



The COFAR VOICE

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

July 2007

Volume 9/ Number 3

State Budget (Story on page 3); DMR's Fiddled Statistics (Story on page 5)



Carol Alexander, Oct. 2006. Note bandage and arm bruises – gone now! (photo by Stacey Alexander)

Advocacy Works!

Four Cases We've Been Following

COFAR has been tracking a number of cases that suggest what COFAR President David Hart termed “a disturbing trend, if not a pattern” of DMR mismanagement and lack of oversight. “The good news,” he added, “is that the system can be made to work for individuals if their advocates are patient and determined. Family members and guardians increasingly have to know and supply medical history, and when overtaxed staff resent that, it’s a recipe for trouble. You can also see how the Disabled Persons Protection Commission (DPPC) has become the crucial safety net as DMR’s internal processes are failing.”

Alexander case

Carol Alexander is 57 years old and has mental retardation. A former resident of the Fernald Center, she has been living at a residence operated by the North Shore Arc for 27 years. Beginning in January 2006, Tracey Alexander, Carol’s sister and guardian, began noticing a series of unexplained bruises and fingerprint marks to Carol’s thigh and later on her groin area and stomach.

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Fernald Responses In: DMR Rejects Court Authority

May 30 was the deadline set by federal Judge Joseph Tauro for all parties to respond to the Court Monitor’s report. (See “Sullivan says keep Fernald open,” *COFAR VOICE*, May, 2007.) COFAR’s letter strongly supported the findings of US Attorney Michael Sullivan and asked the Court for him to continue as monitor.

Other parent-based organizations filed letters to stop forced transfers and keep the facility open. The Paul A. Dever Association for Retarded Citizens, Inc. objected to part of the monitor’s report which, Dever families argued, permitted DMR to selectively authorize transfers as “equal or better” which might be to private operated homes the report had shown to be more hazardous. The Wrentham Association, continuing to argue for the Court to include that facility, detailed the special needs of people now in state facilities, and emphasized the importance for DMR to make good on “right of return” letters as even the least disabled people in this population age and may require more intensive supports. Ann M. Witham, a former Fernald employee who had become court-appointed guardian for one of her former patients, described the “warnings” that DMR gave to guardians that those transferring out of Fernald early would have the best chance of decent placements for their relatives and wards.

DMR’s response was to deny that the court had any jurisdiction, and that it was fully in compliance with the 1993

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FOX 25 undercover report on abuse and neglect

Fox25 News Undercover aired a report on abuse and neglect in Massachusetts group homes May 15, including cases provided by COFAR members and advocates. You can view this shocking report on the internet at: <http://tinyurl.com/2jros6>.

WARNING: Graphic photos of abuse

Fernald responses in

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settlement. It also argued specifically that the federal court has no jurisdiction where state law has given DMR authority over transfers. Midway through the 61-page “brief,” DMR produced new figures claiming that a Fernald bed cost more than 2.5 times as much as community-based placements. (See “How DMR fiddles statistics,” page 5.) DMR also flatly denied the Monitor’s finding of increasing abuse and neglect in provider-operated group homes, producing charts and tables to suggest that the rate of substantiated claims of abuse and neglect was higher in group homes than in facilities in only two of five years.

Much of DMR’s response can be summarized as “Trust us, we’re the experts.” But some of the “evidence” was citing comparisons of Massachusetts to other states on number of DMR patients with access to dental services – which, ironically, are provided primarily at DMR state facilities!

Also supporting DMR was a brief filed by the ARC of Massachusetts and the Disability Law Center. It is unpleasant to see the Disability Law Center, funded by federal tax dollars under a law which requires family involvement, to take a position contrary to family-run groups and the federal court. It is more unpleasant to see the ARC, which was once the refuge of all parents of children with developmental disabilities, argue “This recommendation [to allow families and guardians to keep loved ones at Fernald] effectively shifts community placement decision-making authority from mental disability professionals to guardians and to this court.” (Page 2) This article does not list the ARC among the parent-run organizations in the case, because its own filing says that it prefers decisions to be made by “mental disability professions,” not families. The long brief and its many appendices rely heavily on survey research about the success of community placements. COFAR agrees that many community placements have worked well. We don’t agree that “one size fits all.” Surveys show averages and overall results – they aren’t about individuals. But everyone is an individual, and everyone served by DMR has an individual plan. The ARC brief goes beyond the DMR’s in attacking the very concept of guardianship, pointedly arguing that the interests of guardians may be different than that of their wards.

