



# The COFAR Voice

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

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## 'Dismal' FY '17 budget approved for DDS

The state House and Senate largely followed Governor Charlie Baker's budget script for the fiscal year that started July 1, opting to provide for only modest increases in some programs for the developmentally disabled and cuts in others.

As the budget process approached the start of Fiscal Year 2017, lawmakers were wrangling over relatively small differences among the three budget versions proposed by the governor, House and Senate.

Ironically, it was Republican Governor Baker whose proposed funding for Department of Developmental services programs was the highest among the three versions.

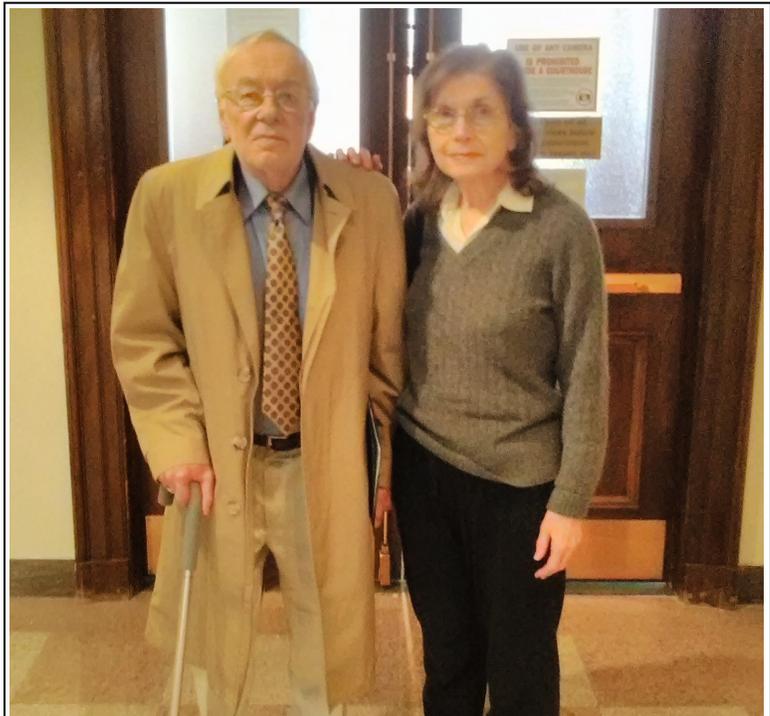
The Senate proposed the lowest funding levels, having proposed the deepest cuts in the developmental centers line item and \$700,000 less in spending for the community day line item than what the House and the governor proposed. In the end, a House-Senate conference committee adopted the Senate versions of those two line items.

The low funding level approved for the community day line item could threaten to derail the administration's three-year-old program to close sheltered workshops and transfer the participants to the mainstream workforce. (See story on Page 3.)

"It's really a dismal budget as far as its impact on some of our most vulnerable citizens," said COFAR Executive Director Colleen M. Lutkevich.

Lutkevich noted, though, that one slightly brighter spot in that otherwise bleak picture concerned the Disabled Persons Protection Commission. Although Baker had proposed level-funding that agency in his Fis-

See BUDGET, Page 3



**FAMILY RIGHTS** — Stan and Ellen McDonald stand outside a courtroom in Middlesex Probate Court following a March 17 hearing on guardianship of their son, Andy. A new Supreme Judicial Court ruling could boost the rights of family members such as the McDonalds in DDS guardianship cases (See story on Page 4). The news was not as good regarding a family rights bill in the state Legislature (See story on Page 5.)

## Rise seen in deaths in DDS community system since 2008

Data available on the Department of Developmental Services website show a significantly higher number of deaths occurred among DDS clients living in the community residential system in 2013 than in 2008.

COFAR analyzed the mortality data in DDS reports between 2008 and 2013, the most recent year available. In 2008, the administration of then Governor Deval Patrick announced a major initiative to close large state-run developmental centers and to move the residents of those facilities to community-based group homes.

See DEATHS, Page 5

## ***Is community-based care just cost cutting?***

**...Other voices...**

The DD News Blog (at [theddnewsblog.blogspot.com](http://theddnewsblog.blogspot.com)) asks the question whether federal policy is forcing states to reduce options for residential care for people with developmental disabilities in order to save money.

In a May 15 post, the blog noted that the federal government has adopted new regulations that will cut or eliminate Medicaid for programs deemed to involve congregate care. Yet, as the blog post pointed out, “congregate care allows for the sharing of resources and lessening of feelings of isolation. It should not be ruled out as an option.” COFAR agrees, and has made this same point about DDS policy.

