

DEADLINE ALERT! HOTEL RESERVATIONS MUST BE MADE BY MAY 12. REGISTER TODAY!!

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YOUR FAMILY ASSOCIATION CAN HELP!

Distribute Annual Meeting/Initiative Flyers and Sponsorship Flyers
Put information about these opportunities in your newsletters.
Sponsor someone from your group to attend the meeting.
Contact Tamie at 605-399-1624; Tamie327@hotmail.com for information

VOR Weekly E-Mail Update

May 1, 2009

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ACTION ITEMS UPDATE

1. H.R. 1255 COSPONSOR UPDATE - ONGOING CALL FOR ACTION

2. PETITION UPDATE: We're closing in on 2,000 signatures!!

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1. H.R. 1255 COSPONSOR UPDATE - ONGOING CALL FOR ACTION

We are now up to 24 cosponsors with many more Congressional offices expressing interest.

WE NEED YOUR HELP!

A. Review the list of cosponsors below.

B. If you don't see your U.S. Representative, visit <http://vor.net/HR1255positions.htm>, then -

C. Call your Representative and ask for the Health LA. Specifically request that your Representative COSPONSOR H.R. 1255

D. CALL BACK WEEKLY TO FOLLOW UP ON YOUR REQUEST.

If not us, who? Representatives and their staff are very, very busy. They will not cosponsor the best of legislation without constituent requests. It is especially critical that ADVOCATES IN SUPPORT OF H.R. 1255 CONTACT CONGRESS. We know our opposition is working hard to oppose H.R. 1255. It is vital that U.S. Representatives hear from FAMILILES IN SUPPORT OF H.R. 1255.

Thanks so much! Contact Tamie at 605-399-1624 or Tamie327@hotmail.com with any questions.

H.R. 1255 COSPONSORS as of May 1, 2009

Sponsor: Rep. Barney Frank (D-MA)

Democrats

Rep. James Moran (D-VA)
Rep. Steve Cohen (D-TN)
Rep. Paul Kanjorski (D-PA)
Rep. Debbie Wasserman Schultz (D-FL)
Rep. Michael Capuano (D-MA)
Rep. John Olver (D-MA)
Rep. John Barrow (D-GA)
Rep. Luis Gutierrez (D-IL)
Rep. John Larson (D-CT)
Rep. James McGovern (D-MA)
Rep. Pete Stark (D-CA)
Rep. Charles Gonzalez (D-TX)
Rep. John Lewis (D-GA)

Republicans

Rep. Ted Poe (R-TX)
Rep. Ron Paul (R-TX)
Rep. Bob Goodlatte (R-VA)
Rep. David Dreier (R-CA)
Rep. Daniel Lungren (R-CA)
Rep. Frank Wolf (R-VA)
Rep. John Culberson (R-TX)
Rep. Charles Boustany (R-LA)
Rep. Peter Roskam (R-IL)
Rep. John Boozman (R-AR)
Rep. Anh "Joseph" Cao (R-LA)

***=Original cosponsors**

2. PETITION UPDATE: We're closing in on 2,000 signatures!!

Keep up the great work!! Tell everyone about this common sense petition and ask them to sign on!! NUMBERS COUNT!! Visit <http://www.vor.net> and click on the Petition link on the home page.

3. MASSACHUSETTS: Reps vote to keep centers for disabled

Associated Press

Thursday, April 30, 2009

Boston (AP) - House lawmakers have voted to block Governor Deval Patrick's plan to close four state institutions for the developmentally disabled.

The House approved an amendment Wednesday night that would keep open the institutions slated for closing, including the Fernald Developmental Center, and conduct an analysis of their cost and quality.

The amendment goes next to the Senate. The final House budget still has to be voted on, and Rep. Todd Smola, R-Palmer, says he wouldn't be surprised if Patrick vetoed the amendment.

Patrick has argued closing Fernald and the other facilities will put residents in more comfortable settings and free resources to better serve the department's other clients who get community-based services.

Advocates have fought unsuccessfully in the courts for years to stop the closing of Fernald, where some people have lived for decades.

4. TEXAS: Efforts to consolidate, close Texas state schools for disabled fail

Tuesday, April 28, 2009

By Emily Ramshaw

The Dallas Morning News

AUSTIN - Efforts to start consolidating state schools for the mentally disabled in favor of community-based services crumbled Tuesday as lawmakers in both chambers agreed they would be unable to pass such sweeping legislation.

Though House and Senate committees moved forward with a bill to dramatically reduce waiting lists for services in the community and to let people with disabilities choose how they receive care, the measure was stripped of anything contentious.

