



The COFAR VOICE

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COFAR Annual Dinner full of promise...and fun

*And Tickets are still available. Call
COFAR at 508-339-3379!*

COFAR's Annual Dinner, set for October 29 at the Newton Marriott Hotel, promises to be an evening of both celebration and reaffirmation, predicts Executive Director Colleen Lutkevich.

"It's shaping up to be a celebration of the efforts of the legislators and volunteers who have done so much over the past year to ensure that we continue to have choice and access to quality care for the mentally retarded," Lutkevich says. "But I think it will also be an evening to reaffirm our resolve not to let the Romney administration continue on its course to dismantle our system of care. Most of all, though, the evening promises to be a lot of fun."

Lutkevich has been overseeing efforts over the past several weeks to select the speakers and honorees, send out the invitations, and do all of the other last-minute organizing needed for the organization's social event of the year.

James Florio, former Governor and Congressman from New Jersey, will be the keynote speaker. Also expected to speak at the dinner will be Massachusetts Congressman Edward Markey, a longtime supporter of the rights of the mentally retarded.

Among those who will be honored, in addition to Markey, are state Senators Susan Fargo (D-Lincoln) and Richard Tisei (R-Wakefield); and state Representatives Thomas Stanley (D-Waltham) and Brad Hill (R-Ipswich)—all of them longtime COFAR supporters, and supporters of legislation and policy benefiting the retarded and their families.

Providing the musical entertainment at the dinner will be the renowned Blue Horizon Jazz Band.

The event starts at 6:30 p.m. with a cocktail reception. Dinner will be served at 7:30. Tickets are \$40.00 per person.



SCRRRI residence in Leominster where Paul Frain suffered neglect.

Advocacy seen as the key to better care

Provider system fails in case of Paul Frain

[First in an occasional series of articles on care in the DMR system.]

For nearly five years, Paul Frain's family couldn't seem to do anything to end the nightmare that Paul was going through in a group home in Leominster.

Mentally compromised since an operation shortly after birth for a brain tumor, Paul had been placed by the Department of Mental Retardation in the privately-run residence where he seemed to be continually getting injured and suffering the emotional trauma of intimidation from another client.

Neither Paul's mother, Maryalice, nor his brother Tom, who is now COFAR Board President, could seem to get anyone at DMR to listen. Nor could they make any headway with the vendor agency, South Central Rehabilitative Resources, Inc. (SCRRI).

The SCRRI group home on West Street in Leominster was overcrowded with 11 adults living there. Despite the fact that Paul, now 40, was subject to frequent seizures and often fell, he had been placed in a second-floor bedroom. There were inadequate railings on the stairs and no safety railings in the one working bathroom in the residence.

The Frains raised these issues with DMR officials and employees of the West Street residence several times. Maryalice, in fact, wrote a number of letters expressing these concerns, culminating in a letter in frustration to the then Secretary of Human Services in June of 1992. Then, one day in January 1993, Paul was shoved against a wall by another client. The next month, he fell down the stairs in the West Street residence and ended up in the hospital for three days with a concussion. More injuries and intimidation followed.

It was only after the issuance of a scathing report by the Disabled Persons Protection Commission (DPPC) in May 1995, upholding a series of allegations of neglect against DMR and SCRRI in the case, that DMR began to consider the family's long-standing pleas that Paul be moved to another residence. And it was only after Tom, armed with the DPPC report and threatening a lawsuit and to go to the media, that the DMR reversed its long-standing refusal to move Paul out. He is now living in a state-operated group home in Clinton, and there have been no further instances like those that occurred in the Leominster group home.

Advocacy seminars planned

Tom Frain, now a believer in the power of vigorous advocacy, wants to share his experience and hard-won knowledge in that area with other families in similar situations. COFAR is seeking grant funding to launch a series of free seminars next year that will provide information and training to families of the mentally retarded in how to advocate on their behalf before DMR. Tom will moderate the proposed seminars, which will also train families in organizing and advocacy techniques on Beacon Hill.

Problems from birth

Paul Frain, now 40, has had a history of neurological difficulties stemming from the removal of a brain tumor in 1964, the year he was born. Post surgical complications included severe left side seizures. He also has had gastric ulcers, scoliosis and two heart attacks. He is described in the DPPC investigation report as having numerous interests including visiting with his family, music, and working as a

dishwasher. He was also described as an enthusiastic and dedicated employee who produced high quality work.

