



The COFAR VOICE

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Funding shortfalls seen for state-run care

The House and Senate this month approved limited funding increases in some community-based accounts in the Department of Developmental Services budget for the coming fiscal year, but rejected increases proposed by the governor in state-funded care.

The two chambers wrapped up their consideration of the governor's state budget proposals for FY 2014 and appointed a conference committee as of early June to iron out differences between each chamber's budget plans.

"Once again, the Legislature has turned its back on some of our most vulnerable residents," said COFAR President Thomas Frain in reaction to the budget actions. "State-run care is an integral piece of the overall fabric of care in the DDS system."

In the DDS budget, the Senate approved a \$9.1 million increase in funding for state-operated group homes, but that funding was still \$1.5 million short of the increase the governor had proposed. In January, DDS projected the closures of two to three group homes if the governor's full \$10.6 million increase was not approved. As the administration has moved to close state developmental centers in Massachusetts, many of the residents of those centers have moved to state-run group homes.

George Mavridis Foundation to match donations made to COFAR (Page 3)

A possibility remained in early June that the conference committee would cut the Senate funding for the state-operated residences by an additional \$460,000.

The House and Senate also rejected amendments to restore cuts in the governor's proposed budget for state service coordinators who work with DDS clients in the community system to ensure that they receive adequate services. The governor's budget would have increased the DDS administrative account, which funds service coordinators, by \$1.7 million over current-year funding. The House and Senate each cut this increase roughly in half.

Neither the House nor Senate approved proposed amendments to restore any funding to the developmental centers. According to DDS, the governor's budget itself
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PROVIDING TESTIMONY – Lauren Baletsa (left), who testified May 21 before a legislative committee about living with Prader-Willi Syndrome, which is often associated with autism, poses with Michael Marchese, vice president of adult services at Latham Centers, a residential facility that provides services to Baletsa. Baletsa was one of many speakers who urged passage of legislation that would expand state services to all people with developmental disabilities (Story below).

SPECIAL REPORT: Part II

Solutions eyed to the autism crisis

Facing a void in services and residential placement opportunities available to their 26-year-old son with autism, Linda Davis and Chuck Yanikoski did what a growing number of parents in their situation have done around the country.

They started a volunteer-run, nonprofit organization to fill that gap and provide the missing services. The SAGE Crossing Foundation, based in their hometown of Harvard, MA, is now teaming up with a Department of Developmental Services provider to develop the state's first residential program for autistic adults that will offer farm work, crafts, and other daily activities.

A question that Linda Davis posed in an article she wrote
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State care facing shortfalls

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would not fund the continued operation of the Fernald Developmental Center, while the other remaining facilities would experience a \$2.6 million reduction in their budgets. This could result in reduced care and conditions in the facilities.

But those cuts in state care line items do not appear to have been used to boost most community-based line items. The governor proposed level funding for FY 14 in the family supports line item and the Turning 22 program, and proposed a slight cut in funding for autism services.

The House and Senate approved increases over the governor's proposals in family supports by \$2 million and autism services by roughly \$1 million, while the Senate approved a \$1 million increase in Turning 22. The House approved higher funding amounts for transportation and day program accounts than the Senate. It remained to be seen how the conference committee would resolve those differences.

Legislators reject DDS study

Despite mounting evidence that the state's ongoing privatization of services to persons with developmental disabilities is resulting in substandard and poorly monitored care, the Legislature this spring declined to undertake a comprehensive study of the issue.

Leaders in the House would not permit a proposed state budget amendment requiring an independent study of the Department of Developmental Services system to reach the floor of the chamber for debate. No amendment was filed in the Senate.

COFAR had urged the filing and passage of the amendment, which would have included an analysis of the impact of closing the Glavin Regional Center in Shrewsbury and the overall impact of the state's long-term policy of outsourcing residential and other services to corporate providers.

