



The COFAR Voice

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Secrecy shrouds guardian payments

A lack of transparency and accountability appears to characterize the state's financial payment system for professional guardians of developmentally disabled persons.

An investigation by COFAR also found that state policies and regulations appear to give professional guardians an incentive to do little work representing individual clients while taking on as many clients as possible.

COFAR believes reform of the probate and professional guardianship system is needed, and one solution might be a proposal in the Legislature to establish an independent Public Guardian agency. Another is a perennial bill to boost judicial consideration of parents as suitable guardians for individuals. (See story on both bills on Page 4.)

The Department of Developmental Ser-

Two tireless advocates — John Sullivan and Roland Charpentier — have died. Obituaries on Pages 2 and 5.

vices pays attorneys and corporate providers to provide guardianship services in cases in which family members are either unavailable or unable to serve as guardians of developmentally disabled adults. All guardians of persons over 18 must be appointed by probate court judges.

A list provided by DDS of guardians it employs shows that the Department's total payments to those guardians increased from \$602,474 to \$800,476 between Fiscal 2013 and 2016. The number of paid guardians rose from 68 to 80.

The highest-paid guardian was a corporate provider — The Arc of Bristol County — whose total payments rose from \$129,000 to

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SHELTERED WORKSHOP CLOSURES — Patty Garrity with her brother, Mark, who lost his DDS sheltered workshop in September 2016. Like the family of Danny Morin, another DDS client, the family of Mark Garrity has faced frustration and confusion since all workshops were closed in Massachusetts. (Story on P. 2)

FY '18 budget cuts funding for state-run group homes

The state Legislature and governor signed off on a Fiscal Year 2018 budget in July that makes some of the deepest cuts yet in funding for state-operated group homes and other programs managed by the Department of Developmental Services.

Yet funding for *privatized* group homes was still increased by tens of millions of dollars under the budget, although that increase was somewhat less than what Governor Charlie Baker had originally proposed last January.

The cuts in Baker's final budget for Fiscal 2018, which began July 1, include a \$10.5 million reduction from the previous fiscal year in funding for the state-operated group homes.

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John Sullivan dies at age 97



John L. Sullivan, a founding member of COFAR and a central figure in class action litigation that led to a major improvement in care of the developmentally disabled, died June 29 at the age of 97.

In the 1970s, while Sullivan's daughter, Jean, was living in what is now the Wrentham Developmental Center, Sullivan became a plaintiff in the landmark *Ricci v. Okin* lawsuit. The class action suit was brought to challenge conditions in large institutions in Massachusetts that then housed thousands of individuals.

At that time, Sullivan became a member and then president of the Wrentham Parents Association. He was also a founding and executive board member of the Arc of Massachusetts, but he opposed the Arc's subsequent decision to advocate for closure of the developmental centers. He believed those facilities should remain as a residential option to individuals and their families.

Sullivan's disagreement with the Arc's direction led him to drop his membership in that organization and to found COFAR in 1983. In March 2012, he was presented with a lifetime achievement award by the Department of Developmental Services.

Sullivan's other daughter, Colleen M. Lutkevich, has carried on his advocacy work and has served for many years as the volunteer executive director of COFAR. "My dad worked and fought his whole life to make the system work for the least fortunate among us," Lutkevich said. "His advice was always, 'never be afraid.'"

Sheltered workshop closures result in less work, more confusion

In the wake of the closures of all remaining sheltered workshops for persons with developmental disabilities in Massachusetts last year, at least some families appear to be struggling with a confusing new system that appears to provide less meaningful activities for their loved ones.

The families of Mark Garrity (see photo on Page 1) and Danny Morin appear to be cases in point.

COFAR interviewed family members of the two men who have each continued to attend day programs where their sheltered workshops had formerly been operated by providers funded by the Department of Developmental Services.

Paid piecework and assembly work that had been given to Garrity and Morin to do in their sheltered workshops in Braintree and Agawam respectively were initially taken away last year and replaced by day program activities that neither man could relate to. In each case, their provider agency came up with a makeshift solution to the problem that allowed the men to continue doing work similar to what they had done before. But in each case, the solutions were implemented despite a lack of clear guidance from the federal and state governments on the type of work and activities that were now permitted for the men.

