



The COFAR Voice

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When family rights are trumped in care of disabled

What happens when service providers, clinicians, and other “experts” don’t see eye-to-eye with family members in the care of individuals with developmental disabilities?

In a number of cases, families may find that their decision-making authority, guardianship, and even contact with their loved ones are taken away from them.

COFAR has investigated two cases in which family members have become embroiled in disputes with providers over the care of disabled individuals. In both cases, court-appointed guardians, probate court judges, corporate providers, and state agency personnel have consequently acted to remove those family members as guardians or imposed or upheld restrictions on contact between them and their loved ones.

In a third case, the Department of Developmental Services sought to remove a family member as guardian of her son and to appoint

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Former ICF residents largely staying with state care

Residents of four developmental centers that were targeted for closure by the Patrick administration in 2008 overwhelmingly chose to be transferred to other state-operated care settings, according to data provided by the Department of Developmental Services.

A total of 372 people have been transferred since 2008 from the Fernald, Monson, Glavin, and Templeton developmental centers to other settings, according to the DDS figures. Of that number, 325 – or 87 percent – were transferred either to the remaining two developmental centers (primarily to the Wrentham Developmental

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JOINT WAYS & MEANS HEARING — Members of the state Legislature’s House and Senate Ways and Means Committees listen to testimony on March 8 at a joint committee hearing at the State House on the Fiscal Year 2015 State Budget. COFAR delivered testimony to the panel on the governor’s proposed budget for DDS.

COFAR calls for more balance in DDS funding

Saving sheltered workshops seen as priority

COFAR is asking state legislators to restore balance to the Department of Developmental Services budget in light of Gov. Deval Patrick’s proposal to boost funding for corporate providers by \$162 million at the same time that he has been seeking to close developmental centers and now sheltered workshops.

If the Legislature accepts the governor’s proposals for the coming fiscal year, it would bring the DDS corporate provider line item to over \$1 billion, which would represent a 64 percent increase in funding since FY 2007, adjusted for inflation. Meanwhile, Patrick’s proposed budget for DDS calls for additional funding in the DDS Day and Work program line item, which would be used to transfer participants of sheltered workshops in Massachusetts to day programs (see story on Page 4).

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'Real Lives' bill changes proposed

In the wake of concerns raised by COFAR over a bill that calls for "self-determination" in services for persons with developmental disabilities in Massachusetts, a legislative leader has redrafted the bill so that it would no longer subsidize corporate providers to the Department of Developmental Services for not providing services.

The redraft, which was done by the office of state Senator Michael Barrett, co-chair of the Children, Families, and Persons with Disabilities Committee, makes several other changes as well in response to COFAR's concerns. Among them is a requirement that more than half the membership of an advisory board established under the bill consist of family members and other participants who are "financially independent" of any provider of services to DDS clients.

The legislation, known as the "Real Lives" bill, is intended to give individuals more choice and say in the services they receive from DDS. COFAR President Thomas Frain said he remains concerned, however, that the "self-determination" provisions in the bill "essentially put money into the pockets of people who are disabled, potentially making them targets for exploitation."

Frain said he is also concerned that the bill does not explicitly provide DDS clients with a choice among all residential options, including Intermediate Care Facility (developmental centers) and state-operated group homes, in addition to other forms of community-based and home-based care. Also, the bill would establish positions, such as "independent facilitators," which might be duplicative of existing state positions, such as service coordinators. COFAR believes the independent facilitator positions should be removed from the bill.

It was not clear when Barrett's full committee will consider the bill.

Families seen as losing rights in disputes over care

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an attorney in her place as a result of a dispute over whether the young man needed 24-hour nursing care.

In each case, family members have been accused of advocating too aggressively on behalf of their loved ones. These cases have raised parallels in many of the family members' eyes with the much more high-profile case of Justina Pelletier, a teenager, who was removed from her family by doctors at Children's Hospital in Boston last year and kept in a locked ward for almost a year because the doctors disagreed with the family's medical assessment of their child's condition.

The Duzan case

Sara Duzan's mother and father, Maryann and Paul, lost their guardianship of Sara in 2009 after Maryann admitted that she had slapped Sara on the cheek on one occasion. At the time, the Duzans were alleging that Sara was being subjected to abusive restraints in a group residence in New Hampshire.

Sara has a condition known as Smith Magenis Syndrome, a genetic disorder characterized by intellectual disability and behavioral outbursts. The family maintains that the use of restraints to control those behaviors actually makes them worse. Records indicate that both DDS and the Massachusetts Disabled Persons Protection Commission failed to investigate the family's allegations of abuse, but instead sought to remove the family members as Sara's guardians.

