

COFAR POSITION STATEMENT OPPOSING THE CLOSURE OF THE FERNALD CENTER AND OTHER STATE-RUN INTERMEDIATE CARE FACILITIES FOR THE RETARDED

The Coalition of Families and Advocates for the Retarded (COFAR) calls upon public officials to reject the proposal by Governor Romney that The Fernald Center in Waltham and the remaining state-run intermediate care facilities for the retarded in Massachusetts be closed.

We believe that the closures of these facilities will not save the state money and, contrary to the hope of those supporting these closures, will not result in equal or better care for the hundreds of severely and profoundly retarded people currently residing in them. We think this conclusion is inescapable.

Misunderstandings Persist Over Conditions at State Facilities

COFAR believes that much of the public policy decision making and the positions of those who support closure of these facilities are based on the false premise that Fernald and the other state facilities are the stereotypical "warehouses" for the retarded that we all know about from years gone by, and which COFAR and its member organizations were instrumental in ending. The fact is, ***Fernald and the other state facilities are wonderful facilities, with spacious, colorful rooms for residents, with amenities and support services that are unmatched in the country if not the world. The facilities provide a wide range of medical, dental, and psychiatric services to the residents, as well as physical, respiratory and occupational therapy services, speech and communications services, and adaptive technologies, such as wheelchairs retrofitted with switching devices.*** We invite legislators to come and visit Fernald for themselves before casting a final vote on this issue.

Second, much of the public policy decision-making of those who support closure of Fernald and the other state facilities is based on an inaccurate understanding and characterization of the residents there. ***These residents are the most severely and profoundly retarded in the state. Many are on respirators and have a variety of severe medical problems in addition to their mental disabilities. If one doesn't take into account the actual makeup of the population at Fernald, one might assume the residents could be cared for in the community. But that is not who***

these people are. These are people who need a different level of care and attention. These are not the mentally retarded who will ever bag your groceries at Stop & Shop. To misrepresent who these people are and what they truly need is not only bad policy, it is life threatening. And the assumption that most, if not all, of these residents could be moved out into the community is a false and dangerous one.

Equal or Better Care?

As you know, most of the residents of the state facilities are entitled under a 1992 consent decree stemming from the landmark Ricci v. Okin federal lawsuit to receive equal or better care if they are transferred elsewhere. Yet, it is a fact that there are no community residences anywhere in this state at this time that can provide equal or better care to that which the residents of Fernald and the other state facilities currently receive. It would be a violation of the Judge Joseph Tauro's consent decree to attempt to force these residents into a substandard setting that violates the equal or better standard. Ejecting these fragile and vulnerable residents into the existing community-based system would be a death sentence to many of them.

Questions Persist Over Community-Based Care

COFAR strongly disagrees with recent statements that Massachusetts has a top reputation for facilitating the transition of residents into the community and that residents of these facilities and their families would choose community-based providers if plans were offered to them.

The Massachusetts House Post Audit and Oversight Bureau concluded in 1997 that the Department of Mental Retardation's oversight of the community-based delivery system raised "**grave doubts about the (DMR's) commitment to the basic health and safety issues and ensuring that community placements provide equal or better care for DMR clients.**" The Post Audit report also stated that "(d)espite DMR's substantial efforts to place its clients into the community, all too often DMR clients are isolated not only from the community but from protective services as well....**Many cognitively disabled persons went from intense and tailored special education services provided by school systems to little or no service once they entered the community.**"¹

Since the House Post Audit report was issued in 1997, Massachusetts has by no means been immune from these issues arising from inadequate state oversight and quality assurance in place in the community. The Boston Globe reported in February of this year, for example, that since 1997, the state Disabled Persons Protection Commission had investigated 19 complaints of client injury at

Community Group, Inc., a for-profit company hired by the state to provide housing and job training for people with mental retardation. Officials were quoted as saying they were concerned about the well-being of many of the 85 clients the firm was caring for at 21 group homes in eastern Massachusetts. In addition to the accusations relating to poor care, a state audit found that the company had secretly raised more than \$1 million selling products made by its clients with disabilities and used the money for a Mercedes-Benz, country club membership, and other perks for company management.

