



The COFAR VOICE

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

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Special Numbers Issue

Why We Need HR3995

What if you opened a newspaper and found out that you were in a class-action suit you never heard of? And the story read: that government-funded lawyers were using your name in a suit to get you evicted from your own home? This is what actually happens, not in some foreign dictatorship, but right here in the United States. It has happened in several states to people with severe or profound MR/DD and their families. Lawyers for the Protection and Advocacy Services (in Massachusetts, the Disability Law Center) initiate class action suits against federally licensed IFC/MRs (In Massachusetts, the six large developmental centers) in the name of residents they've never met.



US House Sponsor,
Rep. Barney Frank

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Editorial:

Numbers Game Hurts Us All

2007 was the year that the 25-year-old argument about the best settings for care for people with severe and profound mental retardation/developmental disability turned into a numbers game. Despite last year's alluring (if false) financial case made by DMR and exaggerated by some advocates for closing all facilities (See "The Top 20 Fernald Number Errors," page 3), federal and state courts upheld the longstanding rights of our loved ones to appropriate and stable treatment and family choice.

But the discouraging reality is that *everyone* with MR/DD and *all* of our families will pay for the numbers games of 2007.

First, the debate over per capita costs is a setback on what all our loved ones and families, on all sides, have been fighting all our lives: **to make the world see that people with mental retardation are people, not numbers.** That, as one guardian put it, "My sister is not just a piece for them to move around on a game board."

Second, as is usually attributed to Mark Twain, "A lie can travel halfway around the world before the truth gets its boots on." What many uninterested voters and legislators will remember is that "the Department of Mental Retardation spends \$259,000 a year on every single person with mental retardation." That delusion will make it harder for *any* disabled person to get help.

Third, advocates for people with MR/DD enter the state budget season with our divisions fully exposed. Many of us have been misled to believe that closing down one level of treatment will fund help for others. Articles in this issue will show what's wrong in that dangerous assumption. The painful truth (see "Massachusetts Lags," page 2) is that these services are underfunded at all levels, even relative to nearby states.

The gatekeepers have us fighting each other at the gates, when a united effort would open those gates.

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To try to save the secure and comprehensive treatment their loved ones need, and to save their longtime homes; residents, family members and guardians have been forced to hire expensive private counsel, and to attempt to become parties to the cases, not always successfully. Their own tax dollars are funding suits to eliminate or downsize a whole level of treatment, and cutting a big hole in the safety net for all intellectually disabled people.

HR 3995, sponsored by US Rep. Barney Frank, insures individual and family choice in federally funded class-action lawsuits against ICF/MRs. The bill was improved in consultation with national representatives of the P&A attorneys and the ARC, although these groups continue to oppose the law. The bill now requires the class-action lawyers to inform the facility they intend to sue, and the facility to inform the residents and guardians. Residents and guardians can opt out of the lawsuit, or do nothing and join in.

At press time, the bill had 15 co-sponsors, including Mass. Reps Capuano, Lynch, and McGovern. The ARC of Mass website has a special link to ask Mass. Congressmen and Senators not to co-sponsor the bill. COFAR urges officials to sign on as co-sponsors. To read the bill, check a list of P&A class-action lawsuits, or for more information, see, <http://www.vor.net/DDAct2007.html>.

Massachusetts Lags on MR/DD Funding

Contrary to media stereotypes, Massachusetts is not a generous state for human services or disability spending. It is fourth among all US states in per capita income, but only 18th in MR/DD spending relative to income. Connecticut, Maine, New York, and Rhode Island are all in the Top Ten, so it's not a matter of size, wealth, or region. And contrary to what some advocates imply about the developmental centers draining the budget, Massachusetts is 19th in spending on community placements relative to income, but down to 26th on spending for "institutional" settings. Overall, the Commonwealth ranks 22nd on residential placements per state population. Again, four of the five states on our borders offer more residential placements, and so does Maine. COFAR president David J. Hart says, "Look at these numbers, and you can see why advocate groups are fighting each other – This state just isn't coming up with enough residential placements at any level of care – and it's just starting to get interested in the supports that could help families keep their relative with MR/DD at home."

