



The COFAR VOICE

The Official Newsletter of the Massachusetts Coalition of Families and Advocates for the Retarded, Inc. (COFAR)

December 2003 Issue:

Volume 5/ Number 5

State facility has been 'well suited' to daughter's needs

Milley's reject suggestions that they are naïve, uninvolved, afraid of risk

[Second in an occasional series on care in the DMR system in Massachusetts]

Beth Milley likes having her hands immersed in water, and she likes the wind blowing in her face.

But her parents, Fred and Carolyn, can mostly only guess at the preferences of their 41-year-old daughter. It's not as though she could possibly tell them what she likes. Beth has the mental functioning of a seven-month-old infant, and has lived since she was five years old at the Hogan Regional Center in Danvers, one of six remaining large, state-run facilities for the mentally retarded.

Fred and Carolyn are Hogan supporters, and they take issue with the suggestion that parents like them should place their retarded children in smaller, group-home settings. A recent paper circulated by an advocacy group for privately provided care was particularly upsetting to them. It posed the question: "At what point are these parents (of retarded children, living in institutions) trying to close their son or daughter off from the ordinary risks that are inherent in human life?" The paper went on to assert that these "hyper-vigilant" parents should not be afraid to place their mentally retarded children in small, community-based residences, where they will experience freedom and the "ordinary joys" of life.

"We have not tried to close Beth off," Carolyn Milley says. "We have simply found the care at Hogan to be well suited to her needs." She notes that Hogan provides her daughter with "good physical care," medications, a day program on site, and occupational and other types of therapies. "How can
(Please see Beth Milley, page 2)



A LITTLE HELP FROM OUR FRIENDS — Former New Jersey Governor James Florio, center, at COFAR Annual Dinner in Newton with Massachusetts State Representatives Thomas Stanley, D-Waltham, left, and Ted Speliotis, D-Danvers.

Annual Dinner exceeds expectations

Ex New Jersey Governor Florio, Massachusetts Rep. Markey decry governmental indifference to the 'voiceless'

With a mix of style and substance, COFAR's Annual Dinner brought together people from throughout the system of care for the mentally retarded on October 29 for an evening of both celebration and resolve to preserve that system.

"In terms of attendance, it exceeded our expectations," said COFAR Executive Director Colleen Lutkevich. "We're especially appreciative of the many legislators who attended, and the many DMR staff—more than 50—who took time out of their busy schedules to support us."

(Please see Dinner, page 2)

Annual Dinner was a success

(Dinner, continued from page 1)

Lutkevich insisted the credit for the success of the event, held at the Newton Marriott Hotel, should go to the volunteers who helped in organizing it. She singled out Board member Debra Cooksey for special mention. "Without her efforts, we'd still be trying to plan this," she said.

More than 250 guests attended the dinner, which included a keynote speech by former New Jersey Governor James Florio, and a conference call, broadcast to the room, from Massachusetts Congressman Edward Markey, who was in Washington.

Markey was honored at the event, as were four state legislators, all of whom have demonstrated long-term support and commitment to the welfare of the mentally retarded. Those honored lawmakers were state Senators Susan Fargo, D-Lincoln, and Richard Tisei, R-Wakefield; and state Representatives Thomas Stanley, D-Waltham, and Brad Hill, R-Ipswich.

Stanley, who was instrumental in obtaining passage of the budget legislation saving the Fernald Developmental Center in Waltham from immediate closure, said that should the facility be closed, "my number one priority will be the residents (there)."

Florio maintained that government is failing the test of providing for the mentally retarded and others among society's most vulnerable citizens. "It is in vogue to bestow benefits on the influential and the powerful and to impose budgetary pain on the voiceless," the former New Jersey Governor and Congressman said.

Markey, sounding a similar theme, maintained that: "Our nation is failing that test of providing for those who have too little. Huge tax cuts enacted in Washington are forcing unconscionable reductions in services. Our state is failing the test when its cuts programs and moves to close facilities such as Fernald."