"Refusing even to allow debate on whether to have this study is unfortunately par for the course for the Massachusetts Legislature," said Colleen Lutkevich, COFAR executive director. "The providers seem to have a tremendous amount of influence in the Legislature, but the public and the most vulnerable among us with developmental disabilities don't appear to be a part of the discussion."

COFAR had suggested to key lawmakers that the proposed DDS study be similar in scope to an ongoing study of the Department of Mental Health system, which was approved by the Legislature last year. That study includes a review of the costs and benefits in closing Taunton State Hospital.

In September, House Speaker Pro Tempore Patricia Haddad, a member of the House leadership, made a strong statement in support of an independent study for Glavin and the DDS system as a whole. Haddad had previously

spearheaded the effort in the House last year to save Taunton State, which is in her district, from being closed.

"Someone has to be the first to say we're not afraid to have an outside study done to tell us what's wrong and what's right," Haddad said in a September meeting with Glavin families and a number of other legislators and their staffs.

Haddad was also critical of the administration's promise that services provided by facilities such as Glavin and Taunton State can be replicated in the community system. "There are more horror stories than good stories in the private sector," Haddad said. "You're asking people to trust a system that has a lot of flaws."

However, Haddad ultimately declined to co-sponsor the budget amendment in the House for the DDS study. After September, she made no further public statements regarding either a DDS study or Glavin.

In calling for the DDS and Glavin study, COFAR noted to lawmakers that thousands of people who are eligible for residential and other services from DDS, continue to wait for those services due to a lack of adequate funding of the system. Since 2008, funding for the developmental center line item in the state budget has been reduced by \$70 to \$80 million.

COFAR further noted that in closing state facilities, DDS was increasingly outsourcing care and services to corporate providers, which are nevertheless state-funded.

'Real lives' bill approved as House budget amendment

A legislative conference committee on the state budget was set to consider in early June whether to approve budget language allowing so-called self-directed services for people with developmental disabilities.

Originally re-introduced in the current legislative session as the 'Real Lives' bill, the measure was approved by the House in April as an amendment to the budget. The Senate, however, rejected a similar proposed amendment, sending the issue to the conference committee.

COFAR was continuing to object to provisions in the legislation that appear primarily intended to benefit corporate providers. COFAR is also objecting to the effort to adopt the measure as part of the budget, arguing that the action could result in approval of the legislation without either a public hearing or a recorded vote.

Self-directed services will reportedly give Department of Developmental Services clients and guardians more choice in the types of services they can receive and how and where the clients live. This year's bill (H. 151) was referred in January to the Children, Families, and Persons with Disabilities Committee.

COFAR maintains that the legislation, as written, appeared to give corporate providers both an unnecessary state subsidy for not serving clients and a disproportionate say in the development and operation of the self-directed services program.

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One of those provisions would establish a “contingency” fund, one of the purposes of which was to reimburse providers if clients choose to leave them in order to receive residential or other services from different providers.

COFAR was also objecting to a separate provision in the bill that would establish a “Self-Determination Advisory Board,” which would “evaluate and advise the Department on efforts to implement self-direction.” The legislation listed several provider-based organizations as members of the Advisory Board, including the Association of Developmental Disabilities Providers, which represents the providers, the Arc of Massachusetts, “support brokers,” and a number of community-based advocacy organizations. No state employee unions or organizations with a different point of view were included.

The bill also did not appear, as written, to assure that state service coordinators would maintain their current role in overseeing and coordinating community-based care to DDS clients.

Parent fights to keep guardianship of disabled son

Locked in a dispute with the Department of Developmental Services over the proper care for her intellectually disabled son, a Massachusetts woman has found herself fighting to retain her role as her son’s guardian.

DDS filed last fall in Middlesex Probate Court to remove Patricia Feeley, a COFAR Board member, as guardian of her 27-year-old son, Michael, and to appoint a Woburn attorney in her place.

Following a preliminary hearing in April, a probate court judge had scheduled a status update hearing in the case for June 17.