In 2010, a probate court judge ruled that none of the family members was fit to be guardians to Sara, not because they were abusive, but because they had allegedly been uncooperative with the New Hampshire provider and other clinical authorities. The judge, while acknowledging the family's "undeniable love" for Sara, nevertheless appointed an executive of a Massachusetts-based provider as her guardian. That individual, who had been guardian to 24 other persons, stepped down as Sara's guardian in 2011.

In November of 2013, Lynne Turner, Sara's current guardian, cut off all contact between Sara and her family. Turner alleged that phone calls and visits from the family members to Sara in her current group home were causing Sara to have behavioral outbursts. But Turner acknowledged to the probate court in December that she had never visited Sara in the residence, where she had placed her in July, and was relying on an assessment of a clinician in the residence of the family's effect on Sara.

COFAR has noted that there appeared to be little evidence in the clinical record that family phone calls or visits were causing Sara's emotional outbursts. Such outbursts are typical of persons with Smith Magenis Syndrome. In a March 19 letter to Andrea Barnes, a psychologist appointed as a special master in the probate case, Kate Sullivan Feeney, an attorney for the Duzans, maintained that Sara has been kept isolated in the group home not only from her parents, but from her extended family and her friends. "Exactly who, if anyone, is approved to contact and visit with Sara other than agents of the state?" Feeney asked in her letter.

Feeney also contended that Turner, as guardian, and Barnes, as

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special master, failed to personally investigate charges by Sara that she had been injured last September at the group home, which is run by a corporate provider called Becket Family of Services.

Feeney further maintained that Turner had placed Sara in the residence in which the other residents have mental health disorders and are not intellectually disabled. And she noted that while Sara had been restrained and placed in seclusion dozens of times in the Becket residence and has tried to injure herself there, she never needed to be placed in restraints while she was at home.

Turner maintained in February that Sara has “has been progressing very well” in recent months in the Becket facility. Both Turner and Andrea Barnes, however, have each contended in emails and letters that it was the other’s responsibility to provide Sara’s clinical records, which would verify her condition, to her family.

The McDonald case

A probate court judge ruled in 2006 that Andy McDonald, who has a moderate intellectual disability, was sexually dangerous and should never be permitted to return to his parent’s home in Sherborn, MA. That position is shared by Andy’s current guardian, Dennis Yeaw, a Shrewsbury-based attorney, even though Andy, 46, has never been charged with a sexual offense. Yeaw has had some 100 wards in addition to Andy.

Middlesex County Probate Judge Edward Rockett ruled that Stan McDonald, Andy’s father, must personally tell his son, in the presence of clinicians, that his son would never be allowed to go home again. Stan, 78, has been fighting for years for home visits for his son. He contends that not only does Andy not pose a danger, but Rockett’s 2006 probate court decision that ruled him dangerous was based on erroneous and contradictory information.

Andy has not exhibited any significant behavioral problems in close to a decade and has been taken on community outings to many places other than his home without any behavioral incidents, according to Stan and to notations in his clinical care plan. Over the years, Andy has been subjected to inappropriate residential placements and treatment, in many cases because a series of court-appointed guardians, state agencies, and providers made the wrong decisions regarding his care, Stan says.

In 2012, a clinical team report or assessment was done of Andy’s level of disability for the probate court. But, contrary to written probate court instructions, Stan was never interviewed for that assessment. He has also never been presented with a copy of the report or informed of its conclusions.

The Feeley case

In 2012, DDS tried to remove Patricia Feeley as guardian of her profoundly intellectually disabled son, Michael. The Department has been involved for years in a dispute with Feeley over Feeley’s contention that her son, who has type 1 diabetes, needs a residential care setting with 24-hour nursing.

DDS, which has taken the position that Michael does not need round-the-clock nursing care, asked a Middlesex County Probate Court judge in November 2012 to appoint James Feld, a Woburn attorney, in Feeley’s place as Michael’s guardian, even though Feld had never met Michael. After a year-long battle in court, DDS agreed in November 2013 to dismiss its petition to remove Feeley as Michael’s guardian for reasons that are unclear. As of March, Feeley has remained as Michael’s guardian, but DDS has still not offered him a residence with the nursing care she is seeking for him.

Records sought from DDS on guardians

In light of new questions about court-appointed guardians (see story at left), COFAR has asked for records and information from DDS on guardians appointed to work on behalf of the Department.

In a March 3 Public Records request, COFAR asked for a list of such guardians, the number of wards they represent, the fees paid to them, and their hours worked.