Florio, who was introduced to the crowd by his longtime friend, Waltham businessman David Kaloupek, acknowledged COFAR's efforts and mission. "For too long, public policy toward the mentally retarded has oscillated between inhumane warehousing and callous disregard," he said. "COFAR speaks to sensible alternatives to these polar positions."

The crowd at the event included close to two dozen state legislators, volunteers and family members of mentally retarded residents in facilities and community homes around the state, members of state employee unions, direct-care workers, and government officials.

COFAR President Thomas J. Frain called for higher wages for direct care staff at both state facilities and community-based residences for the retarded, and for the passage of legislation that would provide for more resources to the Disabled Persons Protection Commission to investigate abuse and neglect in the system. He also called for "increased scrutiny" of the continuing privatization of care for the

retarded, calling it "a huge problem (inviting) waste, fraud, and abuse into the system.

"If we let these services go and be privatized, if we allow the cutting of taxes and services, we all lose," Frain said. "It is wrongheaded to balance the budget on the backs of the retarded."

The legislators on hand at the event included Senators Robert S. Creedon, Jr., D-Brockton; Tisei; Steven Tolman D-Boston; and Representatives Mark Carron, D-Southbridge; Robert K. Coughlin, D-Dedham; Hill; Paul Donato, D-Medford; James B. Eldridge, D-Boxborough; Kay Khan, D-Newton; Thomas Kennedy, D-Brockton; Peter J. Koutoujian, D-Newton; Barbara A. L'Italien, D-Andover; James R. Micelli, D-Wilmington; Harold P. Naughton, D-Clinton; Alice H. Peisch, D-Natick; Smitty Pignatelli, D-Lee; Frank I. Smizik, D-Brookline; Theodore C. Speliotis, D-Danvers; and Stanley. Also attending were representatives from the offices of Senators Therese Murray, D-Plymouth; Fargo; and Pamela Resor, D-Acton.

Former state Senator and 2002 gubernatorial candidate Warren Tolman also attended the event.

Hogan appropriate for profoundly retarded resident

(Beth Milley, continued from Page 1)

someone who doesn't have a child in a large facility know what's best for someone who does?" Carolyn adds.

For the Milley's however, it may only be a matter of time before their long-time choice of residence for their daughter is taken away from them. The Romney administration has targeted the state facilities for the retarded for closure and has steadily reduced staffing and funding for them. COFAR is continuing to advocate for the preservation of these facilities, which continue to provide a more comprehensive level of care than do the privately run residences for the retarded in Massachusetts.

The Milleys insist that they are hardly naïve when it comes to seeking the best living situation possible for their daughter.

"How can someone who doesn't have a child in a large facility know what's best for someone who does?"

They have long been involved at Hogan on committees, commissions and parents groups. They know what both Hogan and the community have to offer, and they understand their daughter's needs after four decades of caring for her.

"There are some shortcomings at Hogan," Fred says. "But we speak up if things are wrong." The issue is not about the ordinary risks in life, Carolyn adds, but about appropriate care.

No sign of recognition

Fred and Carolyn have placed brightly colored curtains in the window of Beth's private room at Hogan, and they've put up some bright pictures on the yellow-tile brick walls. There is a rocking chair in a corner. Down the hall in a large room, Beth spends her time before dinner in another rocking chair that was adapted by Hogan's Assistive Technology Unit to stay in place as she rocks. On the hallway walls are two framed, black and white photographs of her.

Beth's day program is in a separate building. On a weekday morning in mid November, she is sitting in an armchair in her dayroom with four other residents of the facility. An attendant is sitting with them. As her parents and a visitor enter the room, Beth does not look up or show any sign of recognition of her mother or father. She rocks back and forth in the chair.

Carolyn points out a plate, spoon, and cup on a nearby lunch table that are all adapted to fit Beth's eating requirements. At Carolyn's suggestion, an attendant walks Beth to the lunch table and sits her down. "Now she's going to want to eat," her mother says. "It's one of her pleasures in life." The attendant says she will be back with some yogurt. Carolyn places the spoon in Beth's hand. The attendant doesn't return for a few minutes, but Beth appears as though she might sit there forever, waiting and rocking.

