions," which are described in the current regulations. These Level I and II categories appear to be replaced by "Universal and Targeted Supports," which seem to have much more vague definitions. COFAR also opposed a proposed change in a separate section of the regulations reducing privacy rights of persons with developmental disabilities.

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**Thank You!**