



# The COFAR Voice

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

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UP CLOSE AND PERSONAL — Wrentham Developmental Center resident Tom Doherty meets Red Sox third baseman Xander Bogaerts (back to camera), at Sox spring training camp in March. (Photo by Fenway Sports Management)

## From Wrentham to Fort Meyers: a dream comes true

[This article was written by Mary Ann Ulevich, Tom Doherty's cousin and guardian]

Tom Doherty, a resident of the Wrentham Developmental Center, had a lifelong dream of watching the Red Sox at spring training.

His dream came true this past March when two Wrentham Center staff members, Deborah Mullett and Chris Sawtelle, accompanied him and a housemate, Ed, on a trip to Fort Meyers in Florida. Once there, they participated in four days of games, barbecues, autograph sessions, and batting practice.

This trip is an example of the Wrentham staff's commitment to listen to residents' goals and find ways to achieve them. At Tom's annual ISP review last fall, the

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## State-operated homes not offered to most

Patricia Murphy knows first hand how difficult the Department of Developmental Services has made it for people either waiting for services or receiving inadequate services in privatized group homes to obtain state-run residential placements in Massachusetts.

Murphy had to file a lawsuit in federal court to force DDS to move her sister, Kathleen, from a privately operated group home to a state-run residence. DDS funds group homes run by both corporate providers and by DDS staff.

Patricia Murphy maintains that her sister was subjected to inadequate care in two separate privately operated group homes, and was inappropriately medicated in at least one of them. Yet, she said, DDS refused her repeated requests to move Kathleen to a state-operated residence until she filed the federal lawsuit last year.

Patricia Murphy and her brother, Kevin, co-

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## Sheltered workshops preservation fight advances

The effort to save sheltered workshops for people with intellectual disabilities from closure in Massachusetts got a major boost in late June as a legislative budget conference committee approved language to keep the facilities operating.

COFAR joined with the workshop proponents in urging legislators to adopt the protective language that states that the administration must continue to fund the facilities if people choose to remain in them. As of early July, the proponents were gearing up for a final effort to persuade lawmakers to override a possible line-item veto by Governor Deval Patrick of the protective lan-

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## Omnibus autism bill passes House

The House in April approved an omnibus bill that would extend state services to people with autism and Prader-Willi Syndrome, a condition often associated with autism.

COFAR and the Disability Law Center, however, have expressed concerns about the legislation (H. 4047) because it appears to arbitrarily name two conditions as eligible for services and to leave out other conditions. The measure was sent to the Senate Ways and Means Committee.

The bill includes language from a separate piece of proposed legislation that would establish a permanent state autism commission in Massachusetts.

The overall bill, which defines “developmental disability” as including autism and Prader-Willi Syndrome, was a compromise, negotiated between the Department of Developmental Services and a small group of legislators and advocates. The definition, which has not been aired in a public hearing, may violate both the federal Rehabilitation Act and the Massachusetts Constitution, both of which prohibit discrimination solely on the basis of disability.

State law currently restricts eligibility for services from DDS to persons having an “intellectual disability” as measured by an IQ score of approximately 70 or below. H. 4047 is intended to expand DDS eligibility to include persons with developmental disabilities. Intellectual disabilities are considered a subset of developmental disabilities.

COFAR and the DLC supported a previous definition of developmental disability in the proposed legislation. The previous definition stated that a developmental disability involves “substantial functional limitations” in three or more “major life activities.” That previous definition did not restrict developmental disabilities to specified conditions. Thousands of people in the state have developmental disabilities, but are not currently eligible for DDS care.

## State-operated group homes kept a secret

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plaintiffs in the lawsuit, maintain that they are not alone. The lawsuit charges that DDS has a policy of offering only corporate-operated residential care as an option to persons either seeking residential placements or who are dissatisfied with existing placements. According to the suit, this policy violates federal and state laws, which require people to be given a choice among all available settings of care. (The Murphys are represented by attorney Thomas Frain, COFAR Board president.)

Data from DDS and state budget data appear to confirm that the administration has placed a priority on supporting and expanding its corporate, provider-run residential network, potentially at the expense of state-run care. While new state-operated group homes have been built since 2008, they appear to have been intended to accommodate only the residents transferred from developmental centers marked for closure.

Thousands of intellectually disabled individuals are reportedly waiting for residential services in Massachusetts, although the state does not maintain an official waiting list that would publicly identify the number of people of waiting. Others, such as Patricia and Kevin Murphy, are apparently trying unsuccessfully to move family members or wards in the DDS system from provider-operated to state-operated care.