All references to state school closure or consolidation were removed, as was a provision that would have ended state school admissions of people under 22. Downsizing private institutions for the disabled is also off the table.

Some advocates for the disabled have argued that the state schools are dangerous and inefficient, and that community care is safer and more cost-effective.

Longtime state school families have fought back, saying community care is unregulated and unsafe, and that many people have disabilities too profound to live at home or in group homes.

Lawmakers who support closing some state schools could still try to add amendments to the reform bill, which calls for a strategic plan for state disability services that cuts the wait time for community-based care down to two years.

But they say opposition from their colleagues with state schools in their districts is so intense that anything that hints of a downsizing is unlikely to pass.

"There will be no change from the status quo," said Sen. Eliot Shapleigh, D-El Paso. "We continue to understaff and underfund this system. We need real reform from statewide leaders... and that has not happened."

Opponents of closure or consolidation say the current reform bill, plus a state school safety bill that has passed the Senate and is awaiting a vote in the House; do enough to address problems in the care system. They say the state schools are effective and serve an important purpose, and that closing any of them would be disastrous.

"The problems - and there have been problems - are being corrected," said Rep. Jim McReynolds, D-Lufkin, who has a state school and community group homes in his district.

Though the movement to close or consolidate state schools started in the House, the Senate has seemed more receptive.

On Tuesday, after endorsing the "reform-lite" state school plan, the Senate Health and Human Services Committee added a disability services advisory board to the bill. The board could eventually consider consolidation issues.

5. CALIFORNIA: Settlement gives developmentally disabled help

Summary: The lawsuit, Capitol People First v. DDS (California), has been settled. This lawsuit was filed by California's Protection and Advocacy agency, now called Disability Rights California.

CALIFORNIA: Settlement gives developmentally disabled help

Bob Egelko, Chronicle Staff Writer

San Francisco Chronicle

Tuesday, April 28, 2009

The dwindling number of developmentally disabled Californians living in hospitals and nursing homes is likely to shrink further with the settlement of a lawsuit intended to help those who want to move to smaller centers or private homes.

The settlement, approved Friday by an Alameda County Superior Court judge, requires the state to provide more information to people in institutions about their options to live in their own communities, and to assist those who choose to do so.

The goal is "ending segregation and isolation of people with developmental disabilities so they can live quality lives with dignity and independence," said William Leiner, a lawyer with Disability Rights California [P&A], which represented plaintiffs in the class-action suit.

Although the settlement does not require anyone to move, Leiner said, it is based on the premise that many institutionalized people would be better off in small group homes or their own residences, with attendant care if needed.

Developmentally disabled people include the mentally disabled and some who suffer from conditions such as autism and cerebral palsy. About 200,000 receive state aid through regional centers in California.

Since passage of a 1969 state law that required California to provide services and support for local placement and support services, the population of state hospitals for the developmentally disabled has declined from 14,000 to fewer than 2,400, officials say. Another 4,500 live in nursing homes and other large private institutions.

At the hospitals, now called developmental centers, annual care for each resident costs \$270,000, far more than the expense of support services at a small center or a private home, Leiner's organization said. One of the five hospitals in the state, Agnews Developmental Center in San Jose, is in the process of closing.

The lawsuit, filed in 2002 by developmentally disabled individuals and advocacy groups, accused the state of failing to live up to the 1969 law.

The settlement requires the state to increase efforts to inform staff and residents about community living options, and to assign caseworkers to annual meetings on the status of each hospital patient, scheduled so the patients can attend.

State officials must also ask the Legislature to continue funding for new housing options, the downsizing of large private centers, and assessments and help for residents who want to move.

6. ILLINOIS: Howe should close, state panel says; parents vow to fight; Governor undecided

Below the article: The families react - Howe Family and Friends Association Press Release.

Kristen Schorsch
Southtown Start
April 28, 2009

Howe Developmental Center in Tinley Park should close, a panel of lawmakers charged with making a recommendation to Gov. Pat Quinn voted this morning.

Quinn has the final say. An aide to Quinn this morning asked the panel to postpone the vote to give the governor more time to decide what to do, but the panel voted anyway.

The governor's predecessor, Rod Blagojevich, wanted to shutter Howe.

About 300 people with severe developmental disabilities live at Howe, 183rd Street and Harlem Avenue, in a cluster of homes built in the early 1970s.

The state Department of Human Services, which oversees the center, announced in September it wanted to close the facility. Residents could choose to live in homes in communities or in other state facilities.

Two years ago, DHS lost the ability to bill for Medicaid reimbursement after Illinois Department of Public Health investigators found Howe staff members failed to observe, report and investigate several instances of neglect and abuse.

