
VOR is the only national organization advocating for a full range of residential and support options for people with mental retardation, including Medicaid-certified Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) and home and community-based care. VOR supports choice

VOR Weekly E-Mail Update August 11, 2006

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 2. VOR commends Harkin for H.R. 3717, the Promoting Wellness for Individuals with Disabilities Act of 2006
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 8. DON'T YOU THINK THIS UPDATE PROVIDES GREAT INFORMATION AND TIMELY UPDATES?? Please consider supporting VOR's good work. Join or contribute today please! A membership and contribution form is included at the end of this update.

COMING UP: State News - Friday, August 18; no Update, Friday, August 25.

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1. August is a GREAT time to visit your Congressional Representative and Senators in District Offices

To find out who your Representative and Senators are, visit <http://www.congress.org>. This website will also give you addresses and phone numbers for District offices.

If you do visit, be sure to acquaint them VOR and our key issues, including:

- (A) opposition to Sunset Commission proposals (see below)
- (B) Support for health care legislation, including H.R. 3717 (see below)
- (C) Support for adequate Medicaid funding

To see VOR's positions on these issues, visit:
<http://www.vor.net/LeaveBehindPositions2006.html>. Updates to some of our high priority issues are also contained in this update.

Feel free to share these position papers with your U.S. elected officials.

Thank you!

2. VOR commends Harkin for H.R. 3717, the Promoting Wellness for Individuals with Disabilities Act of 2006

August 8, 2006

The Honorable Tom Harkin

U.S. Senate Washington, D.C. 20510

Dear Senator Harkin,

On behalf of VOR's members and our family members with mental retardation, it is a great pleasure to extend sincere gratitude to you for introducing

H.R. 3717, the Promoting Wellness for Individuals with Disabilities Act of 2006.

In June 2006, VOR members called on Congress to embrace a "legislative solution addressing the widespread lack of access to quality health care for people with mental retardation." Our position paper [see, <http://www.vor.net/HealthCarePosition.html>] included the following goal, which is also included in H.R. 3717:

* Incentives for Medical Schools to include disability-specific curricula, including required rotations or residencies at residential and clinical programs serving people with mental retardation.

Your proposed legislation recognizes that people with mental retardation often have extensive health challenges, but lack access to needed health care professionals. H.R. 3717, when passed, will put in place a necessary foundation to ensure that all future health care professionals will receive hands-on training in providing health care to patients with disabilities, including people with mental retardation. Your legislation also includes a provision that will immediately promote good health outcomes, wellness programs, and preventive health screenings.

We believe that H.R. 3717 is an important step forward for our goal to address the widespread lack of access to quality health care for people with mental retardation. We thank you for your compassionate leadership.

Sincerely,

S. Mary McTernan, Ph.D.
President

3. Sunset Bill Pulled From Floor Schedule; Tiahrt Optimistic About His Bill's Passage

Roll Call Jennifer Yachnin July 31, 2006

Objections from moderate Republicans put passage of a key budget reform sought by conservative GOP lawmakers in limbo last week, prompting House leaders to shelve debate on the measure until after the August recess.

The Government Efficiency Act, authored by Rep. Todd Tiahrt (R-KS), had been slated to go to the floor late last week but was scrubbed from the schedule Thursday afternoon. The bill would establish a federal commission to evaluate government funded agencies or specific programs and issue recommendations to Congress on whether those bodies should be consolidated, abolished or otherwise altered.

Moderate lawmakers led by Rep. Sherwood Boehlert are seeking a half-dozen amendments to the bill, of which the New York Republican stated: "As presently constituted, it does not represent good public policy."

"I question the need and appropriateness of this legislation," Boehlert said Wednesday, testifying before the Rules Committee.

Among his proposed changes, Boehlert targeted the commission's composition, which under the current legislation would include seven members appointed by the White House with four of those individuals selected in consultation with the majority leadership of both the House and Senate.

The amendments would require all appointments to be made by Congress and would add two House Members and two Senators to the panel.

In addition, Boehlert, who chairs the Science Committee, called for the commission to hold public hearings.

