

60! That's how many U.S. Representatives have cosponsored H.R. 1255. Have YOU requested a meeting or called your U.S. Representative? Click here for an Action Alert. If not us, who?

VOR Weekly E-Mail Update
August 7, 2009

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Massachusetts: Lesson in Effective Grassroots Advocacy.

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1. About this Issue

For the past several years, VOR has sponsored a State Reports Forum in Washington, D.C. Held the evening before VOR's Annual Conference, the State Report Forum is a moderated event that allows participants to give an update on happenings in their states, relating especially to the issues that concern choice advocate, such as family decisionmaking and protecting the range of service options.

This year, David Hart, President of the Massachusetts Coalition of Families and Advocates (COFAR) (<http://www.cofar-mass.org/>) gave his state's report and discussed COFAR's advocacy activities, planning and successes. The grassroots advocacy efforts of COFAR are nothing short of amazing. We are sharing it here, along with his complete report, in the hope that VOR advocates from around the country might cull from it some good lessons learned and put some or all of what COFAR has accomplished to good use in their own states.

David Hart's brother is a resident at a Massachusetts' Developmental Center. COFAR is VOR's statewide Massachusetts affiliate and David serves on VOR's Legislative and Government Affairs Committees.

2. A Lesson in Grassroots Advocacy

By David Hart

(Excerpt from his Massachusetts Report at the VOR State Report Forum in Washington, D.C. His full presentation follows)

The battle in Massachusetts to close the six publicly funded ICF/MR Developmental Centers continues. To date none have closed, however, Fernald the oldest Developmental Center in the

United States is slated to close June 30, 2010. There is some talk saying that Fernald could close as early as this year due to excessive budget cuts to health and human services.

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January 2009, COFAR and two unions, MNA and AFSME met to formulate a plan of action. The plan was simple, realizing that this fight would end up in the Legislature; we focused our efforts there and began what I call a "Re-Education" of the Legislature. This Re-Education consisted of a ten step plan:

- A. A 50,000 piece mail drop of post cards, addressed to individual representatives, senators and the governor personally signed by all COFAR and union members.
- B. A series of Op Ed letters were published discussing our side of the closure argument.
- C. Calls, calls and more calls to legislators.
- D. Demand DMR and the Governor prove their numbers out. (Like the Romney administration COFAR was able to argue that closure would be revenue neutral at best and in fact cost the taxpayers more money in the long run).
- E. Demand DMR produce in writing the so-called Plan. (to date nothing has been produced).
- F. Re-educate the legislators what the Olmstead Decision really says.
- G. Produce a series of "white papers" for the legislators to read on several topics such as: cost studies, mortality rates, one size does not fit all, impact of eviction and others
- H. Finding a representative and senator to file an amendment to the facility line item asking for a full feasibility study to be done by an outside party prior to any closure.
- I. Getting as much press as possible.
- J. Continue to advocate for other MR/DD issues and budget items (COFAR did not want to get the reputation of one issue only. Because, it hurts the public face of the organization and could be used against it).

3. Through the lens of a Choice Advocate: State of the State in Massachusetts

**Delivered by David Hart, President, COFAR
VOR State Report Forum
VOR 2009 Annual Conference
Friday, June 12, 2009**

The battle in Massachusetts to close the six publicly funded ICF/MR Developmental Centers continues. To date none have closed, however, Fernald the oldest Developmental Center in the United States is slated to close June 30, 2010. There is some talk saying that Fernald could close as early as this year due to excessive budget cuts to health and human services.

The Groton 43 continues their fight to prevent 43 severely disabled individuals with cognitive levels of under 12 months from being evicted from their home.

These individuals live in a pediatric nursing home run by Seven Hills. They are being evicted because they are over 18 years of age. Many of the 43 have spent their entire lives at this nursing home and have thrived.

The Groton 43 are the un-intended victims of the Rolland nursing home case which began 10 years ago. The intention of the case was to move elderly people with MR/DD out of nursing homes which did not meet their individual needs. DMR and the usual cast of "tax-supported class action lawyers" came to a settlement with the plaintiff, in which DMR is required to move 640 people out of nursing homes and into the community over the next 4 years.

The Groton 43 and others were part of this class-action but never knew it. The guardians of the Groton 43 went to court to opt out and on May 22, 2008 the court rejected the objection of the Groton 43. There is no better example of why we are advocating for HR 1255 this week.

DMR and ArcGB, a corporate guardian, evicted a 91 year old Fernald resident Anna Tross, against her will and moved her to the community. When friends, Fernald workers, family, including her sister went to visit her they were rejected by staff at the group home.