Paul was first moved into the SCRRI residence at 154-156 West Street in Leominster after a March 1990 incident in another community residence in Fitchburg in which he fell and was found unconscious in a bathroom.

From the start of Paul's residence in Leominster, Maryalice expressed concerns about the house. She wrote to SCRRI that she was worried about the staircase in the house, where Paul was given an upstairs room. She noted that he frequently fell due to his propensity for seizures. In her letter, she asked that side rails on the stairs be improved, and that there be close monitoring of Paul when he was on the stairs.

In January 1992, his mother again expressed concern—this time about another client in the home who was potentially violent. That month, Paul came home to her for a visit with scratches across his back. There were 11 adults in the West Street residence and one working bathroom, according to Tom.

In May 1992, Maryalice wrote to the DMR area director that the residents of the house were combative and that Paul was having seizures. The staff disputed this, but the DPPC investigative report notes that the program had failed to report at least two of his seizure incidents.

Finally, on June 30, 1992, Maryalice wrote to David Forsberg, then secretary of health and human services, that she had been "getting nowhere" with DMR. Her letter stated that the house in Leominster was more crowded than the one in Fitchburg, but it had no more staff. It was affecting her son's health. He had suffered broken teeth, concussions, a black eye, and an increase in seizures, which had previously been controlled adequately by medications. She was afraid he would suffer even more serious injuries, but had received little or no response to those concerns.

By July 1992, Paul's mother was asking for a change of residence. She expressed frustration to the area DMR service coordinator that she was unable to get a meeting about this with the area director.

In an interview, Maryalice said that this was typical of her dealings with DMR. "I found that the people in DMR smile a lot, but they're not the most responsive group in the world. They tend to 'yes' you to death, and then nothing seems to happen."

Incidents throughout 1993

According to the DPPC report, Paul was shoved by another client into a wall on January 9, 1993. Then, on February 4, more than a year after Maryalice had first expressed concern about the stairs, Paul fell down the stairs while going to his room. His head hit the floor at the bottom of the stairs and he was knocked unconscious. He was taken to Leominster Hospital, where he was found to have suffered a concussion and was kept in the hospital for three days. Only now, at his mother's insistence, was he moved to the first floor of the residence.

Tom Frain said it was only after he had called the Governor's Office that the DMR area director even returned his calls about the stair issue. "My experience with DMR and SCRRI was that they were extremely recalcitrant (in making changes in response to the family's concerns)," Tom says. "It was always the same response: 'Maybe Paul should find someplace else to live.' This would intimidate my mother. Everyone knows there are no other programs. I took it as a veiled threat that he would be out on the street if we didn't shut our mouths."

Yet, he said, when he asked them about this, "they admitted they couldn't move him without my mother's permission as his guardian." Tom said this was a turning point in his mind on the nature of advocacy. "It taught me not to be afraid to advocate, to push ahead no matter what anyone said, to push for what's right."

"I don't have a good answer."

On October 29, 1993, Paul suffered another injury when he fell in the shower. His mother then requested that the vendor place support bars in the shower. This was recommended in December by the DMR service coordinator. However, during an interview with a DPPC investigator in 1995, nearly a year and a half later, the service coordinator said she never checked to find out whether her recommendation had been implemented. The DPPC investigator noted that she inspected both of the residence's first-floor bathrooms and found no handrails in either shower nor evidence that holding bars had ever been installed.

When asked whose responsibility it was to follow through with DMR recommendations, the service coordinator replied, "we're all responsible," according to the DPPC report. The investigator wrote that the DMR service coordinator's supervisor was asked about other issues of documentation and DMR's responsibility for monitoring residential programs. She responded: "We do the monitoring from here (the DMR area office). We've never gone into a program and looked at the documentation."

When asked why, after almost a year and a half, the bars had not been installed in the shower to ensure Paul Frain's safety, a SCRRI employee stated to the investigator: "I don't have a good answer..."

Prolonged seizure

On February 15, 1994 at 5:45 a.m., the staff was unable to wake Paul up. He appeared to be having a seizure, which lasted 15 minutes. Yet, he wasn't taken to the hospital. Then, on September 29, 1994, another client threatened Paul. Maryalice made two phone calls at that point to the DMR service coordinator regarding safety of her son. In early November and late October 1994, she met with the service coordinator and a SCRRI employee.

Tom Frain notes that bathrooms in house were broken down, at least one shower was out, and bills were unpaid. He said the cable TV bill for the entire house was in Paul's name and that he was paying the bill for the whole house. Maryalice said she was concerned about Paul's doctor's bills hadn't been paid and that he had missed a medical appointment for a Hepatitis B shot.