Another amendment would extend the period for Congress to review recommendations from the commission to 45 legislative days from the 30 days proposed by Tiahrt. Boehlert has also called for language that would allow Members to offer amendments to the commission's proposals, something that would be permitted only in committee under the current bill.

While no one on the Appropriations Committee has offered formal changes to the measure, panel members also have questioned the need for such a commission.

"We feel pretty comfortable with the level of oversight we have here on the committee," Appropriations spokesman John Scofield said before the Rules meeting Wednesday.

"We were successful in eliminating 53 programs. That's not just proposing, but actually getting through the system," he said, adding that the House has slated 95 additional cuts in fiscal 2007 spending bills.

While the Rules Committee reviewed the measures Wednesday, it has yet to vote on parameters of debate for the measure, including what amendments Members would be allowed to consider on the floor.

Without a decision on whether those amendments will be included in the bill, one Republican aide, who spoke on the condition of anonymity, said:

"Opposition has stayed quite strong from moderates and Democrats."

But Tiahrt who asserted Friday that his legislation has also been squeezed by time constraints as the chamber sought to finish items such as a minimum wage proposal in advance of the August recess does not expect those objections will defeat the bill.

"I didn't see anything that was not insurmountable," he said. "I think we answered almost all the concerns."

Despite the apparent setback, House conservatives expect the measure, as well as a broader proposal by Rep. Kevin Brady (R-Texas) to establish a sunset commission that would impose automatic expiration dates for federally funded programs, will return to the chamber's calendar in the fall.

"We look forward to working with leadership to enact real budget process reform after the August district work period," said one Republican aide to House conservatives.

The review commissions are among four budget reform measures which also include earmark reforms, emergency spending guidelines, and line item veto legislation that conservative Republicans demanded from House leadership during negotiations over the 2007 budget blueprint earlier this year.

The House approved legislation granting the president line-item veto authority in June.

In addition, although discussions between the House and Senate over lobby reform legislation have reached a stalemate. The standoff centers on House leaders' insistence on legislation targeting the political committees know as 527s House leaders announced Wednesday they will seek to amend the chamber's rules to apply earmark reform measures for the duration of the 109th Congress.

4. Good News!! Cost Sharing and the DRA

As VOR has previously reported, the Deficit Reduction Act contained an apparent drafting error that, if enforced, would have allowed states to impose unlimited cost sharing obligations on Medicaid beneficiaries at or below 100 percent of the Federal Poverty Level. VOR, along with other organizations and even Members of Congress, had been calling on Congress and the Administration to figure out a fix that would protect low income Medicaid beneficiaries. See, <http://www.vor.net/DRACorrection.html> for VOR's position paper on this issue.

Recently, CMS officials reported to VOR that on June 16, 2006, CMS released a letter to State Medicaid Directors regarding sections 6041 and 6042 of the Deficit Reduction Act, which states in part, that CMS plans "to apply the limitation of section 1916 of the [Social Security] Act to beneficiaries at or below 100 percent of the Federal Poverty Level (FPL).

Further guidance will be provided through the rulemaking process."

What this says, in essence, is that the DRA provision relating to cost sharing and low income Medicaid beneficiaries will not be enforced and that CMS will further ensure of that during the rulemaking process. Of course, VOR will watch that rulemaking process closely, but we are heartened by the attention to our concerns.

5. HHS Provides Funding to States For Alternatives to Nursing Home and ICF/MR Care in Medicaid: "Money Follows the Person" Helps States Rebalance Long-Term Care Systems

Since passage of this bill, we have attempted to work cooperatively with CMS as it prepares to provide technical assistance to states that plan to request funding for MFP initiatives. The focus of our communications with CMS has been (a) Choice - MFP should not be used as a tool to force the transfers of individuals from facility settings; and (b) continuity of care - states need to be prepared with an adequate community-based infrastructure, including access to health care, quality housing, a quality workforce pool, transportation, etc. Going forward, VOR will attempt to assess which states are pursuing MFP grants and keep you informed.

PRESS RELEASE

HHS Provides Funding to States For Alternatives to Nursing Home and ICF/MR Care in Medicaid --

"Money Follows the Person" Helps States Rebalance Long-Term Care Systems

States will get additional help from the federal government to support elderly and disabled Medicaid recipients who wish to live in the community rather than institutions, HHS Secretary Mike Leavitt announced today.