An amicus brief was filed by a group organized by the Association for Developmental Disabilities Providers, described in a Globe story as “16 advocacy groups for families and the developmentally disabled.” Actually the signers were mostly providers or unions of employees of providers, as well as the national ARC and the National Disability Rights Network (the national umbrella of the Disability Law Center). And this brief also supports “professionals,” not families, as decision makers. It argues that the decision should be based on the national “trend” toward community-based services.

Trends, by their nature, do not last forever, and are not for everyone.

With these responses, the questions before the Court are whether to continue the moratorium on Fernald transfers in effect since 2005, whether to accept the Monitor’s recommendation to allow present Fernald residents to remain in their home, and whether to continue federal Court involvement in the care of the mentally retarded.

Advocacy Works

Advocacy, *continued from page 1*

The house manager then reported that Carol had begun to exhibit troubling behaviors, including unexplained crying, kicking and screaming episodes. In April 2006, the house manager reported that Carol had accused another individual of sexually assaulting her in her room at night.

Yet the house manager, in a series of emails, continued to discount the possibility that anyone was sexually abusing Carol in the group home, and suggested Carol might have been reliving an abusive experience from her past. She continued to insist that Carol was engaging in self-abusive behavior. Tracey Alexander, however, began to suspect that Carol might have been abused by someone else. It wasn’t until August 2006, some eight months after Carol’s unexplained injuries and behaviors were first discovered, that the staff of the group home reported the situation to the DPPC for investigation. At that time, Tracey began having Carol stay at her home three nights a week.

Problems at the group home continued, and the group home manager continued to ignore Tracey’s 50-years-plus knowledge of her sister, and even previous DMR evaluations of Carol. ARC higher-ups refused to return Tracey’s emails, and took Carol in for a CT scan without consulting her family. Last fall, Carol was threatened with eviction, because Tracey – an intensive care nurse and longtime union representative – refused a medication change with dangerous side effects. In May of this year, 16 months after the initial injuries, Carol was picked up from her workplace, and Tracey learned “she had a large black and blue mark (it was deep purple) on her abdomen, 5 inches long, 2 inches tall. I asked Carol how she got this... her usual answer is, ‘I dunno.’ This time I was stunned. She told me that her group home manager had been hitting her. I reported the black-and-blue and Carol’s statement to the DPPC.”

“I took Carol back to work on Monday and she went back to [the group home] on Monday afternoon. I picked her up on Tuesday and she had a new abrasion on her right forearm...she had been there for one evening!!!

“On Wednesday, May 9, I took Carol to the North Shore DMR and we had a meeting with service coordinators and DMR executives, showing them pictures of previous injuries as well. Carol was placed in respite care [the next day].”

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State DMR Budget Goes to Governor's Desk

As we go to press, the FY2008 Massachusetts budget has passed through the conference committee. Your phone calls to legislators helped in several victories. The budget overall is slightly higher than last years, even when adjusted for salary increases, but some crucial areas will require cutbacks. The governor may now veto line items, which may require further legislative action.

The budget restores separate line items for "community residential," and for "community state-ops," thus reversing the governor's attempt to eliminate what COFAR Vice President Thomas J. Frain has described as "the last firewall against complete privatization of the community service system." It adds about \$85,000 to the governor's proposed budget of the Disabled Persons Protection Commission (DPPC), thus preventing layoffs; however this independent investigator of abuse and neglect remains backlogged and understaffed.

The conference committee budget slightly increased day programs and autism over both houses, and keeps the higher Senate figures for: transportation, turning-22, and facilities. However the facilities budget is still below adjusted salary increases, and thus may require cutbacks. State-operated homes are essentially level-funded.

