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Questions? Contact Tamie at Tamie327@hotmail.com or 605-399-1624.

VOR Weekly E-Mail Update

March 28, 2008

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1. State files Fernald appeal

Summary: In August 2008, Federal Judge Tauro barred officials at Fernald from moving any residents unless they and their guardians agreed. Governor Deval L. Patrick, like Governor Mitt Romney before him, wants to close Fernald and move residents to group homes. The Patrick administration's appellate brief was just filed with the US Court of Appeals for the First Circuit. The families (plaintiffs/appellees) have 30 days to reply. VOR, and its statewide affiliate, COFAR, are preparing to participate as Amicus Curiae in the appeal.

State files Fernald appeal

By Richard Conn

Daily News staff

Mar 20, 2008

WALTHAM - The state yesterday filed an appeal brief of a federal judge's ruling that residents who want to stay at the Fernald Developmental Center must be given that chance.

U.S. District Judge Joseph Tauro ruled in August that Fernald must remain an option for its current residents. He said last month though that his ruling was not intended to interfere with the state's plan to close Fernald.

However, the state's appeal, which was filed in the U.S Court of Appeals, argues that Tauro's order does just that.

"Contrary to the court's disclaimer, the August order effectively constituted an unlawful command that the (Fernald Developmental Center) remain open," the state argues in its appeal.

The state originally announced plans to close Fernald in 2003, and said doing so would be in line with a national shift away from institutional care to community living for the developmentally disabled.

The state's appeal argues that for the Department of Mental Retardation to comply with Tauro's order, Fernald would have to be kept open as a placement option for each resident "indefinitely."

A group of guardians known as the Fernald League has waged a legal battle to keep Fernald open, claiming residents - many of whom have lived there for some 50 years - should have the right to stay.

State officials argue the 196-acre campus is too expensive to keep open. Fernald League members have disputed figures the state has offered concerning how much it costs to care annually for a resident at Fernald.

Marilyn Meagher, president of the Fernald League, said late yesterday she had not had a chance to look at the state's appeal.

Meagher said the Fernald League has 30 days to file a response.

Tauro ordered the U.S. Attorney's office last month to investigate whether a 91-year old woman who lived at Fernald for more than 50 years was moved against her will to a group home in Bedford.

2. Developmentally disabled nursing home residents are facing transfer

By Richard Conn/Daily News Staff

Daily News Tribune

Mar 20, 2008

WALTHAM - The state has reached a settlement in a class action lawsuit that will result in the transfer of more than 600 developmentally disabled nursing home residents to community living facilities.

Waltham-based Arc of Massachusetts - an advocacy group for the developmentally disabled - served as an organizational plaintiff in the lawsuit, which was filed in 1998 on behalf of some 700 people with developmental disabilities in nursing homes throughout the state.

The suit argued that residents were inappropriately confined to nursing homes and many weren't receiving the "specialized services" they needed.

Leo Sarkissian, executive director of Arc, said yesterday that negotiations on the settlement began in earnest last fall.

"By January an agreement was in pretty good shape," Sarkissian said. According to the terms of the settlement, 640 individuals will be placed into community care environments, such as group homes, over a four-period beginning in 2009.

A press release issued yesterday by the state Department of Mental Retardation said the other nursing home residents have conditions or personal circumstances that preclude them being moved to community settings, but they will continue to receive "active treatment."

Health and Human Services Secretary Judy Ann Bigby said in the release that the settlement is part of the state's initiative to shift care for the developmentally disabled to community living.

"This is an important step in moving forward with our Community First agenda," Bigby said. "It accelerates the process of community placement for hundreds of individuals

over the course of a four-year period.

"The settlement of this long-standing case from previous administrations is a collaborative effort between state agencies, the Attorney General and the plaintiffs." A previous settlement in the case was reached in 1999, which resulted in about 800 individuals placed into community facilities between 2000 and 2007.

However, negotiations between the two sides stalled over the "quality of specialized services" that residents who remained in the nursing facilities were receiving, Sarkissian said.

U.S. District Court Chief Magistrate Judge Kenneth P. Neiman ruled last April that the Department of Mental Retardation had not provided nursing facility residents with adequate care. He ordered the parties to select a court monitor to review the services provided to those residents.

Sarkissian said the settlement showed that state officials are committing to provide those with mental retardation and other developmental disabilities with community care options.

"What we're pleading with the Legislature and the governor to do is make an even larger investment in community services," Sarkissian said.

3. COFAR editorial: The Numbers Game Hurts Us All

Summary: This editorial and the article that follows appeared in the Massachusetts Coalition of Friends and Advocates for the Retarded (COFAR) February newsletter. In these articles, COFAR takes on (very, very effectively) cost myths, including "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." As many VOR members know, in 2003, VOR helped coordinate a cost comparison study that is still used today by advocates to debunk the "community is always cheaper" myth. Original reprints of this cost study are available. Contact Tamie at Tamie327@hotmail.com for more information.

The COFAR Voice
Vol. 10, Number 1
February 2008

<http://www.cofar.org/COFARNL021508.pdf>

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 advocates for closing all facilities (See "The Top 20 Fernald Number Errors," page 3 [below] federal and state courts upheld the longstanding rights of our loved ones to appropriate and stabile 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 mislead 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 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.

4. From COFAR - The Top 25: Fernald Number Errors

The COFAR Voice
Vol. 10, Number 1
February 2008

<http://www.cofar.org/COFARNL021508.pdf>

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 group homes. So some of those costs should not be in any calculation about savings of closing Fernald, and 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 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 use 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.)

Tamie Hopp

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