Occupational and physical therapists have worked hard with Beth over the years, Carolyn says. But they have been able to make only minimal progress. She can't walk without close supervision; she will always wear diapers and can't feed herself. "If you help her out of a chair, she walks somewhat like a toy soldier," Carolyn explains. "She can't get out of a chair herself. If you fold her hand around a spoon and help scoop food onto it, she will duck her head and eat what's on the spoon."

Fred says that there have been times when Beth has seemed to be aware of her parents' presence. But Carolyn maintains that can't be considered recognition. "Recognition would imply she looked at someone and focused. We have the feeling that she senses people that have cared for her for a long time—their voice and manner of dressing her, for instance. But she doesn't focus on a face or look you in the eye. I once saw a T-shirt that said: 'I live in my own little world, but it's okay because they know me here.' I think that's appropriate for her. She seems to inhabit a world where she's taken care of.

"It would be nice," Carolyn adds, "if she ever looked at Fred and her eyes lit up and she said 'that's Daddy.' But she doesn't care who she's with. We don't get some of the heartaches [that families of higher functioning mentally retarded children have], but we don't get the rewards either."

Never any diagnoses of a cause

Beth is the second of four children born to the Milleys. Their other children—three boys—are not disabled. Fred and

Carolyn first suspected something was unusual about Beth when she was 10 months old.

"She was bright and alert," Carolyn says. "But she never used her hands. A baby learns from the top down. They first learn to hold their head up, then to wave their arms and then grasp with their hands." But Beth's learning stopped at the arms, she says. "She never found her hands. You could hold a cookie in front of her and she would never take it no matter how hungry she was."

Carolyn says their pediatrician insisted nothing was wrong with her. Unconvinced, they went to a pediatric neurologist at Massachusetts General Hospital, who diagnosed Beth with mental retardation. On Beth's second birthday, the neurologist said that her retardation was probably going to be very severe. Carolyn adds that the doctors at Mass General were never able to determine a cause of her disability.



Beth Milley with her parents, Carolyn and Fred, in Beth's dayroom at the Hogan Regional Center.

For the next year and a half, the Milleys tried to care for Beth at home. But it became more and more difficult, particularly after Carolyn had her fourth child. "(Beth) had become very raucous and often agitated," Carolyn says. "There were nights when she'd make so much noise, we'd have to close the windows to keep from disturbing the neighbors." She says Beth would often spend much of the night rolling around and banging on the sides of her crib. Finally, they would put her on quilts on the floor so they could get some sleep.

When Beth was three and a half, the Milleys applied to place her in the Fernald Developmental Center in Waltham, but there were more than 600 people ahead of her on a waiting list. They agreed to her placement in a pediatric nursing home in Great Barrington. At the time, the Milley's were living in

Reading, necessitating a three-hour trip each way to visit her. Then Hogan opened in 1967, and Beth was admitted there just before her fifth birthday into what was then referred to as the nursery building.

Hogan was a brand new facility when Beth first moved there, but it was designed in an obsolete way, Carolyn says. There was a bedpan beside every crib, even though the residents in Beth's building were all babies in diapers. Carolyn says she spent a lot of time canvassing women's groups for soft brushes and gentle soap. The soap and combs provided at Hogan were the same as those at the correctional center in Walpole.

Since Hogan was so new, it was not part of the class action suit that was filed by parents of several of the older state facilities in the early 1970s. Hogan was also unlike the older institutions in that it was comprised of four separate buildings—the nursery unit, the infirmary, the adolescent unit, and the adult unit. The original plan was for children to leave the nursery unit at the age of eight. But because so many of them were so profoundly retarded that they never progressed in their mental ages, many, including Beth, remained in the same building well into their adult years.

