

**Join Us! Help Commemorate VOR's 25th Anniversary!!**

VOR will host its Annual Meeting, Washington Initiative, Special Anniversary Celebration, and the 2nd Annual Capitol Hill reception, beginning June 13, 2008 in Washington, D.C. Visit <http://vor.net/2008AnnualMeetingandInitiative.htm> for more information on the Annual Meeting and Initiative.

Be a Sponsor / Get a Sponsor: Select a sponsorship category you would like to support! Help with the Capitol Hill Reception expenses, support the 25th Anniversary Reception, help fund the successful day-long Annual Meeting, including breakfast, lunch, speaker sessions, participant handouts, help with the expenses for the critically important Washington Initiative, and more! See <http://vor.net/2008Sponsorship.htm> for details. Questions? Contact Tamie at [Tamie327@hotmail.com](mailto:Tamie327@hotmail.com) or 605-399-1624.

=====

Have you contacted your U.S. Representative and asked him/her to cosponsor H.R. 3995? If yes, have you followed-up? Contact Tamie with any questions and to receive H.R. 3995 advocacy materials (605-399-1624; [tamie327@hotmail.com](mailto:tamie327@hotmail.com))

-----

VOR Weekly E-Mail Update  
April 11, 2008

-----

=====

STATE NEWS

- 1. NEBRASKA: Beatrice State Developmental Center: A Guardian's Perspective
- 2. MEDICAID and the States: Bill Advances to Suspend Medicaid Cost-Shift Rules
- 3. MASSACHUSETTS: State Settles Lawsuit over Placement of Disabled
- 4. FLORIDA: Nursing Home Residents Sue for At-Home Services (excerpts)

=====

- 1. NEBRASKA: Beatrice State Developmental Center: A Guardian's Perspective

-----

Summary: The following editorial appeared in the Omaha World Herald on April 4, 2008. The writer, Margaret Huss, is the legal guardian to her 43-year-old brother who has resided at Beatrice State Developmental Center for 25 years. She is an attorney and lives in Omaha with her husband and four sons.

Opinion: Beatrice center is best for some, despite flaws; don't eject them  
By Margaret N. Huss  
April 4, 2008

I've read the recent news coverage related to the Beatrice State Developmental Center in which the U.S. Department of Justice and some state officials cite a federal law that individuals with disabilities should be provided the most integrated setting appropriate to their needs.

What I have not seen is an acknowledgement from decisionmakers that, in fact, the state of the law is a little more complicated than that. Sometimes, what's important is what is not said.

What is not said is that in 1999, the U.S. Supreme Court (*Olmstead v. L.C.*) expressly stated that nothing in the Americans With Disabilities Act condones termination of institutional settings for people unable to benefit from community settings. The court went on to say that there is no federal requirement that community-based treatment programs be imposed on people who do not desire them.

What is not said is that in the *Olmstead* case, the Supreme Court set forth a three-part

test for determining whether a community setting is appropriate for a given person. The second prong of the Olmstead test is whether the transfer is opposed by the affected individual. Many of the residents at Beatrice have been adjudicated to be mentally incapacitated and thus have legal guardians, who often are family members, to make decisions in the best interest of the individual.

According to recent news articles, state officials may transfer residents out of the Beatrice center notwithstanding the express wishes of guardians. Taking such action appears to be in direct violation of federal law.

A casual observer might ask: Why, given all the problems at Beatrice, would guardians persist in desiring that their loved ones remain at the center?

Many parents and guardians remain committed to Beatrice because, in spite of its identified shortcomings, they know it to be the best of all available options for their loved ones. Many have tried community-based services, with poor results.

Most guardians are very familiar with the developmental disabilities landscape. They know that community-based programs are no panacea. These programs face the same staffing and funding shortages that plague the Beatrice center. Such programs also suffer from an acknowledged lack of continuity of care, oversight and accountability. This is because in community-based care, each facet of an individual's care (such as residential services, health and dental care, vocational services and transportation) is actually provided by a separate agency, each with separate staffs, protocols and procedures. Historically, many of these agencies are here today and gone tomorrow. If guardians know Beatrice to be the best, least restrictive place for their loved ones, we should listen to them. VOR (<http://www.vor.net>), a national advocacy organization that speaks for people with mental retardation and argues for choice, says it best: We should seek to move past the institution versus community debate and work toward ensuring that all people with developmental disabilities are safe and healthy, regardless of where they live.

The Beatrice State Developmental Center is a good and needed facility, staffed with many competent and caring people who face daunting challenges with very limited resources. State decision-makers must have the will to fight for those most vulnerable citizens who call the center their home.