The attorney, James Feld, was described in the DDS petition as an “advocate” for Michael Feeley, but DDS acknowledged in a court document that Feld had never previously met Michael.

DDS has not alleged any abuse or neglect of Michael, and in fact, has described Feeley in court documents as “devoted to him” and “concerned for his well-being.” However, the Department contended that Feeley rejected several suggested residential placements for her son and was not acting in his best interest. The Department further alleged that Feeley’s home, where Michael has lived his entire life, was not safe because it had excessive “clutter” in it.

Feeley has actively sought for several years to place her son, who has type 1 diabetes, in a suitable DDS facility. She maintained that DDS was seeking to remove her as her son’s guardian because the Department didn’t want to provide a residential facility for him with 24-hour nursing care.

In a May 28, 2010 assessment, a physician at Children’s Hospital in Boston wrote that Michael’s blood glucose level

spiked at times “for no apparent reason,” and that “it is not possible to predict when that might occur.” The doctor’s assessment added that a nurse “needs to be present and able to attend to Michael’s needs at any time to avoid a delay in Mike receiving appropriate medical intervention.”

Feeley denied that her home was unsafe, and her attorney, Stephen Sheehy, contended that the clutter issue was a “red herring.” Sheehy noted Feeley herself had been seeking a suitable residential placement for her son, outside of her home. He added that DDS had failed to provide a clinical document, justifying its decision not to provide a setting for Michael with 24-hour nursing care on site.

Sheehy also said DDS last year informed Feeley that Michael was not entitled to a DDS care plan, known as an Individual Support Plan (ISP), which would specify nursing services for him, because he was not receiving any services from the Department.

Mavridis Foundation to match donations to COFAR

George Mavridis, a past president of COFAR and a longtime advocate for people with developmental disabilities, has come to the aid of COFAR in a major way with a matching fund contribution offer.

Mavridis, through his foundation, will match donations provided to COFAR up to a specified limit.

Colleen Lutkevich, COFAR executive director, said she was very thankful to Mavridis for his contribution and urged COFAR members to take up Mavridis’s challenge. “We hope George’s very generous offer will spur others to contribute to COFAR and help keep us viable for the foreseeable future,” Lutkevich said.

In addition to serving as president of COFAR, Mavridis served as president of the former Fernald League and is currently a member of the legislative committee of the VOR, a national advocacy organization with which COFAR is affiliated. As a VOR legislative committee member, Mavridis has traveled to Washington, DC, each June for many years to advocate in Congress behalf of intellectually disabled.

Mavridis was a longtime guardian of his cousin, Joanna Bezubka, who died in January 2012. Bezubka was a former resident of the Fernald Developmental Center and later lived in a state-operated group home north of Boston.

Member donations are vitally needed to enable COFAR to continue its research, advocacy, and public information services on behalf of people with developmental disabilities in Massachusetts and their families and guardians.

Donations can be mailed to COFAR, Inc., 3 Hodges St., Mansfield, MA 02048. You can also donate online by going to our website at www.cofar.org. Thank you!

Autism crisis solutions eyed

AUTISM, continued from page 1

for the journal *Granta* in August 2012 about her and her husband's life with their son Randy, appears to hold the key to their decision to found the SAGE Foundation. "Do we give him (Randy) up to an overwhelmed and under-funded system with an increasingly long waiting list, to an unaccepting world – and if so, when?" she asked in the article.

Davis and Yanikoski are not alone. An article in *Chicago Magazine* in March noted that parents of autistic children around the country are creating their own programs to provide services to them. But it doesn't appear parents and volunteers will ever be able to fill the gap in services without government help.

In Massachusetts, a legislative committee was considering proposed bills in late May that would help fill that gap by requiring the Department of Developmental Services to serve people with autism and other developmental disabilities who are currently not eligible for that care. The main such bill under consideration (H. 78) was referred in January to the Children, Families, and Persons with Developmental Disabilities Committee. COFAR included the bill on its legislative priority list for the coming fiscal year.