The final budget went below both houses for administration, and split some of the difference on family support, and community residential.

Two key priorities for COFAR – substantially increased funding for the DPPC and increasing the number of DMR service coordinators – did not pass either house, and will have to be revived in the future. Both are essential as DMR oversight continues to deteriorate amidst the challenges of an increasingly privatized and diffused system of care. (See "Advocacy Works" page one.) COFAR executive director Colleen Lutkevich suggests, "Let's use a whole year's political cycle to get these important items back into the budget process for FY2009!"

Advocacy Works

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The group home had been Carol's home for 27 years, and Tracey reports: "Carol has been in Respite for six weeks...there is not one mark on her body....not one black and blue, not one rubbing abrasion, not one laceration...nothing. She is laughing, talking, telling stories she has not told in years...she is so relaxed. I took Carol to see her psychiatrist on May 31....he had not seen her for about 3 months. When she walked in, he looked at her bare arms, her hands...listened to her chatter away. His eyes just about fell out of his head....he asked me, 'WHO IS THIS?' He said he just couldn't believe how different she was, and how relaxed she was."

"What caused the change? People at Respite paid attention to her. Developmentally, Carol is about 3 years old. All she wants is for someone to listen to her stories." Also, whatever was going on in the group home has stopped. Allegations of abuse and neglect are still under investigation. Although Carol is a Ricci class client, and entitled to "equal [to facility] or better treatment" in any transfer, the nearest state-operated group home was too far from family, so she will be going to another private group home, where staff has been more responsive.

Medeiros case



Kristine Medeiros, wearing protective helmet with plastic faceguard.

Gloria and Bob Medeiros's daughter, Kristine, 37, lives in a group home run by Nexus, Inc., in Woburn. She has mental retardation and autistic tendencies, and developed retinal detachment in one eye since moving to the home five years ago. She is now blind in that eye.

In April 2006, Nexus and DMR required Kristine, who bangs her head against hard objects, to wear a helmet with full face guard at all times other than when she was asleep or taking a bath. The parents said they didn't feel that the face guard was necessary, particularly since Kristine's doctor had voiced that same opinion. Moreover, the face guard made the helmet uncomfortable for Kristine, and restricted her vision and even her breathing. But Gloria Medeiros said she and Bob were able to get Nexus to agree to remove the face guard, only after writing to Kristine's doctor. Gloria Medeiros said she was later criticized by Kristine's DMR service coordinator and by Nexus administrators for "going outside the team" in asking the doctor to recommend removing the face guard.

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Advocacy Works

Advocacy, continued from page 3

According to documentation provided by Medeiros to the DPPC, the group home staff also often given Kristine the wrong eye drops control eye pressure relating to the retinal detachment. In a number of cases, the staff forgot to administer the drops entirely or administered them improperly, despite repeatedly being informed of that. The staff also cancelled several scheduled medical appointments for Kristine. One staff member and the house manager allegedly loudly and frequently berated Kristine; and Gloria Medeiros said she has frequently been treated rudely and abusively by both the house manager and her supervisor.

In October, Medeiros said, Kristine complained of a sore eye. The house manager allegedly insisted that she had been rubbing her eye and did not take her for medical treatment. Medeiros, however, took her daughter to an ophthalmologist, who diagnosed it as an abrasion on her cornea. "She could have gone blind in her remaining eye," Medeiros said. Medeiros said Nexus administrators have recently requested that Kristine be removed permanently from the group home. She said Kristine has an excellent relationship with the other residents of the home and "will be traumatized when she finds out she will have to move."

Carella case

Ann Marie Carella, a resident at the Hogan Regional Developmental Center, has mental retardation and mental illness and numerous medical problems, including a susceptibility to delusions, panic attacks and epileptic seizures.