(Source: *The State of the States in Developmental Disabilities, 2005*. Coleman Institute for Cognitive Disabilities, University of Colorado)

Demographic Double Trouble: *Aging Clients, Caregivers to Challenge DMR Capacity*

The good news is that medical advances are greatly extending the life spans of people with MR/DD. In the 1930s, people with MR/DD had average lifespan of less than 20 years, but are now mostly living into old age. While the treatments for heart defects, seizures, and poor living conditions have come faster than ways to overcome most of the intellectual disabilities, this is still the good news.

The bad news is that some of the underlying causes of MR/DD carry higher risks of dementia as people age, and so providers and caregivers must make careful plans to accommodate the increasing and sometimes unusual disabilities of already overburdened people. As COFAR Executive Director Colleen Lutkevich notes, "There is no sadder aspect of the lack of residential services in our state and nationally than people with MR/DD stuck in ordinary nursing homes, where they are losing the skills and independence they worked so hard to attain -- because the staff is not trained to accommodate their special needs."

And the worst news of all is the aging of the US population as a whole, and especially the "baby-boomer" population (born 1946 to 1964) that is starting to reach retirement age in 2011. The number of people in the US over age 65 will more than double from 2110 to 2050. Nationally, 61 percent of the MR/DD population now lives with family; about 11 percent in a supervised residential setting. But one quarter or more of the family caregivers in that first group are already over 60. A 2004 estimate for Massachusetts had more than 17,000 persons living with caregivers over 60!

How will the state provide residential placements for most of those people in the years to come? Is this the right time to be shutting down developmental centers where comprehensive medical and psychiatric services – already in place -- could be providing state-of-the-art treatment to people otherwise fated to be left in restraints in nursing homes? Some aging people with MR/DD could stay with aging relatives longer if community wraparound services were more available. In some other states, developmental centers have been combined with community resource centers, providing better services to the community and more community integration for the residents.

To learn more about the problems of an aging MR/DD population, the COFAR Voice attended a seminar, "Age with Me" given by the Association of Developmental Disabilities Providers. We don't agree with ADDP about closing facilities, but this all-day seminar showed that they are committed to preparing direct-care staff and house managers in the community system, if not the system as a whole.

The Top 25: Fernald Number Errors

COFAR borrowed striking TV writers for David Letterman to put the Fernald part of the numbers game into a Top-10 list. They needed 25 items just to cover the four basic “inexactitudes:” The too-high per capita figures for Fernald residents, the too-low per capita figures for moving those residents into the community, the apples-oranges comparisons, and the idea that closing Fernald might help other DMR clients.

25. DMR in a May 31, 2007 court filing set the per capita cost of keeping someone at Fernald at \$259,000 versus a community cost of \$102,000. In a September press release, the per capita cost had declined to \$239,000. Did the state save \$4 million/year (\$20,000 per resident times about 200 residents) at Fernald in less than four months? Nope. Did they apologize for telling the court the wrong number? Nope. They just changed their estimates.

24. Estimates? That’s right. DMR doesn’t actually keep track of what it spends, person by person. They have not revealed the basis of the \$259,000 number, but it is probably a projection of estimates made in 2001.

23. They based their \$239,000 estimate on projected FY2008 expenditures, minus estimated “attrition,” using the 181 resident census of the first quarter of that year. Nine budget components were estimated, with five of them estimated to increase. The largest item was payroll, which was estimated to increase by 8%, despite a note to the same line of the spreadsheet, “as FDC payroll decreases, the savings are redirected to the community system...” The payroll number either increases or decreases. It can’t do both.

22. DMR per capita estimates are based on the number of residents at Fernald, which population continues to decline because of DMR’s efforts to move people out, as well as natural deaths. So by last fall, the population was down to 181. Not only does the declining population make the costs per person look higher without actually increasing the bill – it is probably a wasteful inefficiency.

21. DMR persistently includes the budget for the Marquardt Nursing Center, but does not add the 29 patients there to the Fernald census, because DMR does not want to close Marquardt. Adding the Marquardt patients would bring their current estimate down to 206,000 per resident per year.