All sheltered workshop programs were closed in Massachusetts as of last summer as a result of federal requirements that developmentally disabled people work in "integrated employment" settings in which a majority of the workers are not disabled. The closures of the sheltered workshops in Massachusetts resulted in the removal from those programs of close to 2,000 participants, but those closures do not appear to have translated into a steady flow of people into integrated employment. (See July 2016 *COFAR Voice*.)

"I'm not opposed to finding jobs in the community or expanding day programs," said Barbara Govoni, the mother of Danny Morin. "I get it all has to do with money, but I feel that a group of people are being discriminated against based on the fact they had no voice or vote."

For months, after his workshop was closed in September of 2016, Mark Garrity was frustrated and angry, according to his sister, Patty. The new program provided day program activities for Mark, but, as Patty put it, they "went over his head." He wasn't interested in nature walks or painting or cooking. He also didn't understand a class on money management. But as of March 20, program officials said they had found paper shredding work for Mark for two out of the four hours a day that he attended the program.

The paper shredding arrangement for Mark was done after the DDS southeast regional director determined that it would not violate the new federal rules. The regional director said the permission he gave to the program to offer paper shredding was purely verbal. There was nothing placed in writing about it.

Similarly, Danny Morin receives a schedule of activities every month in his day program. "I'm not saying it's bad," his mother said, "but it's not what he is interested in." Volunteer work is available as well at a local homeless shelter, and residents are taken on walks to the local library and other locations. "Danny doesn't want to do that," she said. "He wants to work."

FY '18 budget cuts state-ops

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The cuts also include a \$2.2 million reduction in the DDS administrative account, which funds critically important service coordinators. But the state-operated group homes were the hardest hit of any DDS funding account.

In January, when Baker submitted his Fiscal 2018 budget to the Legislature, he proposed \$59.9 million in additional funding for privatized DDS group homes, while at the same time proposing a \$1.8 million cut in the state-operated group home account.

The House and Senate initially largely rubber-stamped Baker's DDS budget plans. Then, in early July, a House-Senate conference committee, working behind closed doors, recommended a cut more than five times deeper for the state-operated group homes. That cut was \$10.4 million.

The governor's final budget went even further, cutting state-operated group home funding by \$10.5 million for Fiscal 2018. That amounts to a \$15.6 million cut when adjusted for inflation.

Meanwhile, the governor's final budget only moderately reduced the *increase* Baker had initially proposed for the privatized group home system — lowering that proposed \$59.9 million increase to \$47.6 million.

Researcher pursues Down syndrome, Alzheimer's links

A Harvard University research scientist is helping lead a 5-year, multi-center study to find "biomarkers" that may enhance understanding of the links between Down syndrome and Alzheimer's disease.

Dr. Florence Lai of Harvard University, McLean Hospital in Belmont, and Massachusetts General Hospital, said the study is examining why the average person with Down syndrome develops symptoms of Alzheimer's disease in their early 50's while a very few escape the disease altogether.

Over several decades, Lai has evaluated and followed some 750 individuals with Down syndrome, including Joanna Bezubka, a cousin of COFAR Board member and former president, George Mavridis. Joanna died of Alzheimer's disease in 2012 at the age of 60.

MGH's facility at the Charlestown Navy Yard is one of seven sites around the country and England that are involved in the study.

State-operated group home population may be dropping

Data provided by the Baker administration show that the number of residents in remaining state-run residential programs for the developmentally disabled has begun to decline, raising questions about the state's policy for the future of state-run services.

The data, which were provided under a Public Records Law request, indicate that the 2016 fiscal year may have been the peak year for the residential population in state-operated group homes and the Wrentham and Hogan developmental centers.

DDS nevertheless declined comment on whether the department had plans to phase out state-run group homes altogether.

DDS operates or oversees both state-run and privatized systems of residential care in Massachusetts. The state-run system, which is now much smaller than the privatized system, includes the two remaining developmental centers and the state-operated group homes.