Carol Carella, her sister and guardian, said her attempts to ensure adequate care for Ann Marie have been met with defensiveness and, at times, outright opposition from some of the Hogan administrators. "It is my opinion that my role as a guardian and advocate for Ann Marie is being undermined," Carol Carella wrote in a January 1, 2007 letter to COFAR. "I have been told by unnamed staff that they have never seen a family member treated as rudely and with such poor regard..." In her letter, Carella, herself a nurse, maintained that she has "only the highest praise for the majority" of the direct-care, nursing, and day program staff and doctors at Hogan." But she said "it was clear that significant issues were being ignored...(and) my attempts to have them addressed have been met with stalling tactics, criticism, ridicule and refusals."

Among Carella's allegations were:

- Ann Marie suffered a seizure in April, 2006, requiring her transfer to an Intensive Care Unit at Beverly Hospital. It took two weeks before Carol Carella was able to arrange for her to be evaluated by a psychiatrist and to have her clinical team at Hogan review her sister's medications.
- Zyprexa was prescribed at that point for Ann Marie, who was severely sleep deprived. Administrators and clinical team members delayed approval of it.

- Carol Carella was never provided with explanations for a series of injuries that Ann Marie suffered. Carol Carella said a Hogan administrator later told her nothing could be done to ensure her sister's safety other than to restrict her to her apartment at Hogan.

In an interview, Carol Carella also said a Hogan administrator threatened to discharge her sister after Carol made a decision to stay two nights at Hogan with her last May because of her sister's "new development" of unsteady gait and seizure activity. She wrote that she notified the secretary in Hogan's administration office of her intent to stay and that no one had ever said this was inadvisable. However, she was told by a Hogan administrator after the second night that her sister would be discharged if she stayed one more night with her.

Carella said she was told at a subsequent meeting that Hogan has no posted or written visiting hours or rules on visiting. She then said she was told by another administrator at the same meeting that "when I am in the building, she knows every move I make." Carella said the comment "made me feel violated, as though I were being stalked."

Dennis Collins, a cousin of Carella, attended that meeting and confirmed Carella's account.

Accident at Abington group home

An accident in April 2006 at a group home in Abington raises questions about the adequacy of DMR oversight of staff training in the community-based care system. The victim, a 45-year-old woman with mental retardation who is non-verbal, was apparently run over by a van driven by a staff worker at the home, which is operated by Growthways, Inc. According to the Disabled Persons Protection Commission, which investigated the incident, the victim had gone outside the residence unsupervised as one of the caretakers was backing up the van to take other residents out for coffee. The caretaker didn't see her and apparently ran over her, leaving a tire-mark across her shirt.

Two of the staff workers appeared to have tried to cover up the incident by removing and washing the woman's clothes before they called 911. The DPPC found that the victim was seriously injured as a result of "an act or omission" by two of the caretakers. A third caretaker had left the group home by herself prior to the accident, to get something to eat, which was against company policy.

The victim suffered a compression fracture of the spine, six broken ribs and numerous lacerations and abrasions. She spent four days at Brockton Hospital before being transferred to rehabilitation facility. She spent a month there before being discharged back to the home.

All three caretakers were suspended and later terminated by Growthways, according to the DPPC report. The DPPC recommended that that all staff working for Growthways be trained in first aid and how to respond to emergency situations. The report stated that documentation of the training should be provided to DMR.

How DMR Fiddles Statistics

Advocates of closing Fernald and other large facilities have been throwing around some new DMR numbers that would make a strong case – if they were valid. The Boston Herald editorial (“**Keep Fernald open, and others will pay**” June 5, 2007), has this version: “It costs the commonwealth \$259,000 per person annually to care for residents at Fernald. In community-based settings, the cost is \$102,103. That adds up to millions each year that is not being spent on other community-based programs for the disabled.

There only four problems with this argument: The first number is not real. The second number is not real. The comparison is not real. And, unfortunately, the experience of decades of budget cutting is that any savings realized by closing large facilities will not go back toward helping the former residents or other developmentally delayed citizens. That one is almost certainly unreal, as well.

\$259,000 a year at Fernald?