20. The Fernald League looked at the DMR spreadsheet, added back the Marquardt patients, and divided some expenses that serve 265 homeless people sheltered there, and calculated the Fernald resident per-capita number at \$195,421.

19. But, that still includes the building upkeep for Tufts Dental, the DMR regional offices, the Howe library, the

athletic facilities, and community work programs, which are used more by people living in the community than by Fernald residents. And the state does not intend to close Tufts Dental or the regional office, and plans to convert at least four other buildings into state-operated groups homes. So some of those costs should not be in any calculation about savings of closing Fernald, and the some of the rest should be moved over to the community-placement number, and subtracted from the Fernald resident cost.

18. Nearly three-fourths of the buildings on the Fernald campus are unoccupied, but still using heat and electricity. The state could mothball these buildings properly and reduce the cost per patient even more.

17. The *COFAR Voice* has not seen a full Fernald budget to audit it. The last time we looked, it included the \$91,900 salary of the facility director, who spent 40% of her time at the Hogan Regional Development Center – in Danvers! This month, she is now full-time at Fernald, but what other non-Fernald items have been padded onto the Fernald budget?

16. Mandatory overtime (see “DMR’s Millions for Mandatory Overtime,” page 5) is considered to be especially prevalent at Fernald due to unannounced hiring freezes and the state’s intention to close the facility. With some people making more in overtime than in base salary, this inefficiency also adds unnecessarily to the cost of Fernald residency.

15. Moving on to the \$102,000 figure for per-resident care in the community, it too is an estimate. The estimate is based on a basket of DMR-only costs for community residential clients now. This however ignores other tax-supported benefits for community-system residents which Fernald residents do not use, such as food stamps, HUD Section 8 housing subsidies, Department of Transportation subsidies, as well as dental and medical services provided at facilities (and therefore included in the budget of Fernald!)

14. When a DMR panel made an actual study of 71 of the 142 individuals who had left ICFs/MR in FY 1998 and 1999, their estimate for FY2002 was that the average annual per person community cost was \$134,247. This study is no longer quoted.

13. The 1998-1999 transfers were younger and healthier and less profoundly retarded than the remaining residents at Fernald are today, so that figure would be even higher comparing people at the same level of disability. But using that FY2002 figure and the 3% inflation projected by the DMR panel that did the study, the figure for FY08 would be \$160,298 per person going from a facility to the community.

12. Another working group of the same 2001 commission report estimated a scenario for closing all the facilities, projecting an FY2008 operating cost of \$151 million for 868 surviving consumers entirely in the community. That would work out to \$173,963 per person. (The Commission had several working groups that didn’t work together so carefully.)

11. No average of costs for community residents (of whom most are mildly or moderately retarded), will work for Fernald

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transfers (who are mostly seriously or profoundly retarded and medically and behaviorally complicated). These fragile and aging residents will require more costly care in any setting: home, community, or facility.

10. Residents leaving Fernald will have a right to choose another IFC/MR. That is part of the 1993 Ricci court settlement, and was affirmed by HHS Secretary Bigby last September. Of the residents who transferred out under the pressure of the closing notice in 2003-4, 60 percent went to another facility, and many of the rest went to state-operated group homes. So the comparison of per-resident costs with those at private group homes is mostly irrelevant.

9. By definition, anyone going from a Massachusetts facility to a community placement receives a lower standard of care because only the six developmental centers meet the federal standard as IFC/MRs. Moreover, Fernald residents under the court settlement have a right to "equal or better treatment." Last August 14, Judge Tauro upheld that Fernald must be an option in their annual treatment reviews, supporting the idea that a long-term home with familiar staff often cannot be equaled even at another facility.

8. Even if DMR's per-capita cost figures were real, and every remaining Fernald resident chose to move to the \$102,000 setting, the \$137,000 difference times the 181 residents would be \$24,797,000. Divide that by the 32,000 other DMR clients and it would provide less than \$2.13 per day in additional services for each DMR client.