According to DDS data, the Department has built 49 new state-operated group homes since 2008. But **it has closed 28 such residences during that same period**, resulting in a net increase in state-operated residences of only 21. Other data show that there are apparently vacancies in state-operated group homes. Nearly all of the 99 residents living in the 28 residences that have been closed were moved to other state-operated residences.

According to DDS data, more than 87 percent of the 372 people who have been transferred since 2008 from four developmental centers marked by the administration for closure have gone either to state-operated group homes or to two remaining developmental centers. Only 47 people — less than 13 percent of the total — were transferred to corporate, provider-run group homes. This appears to reflect a choice made by families for state-run care.

Despite the apparent need and preference for state-run care, the Legislature approved a Fiscal Year 2015 budget on June 30 that would result in an increase in the provider residential line item of 16.5 percent in inflation-adjusted terms, more than double the 6.5 percent increase approved in the state-operated residential line item. (See budget story on Page 5.)

In a letter to COFAR President Thomas Frain, dated June 20, a DDS attorney maintained that it was “misleading” for COFAR to contend in a June 9 post on the COFAR Blogsite (at [www.cofarblog.wordpress.com](http://www.cofarblog.wordpress.com)) that the DDS has placed a priority on funding provider-run residences and that families in the DDS system prefer state-run care. The DDS letter contended that only a small fraction of DDS clients receive state-run care. The letter, however, did not address the point of the post that most DDS clients are unaware of state-run care as a residential option. The letter also did not respond to the post’s question why close state-operated residences when people are waiting for years for residential care.

## Competing 'Real lives' bills under consideration in Legislature

The state Legislature has been grappling this spring with two different versions of a bill intended to provide intellectually disabled persons with choice and "self-determination" in obtaining services from the Department of Developmental Services.

One of the versions of the so-called Real Lives bill, which was originally drafted by Representative Tom Sannicandro, contains several provisions that have turned it into a vehicle to benefit DDS corporate providers. COFAR has strongly opposed that version.

The second version of the self-determination legislation is a redraft of Sannicandro's bill, which was done by Senator Michael Barrett, co-chair of the Children, Families, and Persons with Disabilities Committee. Barrett's redraft greatly improved Sannicandro's version of the bill by removing the overtly provider-friendly provisions from it. However, while Barrett's redrafted bill was approved by the Children and Families Committee, the Health Care Financing Committee removed Barrett's redraft and restored Sannicandro's version in early June.

Sannicandro's version of the legislation has been heavily supported by the Arc of Massachusetts and other organizations allied with corporate providers to the DDS. Those organizations even attempted this spring to insert the measure as an amendment to the Fiscal Year 2015 state budget.

In late June, a House-Senate budget conference committee rejected the Sannicandro Real Lives budget amendment. That version, however, was still alive in early July in the form of the bill approved by the Health Care Financing Committee (H. 4237), and was set to be approved by the full House and sent to the Senate.

As COFAR has reported, Sannicandro's proposed legislation would put the Arc and the Association of Developmental Disabilities Providers (ADDP) on an advisory board created to help DDS develop the self-determination program, and would establish a "contingency fund" that would compensate providers financially when residential clients leave them for other providers (effectively paying them for not providing services).

Barrett's redraft not only would remove the contingency fund as well as all references to the Arc and the ADDP from the bill, it would require that more than 50 percent of the advisory board be made up of individuals who are financially independent of any DDS provider.

Under both versions of the bill, individuals with developmental disabilities or their guardians would be given a certain degree of authority to develop their own state-funded budgets from which they could select and "purchase" services identified in Individual Care Plans (ISPs).

While COFAR has indicated a preference for Barrett's redraft, both versions of the bill raise certain concerns. In a letter sent to Barrett's office in January, COFAR suggested that the bill include a requirement that participants in self-determination be provided with the explicit choice, as specified in federal law, of all residential options, including Intermediate Care Facility (ICF) and state-operated group homes, in addition to other forms of community-based and home-based care.

Thomas Frain, COFAR Board president, further maintains that in giving more authority to individuals and guardians on how to spend funds for DDS services, self-determination legislation increases the risk they will be exploited by private interests seeking the money for themselves.

## National background check bill advances

A long overdue bill requiring a national background check of persons hired to work in the DDS system was approved by the Legislature's Judiciary Committee.

The bill (H. 4125) had originally been sent to the Judiciary Committee in January 2013 and remained stalled there for almost a year and a half. In late May, the Judiciary Committee sent the measure to the House Ways and Means Committee.

