



The COFAR Voice

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Maureen Shea (right) speaks with COFAR Vice President Anna Eves at an informational hearing in February about Shea's proposed bill (S.73), which would help ensure that the staff of DDS residential facilities are adequately trained in using medical equipment. Shea's son, Tommy, died in a group home after staff apparently did not properly install his seizure monitoring equipment. (See story at right on COFAR priority legislation.)

Paper: promises of equal care went unheeded

When retired U.S. District Court Judge Joseph L. Tauro died last November, he was remembered as a giant in the history of care for the developmentally disabled in Massachusetts.

Tauro, who died at the age of 87, had presided over the landmark Ricci v. Okin class action litigation over conditions in the state's institutional system in the 1970s and 1980s. By the time of his official disengagement from the case in 1993, his rulings had improved the lives of thousands.

But a review of the history of the care of the developmentally disabled since Tauro's disengagement shows that successive governors in Massachusetts failed to heed Tauro's key admonition that care in community-based, privatized facilities must be equal or better than the

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Group home transparency bill tops COFAR priorities

COFAR is seeking passage in the new 2019-2020 legislative session of a bill that would provide online information for the public about the performance of group home providers and their records of substantiated cases of abuse and neglect.

The bill (H.93) is one of several measures for which COFAR is advocating in the legislative session that began in January. Other bills that COFAR is supporting include:

- A bill (H.1415) that would require probate court judges to presume that the parents of developmentally disabled persons, or third parties designated by the parents, are suitable as guardians for those individuals.
- A bill (H.125) that would establish an independent state agency that would inspect and license group homes for individuals with intellectual disabilities. Currently, licensing of group homes is carried out by the Department of Developmental Services. DDS also manages or funds the operation of those group homes -- a situation that

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Family members allowed to resume visits with woman with I/DD after being denied contact for 3 years (Story on Page 3).

COFAR seeking safeguards in Supported Decision Making

COFAR has voiced concerns about a bill filed in the current legislative session that would authorize the use in Massachusetts of "Supported Decision Making" (SDM), a process that is billed as an alternative to guardianship of persons with developmental disabilities.

Under SDM, guardians would be replaced in some cases by informal teams of "supporters" who would help developmentally disabled persons make decisions about services, living arrangements, finances, and other matters.

State Representatives Aaron Vega and Paul Tucker, the principal co-sponsors of the bill (H.172), agreed to schedule a

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Mary McTernan, long-time advocate, dies

Mary McTernan, a key advocate for the developmentally disabled, died on January 26 at the age of 79.

McTernan served as president of COFAR from 1992 to 1994, and was president of the VOR, COFAR's national affiliate, from 2005 until 2009. She served on the VOR Board until 2014.

McTernan was involved in an effort to protect the rights of residents of developmental centers in Massachusetts, and was named in 1993 to the Governor's Commission on Mental Retardation.

She also wrote much of the language of a bill originally sponsored by former Massachusetts Congressman Barney Frank to give families and guardians of residents of developmental centers the right to opt out of federal class-action lawsuits seeking to close the residents' longtime homes.

Bill would expand DPPC secrecy

A bill filed in the state Legislature would designate a potentially large portion of the records of the Disabled Persons Protection Commission as non-public.

In February, COFAR contacted Representative Sean Garballey, the House sponsor of the bill (H. 117), to express concerns about the measure. The bill would also make several other changes to the DPPC's enabling statute, including renaming the agency the Commission for the Protection of Persons with Disabilities (CPPD). COFAR specifically raised concerns about a provision in the bill stating that all records of the CPPD containing confidential or personal data "**shall not be public records.**"

COFAR's concern is that this language could effectively exempt all of the agency's records from public disclosure even if confidential information in the records were redacted. COFAR noted that while the DPPC's regulations do state that the DPPC's records are not public, the agency's enabling statute implies that the records are public as long as confidential information is protected.

COFAR raises concerns about Supported Decision-Making

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meeting in mid-March with COFAR President Thomas Frain and COFAR Voice Editor David Kassel to discuss the possible adoption of provisions that would prevent potentially adverse outcomes from SDM such as the marginalization of family members.

In an email to the two representatives and their staffs, COFAR noted that the bill lacks a standard for determining the cognitive ability of an individual who would be eligible for an SDM arrangement. That standard should be determined through research, the email stated.