7. At the still-iffy estimate of the Fernald League's \$195,421 number minus the inflation-adjusted actual costs from the 1998-1999 transfers, the "savings" of closing Fernald *might* be less than \$6.4 million per year. That would be \$200 per year, less than one dollar per day, for each DMR client.

6. In fact, when the closure was first "announced" in 2003, DMR suggested that savings would be less than \$2.4 million per year, and that the real motivation for closing Fernald was the superiority of the community system for these individuals. Only when court monitor US Attorney Michael Sullivan reported an increased danger of abuse and neglect in private

non-profit group homes, did DMR and advocates of closing all facilities blanket the media with erroneous cost claims.

5. The four state-operated group homes built to take up Fernald residents cost an estimated \$250,000/bed to build, and are on 20-year leases for \$100,000 per year. (Details of this are still held secret by DMR.) Adding 181 Fernald residents to an already full community system would probably cost the state *more* than it is paying now.

4. Given federal Medicaid cuts, state revenue shortfalls, and the likelihood of a coming recession, there is no guarantee that any savings generated by closing Fernald would stay in the DMR budget.

3. There is no law requiring any proceeds of selling the Fernald campus to be used for the benefit of people with MR.

2. DMR has persistently refused to look at proposals for downsizing Fernald, making it more efficient, and enhancing its additional functions as a nursing care center, community resource center, and respite center. (Massachusetts DMR has no respite capacity outside the six developmental centers.) Their argument is that this would require new investment. But a plan to sell most of the campus might finance the new investment, and unite all advocates.

And now...

The Number One Fernald Numbers Error:

1. Advocates of closing the facility have been repeatedly quoted about how their loved one in a community setting is being denied vital services because of the expense of Fernald.

Few other advocacy groups are so badly split on severity of diagnosis and age. Mental health advocates do not argue that the people with schizophrenia are soaking up resources that could help the people with bipolar disorder. The AARP does not blame the people in their 90s for getting more benefits than the people who retire at 62.

So why do some family members of people with MR/DD believe that the residents of the Fernald Development Center are holding back their own loved ones? Even though the numbers don't work and can't be made to work?

Because we are all in pain that cannot be measured by numbers. Because we are all angry. And our pain and our anger are not errors.

Seeing the residents of Fernald, their families and guardians, as the obstacle to reforming an underfunded, undersized, under-regulated, and under-supervised DMR community residential system is the Number One Fernald numbers error. Forcing another 181 Fernald residents into that system would be dangerous to them and no benefit to those now using the community residential system, or the thousands waiting to get into it.

(Special thanks to The Fernald League for DMR documents obtained under the Freedom of Information Act.)

Repair Numbers Are Wrong, Too!

Last June, an NPR report quoted a figure of \$200 million to repair the six Massachusetts developmental centers. COFAR pointed out that DMR had quoted \$15-20 million in its court filing for repairing Fernald, which they described as the most expensive to repair. So how could the other five centers average twice as much to fix? In fact, DMR's estimate for all six facilities in the 2001 study was \$35 million, and the highest estimate for ADA compliance was under \$93 million.

In a May 31 court filing, DMR estimated that it would take \$14-20 million to repair the buildings at Fernald. In response to the Fernald League FOIA request, DMR explained that a 2001 figure made by the state buildings estimating method, CAMIS, was \$14,487,319, "This figure was reduced to reflect the view that CAMIS data was over-inclusive of some of the buildings on campus that DMR did not intend to use."

The Extra Costs of (not) Closing Fernald: Your Tax Dollars at Work

As this issue of the *COFAR Voice* looks at the exaggerated, estimated, and in fact imaginary savings to be gained by closing Fernald, let's not forget the very real and measurable costs of trying to close it illegally.

To get ready for the "planned exodus" from Fernald, DMR had constructed four new state-operated group homes, which sat empty for much of 2007. (To her credit, Commissioner Elin Howe began moving people into some of these much-needed beds late in the year.) The construction contracts for these group homes have been kept secret, however one case examined by the *Voice* in public records, involved use of the state bonding power. These homes were reportedly built with 20-year, \$100,000 leases. When the *COFAR Voice* was able to visit one of the new homes on the Glavin campus, it was very well equipped and ADA-compliant. To be clear, COFAR is in favor of more state-operated group homes; but not in favor of keeping them empty, or making bad deals with private contractors to build them, nor of lease deals where after spending \$2 million the state has no ownership.