In fact, the issues in Massachusetts raised by community-based care are national in scope. The Voice of the Retarded, a nationwide organization supporting choice in service options for the retarded, contended in February that "any realistic examination of the nationwide community services system reveals glaring weaknesses in the capability of current services systems to deliver high quality supports to individuals with mental retardation and developmental disabilities."²

In a major ruling on the matter in Tennessee, a U.S. District Court judge concluded in February that the public interest was better served if a state-operated intermediate care facility for the mentally retarded (ICF/MR) remained open "given questions surrounding the care received in the community setting and the stakes involved in such placement."³

As for the statement by supporters of closure that retarded residents of state facilities tend to choose to live in the community if plans are offered to them, COFAR would note that for the most severely retarded people, the concept of a "choice" such as this is meaningless. In fact, the guardians of hundreds of these residents have consistently opposed their relocation to the community. The task force itself noted that it took 10 years to close the Dever School in Taunton due to a lack of consensus over the closure.

Misperceptions Persist About the Cost of Institutional Versus Community-based Care

The administration assumes there will be savings to the state budget in closing Fernald and the other ICF/MR facilities. COFAR does not believe this assumption is based on real world studies or evidence. In fact, ***studies have shown that comparable community-based care is not less expensive than state-based care.*** These studies have pointed to staffing levels, resident characteristics, sources of funds, cost shifting, and regional differences as being the determining factors influencing the actual costs of care.⁴

COFAR believes that if DMR intends to provide the same level of care in the community that is required by the Fernald residents alone, the cost of doing so would far exceed any benefit there would be to closing the facility. In essence, DMR would be required to fund dozens of mini Fernalds, with around-the-clock staff and specialized services. DMR would need to find locations, permit and build new facilities throughout the state, and would need to monitor and supervise the care in these facilities in all of those different locations. The infrastructure costs, the staff costs and the operations cost would be ten times what it costs to operate Fernald. Given the fact that by DMR's own estimates, there are thousands of retarded residents currently on waiting lists for community-based care, it makes little sense at this juncture to eliminate a crucial segment of the state's service delivery—the state facilities.

Finally, a word about the administration's plans to sell the land at Fernald and the other state facility sites. COFAR has long argued that it is possible to operate Fernald and the other state facilities more cost effectively. We are therefore ready to work with the administration and the legislature on developing a comprehensive plan that will provide for appropriate and compatible uses for the grounds and facilities at these sites, while retaining them as homes for their current residents. These possible uses range from locating affordable housing to siting state agencies there.

If one looks at Fernald as a postcard, the current level of services provided at the campus could be considered a postage stamp component of that space, leaving the remainder of the land to be sold off for innovative and more profitable uses. COFAR would note that the task force did state that it would encourage "appropriate housing" on some portion of Fernald's campus for current Fernald residents.

¹Report on the Massachusetts Department of Mental Retardation: An investigation by the House of Representatives Post Audit and Oversight Bureau, June 1997

²The Voice of the Retarded report entitled "Call to Action to State and Federal Policymakers" noted that the number of persons living in small, community-based living arrangements more than doubled from about 98,000 in 1990 to almost 239,000 in 2000. The report stated that "(T)here is little doubt that the explosion in the number of these small, community-based residential sites is posing substantially greater quality management and system infrastructure challenges for states and local developmental disabilities authorities."

³Voice of the Retarded membership letter dated March 5, 2003.

⁴ Walsh, Kevin; Green, Regina; and Kastner, Theodore, "Institutional and Community-based Systems for People with Mental Retardation: A Review of the Cost-Comparison Literature," Developmental Disabilities Health Alliance, Inc., May 2002.