State care preferred

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Center. Only 47 people – or 13 percent – were transferred to corporate, provider-run residences.

Those numbers are sharply different from what DDS had projected in a Community Services Expansion and Facilities Restructuring Plan in 2009. At that time, DDS projected that slightly more than half of a then projected total of 402 developmental center residents would be transferred to provider-run residences.

The number of residents actually transferred to other developmental centers (169) was more than double what DDS had projected in 2009, while the number actually transferred to state-operated group homes (156) was 39 percent higher than what DDS had originally projected. In contrast, the 47 developmental center residents actually transferred to provider-run residences is 77 percent fewer than the 206 that DDS had projected. Despite the relatively small number of former developmental center residents choosing provider residences, the DDS numbers show that 157 new provider-run group homes have been built in the state since 2008.

Executives get over \$80m a year

Executives of more than 250 state-funded corporate providers of care to clients of the Department of Developmental Services were making more than \$80 million a year in salaries and benefits as of Fiscal Year 2012, according to a COFAR survey of federal tax forms.

The average compensation among all 559 executives surveyed was \$143,969 per year. Among CEOs, the average compensation was \$185,809, while executive directors were paid an average of \$127,164 in salary and benefits.

According to the COFAR survey, provider executives making over \$100,000 a year on average included 97 executive directors, 92 CEOs, 71 chief financial officers, 31 chief operating officers, and 83 vice presidents. CEOs or presidents of 14 providers made over \$300,000 each.

"I think few people realize what the real cost of privatized care is in Massachusetts," COFAR President Thomas Frain said. "Do Massachusetts taxpayers really need to be paying hundreds of corporate executives millions of dollars for grossly duplicative duties? This makes no sense at all."

We need your help

Since 1983, COFAR has been a force for advocacy, information, and change.

We have weathered many storms together, but have not lost a step, nor have we lost our way. We continue to fight for families, and we continue to place families first when it comes to care for our loved ones with intellectual disabilities. But elected officials and policy-makers pay more attention these days to people with power and influence than to the most vulnerable. We need your help to continue the fight! Please give. Thank You!

COFAR calls for preservation of sheltered workshops

COFAR has urged a key legislative leader to place language in the state budget that would stop the Patrick administration from carrying out plans to close all sheltered workshop programs for developmentally disabled persons in Massachusetts.

The administration's plans to close the sheltered workshops by June 2015 were announced as the federal Centers for Medicare & Medicaid Services (CMS) released a new regulation that will prohibit federal Medicaid reimbursement to home and community-based programs that are viewed as too institutional. Both the Patrick and Obama administrations contend that sheltered workshops are institutional programs that segregate participants from non-disabled persons. But many family members of workshop participants maintain that sheltered workshop programs provide their loved ones with important skills and meaningful activities; and they say they are not prevented from regular interaction with non-disabled people.

The Patrick administration has proposed an additional \$5.6 million under the DDS Day and Work program line item (5920-2025) in the Fiscal 2015 state budget, to transfer people from sheltered workshops to Department of Developmental Services day programs. The Arc of Massachusetts and the Association of Developmental Disabilities Providers are asking for an additional \$5.5 million on top of that amount in order to close the shelters and place the residents in "integrated" or "supported" employment programs in the mainstream workforce.

But in a letter to state Representative Brian Dempsey, chair of the House Ways and Means Committee, COFAR President Thomas Frain and Executive Director Colleen Lutkevich questioned whether job openings exist in the workforce to accommodate many of the participants of the workshops once they are closed. Frain and Lutkevich asked Dempsey to insert language in the day and work program line item that would prevent the closures of the workshops "until such time as all of the current participants in them are secured jobs in the mainstream workforce."

Meanwhile, among the community-based programs that may lose CMS funding under the new regulation are those that are located near or on the grounds of a "public institution," or that "have the effect of isolating individuals receiving...(Medicaid-funded services) from the broader community of individuals..." COFAR has joined with the national VOR and an organization called the Coalition for Community Choice in opposition to the new regulation. According to the VOR, the rule "continues to demonstrate an ideological bias against disabled people who find friendships and benefits from living together and accessing services and amenities 'under one roof.'"

In addition to its efforts to dismantle sheltered workshops in Massachusetts, the Patrick administration has spent the last five years closing developmental centers in the state.

COFAR's blogsite has noted that in some states, such as Delaware, proposals are going forward to integrate developmental centers and other congregate-care facilities into their surrounding communities. "Rather than filing lawsuits to close developmental centers and sheltered workshops, the federal government should be finding ways to make best use of those critical assets," Lutkevich said.