Hogan staff is knowledgeable

"They know how to take care of her at Hogan," Carolyn contends. "They're familiar with her. She can't verbalize her needs. She makes a funny cross between a hum and a buzz if she's upset." That noise can get louder and her cheeks sometimes get flushed if she's really upset. "That's the way you know something is not right in her world. But she can't tell you what it is." If she's feeling good or happy, she may start to giggle spontaneously, she says. "You can't tell why, but as with a baby, you can make it go on, but you can't make her begin to laugh. Through experience we and the staff all know what her different sounds mean."

By the time Beth was 11, the staff had gotten her to walk without anyone holding on to her. She did well in wide open hallways with no obstacles. But if she was headed toward a partly closed door, she would walk right into it, unless someone stopped her. It was only due to constant training at the facility that she now stops before walking into obstacles.

Certified special education teachers have also tried various means of stimulation, from singing to her to helping her hold a watering can in a garden planted outside the building.

"There are two things we know she likes," Carolyn says. "She likes the sound of water and having her hands in water. And she likes the wind blowing on her face." She also enjoys floating on her back in the swimming pool at Hogan.

Over the years, occupational therapists have tried to teach Beth to turn on a fan to blow on her face. She occasionally does it more by accident than anything else. "They work with her to keep her moving," Carolyn says. "If she never got up out of her chair, she could easily become immobile." The occupational therapists also monitor her feeding, and made a diagnosis a few years ago that she was subject to aspirating

her food, leaving her prone to lung infections and pneumonia. As a result, she has a specified diet in which every liquid has to be thickened.

No peace of mind

Over the years, the Milleys have watched the level of services at Hogan diminish. The budget cuts of fiscal years 2002 and 2003 have meant "cutting staffing to the bone," Fred says. Yet the Milleys are convinced that the situation would only be worse in the community.

The Milleys' concern is backed by reports of a rising number of abuse cases in community-based homes in Massachusetts, high staff turnover, and cutbacks in state oversight [see the *COFAR Voice*, September 2003]. Parents looking to the community-based system are also facing a potentially growing waiting list for placements for their children.

For the Milleys, who are now in their late seventies, the uncertainties over their daughter's future are only growing as they foresee the day when they will be unable to advocate as actively as they do now for her well-being. "So much of our lives has gone into advocating for her, and yet there never seems to be an end to the uncertainty," Fred says. "It would be nice if we could feel that Beth was permanently in a situation best for her and not have to constantly be upset about the changes that go on all the time. What we don't have is peace of mind."

"It's important that people understand our recognition of one indisputable fact," Carolyn adds. "Beth's life is not restricted by where she lives—it is restricted by her own, inborn limitations."

[The *COFAR Voice* welcomes accounts from readers of their experience with the DMR system.]

COFAR continues advocacy on Beacon Hill

COFAR, other human services advocates in war of words with Romney administration

COFAR volunteers continued their advocacy efforts on Beacon Hill this fall in what is turning out to be a drawn-out battle with the Romney administration over the fate of the Fernald Developmental Center and other remaining state-run facilities for the mentally retarded.

In testimony before the Legislature's Human Services and Elderly Affairs Committee in October, the COFAR volunteers maintained that the administration's headlong rush to close the

facilities will cause disruption and potentially deaths throughout the system of care in Massachusetts.

Mark Booher, a licensed psychologist and a COFAR member, testified during the October 22 hearing that at least one resident of the Fernald Center and a 38-year-old family member had died unexpectedly “during this period of increased stress because of the Governor’s agenda to close all state facilities for the mentally retarded. How many more deaths need to occur before we realize that the proposal to close Fernald, and possibly all of the DMR facilities, is not right?” Booher continued. “What will it take to understand that the State will not be saving money?”

COFAR had also scheduled a return visit to the State House for November 25 to present lawmakers with a report explaining the organization’s position that all of the current state-run facilities continue to be needed to provide access to comprehensive care for the retarded. The report, entitled “Plain Talk Today and Tomorrow for the Mentally Retarded of Massachusetts,” contends that the administration is accelerating a trend toward a decentralized, privately operated system of care for the retarded that is lacking in oversight and accountability. The report was initially provided to State Representative Antonio Cabral (D-New Bedford), House chairman of the Human Services Committee, in early October (see the October 2003 *COFAR Voice*).