## WORKSHOPS, continued from Page 1

The Patrick administration has announced its intention to close all remaining workshops in the state as of June 2015, although that date has reportedly slipped by six months because the administration did not propose sufficient funding to ensure the transfer of current residents from workshops to day programs.

In late April, at the urging of families, workshop staff, and advocates, the House of Representatives inserted language in the proposed Fiscal Year 2015 budget to protect the workshops. The line-item language (5920-2025) is intended to prevent the planned closures of sheltered workshops if existing participants choose to remain in them.

The Senate did not adopt the protective language. However, a House-Senate conference committee adopted the House language protecting the workshops. The conference committee also approved Senate language in a separate line item (1599-0200), which sets up a \$2 million reserve fund for the transfers of people from sheltered workshops to day programs. The conference committee also approved \$1 million in a similar reserve fund in the House version of the budget.

## **DPPC finds abuse in group home injury**

Charges of abuse and neglect have been upheld by a state agency against a staff worker in a Bedford group home in which Paul Stanizzi, an intellectually disabled man, was seriously injured last August.

COFAR obtained a redacted report in June from the Disabled Persons Protection Commission, which investigated the incident in which Stanizzi was at least partially paralyzed in the residence, which is operated by The Edinburg Center, Inc., a corporate provider to the Department of Developmental Services. According to the DPPC report on the incident, Stanizzi was found lying on his back in his room by the staff worker on the morning of August 27. The staff worker, who had been on the overnight shift, told investigators he had heard noises in Stanizzi's room during the night, but never investigated them and then fell asleep for several hours during his shift. He was the only staff on duty.

After finding Stanizzi unresponsive on the floor at 6:30 in the morning, the staff worker admitted he lifted Stanizzi up, in violation of his First Aid training, and put him in his bed. He then waited approximately 25 minutes prior to calling 911. The DPPC report recommended retraining for staff and regular checks by the provider to make sure staff are awake on overnight shifts, as well as documented bed checks. While the staff worker implicated in this case has reportedly been terminated, the report recommend he not be rehired in the future.

The Middlesex District Attorney's Office stated that it had closed a criminal investigation into the case without finding enough evidence to press criminal charges against the staff worker. The staff worker's name has not been publicly released.

## **We need your help**

COFAR, with support from and its affiliated organizations, the Advocacy Network and the Wrentham Association, provides unparalleled reporting on care and conditions in the Department of Developmental Services system. No other advocacy organizations for the developmentally disabled brings our level of scrutiny. Please contribute to enable us to continue our work. THANK YOU!

## **Pelletier case raises hopes in other DDS guardianship cases**

When Stan and Ellen McDonald tried to discuss a COFAR blog post with their son, Andy, about his June 6 birthday party, they were told to stop, or their visit with him in his group home would be terminated.

And when the parents of Sara Duzan violated a prohibition against talking with Sara about the use of restraints on her in her group home, their contact with her was cut off indefinitely.

The McDonalds' and Duzans' experience seems to illustrate a tendency by the state, its providers, clinicians, the courts, and other authorities to overrule families in the care of their loved ones with developmental and other disabilities. In many of these cases, family members who are not guardians of their disabled loved ones have been subjected to strict and punitive rules not only over contact with them, but even over subjects they can discuss with them.

However, in the high-profile case of Justina Pelletier, the Patrick administration agreed in early June that the young woman, who had been removed from her parents, did belong with her family. In that case, the state Department of Children and Families reversed its opposition to reuniting Justina with her parents, and Justina was finally sent home, after having spent nearly a year in a locked ward in Boston Children's Hospital and then in a residential facility in Connecticut.

"We're hopeful that the Pelletier case will have a favorable impact on the McDonald and Duzan cases and potentially others in which families have been barred from normal contact with their loved ones," said Colleen Lutkevich, COFAR executive director.

Justina Pelletier was removed from her parents' custody by a juvenile court judge after doctors at Children's Hospital disagreed with the family's diagnosis that Justina was suffering from mitochondrial disease. The Children's Hospital doctors claimed her illness is psychological and that the family's efforts to have her treated by other doctors amounted to medical child abuse. In reporting on the state's decision to support the return of Justina to her parents, *The Boston Globe* noted that Executive Office of Health and Human Services Secretary John Polanowicz played a personal role in trying to broker a resolution of the case. The Duzan family has similarly sought a meeting with EOHHS in their case.