A related post on the Autism Society Blogsite (at [sfautismsociety.org/blog](http://sfautismsociety.org/blog)) noted that the new federal regulations are intended to reduce residential options for people with disabilities. The federal Centers for Medicare and Medicaid Services (CMS) contends that the new regulations are intended to eliminate congregate care facilities and programs that are too “institutional” in nature.

But the April 19 Autism Society post by Jill Escher stated that the real and “primary goal of the new rules is to put the brakes on” new residences and programs for people with developmental disabilities because they cost too much. In carrying out this policy, the CMS has enlisted federally funded advocacy groups to “inform on” programs that appear to be “too congregate or disability specific in nature.” The result has been a reluctance on the part of nonprofits, housing providers, and parents to invest in housing or expand programs for people with developmental disabilities.

Escher termed the CMS’s anti-congregate policy discriminatory because it “defines” where people with developmental disabilities can live in order to receive social services. The CMS policy also precludes more than a set number of disabled people from living together. In practice, Escher said, the new rules mean that “if you’re sitting in your parents’ home doing nothing..., that’s ‘community integration.’”

## **HHS IG report on group home abuse is only six pages long**

COFAR has questioned the methodology of a report by the Inspector General of the U.S. Department of Health and Human Services on abuse and neglect in facilities for the developmentally disabled in New York State.

The six-page report, which was issued last September, contained no recommendations. The report, which examined data on emergency room visits by residents of a selected number of facilities, also found that the vast majority of the ER visits were due to residents’ underlying medical conditions and not to abuse or neglect.

COFAR also sent a query in June to the HHS IG about the agency’s reported plans to issue two additional reports on abuse and neglect in facilities in Massachusetts and Connecticut. The IG’s office has not responded to that inquiry.

The COFAR Voice has reported that the HHS IG began in August 2013 to examine data on admissions of persons from group homes and “nursing facilities” to hospital emergency rooms in Massachusetts, Connecticut and New York. An IG investigation had been requested by U.S. Senator Chris Murphy of Connecticut in the wake of exposés in *The New York Times* that revealed thousands of cases of deaths in privatized group homes in New York State due to unnatural or unknown causes. *The Hartford Courant* published a series of articles in 2013 as well about dozens of cases of deaths in group homes in Connecticut due to abuse, neglect, and medical errors.

Since 2013, Murphy has not commented on his call for an investigation, or on the issue of group home abuse. His office has not responded to repeated queries from COFAR about his opinion of the IG’s initial report on the New York system.

The IG stated in its September report that its investigation was limited to Intermediate Care Facilities (ICFs) in New York State in which at least 70 percent of the intellectually disabled Medicaid beneficiaries had an emergency room visit from 2012 through 2013. This resulted in a review of cases involving 109 persons at 12 ICFs. ICFs are a distinct type of residential facility that are required to meet strict federal standards and tend to serve profoundly disabled and medically involved people.

The IG report did not say whether any of the ICFs were actual group homes.

COFAR has questioned the IG report’s lack of recommendations and lack of any critical findings. “We question how the IG could essentially have found nothing wrong, particularly, when we know there is a lot wrong with the system,” said Colleen Lutkevich, COFAR executive director.

In an initial query to the IG, COFAR asked whether the IG’s methodology could have caused the agency to select facilities for its evaluation having the most medically fragile patients. Such a biased sample would potentially show an unusually high number of patients being admitted to ERs or dying due to medical causes and not due to abuse or neglect.

COFAR has suggested that the IG could have, but apparently did not, review existing records in state agencies in New York State on abuse and neglect. The IG could also have, but apparently also did not, try to confirm the newspapers’ findings or examine the actions taken in each state to address the newspapers’ findings.

## Lawmakers approve higher DPPC funding

In one of the few bright spots in the Fiscal Year 2017 budget for programs and services for the developmentally disabled, the House and Senate proposed additional funding for the Disabled Persons Protection Commission.

However, even the increase, as approved by a House-Senate conference committee, was less than what some advocates had hoped would be the case. During debate on the budget, the Senate had approved an amendment that would boost the DPPC's funding by \$350,000 next year -- a nearly 10 percent increase after an adjustment for inflation. The conference committee adopted the more modest House proposal of \$100,000 in funding for the DPPC. Governor Baker's proposed 2017 budget would have only level-funded the DPPC, which is the only state agency in Massachusetts devoted exclusively to preventing and investigating abuse and neglect of disabled persons. Level-funding would amount to a funding cut when adjusted for inflation.

Emil DeRiggi, deputy executive director of the DPPC, had said the additional funding proposed by the Senate would have enabled the agency to hire up to four new staff.

## COFAR updates website Advocacy Guide

We have updated our Advocacy Guide, which is available on our website at [www.cofar.org](http://www.cofar.org).