Further, Linda Curran, who was Anna Tross' case worker from ArcGB, testified in court that Anna did not want to leave Fernald. Curran also stated that she was told by ArcGB CEO that the Arc of Massachusetts wanted all facilities closed and all residents from Fernald moved into residential community placements. Curran also testified that she was told to work with the DMR Placement Coordinator and deputy Assistant Commissioner of Facilities Management Christine Oliveira to move all of her wards. Curran disagreed with the order and was subsequently fired. Anna Tross died earlier this year in her group home without ever seeing friends and family again.

In December 2008 Buddy Edward Smith was found guilty of gang raping, assaulting and stalking a young man with MR/DD over a four year period of time in MA and Rhode Island. After the mother and father of the victim found out about the crimes they went to the police in both MA and RI but hit a "wall".

The District Attorney's office was not corporative either. In fact the DA told the family that they would have to arrange a competency assessment for the victim, pay for it themselves, in order to prove that the victim would be a credible witness. A close family friend found COFAR on the web and wrote us a letter. From that point on, COFAR ran with the story and exerted enough pressure on the powers to be that Smith and his uncle William Senay were arrested.

Mark Zanger, myself and other COFAR members sat in court for an entire week during the Smith case to show support to the family and the victim. The victim testified as did his mother and father and as I stated earlier Smith was found guilty and sentenced to 7-10 years in prison.

After the conclusion of the Buddy Smith trial, his Uncle William Senay was put on trial. The victim and his family testified again and Senay was found guilty and sentenced to 7-10 years in prison just like his nephew.

In 2008 the DMR appealed Judge Tauro's global announcement that the closing Fernald was a violation of individual ISP rights. COFAR and VOR filed a joint Amicus Brief against the DMR's appeal of Judge Tauro's August 14, 2007 order.

On October 1, 2008 a three-judge Federal Appeals Court panel ruled that Judge Joseph Tauro did not have jurisdiction to reopen the Ricci v. Okin case over transfers from Fernald. In October 2008 Governor Patrick announced additional cuts to the facilities line item citing the 08 Appeals Court decision and pending closure of Fernald.

In January 2009, the Fernald League with assistance of outside council filed an appeal to the US Supreme Court. VOR also wrote an Amicus Brief on behalf of the Fernald League. For legal reasons COFAR did not co-author this with

VOR. The basis of the Fernald Leagues appeal to the Supreme Court was based on the validity of a "Consent Decree". Unfortunately, on April 5, 2009 the US Supreme Court decided not to review the appeal, ending this particular avenue for the Fernald League.

In October 2008, Massachusetts Governor Patrick announced several devastating 9c cuts to the state budget many of which were in the Health and Human Service areas. These cuts came from a Governor that ran on the fact that he was a friend of and understood the needs of people who could not take care of themselves and therefore looked to government for help.

December 12, 2008 Governor Patrick along with Commissioner Howe and Sectary of Health and Human Services, Judy Ann Bigby formerly announced the DMR Plan to close 4 of the 6 ICF/MR Developmental Centers in MA.

According to the Governor the plan was based on the Olmsted Decision which Governor Patrick erroneously states that Olmsted favors the community over facility living.

This announcement also came as quite a surprise to the MA Legislators. They found out about the announcement when their constituents who have loved ones living in the facilities called their offices to see what they were going to do.

The Governor stated that by closing 4 of the 6 facilities would save the tax payers of MA up to 60-80 million dollars. He also stated that he was going to pledge 40 million of taxpayer money to build group homes. The other 2 facilities Hogan and Wrentham would be decided at a later date. However, Hogan is scheduled to close in 4 years and Wrentham will close when the last person dies or moves out. This same governor stated that this plan gives everyone "CHOICE". (COFAR has

been advocating for choice for many years and I believe the Governor tried to use our words against us).

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In conclusion, the amendment filed by the Representative and Senator for a feasibility study is currently being debated in Conference Committee along with several other budget items for the MR/DD community.

4. VOR and YOU: Your Membership and Gifts Make a Difference!!

VOR is the only national advocacy organization that expressly opposes efforts to eliminate the facility option while also supporting expansion of quality community programs. VOR advocates that final determination of what is appropriate depends on the unique abilities, needs and desires of each individual, with the input of family guardians where necessary and appropriate.

Editor:

Tamie Hopp, VOR Director of Government Relations & Advocacy

THANK YOU FOR YOUR SUPPORT!

TO JOIN OR CONTRIBUTE: \$25 per individual, \$150 per family organization, or \$200 per provider/professional organization. Extra donations are welcome!

You may pay by check or credit card

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