



The COFAR VOICE

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VOLUNTEER EFFORT – COFAR Board members Pat Feeley (left) and Kathleen Houghton spent a couple of hours at the State House in Boston in December, helping deliver *The COFAR Voice* December issue to the offices of state House and Senate members. We appreciate their efforts and the efforts of all of the volunteers who have given up their time and shoe leather, delivering the newsletter to legislators.

SPECIAL REPORT

Autism services present new challenges for state

It has been compared to a tsunami in its potential to overwhelm the resources the state has to cope with it.

Autism or Autism Spectrum Disorder (ASD), which is actually a range of cognitive disorders, is one of the fastest growing categories of developmental disabilities facing public agencies and caregivers today.

“We’re all going to have to figure out a way to deal with this issue in coming years,” said Thomas Frain, COFAR president. “This will present a major challenge to both the state and federal governments and to advocates and guardians alike.”

Frain, an attorney, represented a developmentally disabled woman in a lawsuit last year that has resulted in

Please see AUTISM, Page 3

COFAR seeks reviews of DDS care

As part of the Legislature’s ongoing budget deliberations for the coming fiscal year, COFAR is urging that lawmakers require a comprehensive, independent study of care in the Department of Developmental Services system.

The proposed study would include an analysis of the costs and benefits of closing the Glavin Regional Center in Shrewsbury and the overall impact of the state’s long-term policy of privatizing human services.

“This may be our last chance to gain an independent perspective on the true cost of corporate care of the developmentally disabled,” said Colleen Lutkevich, COFAR executive director. COFAR has long voiced concerns to lawmakers about the state’s increasing outsourcing of services to corporate providers.

The state took little time to consider a \$1 transfer of Glavin Center land to town (Page 4)

In early March, state Representative Matthew Beaton, a Republican lawmaker from Shrewsbury, said he planned to file an amendment to a state budget bill in the House to require an independent study of closing Glavin. In a message sent to Beaton on March 8, COFAR urged the lawmaker to propose the Glavin study as part of an expanded study of the full DDS system.

COFAR suggested in an email to key lawmakers in February 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 small number of other legislators.

Please see STUDY, Page 2

COFAR urges DDS study

STUDY, *continued from page 1*

She 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."

Since September, however, Haddad has made no public statements regarding either a DDS study or Glavin, and has left it to Beaton to take the lead in advocating for the Glavin study in the House. Haddad's office has referred all inquiries about Glavin to Beaton.

In calling for the DDS and Glavin study, COFAR noted to lawmakers in the February email message 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. In addition, there does not appear to be evidence that the administration's policy of phasing down and closing Glavin and other developmental centers has reduced the number of people waiting for DDS services or shortened the waiting times. Nor has that policy prevented continuing cuts in most DDS community-based budget line items.

Since 2008, funding for the developmental center line item in the state budget has been reduced by close 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. "We have found that corporate-controlled care tends to be focused on the bottom line and on cutting costs, often with reductions in the quality of that care," COFAR's statement to lawmakers continued. "The state employees who deliver care to people with intellectual disabilities in Massachusetts range from clinical psychologists to service coordinators to direct-care workers. They are among the most highly trained and effective workers in the country at what they do. It is these jobs that are being outsourced by the Patrick administration to private corporations."

In the email message to key lawmakers, COFAR also called for legislative reviews of the licensing process for DDS group homes and of the salaries of corporate provider executives. In urging the reviews of the DDS group home licensing process, COFAR noted that its own review found that an undetermined number of providers appeared to be operating with expired licenses, apparently because of a lack of an adequate number of staff in the Department to review licensure renewal applications (See story on P. 5 on licensing delays).

COFAR also previously found that DDS licensure staff did not appear to have followed up in several cases on deficiencies found in inspections of group homes, and that many licensure reports appeared to focus on whether vendors were achieving broad and often vaguely worded goals.

In addition, COFAR last year surveyed more than 30 vendors and found that the average compensation to their top executives increased by almost 17 percent between Fiscal Year 2008 and 2011, while average wages to direct-care workers in those same companies fell by nearly 2 percent during that time. As of Fiscal Year 2011, the average vendor executive's annual compensation in the survey sample was \$230,000.

COFAR has requested that language requiring the DDS and Glavin study be inserted into state budget legislation, which was before the House Ways & Means Committee as of early March.

As of early March, only about 14 residents were left at Glavin, down from 55 residents in 2008. Glavin is one of four state-run developmental centers that were targeted for closure in 2008 by the Patrick administration.