Legislature puts assault hearing on hold

Plans by a state legislative committee to hold a hearing into the alleged assault of an intellectually disabled man at the Templeton Developmental Center last year are apparently on hold.

That is one of several key matters involving developmentally disabled persons that appear to be caught in a start-and-stop legislative process.

On January 31, the counsel to Representative Kay Khan, co-chair of the Children, Families, and Persons with Disabilities Committee, notified COFAR that the Committee planned to schedule a DDS oversight hearing regarding the Templeton assault case.

As of early March, no date had yet been set for the hearing. COFAR sent an email query on March 4 to Khan's counsel, asking for the reason for the delay. There has been no response to COFAR's query.

COFAR has reported that the alleged September 16 assault of Dennis Perry, 64, by Anthony Remillard, 22, at the Templeton Center raises questions about the admission of potentially dangerous persons to the facility. Additional questions have been raised about the subsequent incarceration of Remillard in the Worcester County House of Correction. Remillard is himself an intellectually disabled person. Perry died following the alleged assault.

Meanwhile, a bill to expand eligibility for DDS services to persons with developmental disabilities was folded in mid-April into an omnibus bill that would also establish a permanent state autism commission (H. 4047). In a surprise move, the measure was passed by the House on April 16. However, a separate bill that would require national background checks of persons hired to work with the developmentally disabled in Massachusetts has remained stalled in the Judiciary Committee. As of March 20, the Committee's deadline for acting on the measure was extended through the end of June.

COFAR calls for balance in DDS funding

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The administration is seeking to close all remaining sheltered workshops by June 2015. The governor's budget would also cut the developmental center line item for the coming year by a \$13.4 million, which would bring the reduction in the developmental centers to 47 percent in FY '15 dollars since FY '07.

In testimony delivered to a joint hearing on March 8 of the House and Senate Ways and Means Committee on the FY '15 budget, COFAR joined with the Massachusetts Nurses Association in calling for adequate funding for the developmental centers and a more balanced approach to DDS funding in general. As part of that effort, COFAR is opposing the additional proposed funding to transfer sheltered workshop participants to day programs.

In recent years, the administration has been far more generous in proposing funding to the corporate providers to DDS than it has been to state-operated programs and state employees in the DDS system and even to some other community-based programs. State-operated group homes have been the destination of many of the residents of developmental centers that the administration has closed in recent years (see story on Page 1); and while the governor's proposed FY '15 funding for state-operated residences would represent a 44 percent increase in funding since FY 2007, that increase would still be 20 percent less than the provider-run group home increase over the same period of time.

Proposed funding for service coordinators, who are DDS employees, would barely keep pace with inflation, under the governor's FY '15 budget plan. Service coordinators have seen their caseloads rise dramatically in recent years. In real terms, funding for the DDS administrative line item, which includes the service coordinators, would still be 22 percent lower than it was in Fiscal Year 2007 if the governor's FY '15 budget is approved. In his FY '15 budget, Patrick has proposed a \$1.8 million increase in the DDS administrative and service coordinator line item, which is less than a 1 percent increase from current-year funding in FY '15 dollars.

Other DDS accounts for community-based services have also not fared as well as the provider-run residential account. The governor has proposed virtually no increase for next year in the \$5.6 million line item for the DDS Autism Division, which amounts to a cut of 1.8 percent in FY '15 dollars. The providers are asking for an additional \$3 million in this account, or more than a 50 percent increase. They contend there are more than 400 people with autism on a waiting list for services.

Also facing a cut in real terms in the coming fiscal year in the governor's proposed budget is the Turning 22 program, which funds services for individuals who have graduated from the special education system. Funding for Turning 22 will have been cut by 35 percent since FY 2007 in FY '15 dollars if the governor's budget proposal is adopted. The governor proposed a \$2.8 million increase in the Transportation line item for FY 15, which represents a 20 percent increase in funding over the current year. That total funding of \$15.9 million would still be 4 percent less than what was budgeted for this line item in FY 2007, in FY 15 dollars. For Family and Respite Services, the governor's budget proposal would only increase funding by less than 3 percent in inflation-adjusted numbers.

COFAR, Inc.
3 Hodges Street
Mansfield, MA 02048



COFAR is a statewide, nonprofit education and advocacy organization funded by families of people with developmental disabilities.

Phone: 508-339-3379

Fax: 508-339-5034

Thomas J. Frain, Esq., President, Thomas.frain@cofar.org

Colleen M. Lutkevich, Executive Director, Colleen.lutkevich@cofar.org

David S. Kassel, Newsletter Editor, Davekassel@charter.net

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