A second hidden cost of the state's war on Fernald residents has been the continued inefficient operation of the Fernald Center itself. Instead of negotiating a smaller and more efficient Fernald, freeing much of the acreage for sale or other state uses – DMR allows the facility to run inefficiently, heating empty buildings and mowing underutilized lawns. Either the state is afraid of undermining their case for closure by cutting waste and making more productive use while the residents continue to live there, or they actually want to use unnecessary costs to pad their false comparisons! This issue emerged in public with reports in late 2007 that four of the buildings at Fernald are being used as a shelter for about 265 homeless mothers and children. State government insists Fernald must be closed, and won't look at the "postage stamp" plan, but real-world practicality keeps knocking at the door.

It's hard to calculate how much the state has already wasted by allowing much of Fernald to sit around. If they had admitted the long-established rights of Fernald residents in, say, 2004, and negotiated some version of the "postage stamp" plan, by now tens of millions of dollars might be pouring into the state treasury. Then there is the mandatory overtime expense (See, "DMR's Mandatory Overtime," below right), especially at Fernald where there are informal hiring freezes.

Lastly, the appeal of the case is expensive. Although it doesn't have a line item in the state budget, and the legislature doesn't vote on it, the expense of the appeal comes both directly and indirectly from taxpayer dollars. DMR's appeal will be prepared and argued by state-employed attorneys. The decision is also under appeal by the ARC of Massachusetts. Although the ARC is a private non-profit, part of its funding comes from a state government contract, and almost the entire \$170 million budget of its 20 chapters

(combined) comes from state and federal tax moneys. The ARC's court filings are prepared by the almost entirely federally funded Disability Law Center, and by the Center for Public Representation, which in turn is supported mainly by fees from other tax-supported institutions, about one-quarter being a \$300,000 grant from Mass. Legal Assistance Corporation, itself almost half funded by... our state income tax. DLC and CPR are also handling the ARC's appeal.

The Center for Public Representation was chartered to spend your tax dollars to provide "legal assistance, counsel, and representation to institutionalized and low-income handicapped persons at no charge." The mission statement includes, "to promote change in the quality of lives of individuals with disabilities in Massachusetts." There has been some mission creep, since its website now states that "We seldom provide representation in individual cases." In addition, although we in COFAR do not like the word "institutionalized," it is increasingly debatable that CPR is providing assistance to persons living in state facilities by trying to kick them out of their homes.

An Amicus brief in favor of closing Fernald was submitted in 2007 by, among others, the federally-funded National Disability Rights Network. Other signers included the Association of Developmental Disabilities Providers (AADP), the Mass. Council of Human Service Providers, the and several service providers – all ultimately tax-funded to provide services to people with disabilities, not more grief for the residents of Fernald. When these same organizations file an amicus brief in the appeal, we all get to pay again.

DMR's Millions for Mandatory Overtime

The *COFAR Voice* recently looked up DMR salaries on the *Boston Herald* website. The surprise: not the salaries, but the take-home pay. Seven registered nurses took home more than the salary of the DMR commissioner. Of the 61 people who took home more than \$100,000, only 12 were administrators. There were 37 nurses and 12 psychologists. In some cases, their overtime pay was more than their base salary.

The Mass Nurses Association says that mandatory overtime has been a consistent and dangerous problem for the staff of DMR for years and they have been attempting to negotiate an end to the practice. In negotiations, it has been a chicken-egg problem, in which DMR cites a nursing shortage, while MNA suggests that more nurses would apply for DMR jobs if there weren't mandatory overtime and if the nurses at DMR weren't among the lowest paid nurses in the state. The fact, is there is no shortage of nurses in the state, as Mass. has more nurses per capita than any state in the nation. COFAR thinks paying millions in nursing overtime is inefficient, but we *know* it stresses core staff that care for our loved ones. The vast majority are doing a great job. Eliminate mandatory overtime, and we could cut medication errors and short tempers even more.

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