'Real lives' bill re-filed with few changes

For the second year in a row, a bill has been introduced to enhance the ability of Department of Developmental Services clients and their guardians to "self-direct" services.

But COFAR is continuing to object to provisions in the bill that appear primarily intended to benefit corporate providers.

Self-directed services will reportedly give 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 continues to have a number of concerns about provisions in the bill, which appear 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.

One of those provisions would establish a "contingency" fund, one of the purposes of which is to reimburse providers if clients choose to leave them in order to receive residential or other services from different providers. "This provision appears to us to constitute a state subsidy to providers for not providing services," said COFAR Executive Director Colleen Lutkevich.

COFAR is also objecting to a separate provision in the bill that establishes a "Self-Determination Advisory Board," which would "evaluate and advise the Department on efforts to implement self-direction." The legislation lists as members of the Advisory Board several provider-based organizations, 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 would be included.

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

Autism poses challenges

AUTISM, *continued from page 1*

new state regulations that will expand the number of people with autism and other developmental disabilities who are deemed eligible for care from the state. As a result of his role in the litigation (*Tartarini v. Department of Developmental Services*), Frain was selected by Massachusetts Lawyers Weekly as a Lawyer of the Year for 2012.

Autism Speaks, a national organization that funds research into the causes and treatment of ASD, defines ASD as a group of “complex disorders” of brain development that are characterized by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. Some persons with ASD excel in visual skills, music, math and art. In general, however, people with ASD share an inability to adapt to societal norms and to function successfully without help.

The crisis in care for people with ASD is particularly acute at the young adulthood stage. Special education services for children with autism, which are provided by local school districts, generally end when those children reach the age of 22. At that point, those young adults enter the world of adult-based services, which may not be there for them.

The SAGE Crossing Foundation, a nonprofit organization that provides farm and crafts-based programs for people with autism, has projected that some 220,000 children with autism will reach adulthood in next decade in the nation, and close to 6,000 of those people will be living in Massachusetts. In a 2009 report, the Foundation wrote: “Given that the tidal wave of adult autism is already clearly visible, rushing toward us from the horizon, it is time for us to prepare for its landing, and begin to develop new models of care for this population.”

Like many other states, Massachusetts has few viable models of care for many adults with ASD. One of the key reasons for that is that the statutes that govern DDS only require the Department to serve adults with “intellectual disabilities,” which the Department defines largely in terms of IQ scores.

The new state regulations and a new law stemming from the *Tartarini* case 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. The regulations now require DDS to tie its definition of intellectual disability to a clinical authority, the American Association on Intellectual and Developmental Disabilities, which contends that intellectual disability exists at a score as high as 75. Prior to *Tartarini*, DDS had been routinely denying eligibility to anyone scoring above 70.

But even under the new, more liberal regulations, someone who scores higher than 75 on an IQ test is likely to be rejected by DDS for services even if that person meets a separate requirement in the law and regulations that he or she has a “significant limitation in adaptive behavior.”

While they may have severe limitations in adaptive behavior, sometimes requiring 24-hour supervision, many people with ASD have IQs that are higher than 75. As a result, an untold number of those adults with severe cognitive disabilities do not meet the DDS definition of having an intellectual disability, and they find that they are suddenly ineligible for services of any kind.

Richard Glassman, litigation director with the Disability Law Center, a federally funded legal assistance agency, maintained that given that there are potentially thousands of people in Massachusetts who have developmental disabilities and yet are not considered intellectually disabled by DDS, the Department needs to provide services on a broader basis. The DLC has helped draft a bill in the current legislative session (H. 78, S. 908), which would require DDS to provide services to people with autism and other developmental disabilities that don't fit the Department's definition of intellectual disability. The bill was referred in January to the Children, Families, and Persons with Developmental Disabilities Committee. COFAR has included the bill in its own legislative priority list for the coming fiscal year.

Even among children under 22, however, the need for services appears to far outstrip the availability of those services. “As it stands today, Massachusetts struggles to serve only a fraction of children and adults living with disabilities...” Julie Fitzpatrick and Daniel Shannon of the Massachusetts Developmental Disabilities Council [wrote recently](#) in *The Boston Globe*. Fitzpatrick and Shannon stated that one of the few autism specific services that exist in Massachusetts supports children under the age of nine, but it is limited to a maximum of 130 children, hundreds less than the number that qualify.

Meanwhile, the governor's budget proposal for the coming fiscal year would cut funding for the DDS Autism Division, which manages the children's autism program.