PAUL FRAIN

Report upholds allegations

Among the DPPC report's conclusions were that there was reasonable cause to believe that:

- Paul Frain suffered serious emotional injury (depression, increased isolation) and serious physical injury (hospitalization for three days) after he fell down the stairs in the house.
- DMR placed another client in the West Street home without having obtained a professional assessment of his behavior, resulting in serious emotional injury to Paul.
- SCRRI and DMR employees disregarded Paul's neurologist's recommendation that he be moved to a different residential program because stress level at residence was causing increase in seizure activity, resulting in serious physical injury.
- SCRRI failed to ensure the safety of residents at the West Street residence by increasing or changing the staffing pattern there.
- SCRRI, DMR, and the DMR service coordinator failed to ensure Paul received proper medical

attention after a seizure reportedly lasting 15 minutes in February 1994, resulting in serious physical injury.

- SCRRI failed to install safety devices in the residence, particularly in the bathroom, resulting in serious physical injury to Paul after he fell while showering in October 1993. SCRRI also failed to follow through after injury with a recommendation for placing holding bars in the shower.

The DPPC report recommended that DMR rescind its contract with SCRRI for the West Street program; that Paul be moved to a more appropriate, smaller residential program; that disciplinary procedures be instituted for the DMR area director, service coordinator, and the service coordinator's supervisor; and that the DMR investigate whether SCRRI mismanaged Paul's funds, specifically whether he was made to pay for an ambulance after his February 1993 injury and whether he had paid entire cable bill for the residence.

Tom says his brother is currently living in a group home operated by DMR staff in Clinton. "It's going pretty well," he said. "There will always be problems and he will always need a good advocate." But the nightmare of the West Street SCRRI residence appears to be in the past.

Tom also says that to the best of his knowledge, the recommended disciplinary actions never took place. In fact, one of the DMR officials was promoted after the DPPC report was issued. He said SCRRI, now Rehabilitative Resources, Inc., still exists. One of its group homes was the site of a client death due to staff neglect in May 2002, according to *The Boston Globe*.

Nevertheless, the DPPC report was instrumental in getting Paul transferred out of the West Street residence and into the state-operated group home in Clinton. "The investigator (Barbara Kaye) did a terrific job," he said. "Her report gave us leverage with the Department.

"Our story is the exception," Tom adds. "The rule is that they (DMR) steamroll over people. They ignore abuse and neglect. The DPPC is now smaller (due to budget cuts), yet there are more cases. The only recourse is to have an attorney."

There is one indication in the DPPC report, though, that may attest to the power of strong family advocacy. A January 13, 1995 note in the files of the DMR service coordinator's supervisor stated that, according to a DMR central office official, "it is time to look at serving Paul in some different way as it appears Mrs. Frain is in contact with the right group to apply pressure to the system."

Tom said he hopes the story of his family's experience and their decision to speak out will encourage other families experiencing similar problems to step forward and do the same "rather than be intimidated by DMR."

[*The COFAR Voice* would welcome accounts from readers of their experiences with the DMR system.]

COFAR provides report to Cabral on need for State facilities

COFAR has drafted and presented a report to State Representative Antonio Cabral (D-New Bedford), explaining the organization's position that all of the current state-run facilities for the mentally retarded continue to be needed to provide choice and access to comprehensive care in Massachusetts.

As part of a continuing dialogue with COFAR, Cabral, House chairman of the Human Services and Elderly Affairs Committee, had asked COFAR members who met with him in August, to justify the need for the facilities. Cabral has indicated that of the six existing facilities, at least two are likely to be closed by the Romney administration.

COFAR President Tom Frain, Board member Larry Harding, and volunteer Diane Booher met with Cabral for over an hour on October 1 to present the report, drafted by Booher and Harding. The COFAR members also urged Cabral's support for legislation providing for independent oversight of the quality of care for the mentally retarded and for an independent agency to investigate abuse and neglect in the system.

Frain said that Cabral didn't indicate whether he supports COFAR's position that all of the state facilities should remain open. But he described Cabral as "interested and clearly listening to us. If we can persuade him, he could be a huge ally." A further meeting with Cabral has been set for October 28.

Thus far, the administration has formally announced the planned closure of the Fernald Developmental Center in Waltham. Informally, the administration has indicated that all six facilities could be closed. Last spring, COFAR launched a successful grassroots campaign in support of legislation requiring that the administration undertake a cost-benefit analysis before closing any of the facilities.