The bill states explicitly that under SDM, the developmentally disabled individual is the "decision maker" regarding their services and their financial and legal affairs.

But, as COFAR's email asked, can someone with a profound intellectual disability, for instance, be considered capable of making their own decisions even with assistance from an SDM team? As the Office of the Public Advocate in Victoria, Australia, asked in relation to SDM, is it possible for anyone to make their own decisions "**if they do not have...an appreciation of the significance of the decision they are making or a reasonably consistent set of values?**" (our emphasis).

A number of experts have noted that there has been little research done on the effectiveness of SDM or its potential to subject disabled persons to coercion, manipulation, or exploitation. COFAR's email to Vega and Tucker noted that there was nothing in the language of the bill to prevent human services providers from being placed on the SDM teams — a situation that would appear to set up a potential conflict of interest.

The COFAR email stated that there have been many cases in which family members have made allegations of poor care or conditions in group homes, and the providers have not only ignored the families' concerns, but have, in some cases, retaliated against the families. In too many of those cases, DDS has taken the side of the providers.

There is also no provision in the bill for preventing the exploitation of developmentally disabled persons other than a provision that anyone who has reason to believe that someone is being exploited can report that to the Disabled Persons Protection Commission (DPPC). There is not a requirement, however, that the DPPC actually investigate such a complaint or that the DPPC not refer the complaint to another agency such as the Department of Developmental Services for investigation.

There is also no provision in the bill that would provide for regular auditing or other oversight of SDM agreements.

In addition, COFAR's email noted that there is a provision in the bill that appears to offer SDM as an alternative to guardianship even for children. The language appeared to imply that even children with intellectual disabilities would be considered eligible to make their own financial and legal decisions. COFAR's email stated that it is not clear that even children of normal cognitive ability have that legal right under most circumstances.

COFAR has in recent months called for caution in implementing SDM in Massachusetts, and for establishing standards first.

COFAR lays out priority bills in current legislative session

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results in a conflict of interest for the department.

- A bill (H.88) that would require that optional work activities be made available in DDS-funded day programs. The bill was proposed to address the absence of work activities for developmentally disabled persons who have wanted to continue those activities following the closures of all remaining sheltered workshops in Massachusetts in 2016.
- A bill (S.73) requiring that when a disabled individual is discharged from a hospital to a residential group home, a licensed medical professional from the group home must review and acknowledge the full requirements of the hospital discharge plan with respect to life support equipment, and advise the group home staff on those requirements.

This bill was proposed by Maureen Shea, the mother of an intellectually disabled resident of a group home who died of an epileptic seizure after the group home staff failed to properly install the resident's seizure monitoring equipment. (See photo on Page 1.)

- A bill (H.101) to establish a registry of individual caregivers in the DDS system who have substantiated abuse allegations made against them ("Nicky's Law").

Transparency bill

The group home transparency bill is modeled on an online database system in the state of Illinois. Easily accessible comparative information about group home providers has the potential to help families and guardians in making decisions on placement of their loved ones in those DDS-funded facilities.

Illinois has a human services "provider scorecard," which offers comparative information about group home provider performance. In addition, that state provides an online database that allows comparisons of numbers of abuse allegations and abuse substantiations among individual providers in the state.

The Illinois database appears to be a response to a series of articles in 2016 by *The Chicago Tribune*, which had described a system of privatized group homes in that state in which "caregivers often failed to provide basic care while regulators cloaked harm and death with secrecy and silence." The relative lack of coverage of those issues by mainstream media outlets in Massachusetts, and the relative lack of interest as well in the Legislature, may explain why few if any of these sources of online information are available in this state.

The DDS in Massachusetts does provide online provider licensure reports. But these reports on individual providers often tend to contain vague and generic find-

Barrs reunited with family member after 3 years

After a three-year prohibition on their contact with a 30-year-old woman with an intellectual disability ended last November, the woman's father and sister have been allowed regular visits with her by the Department of Developmental Services.

David Barr and Ashley Barr had been prohibited by the woman's DDS-paid guardian from visiting her starting in November of 2015.

The DDS guardian, Dorothy Wallace told the Barrs in November of last year that she would allow visits to resume because a criminal case involving sexual abuse of the disabled woman had come to an end.

Neither David nor Ashley Barr were charged or involved in the sexual abuse case. Last year, the disabled woman's mother, Nancy Barr, and the mother's boyfriend, John Leone, were sentenced to prison terms in the case. Nancy and David Barr were divorced in 2003.