I applaud those in state government who are attempting to address the issues responsibly, and I urge them to do their own research so that they are in the position to do what's best for Nebraska.

My brother cannot talk, so I do my best to try to speak for him. I grew up with him, and my concern for him goes well beyond that required by law. I consider it an honor to share in his life and to help him bear his considerable burdens.

Despite his challenges, it is clear to anyone who spends time with him whether he is happy or sad or frightened or anxious, even though he cannot speak. But that's because sometimes what's important is what is not said.

Community-based programs suffer not only from staffing and funding shortages but also from a lack of continuity of care, oversight and accountability

-----  
2. MEDICAID and the States: Bill Advances to Suspend Medicaid Cost-Shift Rules  
-----

By Jane Zhang  
April 10, 2008  
Wall Street Journal

WASHINGTON -- Legislation to block Medicaid rules that states said would shift billions of dollars of costs to them began a move through the House.

The House Energy and Commerce Committee's health panel Wednesday unanimously passed the bill, which would put a moratorium on seven rules that, among other things, would end federal payments for physician training and transportation of Medicaid-eligible children to school.

Congress put some of the rules on hold last year; that moratorium expires June 30. The new legislation would hold the rules in abeyance until April 1, 2009, when there will be a new president.

"The Bush administration has and will continue to oppose any moratorium on enactment of our pending regulations," said Mary Kahn, a spokeswoman for the Centers for Medicare and Medicaid Services, which manages Medicaid, the federal-state program for the poor and disabled.

Commerce Committee Chairman John Dingell (D., Mich.) offered a version of the legislation that would give the Department of Health and Human Services an additional \$25 million a year to reduce Medicaid fraud and abuse. It was passed on a voice vote. Because the measure emphasizes cracking down on fraud, Rep. Joe Barton (R., Texas) said, "I'm reasonably confident" the administration won't veto it.

Rep. Frank Pallone Jr. (D., N.J.), chairman of the health subcommittee, said lawmakers are considering attaching the moratorium to a spending bill.

The Congressional Budget Office has estimated the rules would save the federal government \$1.65 billion for fiscal 2008 and 2009, an amount lawmakers must offset with savings elsewhere under the pay-as-you-go budget rules. To help reach that number, the bill would require more scrutiny of Medicaid beneficiaries' eligibility, giving states access to enrollees' financial records.

The expectation is that some will be disqualified because their assets exceed the program's guidelines.

The push to stop the rules has support from all of the nation's governors, who already face budget crunches because of declining revenue tied to the housing crisis; more than half the states predict budget deficits for next year. Medicaid accounts for 20% or more of state spending, and the number of enrollees, about 50 million people, tends to rise when the economy slows.

After Wednesday's vote, a Medicaid spokesman confirmed that Dennis Smith, director of the Center for Medicaid and State Operations and the architect of the rules, is leaving his job this month.

Last week, Mr. Smith said the rules are needed to keep the program afloat and Medicaid "should not become a limitless account for state and local programs and agencies to draw federal funds for non-Medicaid purposes." He said the federal government will pay \$196 billion of Medicaid's \$345.6 billion cost for this fiscal year.

---

### 3. MASSACHUSETTS: State Settles Lawsuit over Placement of Disabled

---

March 21, 2008  
By James Vaznis  
The Boston Globe

More than 600 mentally retarded or developmentally disabled individuals will leave nursing homes in the next four years, to live more independently in an apartment, family home, or group setting, state officials announced yesterday.

Their exodus is a key part of a settlement the Patrick administration reached with advocates for the disabled in a 10-year-old case in which plaintiffs argued that the nursing home placements violated federal mandates, including a requirement that they be in the most integrated setting appropriate for their care. Many were placed in nursing homes even though they are significantly younger than the senior citizens the facilities are designed to serve, reducing their quality of life and contribution to society, the suit contended.

"This is great," said Jean McGuire, assistant secretary of the state Department of Health and Human Services. "This will accelerate further development of community-based services for people with mental retardation or developmental disabilities."

The department, she said, is calculating the cost of caring for these adults in their own residences or group homes.

Services the state will provide to the individuals in their new homes include personal care assistants, nurses, and physical therapists. Many also will have access to recreational activities, educational opportunities, and job training.

The settlement is the second resolution in the case, which was named after Loretta Rolland, a disabled Agawam woman and lead plaintiff in a case filed in 1998 in US District Court on behalf of 1,600 people. It was pushed by Arc Massachusetts (formerly the Association of Retarded Citizens Massachusetts) and the Center for Public Representation, based in Northampton and Newton respectively. Neither group could be reached for comment yesterday.