Through competitive grants, the Centers for Medicare & Medicaid Services (CMS) will give states a total of \$1.75 billion over five years to help shift Medicaid from its historical emphasis on institutional long-term care services to a system that offers more choices for seniors and persons with disabilities from all age groups, including home and community-based services. This Money Follows the Person "rebalancing" initiative was included in the Deficit Reduction Act of 2005 (DRA) currently being implemented by CMS. This endeavor is also a part of President Bush's New Freedom Initiative.

"With this program, people who need long-term care and prefer to live in their own homes and communities can do so," Secretary Leavitt said.

"States will also get more for their money by giving the elderly and people with disabilities more control over how and where they get the Medicaid-funded long-term care services they need."

"We've worked with advocates and states for years to end the institutional bias in Medicaid, and now we've got the best opportunity ever to do it," said Mark B. McClellan, M.D., Ph.D., CMS Administrator. "We need to move as quickly as possible to make that shift across Medicaid. With new Federal funding, there is no longer any excuse for the status quo."

States interested in applying for a "Money Follows the Person" grant can propose new programs to CMS that are aimed at sustaining people in their homes or communities who would have otherwise received care in a nursing home or other institution. The qualified expenditures may be eligible for an enhanced match rate from the federal government equal to an increase of 50 percent of the usual state Medicaid percentage contribution in addition to the usual match rate. In effect, the federal government will pay for 75 to 90 percent of the costs of transitioning individuals out of nursing homes and into community settings, and the associated long-term care benefit costs. Grant funds may also be used to help control how they receive these services.

The higher matching rate will be applied to certain services provided to an individual for a one year period after the individual moves out of an institution and into the community. Funds can be used not only for alternatives to institutional care services, such as home health care; they can also be used for home modification costs, respite services to augment

informal or unpaid caregivers, personal care and assistive devices. In their applications, states are encouraged to coordinate with local and state housing authorities to provide coordinated assistance for community-based housing needs. CMS and the Department of Housing and Urban Development (HUD) have made steps to establish a new interagency liaison to support this coordination.

"We know that accessible, affordable, integrated housing is critical to a person's ability to make the transition into the community, HUD Secretary Alphonso Jackson said. "My agency will strongly urge the Public Housing Agencies and Housing Finance Agencies in the states to work collaboratively with Medicaid programs to help create opportunities for those moving out of institutions into the community."

Each state awarded a grant must continue to provide community services after the year of enhanced match as long as the person needs community services and is Medicaid eligible. The deadline for the first year's applications is Nov. 1, 2006. Demonstration grants will be competitively awarded to states from Jan. 1, 2007 through Sept. 30, 2011. Funds will be available for a five-year period; however, states must participate in the demonstration for a minimum of two consecutive years.

The Medicaid program traditionally pays for care for persons who are elderly and those with disabilities living in institutions who needed help with activities of daily living, because institutional care was the norm when the Medicaid law was enacted forty years ago. To provide home and community-based services, states must get a "waiver" of normal program rules designed to pay for care in institutions. Waivers and demonstration programs offer the promise of significantly lower costs per beneficiary and reductions in overall Medicaid spending as a result of giving individuals control over how to get their services, rather than requiring them to use institutional care in order to get Medicaid long-term care benefits. But rebalancing Medicaid coverage may have some short-term costs, which the new federal program enables states to overcome.

In addition to the Money Follows the Person initiative, the DRA made many changes in Medicaid that will allow states to add home and community-based services to their permanent array of benefits without having to go through the waiver process. For example, under another DRA provision, states now have the option to provide home and community-based services without needing a waiver.

"Even though personal control leads to better results and lower costs for people with a disability, it's still true today that most elderly or disabled enrollees do not have a choice about how they get their long-term care services under Medicaid," said Dr. McClellan. "By working with states, advocates, and Medicaid enrollees to take advantage of these unprecedented opportunities, that's going to change."