Wallace never clearly explained the reason for prohibiting visits with the woman by Ashley and David Barr. COFAR is withholding the name of the disabled woman because she is the victim of sexual abuse.

Wallace was reportedly planning to step down as the woman's guardian as of March of this year. Ashley Barr said in early March that she was seeking to be named a co-guardian of her sister along with a co-guardian expected to be recommended by DDS.

Ashley Barr is being represented in her bid for co-guardianship by Thomas Frain, an attorney who is COFAR's Board president.

During the three-year period in which they were prevented from visiting the disabled woman, neither Ashley nor David Barr were even informed as to where she was living. COFAR attempted unsuccessfully during that period of time to advocate with DDS and with the Barr's area legislators and the media for the reunification of David and Ashley with the woman.

Ashley said her sister is now living in a DDS-funded group home in Haverhill with three other female residents. She said she did not know how long her sister has been there, but noted that the residence is located just minutes away from David Barr's home. Ashley, who lives in Rhode Island, said that while her resumed visits with her sister were initially supervised, she and David have more recently been permitted to take her sister on weekend outings by themselves. She said her sister has also been taken on weekends to visit a paternal aunt who had also not been allowed to contact her until recently.

Tauro's advice to state went unheeded

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care delivered in the state's large institutions.

The review of the history of the care of the developmentally disabled in Massachusetts is contained in an academic paper published in January on the website *In the Public Interest*. The paper, titled "The Pacheco Law: 25 Years of Taxpayer Protection," was written by Elliott Sclar and Michael Snidal of Columbia University, and by David Kassel, COFAR Voice editor and COFAR research and communications director.

Tauro's 1993 disengagement from the Ricci case came the same year as passage of the Pacheco Law in Massachusetts, which also required that before state services could be privatized, the quality of the privatized services be projected to be equal or better and less costly than exiting state-run services. As the Sclar et al. paper noted, however, governors in Massachusetts, starting with Governor William Weld, took few, if any, steps to ensure the privatized care would be equal or better than state-run care.

In 1991, shortly after he took office, Weld appointed a 17-member special commission to consider privatizing state-run human services. A few months later, the commission recommended the closing of three developmental centers for the intellectually disabled, three adult mental hospitals, and three public health hospitals. The commission also called for the development of 2,000 new community residential placements and hundreds of acute-care hospital and long-term nursing care beds to accommodate the residents of the facilities targeted for closure.

Weld's commission promised that no patient would be moved from a state facility slated for closure until an "equal or better" alternative care setting was available. But by the start of the Romney administration in 2003, advocates of residents of the then Fernald Developmental Center were charging that governors since Weld were allowing conditions to deteriorate at Fernald and were not ensuring that care in the community-based system was better.

After Romney announced plans to close Fernald and five other remaining developmental centers, the Fernald plaintiffs in the Ricci case called for Tauro to reopen the case. In a 2006 memorandum in support of reopening the case, the Wrentham Association wrote that privatized DDS services were "not equal to what they were fifteen years ago, and for many (Ricci) Class members, the care they currently receive is far worse than when they first moved into the community."

Sclar, Snidal, and Kassel maintained that the analytic requirements of the Pacheco Law were largely bypassed in the rush to privatize human services in Massachusetts. Their paper was commissioned by state Senator Marc Pacheco to commemorate the 25th anniversary of the law that bears his name.

New co-chair named to disability panel

State Senator Sonia Chang-Diaz from Boston has been appointed Senate chair of the Legislature's Joint Committee on Children, Families, and Persons with Disabilities, the key legislative committee dealing with issues affecting persons with developmental disabilities.

Senator Chang-Diaz replaces Senator Joan Lovely as the panel's Senate co-chair. Representative Kay Khan from Newton remains as House co-chair of the committee in the new legislative session.

COFAR contacted Senator Chang-Diaz's office in early March to ask if she would comment on the committee's ongoing review of abuse in the Department of Developmental Services system. A member of Chang-Diaz's staff said it was still too early for her to issue any statements and that she was still "getting up to speed" on the committee's issues.

The committee, under Kahn and Lovely, held two informational hearings last year as part of its DDS review, the full scope of which has remained unclear. The first hearing was held in January 2018. But while numerous family members and guardians of DDS clients hoped to share their accounts of their experiences with the system, they were not permitted to testify publicly before the panel.