The Guide now contains updated references to Department of Developmental Services regulations as well as new information on Social Security and Medicaid eligibility requirements and issues. In addition, the updated Guide has a new section about regulations governing the use of restraints, seclusion and medication in residential and other care settings. DDS regulations establish standards over the use of these methods as behavior modification techniques.

As the Advocacy Guide notes, behavior modification techniques can be used only with the consent of the individual or their guardian, and only in emergency situations. More information on this and a host of other advocacy issues can be found in the Guide.

## 'Dismal' budget set for FY '17

BUDGET, continued from Page 1

cal 2017 budget, the conference committee agreed with a House proposal to increase the DPPC's budget by \$100,000 for Fiscal 2017. That increase, however, was less than what the Senate had proposed. (See story opposite).

Aside from the DPPC, the Legislature did approve \$6.9 million in additional funding for family respite services, and an additional \$500,000 for Turning 22 services. But there was little else to celebrate in the budget.

The conference committee agreed to a \$472,000 increase in spending over the governor's proposal for the DDS administrative line item, which includes funding for service coordinators. However, the increase wasn't enough to keep up with inflation. Also, at least some of the total additional funding appeared to be earmarked not for the service coordinators, but for the Massachusetts Down Syndrome Congress, a state-funded advocacy organization.

The conference committee also approved a \$1.6 million cut in funding for the DDS developmental centers. The 2017 budget also cuts the commonwealth-operated group home line item by \$212,800, when adjusted for inflation.

## Legislature fails to fund jobs programs for DDS clients

Although the Massachusetts Legislature bought into a plan by the Baker administration to close all sheltered workshops for the developmentally disabled in the state, the Legislature declined this year to provide the funding needed to place the former workshop participants in jobs in the mainstream workforce.

In 2013, the administration and corporate providers to the Department of Developmental Services announced a jointly developed plan to close the workshops and ultimately find "integrated employment" opportunities for the hundreds of former workshop participants. However, after approving initial rounds of funding for the effort in Fiscal Years 2015 and 2016, the Legislature balked at the governor's proposed increase in that funding for Fiscal 2017.

The Legislature rejected a \$4.6 funding increase proposed by Baker for a new line item intended to fund job development staff and programs. Both the 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. Sheltered workshops, in which developmentally disabled participants work on assembly-line tasks for a relatively low wage, are increasingly viewed as "segregating" the participants from their non-disabled peers in the community. All remaining workshops were scheduled to be closed in Massachusetts as of June 30.

COFAR reported in January that relatively few persons had been placed in mainstream work settings thus far.

## **Questions remain over ABLE Accounts**

Based on federal legislation enacted in 2014, families are now able to set up tax-free savings accounts to be used for expenses of individuals with developmental disabilities.

The "ABLE" accounts can contain up to \$100,000 and not affect an individual's eligibility for Social Security or Medicaid benefits. Currently, SSI, SSDI and Medicaid benefits are not available to anyone whose financial assets exceed \$2,000.

But a number of questions remain about the ABLE accounts, including their usefulness in some cases and when family members and guardians should establish them.

Massachusetts enacted legislation in 2014 to authorize the establishment of ABLE Accounts in the state. But as of early June, the Baker administration had not issued regulations governing the accounts, according to the Framingham-based Special Needs Law Group, PC. The law firm advised potential applicants for MassHealth programs to wait until those regulations are enacted before establishing an ABLE Account.

ABLE Accounts can be used to pay expenses for such things as education, housing, transportation, employment training and support, and assistive technology. However, certain expenses, such as food, entertainment, and vacations are not permissible.

The accounts are owned by the disabled individual, who can access the funds directly unless decisions are made by a parent or legal guardian. Massachusetts law also appears to allow corporations acting as "designated administrators" to access the funds as well.

## **SJC rules in favor of family rights in guardianship cases**

A ruling in May by the Massachusetts Supreme Judicial Court that the grandfather of an intellectually disabled woman had a right to intervene in her guardianship case could boost rights for family members of disabled adults.

The SJC ruled that even though the grandfather was not the woman's guardian, he qualified under the state Uniform Probate Code as an "interested person" in the granddaughter's guardianship proceeding. As such, the grandfather had a right to intervene in the proceeding in order to gain permission from the court to visit and communicate with his granddaughter.

The woman was identified in the case as B.V.G. Her father, who was appointed as her permanent guardian, had sought to sharply restrict or prohibit her contact with her grandfather, and, in fact, with all of her other maternal relatives.

COFAR has advocated on behalf of family members in a number of cases in which guardians have restricted their contact with loved ones in the Department of Developmental Services system. Those cases have stemmed from the appointment of attorneys and other non-family members as guardians.