Initially, the case placed more than a thousand people in community-based housing and care between 2000 and 2007. But more than 700 people remained in nursing homes.

The state said it could provide appropriate services for them there, but advocates disagreed and contested in court.

Patrick, an advocate of community-based care, pushed for a resolution. The state will move more than a hundred people a year over the next four years.

The settlement will leave roughly 100 individuals in nursing homes because of age, condition, or circumstances, McGuire said.

---

### 4. FLORIDA: Nursing Home Residents Sue for At-Home Services (excerpts)

---

By Stephen Nohlgren

St. Petersburg Times (excerpts)  
Monday, March 31, 2008

John Boyd, 50, has been paralyzed since 14. He would like an apartment of his own and a job, like when he answered customer service phones for Red Lobster a few years back.

Instead, he lives in a nursing home, a frequent situation when Florida Medicaid pays the bills. That may change. Boyd is one of six other physically disabled nursing home residents backed by the AARP Foundation who have filed a class-action lawsuit against the state of Florida seeking community supports.

Florida spends 87 cents of its Medicaid dollar on nursing homes when caring for the frail and disabled. Only nine states commit a smaller portion to home-based care. Given today's budget crises, Tallahassee is not in an expansion mode. Waiting lists that keep people like Lee and Boyd from blending into the community are likely to get longer, not shorter.

But the clock is ticking.

Baby boomers, who once didn't trust anyone over 30, now face the prospect of their own decline. Other states are moving toward more at-home care. Florida will be pressured to keep nursing home care to a minimum.

"When that spike in demand for services hits, we will have to pay more attention" to home-based care, says Tampa's Sandy Murman, a former legislator who specialized in long-term care. "But then we will be in crisis management mode."

Jacksonville quadriplegic John Boyd is not your typical nursing home resident. He makes runs to Publix and convenience stores on a motorized scooter, buying cigarettes, sodas and lottery tickets for other residents. Until a medical condition interrupted his classes, he studied computer programming at a local community college.

Boyd figures the economics of his care are a slam dunk. Medicaid, a federal-state health program, pays Harts Harbor Health Care Center more than \$4,000 a month to house him and tend to his personal care, a fairly typical nursing home bill for taxpayers. Boyd thinks he could hire his own aides a few hours a day for half as much if he lived in subsidized housing or had his own place with a roommate. He once patched together a similar arrangement while living with his grandmother, until she died in 1994. Florida Medicaid does have a few at-home programs that appear to save money. The Nursing Home Diversion project and others run \$1,100 to \$1,800 a month.

But what's true for some individuals may not apply across the board.

Some nursing home residents require too much care to stay at home. People at home often soak up other public dollars that don't factor into the Medicaid equation, programs such as food stamps, meals on wheels and subsidized housing.

Most important, no one knows how many people avoid public assistance because it would mean living in a nursing home. Give them options and thousands might leap at the chance for aid.

State officials declined to comment for this story, citing the pending lawsuit. But in court filings their lawyers suggest that a wholesale move toward home care could swell the Medicaid budget with new applicants.

"This is exactly the kind of policy decision that courts should leave to the elected state officials," the lawyers said.

-----  
Tamie Hopp

REFERRAL/MEMBERSHIP/CONTRIBUTION FORM  
THREE EASY WAYS TO SUPPORT VOR > REFER, CONTRIBUTE OR JOIN  
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 credit card or check.

TO REFER SOMEONE TO VOR: Use the form below, including the additional sections for referrals.

Mail the completed form (if joining or contributing) with payment to:

Voice of the Retarded  
836 S. Arlington Heights Rd., #351  
Elk Grove Village, IL 60007  
847-258-5273 fax (for referrals or credit card payments)  
kluck146@comcast.net (for referrals or credit card payments)  
FOR REFERRALS: \_\_\_ The contact information provided is for someone I think would consider membership with VOR.

FOR REFERRALS: \_\_\_ You may use my name in any correspondence with this individual. My name is \_\_\_\_\_.

\_\_\_\_\_  
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)  
VOR now accepts Master Card and Visa. If paying by credit card, please provide the following information:

Amount to charge to card:

\_\_\_\$1,000 \_\_\_\$500 \_\_\_\$250 \_\_\_\$150 \_\_\_\$50 \_\_\_\$25 \$\_\_\_\_\_ Other amount

\_\_\_ Mastercard  
\_\_\_ Visa

Card Number: \_\_\_\_\_

Expiration Date: \_\_\_\_\_

Cardholder's Signature: \_\_\_\_\_  
=====