Sara Duzan's court-appointed guardian cut off all communication with her family because phone calls from her family were allegedly causing her to have emotional outbursts. COFAR has reported, however, that there appeared to be little evidence in the clinical record that family phone calls or visits were causing Sara's outbursts. Such outbursts are typical of persons with Sara's condition, a disability known as Smith Magenis Syndrome. Andy McDonald has been prohibited by a court order, his court-appointed guardian, his group home provider, and the state from ever visiting his hometown of Sherborn, even under supervision. That is where his parents, Stan and Ellen, still live.

## **DDS providers get huge budget hike**

The final state budget approved by the Legislature on June 30 for Fiscal Year 2015 will raise the level of funding to DDS corporate residential providers to more than \$1 billion. That's an increase to the providers of more than \$142 million, or 16.5 percent, over current-year spending in FY 2015 dollars.

COFAR had calculated that if the *increase* in the Community Residential line item were reduced slightly – to a 14.7 percent *increase* over the previous fiscal year – the Legislature could re-direct close to \$18 million in additional funding to the state-operated group homes, DDS service coordinators, the Autism Division, Turning 22 program, Respite and Family Supports, and the remaining developmental centers in the state.

That did not happen. While the Legislature approved a 6.5 percent increase in the state-operated group home account, that was far lower than the 16.5 percent increase for provider-operated group homes. The Legislature also approved a 14 percent *cut* in the developmental center line item. That was despite the fact that 87 percent of the residents living in developmental centers marked for closure since 2008 have been transferred either to other developmental centers or state-operated residences (see group home story on page 1.)

The Legislature approved only a \$381,000 increase in the DDS administrative account, which was less than 1 percent in inflation-adjusted numbers. The administrative account pays for service coordinators, who are being phased out of their jobs as the administration and Legislature look to award service coordination work to corporate providers.

Both the governor and the Legislature specified virtually no increase in the Autism Division line item, which amounts to a cut of 1.8 percent in FY '15 dollars. And the governor and the Legislature also specified no increase in funding for Turning 22.

## **Wrentham Center resident enjoys Sox spring training**

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staff encouraged him to identify vocational, personal, and recreational goals. His list included working in the dining room, family visits, and the Red Sox. Tom, 62, has attended local Red Sox games and collects posters, yearbooks and magazines, but he had always hoped to go to spring training as well. He was helped to prepare for his adventure by shopping and packing, practicing appropriate behaviors, and taking his first plane trip. He loves pictures, and his trip is chronicled in an album designed by Deborah Mullett.

Tom moved into the Wrentham Center in December, 2011, after having lived at the Templeton Developmental Center since 1973, when he turned 22. Prior to that, Tom was a student at a residential special education program for 12 years.

When Tom's parents placed him at Templeton, they found it to be a caring, state-of-the-art facility with strong vocational, behavioral and physical supports provided by a dedicated staff. There, Tom worked in the dairy barn and developed strong bonds with staff and residents. When a beloved staff member died, Tom delivered a heartfelt eulogy.

**'Tom's move to Wrentham was handled with sensitivity and respect.'**

Starting in 2008, when the administration began to phase down Templeton, Tom became puzzled by the loss of friends as they moved from their home, and he became anxious about his own future. After weighing choices, including community residential living, we decided that his needs would best be met at the Wrentham Center. This was a difficult choice even though I believe that a continuum of options should be available to provide safe, respectful and comprehensive care for our most vulnerable. Would I be limiting Tom's potential with institutional care? This was a difficult time for Tom, as his home, his friends and his staff changed in December 2011.

Tom's move was handled by the staff at both Templeton and Wrentham with sensitivity and respect. Tom moved into a lovely home on campus, which he shares with five roommates. His bedroom reflects his interests – Red Sox posters and quilt, and a stereo for playing his cherished Beatles' albums. Family-style meals, group activities, individual projects, coordinated care and a welcoming presence characterize his daily life.

I am confident in the choice we made to move Tom into the Wrentham Center. He shares a home with roommates, and their communal life is enriching and familiar. The staff is respectful and supportive, and they help Tom to reach his potential...surely not limiting him.

Tom makes personal choices, is listened to, and encouraged. He is part of the Wrentham community and enjoys meaningful relationships. His joy in seeing cousins, however distant, is disarming. His memories of his parents are filled with delight. Tommy's pleasures are simple: the Beatles, his picture albums, a good day at work, coffee, a cigar now and then, and his memories of his trip from Wrentham this past spring to see his favorite baseball team up close.

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