A second program, operated by the Department of Elementary and Secondary Education and DDS, served 430 children in Fiscal Year 2009 and helped provide home-based alternatives to residential special education placements. But there were some 200 children on the waiting list that year. By Fiscal Year 2011, due to funding cuts in the program, the number of children in the program had apparently dropped to 340, according to a DDS annual report.

A housing and job shortage

In addition to a lack of services, young adults with ASD are facing both a housing and job shortage. This is in part because many people with ASD have cognitive deficits and often exhibit socially unacceptable behaviors that make them unlikely to get hired, even for simple jobs.

The Foundation for Autism Support maintains that “a national crisis now exists regarding the lack of quality group homes, community housing options, job training and vocational programs for adults with autism.”

[According to the Foundation](#), eighty percent of adults with ASD still live with aging parents, raising the question

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and fear in those parents as to what will happen to their children when they are gone. In addition, according to the Foundation, studies document that about 80 percent of adults with ASD are either unemployed or under-employed.

And in what appears to be equally shocking, the Foundation cites a statistic that while more than 600,000 adults with autism live in the United States, as of 2008, there are fewer than 30 identifiable residential providers specializing in autism-specific residential homes, facilities and services in the country. These facilities serve only around 1,500 to 2,000 adults with autism, the Foundation stated.

[A 2012 survey by Autism Housing Pathways](#), a Massachusetts nonprofit, projected a need for up to 10,000 units of affordable housing for adults with autism over the next 20 years "beyond those provided by DDS." (The next issue of *The COFAR Voice* will discuss possible solutions to the autism crisis.)

State had little discussion over \$1 Glavin land deal

State records indicate that the Patrick administration took a minimal amount of time last fall in considering whether to transfer 69 acres of state land at the Glavin Regional Center at virtually no cost to the Town of Shrewsbury, and engaged in no apparent written internal discussions over the transfer of the land.

The records indicate that Department of Developmental Services Commissioner Elin Howe had at least 60 days, starting in mid-October, to consider whether the Glavin land was needed by hers or any other agency. However, Howe took only 14 days before declaring the land surplus and available for transfer to the town, according to the records, which were obtained under a Public Records Law request.

Governor Deval Patrick signed a bill in August authorizing the lease of the land for \$1 a year to the town for the next 25 years. The land, worth an estimated \$12.9 million, will be used for both recreation and farming. COFAR has questioned why the disposition of the land was not subject to a formal planning and reuse process, as has been the case with land at three other developmental centers marked for closure.

In contrast to the quickly decided Glavin land deal, discussions over the disposition of land at the Fernald Developmental Center, also marked for closure, have taken several years and have resulted in a plan for the City of Waltham to buy the property from the state at "fair market value," according to *The Waltham Daily Tribune*.

In an October 12 letter, Carole Cornelison, commissioner of the Division of Capital Asset Management (DCAM), the state's property management and public construction agency, asked Howe to inform Cornelison's office of "the (Glavin) property's present and foreseeable use(s) and

advise whether this parcel of state-owned land is available for other purposes."

The letter noted that DCAM was planning to lease the land to the Town of Shrewsbury and requested that Howe respond within 60 days or ask for additional time if needed.

Howe apparently did not provide any response to Cornelison, other than signing a "transfer request" form for the land on October 26, 14 days after the DCAM commissioner's request.

The transfer request form, which was also signed by John Sites, DDS director for facilities management, and by then Health and Human Services Secretary JudyAnn Bigby, stated only that the property was declared surplus by DDS as of October 26. Bigby's signature was not dated. The transfer request form contained a notation that it was unknown whether the transferred property might be contaminated and a statement that any costs for surveying, remediating, and developing the property must be borne by the town.

The DDS records also included a one-page letter, dated October 30, from Sites to Rosemary Sammarco in the EOHHS Office of Leasing and State-owned Property, requesting that Bigby sign the transfer request form for the land.

COFAR received a total of nine pages of records about the land deal from DDS. In addition to the two letters from Cornelison and Sites and the transfer request form, the nine pages included a two-page copy of the legislation authorizing the \$1 lease arrangement, and a three-page site plan of the land. Neither DDS nor DCAM provided any records indicating there had been any discussion within DCAM, DDS, or EOHHS over whether the land should be subject to a reuse planning process or might have any other possible uses.

In October, COFAR sent an email to the state Inspector General, stating that the \$1 lease "effectively gives away for the next quarter century what appears to be a majority of the state land at Glavin to a non-state entity prior to, and outside of, a formal and deliberative reuse process for the property."

DDS provided records from previous years concerning proposals to transfer land at Glavin to the town and to lease land to a local soccer league, in one case for \$1,500 per year. Those records included internal correspondence going back to the 1990s. The most recent records were from 2008.