In other testimony presented during the October 22 hearing before the Human Services Committee, COFAR Board member Larry Harding maintained that the ultimate result of an ongoing reorganization effort by the Department of Mental Retardation appears to be to eliminate all remaining state facilities for the most severely and profoundly mentally retarded. Harding predicted that when and if all of the state facilities close, guarantees of care to class members of the Ricci v. Okin lawsuit settlement will exacerbate waiting lists for placements in the community and potentially force out people already residing in community-based residences.

Harding urged the establishment of a blue ribbon commission, consisting of legislators, advocates, administration officials, providers, state employee union members and others, which would produce a comprehensive report on the future of the system of care for the retarded in Massachusetts.

Meanwhile, Romney administration officials continued a war of words with advocates for the disadvantaged. A remark by Administration and Finance Secretary Eric Kriss in October, likening state Medicaid recipients to “takers” and taxpayers to “givers,” set off a firestorm of protest among human services advocates, who insist that the administration is showing a disregard for a basic function of government of helping those in need (see related stories on this page and page 1).

Kriss’s remarks came on the heels of controversial remarks by Health and Human Services Secretary Ronald Preston that he was not pressing the Governor to include money in a supplemental budget to forestall the likely evictions of 100

mentally retarded adults living in community residential programs. In November, the House and Senate ultimately approved a supplemental budget that restored \$3.2 million of a \$5.5 million shortfall in the community residential budget.

It wasn’t clear whether the partial restoration of the community residential funds would prevent the planned evictions.

Dukakis raps Bush, Romney at Human Services Coalition Dinner

BOSTON—In a skirmish in the battle over care for the mentally retarded and other disadvantaged citizens, former Massachusetts Governor Michael S. Dukakis delivered a feisty, stinging critique of Republican administrations in Massachusetts and in Washington at a recent Human Services Coalition event.

Speaking at the annual Massachusetts Human Services Coalition’s Fall Celebration on November 12, the one-time Democratic presidential candidate pulled no punches in his description of the presidency of George W. Bush.

“This is the worst intentioned administration I have ever lived under,” Dukakis said, to the responsive crowd of about 70 guests. “Nixon wasn’t this bad. He proposed universal health insurance. Reagan wasn’t this bad. It gets worse every day, at home and overseas.”

The Coalition has been fighting cuts on Beacon Hill in funding for services and programs for the mentally retarded and other disadvantaged groups. COFAR members attended the event.

Dukakis said he finds himself at the age of 70 “getting less patient, not more,” particularly when it comes to health care coverage. He noted that the nation has been debating universal health care ever since Theodore Roosevelt first proposed the idea in 1912.

“We’ve got to get smart and we’ve got to get political,” Dukakis said. Rather than continuing to pass tax cuts, the Legislature should put the public’s money into health care and housing, among other areas, he said.

Dukakis said that in California, former Governor Gray Davis signed a bill into law requiring all employers with 50 or more employees to provide health insurance. He noted that the business community in California, as in Massachusetts, has a “strong self interest” to spread the health care burden across most employers. In Massachusetts, 60 to 70 percent of employers provide health coverage. For the one third that doesn’t, the costs are assumed indirectly by all other employers and by taxpayers when employees become sick and land in emergency rooms. “We have to go to the business community and get them to understand this,” he said.

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:

COFAR
3 Hodges Street
Mansfield, MA 02048
Phone: 508-339-3379
Fax: 508-339-5034

Thomas J. Frain, Esq. President tjf@frainlaw.com
Colleen Lutkevich, Executive Director colleen.lutkevich@verizon.net
David Kassel, Newsletter Editor dkassel@earthlink.net

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

FOR ALL PERSONS WITH MENTAL RETARDATION

COFAR
3 Hodges St.
Mansfield, MA 02048