New state regulations and a new law have loosened the definition of "intellectual disability" to allow DDS to increase the number of people who are eligible for care and services from the Department. Nevertheless, Massachusetts appears to be the only state in the nation that does not grant eligibility for services unless the individual has an "intellectual disability" as measured by an IQ score.

Richard Glassman of the Disability Law Center said research done by the DLC indicates that every other state provides services based on at least some additional measures of disability such as substantial functional limitations or designated impairments such as autism.

As of mid-May, DDS was reportedly supportive of the concept of serving people with all developmental disabilities, but the Department had concerns about the budgetary cost of providing services to those people.

Lucy Berrington, a Board member of the Asperger's Association of New England (AANE), a key proponent of H. 78, said in mid-May that the organization was involved in discussions with DDS over the potential cost of the measure. She maintained that regardless of cost, the bill is needed to provide "a safety net" for people with autism who currently receive no services.

The AANE was also pushing for passage of a related bill that would require the Department of Mental Health to provide services to people with autism who also have mental illness. DMH currently excludes people with autism from receiving mental health services – a practice the AANE calls discriminatory.

At a May 21 public hearing before the Children and Families Committee, a parade of parents and guardians urged members of the committee to support H. 78 and

similar measures that would expand DDS eligibility standards. Several of the speakers told of their frustration in trying to get services for their children who have autism and related disorders such as Prader-Willi Syndrome, which causes compulsive over-eating and related health problems.

Among those testifying was Lauren Baletsa, a 43-year-old woman with Prader-Willi Syndrome (see photo on Page 1), who said her compulsion to eat drove her to forge her father's signature on checks to buy food. She was able to control her eating compulsion only after she entered a state-funded program.

Many other speakers, however, said they were unable to obtain services of any kind for their children because their IQ scores were just above the DDS cut-off point. Karen Kadzen-Pandolfi testified that her son, who is now 23, lost his services a year before because his IQ was measured at 71, one point above the DDS cutoff score. She said her son has a problem with aggression and violent behavior. As a result, Kadzen-Pandolfi said, she must now stay home from her job to care for him. "My life is on hold," she said. "I keep searching for an answer, but there are no answers."

For many, passage of H. 78 appears to offer the only hope for someday receiving government services.

For people like Kadzen-Pandolfi's son, who score just above 70 on IQ tests, there may be hope for services under the new law and regulations that loosened DDS's definition of intellectual disability. The regulations now state that DDS psychologists "should" consider the "standard error of measurement" in interpreting IQ scores and must base their decisions on standards set for intellectual disability by an independent clinical authority.

However, for people whose IQ scores fall outside the statistical margin of error (usually higher than 75), but who still have significant limitations in adaptive functioning, passage of bills such as H. 78 appear to offer the only prospect for someday receiving government services.

Although DDS has not indicated whether it will support H. 78, the governor's Autism Commission in March listed the expansion of DDS eligibility to people with both autism and IQ's over 70 as its top priority. An Autism Commission report criticized both inadequate staffing levels in community-based residential care for people with autism and low compensation of staff, which has led to high turnover. The report also noted that many adults with autism live with elderly parents and have "few options for future housing and support."

The report did not discuss where the funding for initiatives to expand services would come from.

In testimony delivered to the Children and Families Committee, David Kassel, COFAR communications director, maintained that the public lacks an understanding of the immense need for services among people with developmental disabilities. He noted that the May 21 hearing was not covered by any mainstream media outlets.

Sen. Warren's staff tours Wrentham Center

Two members of U.S. Senator Elizabeth Warren's staff toured the Wrentham Developmental Center on May 15 at COFAR's request.

Roger Lau, Warren's chief of staff in Massachusetts, and Kate Moore, a member of the senator's staff, toured both the facility and a group home in Attleboro. On hand for the Wrentham Center tour was Department of Developmental Services Regional Director Richard O'Meara and three top officials with the Executive Office of Health and Human Services, in addition to administrators at the Wrentham facility.