In November, three COFAR members testified as an invited panel in the committee's second informational hearing. Members of the committee asked no questions of COFAR's panel, which included testimony from Richard Buckley about his brother's death due to apparent abuse in a group home in West Peabody in 2001.

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Through our newsletter and our blog posts, we provide information you won't find anywhere else about the care of persons with developmental disabilities in Massachusetts. We also advocate for your loved ones every day. Please contribute to us keep us going. See our back page for details.

Thank You!

Warren faulted on pay for disabled

COFAR has raised concerns about recent statements from Massachusetts Senator Elizabeth Warren that paying a subminimum wage to developmentally disabled persons is exploitative.

In October, COFAR contacted Warren's office to explain the importance of paying subminimum wages to developmentally disabled persons as part of programs to provide them with meaningful work activities. In that regard, COFAR is advocating for a bill at the state level in Massachusetts (H.88) that would ensure such work activities for Department of Developmental Services clients in community-based day programs (See story on Page 1 on COFAR legislative priorities.)

In an email to her office staff, COFAR noted that Warren has proven to be one of the nation's most effective advocates for workers and their financial security. But the email took issue with Warren's role in leading an effort in Congress to eliminate waivers that have allowed employers to pay a subminimum wage to disabled persons who are hired by employers in mainstream work settings.

While Warren maintains that the waivers are exploitative, COFAR noted that state data show that integrated employment opportunities have not materialized for developmentally disabled persons since all sheltered workshops were closed in the state as of 2016.

Corporate providers worked directly with DDS to move participants from the workshops into community-based day programs, which the providers themselves operate. While the providers were subsequently able to increase their revenue for DDS day programs, much of the additional funding sought to provide training for employment never materialized.

In addition, the former workshop participants who were moved to the day programs were offered few, if any, of their previous work activities, and most lost the pay they were earning in the workshops.

Baker's FY '20 budget signals a slight improvement for DDS

Governor Baker's proposed budget for Fiscal Year 2020 appears to signal some slightly better news for some state-run programs funded through the Department of Developmental Services.

But the trend under which funding for corporate, provider-run DDS programs has increased while funding overall has dropped for state-run programs would continue under Baker's budget. The Legislature, which is currently considering the governor's budget, is likely to continue to adopt Baker's DDS line item proposals with no more than minor changes.

Under Baker's budget, funding for DDS state-operated group homes (line item 5920-2010) would rise by 6.8% when adjusted for inflation. That would be an improvement over the current year in which the line item was essentially cut. But even with Baker's proposed increase, the state-operated group home line item funding would remain below the inflation-adjusted funding level for Fiscal 2017.

The DDS administration and service coordinators line item (5911-1003) would increase by 5.4% under the governor's budget. That would be an improvement over the 3% cut in that line item in the current fiscal year.

The state-run developmental center line item (5930-1000) would be increased 2% under Baker's budget, but that would still amount to a small cut in the line item when adjusted for inflation. That line item will have been cut by almost 40% since Fiscal 2012.

Baker's Fiscal 2020 budget would increase funding for the provider-operated group home line item (5920-2000) by \$57.8 million or 4.7% when adjusted for inflation. That line item will have been increased by 48% since Fiscal 2012.

State and provider program funding still going in opposite directions

Despite the modest increases for the state-operated group homes and the administration line items, the overall trend for state-run services is down. COFAR reviewed historical funding from Fiscal 2012 onward for three key state-run program line items and three key provider line items. The funding trends for each group are continuing to go in opposite directions.

The provider line items COFAR reviewed were for group homes, transportation, and community-based day and work. Total funding for those line items was increased by \$441 million between Fiscal 2012 and the current fiscal year when adjusted for inflation.

The state-run program line items COFAR reviewed were for state-operated group homes, developmental centers, and DDS administration. Total funding for those line items was decreased in inflation-adjusted terms by close to \$40 million between Fiscal 2012 and 2019.

DPPC funding

In his Fiscal 2020 budget, Baker proposed a 9.8% increase for the DPPC. That is lower than the 32% increase in funding for the agency in the current fiscal year. The DPPC has gotten more than a 70% increase in funding since Fiscal 2012. But that still has not been enough to enable the agency to hire more than five abuse investigators. The budget of the DPPC is still too small to enable it to investigate more than a small fraction of abuse allegations.

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