The ultimate elimination of state-run residential services would take away a key element of choice for individuals and families in the DDS system. State-run residential centers and group homes provide residential care to some of the most profoundly disabled persons in the commonwealth, and they tend to employ staff with higher levels of training and lower rates of turnover than do corporate-run facilities.

According to the DDS data, the number of residents in state-operated group homes rose from just over 1,000 in 2008, when four of the six developmental centers were targeted for closure, to roughly 1,150 in Fiscal 2016. As of Fiscal 2017, that number had dropped to about 1,130.

The DDS data appear to closely track the closures of the Fernald, Monson, and Glavin developmental centers, starting in Fiscal 2008, and the transfer of the residents of those facilities primarily to existing state-operated group homes and the Wrentham center.

Budget committee rejects living wage for direct-care workers

A House-Senate conference committee on the state's Fiscal Year 2018 budget rejected a proposal in July to require corporate human services providers to boost the wages of their direct-care workers to \$15 per hour.

That living wage language had been proposed by Senator Jamie Eldridge and had been adopted in the Senate budget. In May, SEIU Local 509 released a report charging that major increases in state funding to corporate human services providers during the past six years had boosted the providers' CEO pay, but that direct-care workers were not getting a proportionate share of that additional funding.

Bills to reform guardianship stall

The state Legislature is continuing to move slowly on needed reforms of the guardianship system for persons with developmental disabilities in Massachusetts.

Two key reform bills have remained stuck for months in the Judiciary Committee.

One of the bills (H.3027) would establish an independent agency called a "Public Guardian," which would have centralized authority over the hiring and payment of guardians in cases in which family members are not available to serve as guardians of incapacitated people. Under the bill, the Public Guardian would take over the responsibility from agencies such as DDS of recommending and paying guardians.

While COFAR supports the concept of an independent public guardian, H. 3027 specifies that the public guardian would not actually be a public agency, but rather would be a non-profit agency. COFAR contends the public guardian should be a public agency, which would be subject to the state Public Records Law and other legal requirements that apply to public agencies.

COFAR also strongly supports a second reform measure (H. 887), which would boost the rights of families in the DDS/probate system. The bill would require probate court judges to presume that the parents of incapacitated persons are the suitable guardians for those persons. The measure, however, has never gotten out of the Judiciary Committee.

Both H. 3027 and H. 887 were referred to the committee in January and both remained in the committee as of early August.

Guardian payment system secretive

GUARDIANS, continued from Page 1

\$167,000 between Fiscal 2013 and 2016, a 29 percent increase. The payments to the Arc constituted more than 20 percent, or one fifth, of the total payments to all guardians in Fiscal 2016.

The second highest-paid guardian in both years was Victor Sloan, an attorney in Uxbridge. His payments from DDS rose from \$43,150 in Fiscal 2013 to \$53,288 in Fiscal 2016. Sloan's website lists him a practicing attorney who does criminal defense cases and estate planning in addition to guardianships.

An RFP issued by DDS for guardianship services caps the hours professional guardians can work at 20 hours per year, and caps their total hourly pay at \$50. This appears to give DDS-paid guardians an incentive to take on many clients.

Neither Sloan nor Michael Andrade, the CEO of the Arc of Bristol County, responded to requests from COFAR for comment on the number of wards they or their organizations represented or the amount of time they were able to spend with them. COFAR has calculated that based on the DDS limits, Sloan could have as many as 53 wards or more, while the Arc of Bristol County could have as many as 167 or more wards.

Court records show that Sloan has also been involved as a guardian, guardian ad litem, attorney, or as a "Rogers Monitor" for incapacitated persons in 118 cases in four separate counties during a seven-year period from Fiscal 2009 to 2015. That includes 14 persons for whom Sloan was appointed as a Rogers Monitor, 75 persons for whom he was appointed as an attorney, 19 cases in which he was appointed as a guardian ad litem, and six cases in which he was appointed as a guardian. Those six cases in which Sloan was appointed as a guardian appeared to be in addition to COFAR's estimated 53 cases in which Sloan had been paid by DDS to be a guardian.

COFAR also sought information on the payment of attorneys who are hired under the probate system to provide legal representation to incapacitated persons. In those cases, the court approves attorneys as counsel, and the attorneys are paid by a state agency called the Committee for Public Counsel Services (CPCS).