Cabral has also stated that he is interested in having his committee tour the state facilities, and COFAR has welcomed that as an important informational step for the committee. COFAR members sent letters in September, inviting the committee members to tour the facilities.

Booher said that at least six committee members have expressed interest in touring at least one facility. A visit to the Wrentham Developmental Center had been scheduled, but now must be rescheduled to accommodate legislative sessions on Beacon Hill.

COFAR's report to Cabral, entitled "Plain Talk Today and Tomorrow for the Mentally Retarded of Massachusetts," states that the closure of the Fernald Center is viewed by the DMR

as a pilot program and that steps taken to close Fernald will serve as the basic blueprint for future closure of the remaining five large state facilities.

In making the case for keeping the state facilities, the report discusses a number of instances of instability in the community-based system of care for the retarded. The report notes, for instance, that the Executive Office of Health and Human Services has announced that 25 state-operated residences may be closed to cope with budget cuts due to a \$5.5 million shortfall in the DMR community residential account. Should that happen, more than 100 disabled and retarded people could be without the 24-hour care provided by DMR

The closure of the Fernald Center is viewed by DMR as a pilot program...for future closure of the remaining state facilities.

At the same time, DMR plans to evict Fernald residents while extending an invitation to them to transfer into community group homes and the other large facilities. Where will these Fernald residents all go, the report asks.

The report notes that some State facility residents are waiting for community placement, but there are no community-based residences in Massachusetts that provide a level of tailored services comparable to those required of the State facilities under the Medicaid law. The report further states that DMR buildings and land stands idle while the DMR rents or buys property for administrative staff and retarded residents around the state.

In the absence of state-operated residences for the retarded in Massachusetts, the remaining choices would be privately run homes and group homes operated by private vendors. Privatization of the DMR system will then be complete, the report states. If this occurs, the DMR will have removed a major source of competition for care for the retarded. If sanctions should require the State to shut down a vendor-operated group home for any reason, the only alternative would be another vendor-operated program that operates with some of the same market-driven pitfalls – low wages for staff, high staff turnover, and market competition for land and housing.

The report concludes that the Romney administration is accelerating a trend toward a decentralized, privately-operated system of care for the retarded. This system, however, will lack oversight and accountability. In addition, other costs will rise, among them transitional housing costs, legal costs as DMR faces challenges from class members waiting for

services, short-term staff costs, and operating costs due to high vendor executive salaries.

COFAR criticizes call for less oversight of provider system

Massachusetts' \$2 billion purchase-of-service system for human services needs more oversight, not less, COFAR argued, in a critique of a new report issued by the Massachusetts Taxpayers Foundation and the Massachusetts Council of Human Services Providers, Inc.

In a letter to *The Boston Globe*, published October 2, COFAR Executive Director Colleen Lutkevich maintained that oversight of the system is currently inadequate, as evidenced by a rising number of deaths and cases of abuse and neglect in community-based group homes for the mentally retarded (See September 2003 *COFAR Voice*).

The MTF report, which was released on September 23, argues that the system “puts too much emphasis on bureaucratic processes, compliance with rules and regulations, and achieving narrowly defined programmatic objectives. As a result, the Commonwealth too often falls short in helping clients live better lives.”

The report notes that DMR is by far the largest purchaser of services in the Commonwealth among all agencies in the Executive Office of Health and Human Services. In Fiscal Year 2002, the DMR purchased a total of \$619 million in services from human service providers, nearly the double the amount purchased by the Department of Social Services, the second largest purchaser.

The report contends that the provider system is currently subject to unnecessary and duplicative financial oversight and called for streamlining or eliminating financial reporting requirements for providers.

In her letter to *The Globe*, Lutkevich stated *The Boston Globe* reported in August that a rising number of abuse cases and three deaths in community-based group homes for the mentally retarded since May 2002 were signs of a system that is under pressure from, among other things, a lack of adequate supervision. Furthermore, the *Globe* article noted that because of budget cuts, the Disabled Persons Protection Commission was able to investigate only 5 percent of complaints of abuse and neglect in group homes.

COFAR is a family support, education and advocacy organization funded by member families.

Become a COFAR member and receive your monthly issues of *The COFAR Voice*. For membership information, write to:

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***JOIN COFAR IN OUR ADVOCACY EFFORTS TO PROVIDE
COMPREHENSIVE CARE *The COFAR VOICE****

FOR ALL PERSONS WITH MENTAL RETARDATION

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