Colleen Lutkevich, COFAR executive director, accompanied the group on the facility tour. Lutkevich, whose sister Jean is a resident at Wrentham, later said she thought it was important that Warren's staff was able to see first-hand the level of care that is delivered in Intermediate Care Facilities for the developmentally disabled (ICFs/DD).

Wrentham has not been part of the Patrick administration's plans to close ICFs/DD in Massachusetts. However, new admissions there have been blocked in recent years other than for residents transferred from other developmental centers slated for closure.

In December 2012, COFAR sent a letter to Senator Warren, asking that she support COFAR and the national VOR in criticizing a recent proposal by the National Council on Disability to close all residential "institutions" for the intellectually disabled. The NCD has defined an institution as "a facility of four or more people who did not choose to live together." The NCD is an independent federal agency that advises the president and Congress on issues of concern to the disabled.

DDS makes some progress on late license reports

The Department of Developmental Services appears to have made progress in licensing residential care providers and posting licensure information on the Department's website, but a number of licensure reports appear to remain out of date on the site.

In a follow-up survey in mid-May of licensure information posted on the DDS website for 30 providers around the state, COFAR found that the number of out-of-date licensure reports had dropped from 11 as of last November to seven.

In a May 29 response to a query from COFAR concerning two of the providers, which had been operating with expired licenses, DDS stated that new licenses had been issued to the two providers and that up-to-date licensure reports had been posted online.

The COFAR Voice had reported in March that the Center for Human Development's residential and day licenses had expired in October 2012. As of May 14, the latest licensure

report for the provider on the DDS site appeared to be six months out of date. However, following COFAR's query, DDS indicated that CHD had been granted a two-year license in February.

Also as of mid-May, there was no updated licensure report on the DDS site for Independent Living for Adults with Special Needs. That provider's license had expired in August 2012, and the provider's latest licensure report appeared to be eight months out of date on the DDS site.

In the May 29 response to COFAR, DDS stated that Independent Living had been granted a new license as of December 2012. *The COFAR Voice* had previously reported that a third provider, Vinfen, had been operating for at least a month after its licenses expired in November 2012. As of mid-May, however, a licensure report dated January 2013 was posted on the DDS site. The new licensure report indicated that Vinfen had been granted new licenses to operate through January 2015.

The previously expired licenses appeared to be the result of an inability on the part of DDS to approve the providers' license renewal applications within a prescribed time frame of 60 to 120 days, possibly due to a lack of adequate staffing in the Department. DDS regulations allow providers to continue to operate with expired licenses as long as the providers submit license renewal applications more than 60 days prior to the license expiration dates.

NJ lawmakers act to save developmental centers

A legislative committee and the full legislative Assembly in New Jersey had approved separate bills as of early May that would save two state-operated developmental centers in that state from closure.

One of the bills would establish a task force, which would be required to study the capacity of the community-based system in New Jersey prior to the closures of any developmental centers.

The actions in the New Jersey Legislature appear to stand in contrast to the Massachusetts Legislature, which declined in the current session to support a proposed study of the DDS system in this state (see story on Page 2).

The task force bill was approved in March by the New Jersey Senate's Health, Human Services and Senior Citizens Committee. In April, the full Assembly approved the separate measure, which would require that at least one developmental center remain in each of four designated regions of the state.

Both bills would overturn the recommendation of a previous task force in New Jersey that both the North Jersey and the Woodbridge Developmental Centers in that state be closed. However, if the bills are passed by the full Legislature, they would be likely to be vetoed by New Jersey Governor Chris Christie, who is a proponent of privatized, community-based care.

Colleen Lutkevich, COFAR executive director, said that the task force bill, in particular, might still provide a "roadmap" for other states to follow.

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Please renew your COFAR membership or make a larger donation and the George Mavridis Foundation will match your contribution! (see story on Page 3) *Donations can mailed with this form to 3 Hodges St. Mansfield, MA 02048, or you can donate online at www.cofar.org.*

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