



The COFAR VOICE

The Official Newsletter of the Massachusetts Coalition of Families and Advocates for the Retarded, Inc. (COFAR)

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Turning-22 funding stalls in House budget *Competing budget pressures cited*

Faced with competing budgetary pressures, the Massachusetts House has rejected a proposal for a \$4 million increase in critical Turning-22 funding for persons with mental retardation.

The issue now goes to the Senate, which will begin deliberations in late May or early June on the state budget for the upcoming fiscal year.

Turning-22, which has been level-funded for several years, has become a key focus among advocates for persons with mental retardation this year. The program provides transitional funding for persons with mental retardation who reach the age of 22 and are no longer eligible for school-based special education programs.

In an early morning caucus on April 25, House leaders told members they would have to choose between increased funding for programs such as Turning-22 and increased local aid to cities and towns, according to advocates for persons with mental retardation.

An amendment sponsored by Representative Thomas Sannicandro, D-Ashland, would have increased the Turning-22 line item by \$4 million, from \$6.47 million to \$10.47 million. The amendment was never considered by the House.

“Given that the Legislature and governor are in favor of long-overdue increases in several DMR programs, we’re hopeful that the Senate, at least, will see the importance of a significant increase as well in Turning-22, which is critical to so many people,” said COFAR President David Hart.

On April 10, the House Ways and Means Committee proposed a \$1 million increase in Turning-22 funding as part of a 4.1 percent proposed increase in the total Department of Mental Retardation budget—to \$1.17 billion. The total increase was larger than the 3.6 percent increase proposed in the governor’s budget plan in January. The DMR funding is

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1,000 DAYS WITHOUT A CONTRACT --Fernald Developmental Center staff members and members of the Massachusetts Nurses Association began an afternoon picket in front of the Center on April 27 to protest the lack of a contract. Similar pickets were held at state facilities throughout the Commonwealth (Story on Page 5)

Clinicians in short supply among DMR providers *DMR report provided under Public Records request*

Clinical professionals such as registered nurses and licensed psychologists are in short supply in provider-run residences for persons with mental retardation, according to a survey done for the Department of Mental Retardation.

The survey, done by the Center for Developmental Disabilities Evaluation and Research (CDDER), was obtained under an appeal by COFAR to the state Public Records Division (see story on public records battles on page 2.)

CDDER, which is associated with the E.K. Shriver Center

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Clinicians seen lacking

CDDER, *continued from Page 1*

at the UMass Medical School, reported that less than half the provider agencies surveyed in five regions across the state employed nurses for care of residents in group homes or for other services. In the Metro Boston region, only 28 percent of surveyed providers had a registered nurse on staff; only 11 percent had a licensed practical nurse; and only 1 percent had any advanced nursing services.

For agencies that did not have RNs paid for through DMR contracts, more than half used non-clinical staff to perform health coordination activities.

“This is yet more evidence that the community-based system of care for persons with mental retardation remains under-funded and understaffed,” said COFAR Executive Director Colleen Lutkevich. “The community system is simply not equal to or better than the state facilities.”

A call to DMR Commissioner Gerald Morrissey’s office for comment on the report was not returned.

The report stated that RN and LPN nursing responsibilities include nursing care, clinical assessments and consultations, coordinating care for individuals, and training of direct-care workers to administer medications. Advanced nursing services include medication evaluation and monitoring, emergency response and crisis management, and psychiatric assessments and evaluations in addition to nursing care.

In the Metro Boston region, only 28 percent of surveyed providers had a registered nurse.

The CDDER report also stated that less than 20 percent of provider agencies in each region employed Master’s level psychologists or behavioral specialists in providing any type of care. Responsibilities for those professionals include behavioral screening and development of behavior plans, counseling, and training of direct-care staff and emergency response and crisis management.

The figures were even lower for licensed psychologists, with only 2 percent of agencies in some regions using them for care, according to the report. Responsibilities of licensed psychologists include creating and monitoring psychological treatment plans, training and support for direct-care staff, and evaluations, psychological screening and counseling.

In addition, less than 5 percent of surveyed provider agencies in each region employed a psychiatrist for any type of care, and no agencies in the central or northeast regions employed any psychiatrists. Responsibilities of psychiatrists include development of treatment plans, psychological assessments and diagnoses, training of direct-care staff, and emergency response and crisis management.

The CDDER survey covered a total of 296 provider agencies. Data was collected for the period from 2002 to 2003.

The CDDER report stated that DMR had asked for a clinical resources capacity study using data from DMR contract files. The original design of the project had called for surveys to be sent directly to each provider agency. However, DMR determined that its own area and regional staff had sufficient knowledge to complete the surveys themselves, the report stated. As a result, CDDER sent survey questionnaires to all area and regional DMR offices about contracted clinical resources in provider agencies in their area or region. Inconsistencies were reported between information in the DMR contracts database and current staffing in the agencies.