DDS also provided correspondence involving a bill filed by then Representative Karyn Polito in 2008 to transfer some of the Glavin land to the Department of Agriculture. However, there were no records provided concerning another bill filed by Polito in 2009 to establish a reuse committee for the Glavin land. That bill died in the Legislature's Bonding committee even though similar bills at the time for reuse committees at Fernald, Monson, and Templeton, were enacted into law.

Polito's bill had stated that the proposed reuse committee would be "mindful of the rights of current Glavin residents and their need for adequate and appropriate housing, clinical services, and appropriate staffing..."

DDS providers operating with expired licenses

Despite an apparent problem in maintaining a timely licensure approval process for providers that operate group homes and day programs throughout the state, the Department of Developmental Services has declined to provide information on either the extent of the problem or steps it may be taking to deal with it.

The Department also did not respond directly to a question from COFAR as to why several provider license approvals were taking longer than a prescribed timeframe of up to four months. The lack of timely approvals has resulted in an undetermined number of providers operating with expired, two-year state licenses.

In early January, COFAR asked DDS for any departmental correspondence, memoranda or reports that concern delays in the Department's approval of licensure applications for DDS providers. In a February 1 response to COFAR's records request, Robert Smith, DDS assistant general counsel, stated that the Department was "unable to identify any publicly accessible documents" on the matter.

COFAR made the public records request after a survey it undertook identified at least three providers — the Center for Human Development (CHD), Vinfen, and Independent Living for Adults with Special Needs — that were operating with expired two-year licenses as of mid-December.

The situation 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. That was the case with the three providers identified by COFAR, according to DDS.

In response to a written question from COFAR as to "why it is taking so long in each of these cases" for DDS to approve applications and issue new licenses, Smith stated only that: "The Department states the licensing process for the aforementioned providers has to date complied with the Department's regulations concerning licensure and certification...The Department strives to ensure that the licensure process is completed in as prompt and effective a manner as possible."

National disability panel draws fire

COFAR and the national VOR have raised concerns about ideological statements recently made by the National Council on Disability against residential care and treatment of both the intellectually disabled and mentally ill.

In a paper issued in December, the NCD called for the closure of all residential "institutions" for the intellectually

disabled, and defined an institution as "a facility of four or more people who did not choose to live together."

And in a statement issued in the wake of the Newtown shooting tragedy in December, the NCD appeared to express more concern over the possibility of "expanding institutionalization" of the mentally ill than in ensuring that people who pose a danger to others get needed treatment.

In a joint statement, COFAR and VOR called on the NCD to adopt "a thoughtful and inclusive planning process regarding the future" of care for people with disabilities, and not to wage "an ideological war against institutions." COFAR also voiced its concerns about the NCD in a letter to U.S. Senator Elizabeth Warren.

The NCD, an independent federal agency that advises the president and Congress on issues of concern to the disabled, has been a leading voice around the country against what it terms institutional care.

[In a January 11 letter to Vice President Joe Biden](#), in Biden's capacity as head of the president's gun violence task force, the NCD urged the vice president to avoid any measures that could unnecessarily institutionalize people, involuntarily commit them, or force treatment on them. The letter said little about what the task force could or should do to protect people's safety, such as recommending specialized, inpatient treatment for people whose disease renders them dangerous to themselves or others.

DDS FY '14 budget raises questions

As the House Ways and Means Committee grappled in mid-March with the Governor Patrick's proposed state budget for the coming fiscal year, questions remained over whether the committee would agree to the governor's tax increase proposal to help fund modest increases in some line items for services for the developmentally disabled.

DDS Commissioner Elin Howe noted in a conference call with advocates in January, when the governor proposed his budget, that his budget would depend on legislative passage of his proposal to increase the income tax rate to 6.25 percent. The state's current revenue estimate for the coming fiscal year "doesn't support all of what we're trying to do," she said.

A poll by the University of Massachusetts Lowell and *The Boston Herald* in early March showed some unexpected public support for the governor's tax plan, which also called for lowering the sales tax rate from 6.25 percent to 4.5 percent, and eliminating some income tax deductions. The poll found that 48 percent of registered voters supported the governor's plan, 46 percent opposed it, and 6 percent were undecided.

Governor Patrick's proposed budget calls for increasing a number of DDS line items, but there are also a number of projected cuts in it in both community-based line items and the state service coordinators line item. The developmental centers line item would be cut by \$10.4 million, bringing the total amounting cut to nearly \$80 million since FY 2009.

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