Let’s start with the big number. DMR won’t actually produce any data on what’s included in the Fernald budget. It probably includes every building and program on the campus – many of which are shared with community-based services (which ought to be averaged into that smaller number), and some of which are not used by Fernald residents at all. When COFAR looked at a state audit of salaries, the Fernald budget included at least one very large salary of a person who worked half-time at the Hogan Regional Center – in Danvers! The Fernald number has ballooned in the last few years, probably because DMR “announced” that Fernald was going to be closed and frightened 49 residents into transferring out.

\$102,000 a year in the community?

Now let’s look at that second number, barely over \$102,000. DMR has never published a real audit of that number either. We know it omits some state services like dental programs based at large facilities and stuffed into that big number. We also know that it omits taxpayer-supported services that aren’t in DMR’s budget, such as Section 8 housing subsidies and food stamps. So DMR can claim that it is spending less, but the figure for support of community-based people with mental retardation is not really what government (federal and state) is paying. This lower number is just a shell game.

And the potential savings of closing Fernald are...

The big lie is the comparison. Most of the people remaining in the much-reformed state facilities are not medically able to live in the community at a lower level of care. Of the transfers out of Fernald between 2000 and 2005, 70 percent went to other facilities or ICF/MRs – smaller homes that still have 24-hour nursing care and highly trained staff. (Twelve percent of the people transferred have died.) Whatever it really costs to take care of someone at Fernald -- that is about what it will cost to give them the same level of

care in a community setting. The majority of the real cost is salaries for staff, and the care of a profoundly or seriously retarded person is built on years of relationships and close observation. This can’t be outsourced. If a private vendor had to make an honest individual bid on most the patients at Fernald, the price of care would be close to the real price of a Fernald bed. In fact, some facility patients with behavioral issues or medical fragility would be refused or evicted from community settings.

What *can* be documented about community placements is that they are much riskier for people like the aging present residents of Fernald, with much higher rates of sexual abuse, physical abuse, neglect, and medical errors. Some of the community programs are well run, but all of them pay the working staff much less than at Fernald, and the management much more. The people who actually care for our relatives in those settings have a high rate of turnover, can’t be well screened, and don’t stay long enough to learn the subtle signals of people with real feelings but limited language.

The true reason state government wants to push aging, fragile, retarded people out of their homes – average age at Fernald, 57; average length of stay, 47 years – is to sell off the campus for private development. However, neither the taxpayers nor the retarded residents are going to see the benefits until the DMR produces a real and detailed account of where the Fernald budget is being spent now, and negotiates an honest compromise that guarantees the “equal or better” treatment required by the 1993 Court agreements. Fiddling the statistics won’t get that done.

Short Takes

The Voice of the Retarded (VOR) had its national convention June 8-15 in Washington, DC, with representatives of 28 states. COFAR’s national umbrella continues to grow. Convention delegates visited every Congressional office to urge reauthorization of the Developmental Disabilities Act with amendments to restrict the protection and advocacy services from launching class action suits against facilities without consent of families and guardians.... This just in: **Rep. Barney Frank** has filed H.R. 2839, the amendment VOR wanted. Call your Representatives to co-sponsor and US Senators to sponsor a Senate version.... June 5, COFAR’s board of directors voted to invite DMR Commissioner-designate **Elin Howe** to a future board meeting.... **Wrentham Developmental Center** residents staged “The Sound of Music” April 30. With the assistance of recreational therapists, they made scenery, donned make-up and costumes, and sang the songs.... **COFAR President David J. Hart** imparted some real-world education in human services to a rapt audience of about 20 Harvard students April 23, at a forum organized by two student advocacy clubs. ... **COFAR VP Thomas J. Frain** was in Worcester May 16 to speak to Special Education parents in the second such COFAR seminar. Many more to come.... May 31 was the 20th Anniversary celebration of the **DPPC**, which gave DMR Commissioner Gerald Morrissey the first Krant Memorial award, named for our own Dick Krant.

COFAR is a family support, education and advocacy organization funded by member families. **Become a COFAR member and receive *The COFAR Voice*.** For membership information and information on how to donate and to be on our mailing list, visit our website at www.COFAR.org, or write to:

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