COFAR fighting for DMR documents

‘Stonewalling’ seen at DMR

COFAR has been battling with the Department of Mental Retardation on several fronts for key documents concerning the care of persons in the departmental system.

DMR has declined to release a variety of records pertaining to its new eligibility policy for services and its specifications for the construction by housing authorities of new community-based housing.

“It’s gotten to the point where DMR appears to be stonewalling,” said COFAR Executive Director Colleen Lutkevich.

In one case, DMR released a requested report on resources available to DMR community-based providers only after having been ordered to do so by the state Supervisor of Public Records (see CDDER story on page 1).

Meanwhile, another state agency, the Division of Capital Asset Management, has also declined to provide COFAR with internal evaluations relating to its own procurement process for community-based housing for former Fernald Developmental Center residents.

The following are highlights of the major records requests that COFAR has filed in the past year and where they stand:

Eligibility and provider supports reports

In October 2005, COFAR requested a series of reports and records referred to in DMR’s 2001-2004 Strategic Plan Summaries—a document that can be found on the agency’s website. Several of the requested records concerned DMR’s proposed new MASSCAP requirements for eligibility for services. One of the requested documents was a report prepared by the Center for Developmental Disabilities Evaluation and Research (CDDER) on the mental health and behavioral supports available to DMR providers.

In a November 1 response, Marianne Meacham, DMR’s General Counsel, cited an exemption to the Public Records statute in declining to disclose virtually all of the documents requested, including the CDDER report. The exemption

pertains to “memoranda or letters relating to policy positions being developed by the agency.” The exemption also states, however, that it does not apply to “reasonably completed factual studies or reports on which the development of such policy positions has been or may be based.”

COFAR appealed to Public Records Supervisor Alan Cote, who ruled in February that the MASSCAP records could be withheld under the Records Law exemption until DMR formally issued proposed new eligibility regulations. However, Cote stated that the CDDER report appeared to be a reasonably completed factual study. He ordered DMR to provide the report to COFAR within 10 days.

DMR subsequently asked Cote to reconsider his order to release the CDDER report, and provided him with an *in camera* copy of the report, the cover of which states that the report contained “preliminary findings” and was “not for distribution.”

COFAR urged Cote to uphold his ruling that the report be released, arguing that DMR should not be permitted to keep information secret under the guise of calling it incomplete.

In an April 5 decision, Cote stated that after a thorough review of the report’s contents, he stood by his previous decision that the report was purely factual and should be released to COFAR within 10 days. On April 27, six months after the original request was made, DMR provided the CDDER report to COFAR.

Community-based housing procurement evaluations

Since September 2005, COFAR has sought internal DCAM documents pertaining to internal evaluations of its procurement process for community-based housing (see story on COFAR housing procurement report on page 4). DCAM has declined to provide that documentation, citing another exemption to the Public Records law regarding internal evaluations done “prior to a decision to award a contract.” *The COFAR Voice* has reported that as of mid February, no contracts with housing developers had been signed even though DCAM had selected two private vendors in July 2005, seven months previously, to develop the housing.

Housing plans and specifications

In January 2006, COFAR requested written requirements, plans, and specifications developed for community-based housing for Fernald residents that was being developed by local housing authorities. In March, DMR stated in a letter that all of the housing authority projects were “still in the policy development process,” and that specific plans, specifications and requirements were therefore exempt from the Public Records law.

Fernald cost documents

In early March, COFAR requested records from DMR relating to the annual cost of operating the Fernald Center.

Media reports have put the cost of running Fernald at \$165,000 per resident, citing the state as the source of the information. COFAR believes this figure may include the cost of DMR administrative offices, which are housed at Fernald, and of medical and recreational facilities, which are used by both Fernald and community-based residents.

As of May 5, DMR had not provided any cost documents to COFAR. However, Department staff were “creating” a document with a detailed breakdown of (Fernald) expenses, according to an attorney with the state Division of Public Records. COFAR had asked the Division for help in obtaining the records.

“Amazingly, no single Fernald budget document exists,” Lutkevich said.

DMR demanding care charges from guardians

The Department of Mental Retardation has begun sending letters to guardians and other fiduciaries of persons in DMR care demanding immediate payment of outstanding balances for all charges for care, a number of guardians have confirmed.

In community settings, fiduciaries are required to pay 75 percent of all funds received from Social Security and other sources to DMR as charges for care. The remaining 25 percent is reserved for the personal needs of the person in DMR care.