Since then, the state has covered what it would have been reimbursed - about \$30 million or more a year.

The U.S. Department of Justice also has launched an investigation, which is ongoing, to see if the civil rights of Howe residents have been violated.

Problems at Howe are systematic, DHS argues. Officials there say they want to provide more choices in the community for residents, and the state can start billing again for Medicaid dollars if residents move to certified homes or facilities.

But the panel's recommendation is a devastating blow to parents.

Howe is the only home -- away from their parent's home -- many residents have ever known. Parents say they never would let their children live somewhere where they could be abused, neglected or even killed.

"I'm very disappointed," said Linda Brown, whose daughter Angel has lived at Howe for nearly 20 years. "I think it's very shortsighted of everyone that's involved in this. What it boils down to is money."

State officials repeatedly have denied closing Howe, which shares a 300-acre campus with the Tinley Park Mental Health Center, is about dollars.

HOWE FAMILY AND FRIENDS ASSOCIATION PRESS RELEASE:

The Howe Family and Friends Association is outraged that the members of COGFA think they know better than us what is best for our loved ones. We support the continued operation of Howe Developmental Center because it is the only residence that has been able to consistently meet our loved ones' needs.

The hours of testimony family members provided to COGFA at its December hearing on the closure made this issue very clear. The real "choices" that have been offered to Howe families if our center closes are no choice at all. We would have to choose between moving to another state center much farther away, or settle for fewer services in the community, often in more isolated settings, that could endanger are loved ones.

We know that today's decision was an acceptance of Governor Blagojevich's plan to close Howe and Tinley Park. What matters now is what Governor Quinn decides. We hope and pray he listens to the only real stakeholders at Howe - the residents and their family and friends. If he does, he will keep Howe open.

Betty Turturillo, President
Howe Family and Friends Association
Tinley Park, IL
www.howefamilyandfriends.org

7. KENTUCKY: Federal Funding Restored to Three Oakwood Units

Statewide News Release March 23, 2009

FRANKFORT, Ky. - Gov. Steve Beshear today announced the Centers for Medicare and Medicaid Services (CMS) has verbally informed the state that federal funding has been restored to three of Oakwood's four units.

CMS recertified Units #2, #3 and #4 after accepting plans of correction related to deficiencies identified during a follow-up survey on Jan. 9. Funding was restored to Unit #2 retroactive to March 13; Unit #3 retroactive to Feb. 5; and retroactive to March 4 for Unit #4.

The Cabinet for Health and Family Services (CHFS) is awaiting official word from CMS.

"This is a tremendously significant accomplishment in our efforts to restore federal funding for the entire facility," said Gov. Beshear. "Although a few hurdles remain, I am extremely proud that Oakwood has demonstrated such dramatic progress, and three of the four facilities have now been reinstated to the Medicaid program."

"Restoring certification is an uphill battle for any facility, but we have never lost sight of our goal of addressing the significant issues Oakwood faced at the beginning of this long road," said CHFS Secretary Janie Miller. "We're pleased to be in the position of achieving recertification for three of the four units, and are optimistic that the other unit is close behind.

"The Cabinet has worked hard to place Oakwood on a clear path to recertification, and I commend all the staff for their dedication and commitment. I would particularly like to thank Acting Deputy Commissioner Betsy Dunnigan (Department for Mental Health, Developmental Disabilities and Addiction Services) for her tireless efforts on behalf of the facility."

Unit #1 did not pass the initial survey, which occurred last September. CHFS has been working with the Bluegrass Regional Mental Health-Mental Retardation Board, which manages Oakwood, to address the deficiencies cited in Unit #1. CHFS plans to resubmit an application to CMS for the unit in the next few weeks.

The state has funded Oakwood since federal funding ceased in May 2008. Oakwood's annual budget is approximately \$75 million, \$60 million of which was originally anticipated to be Medicaid funds (federal and state).

Recertification of Unit #2 means the restoration of around \$980,000 monthly in federal funds paid to the state; approximately \$700,000 per month for Unit #3; and in approximately \$840,000 monthly for Unit #4.

Oakwood, the state's largest facility for adults with mental retardation, is located in Somerset. Its current census is 201.

Tamie Hopp

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

VOR (Voice of the Retarded)

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Tamie327@hotmail.com (for referrals or credit card payments)

Name

Address (if paying by credit card, use billing address). All forms must include complete address including zip code)

City St Zip

Phone Fax

E-Mail

Family/Professional Organization Affiliation (if applicable)

If paying by credit card, please provide the following information:

Amount to charge to card: \$ _____

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Cardholder's Signature: _____

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