In the B.V.G. case, the SJC concluded that an individual can be considered an interested person under the Uniform Probate Code simply by being interested in an incapacitated person's well-being. This effectively gives the individual the right to intervene in the guardianship proceeding and to seek to remove restrictions on contact with the incapacitated person.

In one ongoing case on which COFAR has reported, Stan McDonald, the father of an intellectually disabled man, has been seeking permission for home visits from his son, who lives in a group home. While McDonald would appear to be an interested person in his son's guardianship, he has been prohibited even from discussing the prospect of a home visit from his son, Andy.

COFAR is questioning the factual record underlying a probate court decision in 2006 that permanently barred Andy from returning to his hometown.

Stan's wife, Ellen, who is Andy's step-mother, was not permitted to attend a recent probate court hearing involving Andy, even though she, too, appears to meet the SJC's interpretation of an interested person in the case. COFAR maintains that as interested persons, the McDonalds should have input into the terms of Andy's contact with them. The McDonalds have repeatedly called for an independent clinical evaluation of Andy. Their requests have seemingly been ignored, however, possibly because they have not been considered to have standing in the case.

## **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!

## Guardianship bill dies in committee

Despite support from advocacy organizations and a state disability rights council, a bill that would boost the guardianship rights of family members of persons with developmental disabilities has once again effectively been scuttled by the Legislature's Judiciary Committee.

The proposed legislation (H. 1459) stated that probate court judges should presume a spouse or parent to be the proper person to be the guardian of an incapacitated person.

In early March, as a deadline approached for taking action on bills in the current legislative session, the Judiciary Committee co-chairs ordered H. 1459 sent to a legislative study. Sending bills to studies effectively kills those bills for the legislative session.

While the defeat of H. 1459 spelled a setback for the rights of family members in guardianship cases, those rights received a boost as a result of an unrelated decision by the Massachusetts Supreme Judicial Court, which determined that a family member, who was not a guardian of a developmentally disabled person, could intervene in the person's guardianship case. (See story on Page 4.)

Momentum for H. 1459 seemed to be building last year when the measure received support for the first time from the Massachusetts Developmental Disabilities Council (MDDC), a state-run organization that identifies priorities for care for people with those disabilities. The MDDC listed the bill as one of its legislative priorities for 2015-2016. The proposed legislation had been repeatedly filed by state Representative David Linsky since 1999 at the request of Stan McDonald, a constituent of his. McDonald has been involved in a long-time effort to gain guardianship of his son, Andy. In January, Linsky and state Senator Richard Ross sent a letter to the Judiciary Committee co-chairs, urging passage of the bill.

## Rising death rate seen in group home system

DEATHS, from Page 1

The DDS mortality reports were done by the Center for Developmental Disabilities Evaluation and Research (CDDER) within the UMass Medical School. According to the CDDER data, there were 196 deaths in the community residential category in 2008, and that number rose to 254 deaths in 2013. That was an increase of 58 deaths per year, or about 30 percent.

The number of deaths in the community system rose in three of the five years between 2008 and 2013. In contrast, the numbers of deaths in the developmental centers and living-at-home categories decreased fairly steadily between 2008 and 2013, the CDDER data show.

The data appear to raise the question whether the closures of the Fernald, Monson, and Glavin developmental centers, starting in 2008, contributed to the increase in the overall death rate in the community system. The CDDER reports themselves do not discuss that question, although CDDER's 2010-2011 mortality report did state that a statistically significant increase in deaths in the community system between those two years may have been due to people with "high medical needs" having been moved into the community at that time from nursing homes.

## Committee quietly changes medical training legislation

Acting behind closed doors and apparently without a vote, the Legislature's Public Health Committee sharply reduced the scope of a bill this year that would have required health care professionals to receive training in treating developmentally disabled persons.

The new, substituted legislation will expand an existing, voluntary training program in selected medical and nursing schools. The training program, called Operation House Call, has been run by the Arc of Massachusetts for several years.

A House-Senate conference committee subsequently approved \$50,000 in funding in the Fiscal 2017 budget to the Arc to expand the Operation House Call program.

COFAR had strongly supported the original language in the Public Health Committee bill, which also would have required the Executive Office of Health and Human Services (EOHHS), to evaluate discrimination against developmentally disabled persons and to issue regulations to reduce the impact of "disparities in outcomes" for those people in medical settings.

Although the original bill had been stalled in the Public Health Committee for more than a year, COFAR received a notice in March from the office of Representative Kate Hogan, the committee House chair, that the bill had finally been reported favorably by the committee.

However, in early April, Hogan's committee substituted the new language in the bill, which authorizes the expansion of the Operation House Call program. While the program provides training to medical and nursing school students in treating people with developmental disabilities, the scope of the program appears to be much smaller than what the original bill would have required.

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