According to the Dever Association for the Retarded, which first reported the situation in its April/May newsletter, DMR has threatened to report fiduciaries to a collection agency or have the fiduciaries’ future state income tax refunds intercepted.

One COFAR member, who asked not to be identified, told *The COFAR Voice* she recently received a letter from a collection agency stating that she owed DMR \$26,000 for the care of her son, who is a resident at a state facility. She said she had spent the money on care and other needs for her son, but was told she had not provided DMR with sufficient receipts going back several years for the services and other items purchased.

“Most parents and guardians are using this money legitimately for their loved ones, but may not in the past have provided DMR with all receipts. Now DMR is going after them,” said COFAR President David Hart. “It’s part of an attempt to break down the (fiduciary) system so that DMR can control all of the money itself. It’s unconscionable.”

A call to DMR Commissioner Gerald Morrissey’s office was not returned.

Many families, who received the DMR letters, feared they were being personally targeted, the Dever Association newsletter stated. Some fiduciaries had not paid the full 75 percent in charges for care because clothing, medical co-

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payments and other expenses of their wards were greater than the remaining 25 percent of their Social Security or other income. In addition, as a result of recent transfers of several persons from facilities to community settings, DMR has stopped paying for some services, such as podiatry, that the agency provided at the state facilities, according to the newsletter.

According to the newsletter, Dever Class Action Counsel Neil Moynihan sent a letter to DMR in December protesting the DMR collection letters and stating that DMR's threat to take fiduciaries' personal state income tax refunds was not permissible under its own regulations.

At a subsequent meeting in January 2006, DMR promised to send letters to fiduciaries clarifying the charges for care, but no letters have been received, the newsletter stated. DMR then reported fiduciaries to a collection agency which, in some instances, was making daily telephone calls, according to the newsletter.

Hart urged all DMR representative payees and guardians to keep all charges-for-care receipts and to contact their social worker or service coordinator with any questions relating to charges for care.

Community housing efforts falling short

COFAR report sent to feds

The Department of Mental Retardation's efforts to develop community-based housing for former state facility residents appear to be falling far short of the potential need.

That is one of several findings in a report on the DMR housing efforts, which was drafted by COFAR and sent in April to both U.S. District Court Judge Joseph Tauro and U.S. Attorney Michael Sullivan. Tauro has appointed Sullivan as Court Monitor in Ricci v. Okin, the ongoing litigation involving care provided to persons in the DMR system.

The 42-page report, which is available online at www.cofar-mass.org, notes that although DMR announced in 2003 that it intended to close the six remaining large state facilities for persons with mental retardation, starting with the Fernald Developmental Center, the Department has never publicly issued a plan showing how it would accommodate the resulting influx of more than 1,100 facility residents into community-based care. Thus far, COFAR has been able to identify DMR agreements to develop a total of 57 new community-based beds, which would appear to fall far short of the potential need.

The state's procurement process for community housing has thus far resulted in the selection of two private vendors—Toward Independent Living and Learning, Inc. (TILL) and CIL Realty of Massachusetts (CIL Realty) to develop the housing. The Division of Capital Asset Management selected

TILL and CIL Realty in July 2005 to develop a total of 39 beds for Fernald Center residents.

The COFAR report stated that some housing for Fernald Center residents and other persons served by DMR was also being developed in partnership with the Department of Housing and Community Development. DMR provided COFAR with two letters written by DMR Commissioner Gerald Morrissey in August and September 2005 concerning applications submitted by DMR in partnership with the Chelmsford and Billerica housing authorities to develop special needs housing for up to 18 persons with mental retardation.

In the letter concerning the Billerica Housing Authority, Morrissey stated that housing would be created for up to 10 residents of the Fernald Center "who are seeking community placements."

The total of 49 community-based beds earmarked for Fernald residents appears to be well short of the 80 beds specified in DMR's 13-point plan.

According to the COFAR report, the number of community beds earmarked for Fernald Center residents appears to consist of the 10 beds projected to be created by the Billerica Housing Authority and the 39 beds awarded to TILL and CIL Realty. That total of 49 community-based beds earmarked for Fernald residents is still well short of the 80 beds specified in a 13-point plan issued by DMR in 2004 for closing Fernald.

As *The COFAR Voice* has previously reported, both TILL and CIL were selected despite having submitted proposals to DCAM in response to a Request for Proposals that were deficient in several key respects.

Among the other new findings in the COFAR report are the following:

- DCAM selected TILL without knowing whether TILL's proposed group homes were still available to the vendor to purchase.
- DCAM's RFP failed to include requirements necessary for selecting the most qualified developers and contractors.
- DCAM diluted and misinterpreted site identification requirements in its RFP.
- Neither CIL Realty nor TILL's proposals appeared to show any differentiation between "special-needs" and non-special-needs homes.
- TILL has had a record of substantiated cases of abuse and neglect in group homes it has managed.