Because the CPCS is technically a part of the judicial branch of government, it is not subject to the state Public Records law, according to an attorney with the state's Public Records Division. The CPCS would not provide COFAR with any information about the attorneys they employ or the amounts paid to them. While DDS did provide COFAR with a list of guardians it employs, the Department said it would cost COFAR \$3,000 to compile information on what those guardians do for their payments and how many clients they represent.

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Through our newsletter and our blog posts, we provide information you won't find anywhere else about 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!

Roland Charpentier dead at age 84

Roland Charpentier, a longtime advocate for his brother, Richard, and other residents of the former Glavin Regional Center in Shrewsbury, died on July 24. He was 84.

As president of the Glavin Association, a family organization, Charpentier played a key role in a successful effort to save the Glavin Center from closure by the then Weld administration in the early 1990s.



Roland Charpentier (seated at left) with Al Bacotti, a former director of the then Glavin Regional Center, at a breakfast Charpentier organized at Glavin in 2011 for local legislators.

When the Glavin Center was once again targeted for closure by the then Patrick administration in 2008, Charpentier again took up the fight to save it, and organized protests and breakfasts for lawmakers at the Center and on Beacon Hill. This time, however, the forces arrayed against the facility were too strong, and Richard Charpentier and other remaining residents of the Center were moved out as of 2013. Richard died in 2014.

Known for his vivacious and engaging personality, Roland Charpentier worked as an educator and administrator for the Worcester Public Schools for over 30 years. He retired in 1994.

He earned his bachelor's and master's degrees in education from Worcester State College and served in the United States Navy during the Korean War.

Auditor found hundreds of millions of duplicate payments to provider

State Auditor Suzanne Bump reported in April that the state's Medicaid agency paid nearly \$200 million in questionable, duplicate, and improper payments to a corporate provider that acts as a fiscal conduit to the state for mental health services.

Bump's report on the for-profit Massachusetts Behavioral Health Partnership (MBHP) was issued just months after her office approved a contract with the same provider to privatize mental health services in southeastern Massachusetts. Bump's April report concerned an umbrella contract under which Medicaid paid MBHP more than \$2.6 billion between 2010 and 2015.

Woman remains isolated in DDS case

More than a year and nine months after she was removed from the care of her family by the Department of Developmental Services, a developmentally disabled woman is still being kept isolated from her father and sister.

The 29-year-old woman, whose name is being withheld for privacy reasons, is being kept in an undisclosed residence. All contact with her by her father and sister was cut off for unclear reasons by a DDS-paid guardian in November of 2015.

COFAR has been advocating on behalf of the woman's father, David Barr, and sister, Ashley Barr, who have filed to intervene in the case in probate court. David and Ashley have contacted their local state legislators, but have gotten little or no help from them.

COFAR has also tried to encourage mainstream media outlets to report on the case, and has urged legislators to support visitation for David and Ashley, also to no avail.

The Boston-based Disability Law Center temporarily intervened in the case in January to ask a state-appointed attorney who is representing the woman to support family visits if the woman wished that. However, nothing apparently resulted from that effort.

The attorney, Melissa Coury Cote, told COFAR in March that she would not support court permission for visits to the woman by David or Ashley Barr, despite the DLC's request. She provided no reason for opposing family visits other than to say that the woman had not specifically asked her to allow visits from her father and sister.

However, Ashley Barr said that her sister had recently called her father on two occasions and said she missed her family and wanted to see them. The calls were apparently unauthorized. Ashley and David said they did not know whose phone the woman used to contact them. They were concerned the woman may have gotten in trouble for making the calls.

COFAR has reported on a number of cases in which DDS-paid guardians have imposed severe restrictions on family contact with persons in the DDS/probate court system; but the Barr case may be the most extreme of those cases in that in none of the other cases has a DDS client been kept in isolation for such a long period of time, and in no other case has their family not been informed of their whereabouts.

COFAR first appealed to then DDS Commissioner Elin Howe last October to seek permission for the Barrs to visit their family member, but Howe declined to do so. Howe retired in July.

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