A copy of the "2006 Money Follows the Person Rebalancing Initiative Demonstration Program," including the application forms, can be obtained at <http://www.grants.gov/>. For more details about the New Freedom Initiative, visit the CMS Web site at: http://www.cms.hhs.gov/NewFreedomInitiative/02_WhatsNew.asp

August 4, 2006 The New York Times

WASHINGTON, D.C. For more than 25 years, federal law had required that schools nationwide identify children as learning disabled by comparing their scores on intelligence tests with their academic achievement. This meant that many students had to wait until third or fourth grade to get the special education help they needed.

In regulations issued today after changes to the law, the federal Education Department said states could not require school districts to rely on that method, allowing districts to find other ways to determine which children are eligible for extra help.

It was the final step in the federal government's repudiation of the old approach, which had come under severe criticism from advocates for children with disabilities, testing experts and eventually federal officials themselves. Advocates for those children applauded the change.

"If you talk to principals and special ed directors, there is pent-up demand for better ways to serve struggling kids than waiting until they crash and burn in third and fourth grade," said James H. Wendorf, executive director of the National Center for Learning Disabilities.

The new rules also require schools to alert parents as they begin exploring whether children may need special education, another change that won praise from advocates for children with disabilities.

The regulations come after Congress updated laws covering special education for some six million schoolchildren nationwide in late 2004.

Comparing intelligence tests with academic achievement, known as the discrepancy model, came under intense criticism in the debates over the law and over special education.

Federal officials and advocates for children with disabilities contended that the practice of waiting for children to fall behind on tests in third or fourth grade before getting them extra help consigned them to failure,

and opened the way for the disproportionate numbers of poor and minority children to be labeled as needing special education.

The 2004 law abandoned reliance on that approach. And the new regulations favor alternative methods of identifying children who need services, like evaluating the response of struggling children to extra help before the third grade.

The 2004 law also streamlined procedures and reduced the paperwork involved in providing children special education services, and relaxed burdens on schools when children with disabilities had behavioral problems.

A draft of the regulations published in June 2005 prompted an outpouring of 5,500 letters and comments to the Education Department from advocates for children with disabilities, as well as parents, teachers' unions, and state, district and local education officials.

The department posted the final regulations on its Web site today, along with answers to each of the comments it received. The final regulations will be published in the Federal Register on Aug. 14, and will take effect 60 days later.

In unveiling the new rules, Education Secretary Margaret Spellings said her priority was "that we not lose our vigilance for educational attainment for every child."

Advocates for children with disabilities said they were disappointed that the regulations did not address some problems they saw in the 2004 federal law.

For example, the law says that instead of reviewing each disabled child's educational plan every year automatically, schools could review them only once every three years, provided parents agree to the change. The regulations do not help ensure parents are properly notified, advocates said.

"But who is going to make sure that parents now know what they're giving up if they agree to that?" said Ricki Sabia, associate director of the National Down Syndrome Society Policy Center. "The department could have made clear what constitutes that agreement."

Iowa is joining with Maine and Vermont to negotiate lower prices for the drugs they buy for Medicaid recipients, Gov. Tom Vilsack announced Wednesday.

Vilsack said Iowa and the federal government would save about \$11million a year under the new pool. The governments spend about \$391million annually on medicine for Iowa's 300,000 Medicaid recipients, with the state footing about a third of the bill.

"Together, our group of states will achieve pharmaceutical rebates that will far exceed the amount that each state could provide on its own," the governor said in a press release.

The governor said other, unidentified states are talking about joining the purchasing pool.

Roger Munns, a spokesman for the Iowa Department of Human Services, said any savings would be used to run the Medicaid program, whose costs are constantly increasing.

Under the new pool, participating states would retain their power to determine which drugs are covered by their Medicaid plans.

Wednesday's news came after the federal government approved the arrangement.

Federal officials quashed an earlier Vilsack attempt to reduce state spending on drugs. Under that 2003 proposal, Iowa would have arranged purchases of low-cost Canadian medications for state employees and retirees. Vilsack sought federal approval of the idea, but it died amid Bush administration concerns over the safety of Canadian drugs.

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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 5005 Newport Drive, Suite 108 Rolling Meadows, IL 60008 847-253-6054 fax (for referrals or credit card payments) vor@compuserve.com (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)

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