Turning-22 funding at issue

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part of a proposed \$25.3 billion spending plan for the next fiscal year that has focused on health care and higher education as growth areas in state government, according to the State House News Service. Among the DMR line items, the Turning-22 program was projected to fall short in meeting the needs of an expected increase in the number of persons with mental retardation turning 22. Next year, 620 students were projected to need DMR services, up from 450 in the current year.

In other DMR and DMR-related accounts, the House Ways and Means budget plan would accomplish the following:

5930-1000: Facilities: Increase of \$5.9 million, or 3.5 percent, to \$171.9 million. This was larger than the \$1.4 million increase in the governor's budget proposal. The full House subsequently increased this line item by an addition \$150,000.

5920-2010: Community State-ops: Increase of 2.04 percent to \$121.9 million. This was smaller than the 2.22 percent increase proposed by the governor.

5920-3010: Autism: Increase of \$1 million to \$2,200,000. The governor had level-funded this account at \$1,200,000.

1107-2501: DPPC: Increase of 7.3 percent to \$1.9 million. This was more than the 6.9 percent increase proposed in the governor's budget.

Facility workers without contract

A union that organizes nurses and other clinical professionals at the state facilities for persons with mental retardation has begun stepping up a protest campaign against the continuing lack of a new contract with the Romney administration.

In late March, the Massachusetts Nurses Association, Unit 7, organized pickets at facilities across the state to note that workers had been without a contract for 1,000 days (see photo on page 1). As of late April, with the lack of a contract reaching its 1,030th day, the union was running advertisements in newspapers around the state, including *The Boston Globe*, protesting the lack of a contract.

Tom Breslin, MNA Unit 7 coordinator, said the main sticking point in the contract dispute centers around the administration's proposal to provide higher raises and bonuses for some job classifications than others. MNA is accusing the administration of attempting to split the union's ranks. The administration has maintained that it is responding to market

conditions, which make it difficult to recruit registered nurses, in particular. Breslin maintained that it is difficult to recruit workers for all jobs at facilities such as Fernald because the pay and benefits are relatively low there, even though they are higher than in most community-based settings.

Breslin said the state had proposed to give several—though not all—categories of registered nurses pay raises of between 12 and 14 percent over three years, whereas other professionals, such as physical and occupational therapists, psychologists and physicians were being offered 8 percent raises over the same period. "We're proposing a more consistent treatment" of worker raises, Breslin said, adding that the union had also proposed revamping the pay-scale itself.

Beth Gray-Nix, who represents occupational therapists at Fernald, said there are currently only four full-time-equivalent occupational therapists to serve more than 200 residents. Last year, one of the facility's occupational therapists retired, she said, and the administration has refused Gray-Nix's request to replace the person.

Medicaid cuts in limbo

Medicaid funding to the states, which helps pay for services to persons with mental retardation, appears to be in limbo as Congress grapples with disagreements over a federal budget resolution for the upcoming federal fiscal year.

In mid-April, House efforts to pass a Fiscal 2007 Budget Resolution failed, according to the National Voice of the Retarded, which has mounted a lobbying campaign against further cuts.

According to the VOR, in mid-March, the Senate had passed a 2007 Budget Resolution that contained no instructions to cut Medicaid and increased discretionary spending, including Medicaid, to Fiscal Year 2005 levels, rejecting the president's recommended spending cap.

However, in late March, the House Budget Committee proposed funding cuts for discretionary programs of \$8.8 billion in fiscal year 2007 and \$169 billion over five years, and proposed reducing entitlement program spending by \$6.8 billion over five years. The committee also proposed significant increases to defense-related spending as well as \$228 billion in tax cuts over five years, the VOR reported.

The House Budget Committee deal fell apart, however, when a majority of House members expressed concern about overall spending limits and instructions to cut discretionary programs.

The congressional debate comes on the heels of passage by Congress of a federal budget bill in February that would cut Medicaid funding to the states by at least \$6.9 billion over the next five years. The Deficit Reduction Act of 2006 allowed states to cap the number of people served under Medicaid-funded, community-based care.

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COFAR
3 Hodges Street
Mansfield, MA 02048
Phone: 508-339-3379
Fax: 508-339-5034

David Hart, President djhartd@comcast.net
Colleen Lutkevich, Executive Director colleen.lutkevich@verizon.net
David Kassel, Newsletter Editor dkassel@earthlink.net

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COMPREHENSIVE CARE
FOR ALL PERSONS WITH MENTAL RETARDATION

COFAR
3 Hodges St.
Mansfield, MA 02048