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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 December 15, 2006

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Coming Up: Focus on Access to Health Care and Related Services

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- 1. Medicaid's Long-Term Care Beneficiaries
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Urban Institute's Health Policy Newsletter November 30, 2006

In a paper released by the Kaiser Commission on Medicaid and the Uninsured, Anna Sommers, Mindy Cohen, and Molly O'Malley present spending patterns of Medicaid beneficiaries who received long-term care services. Using 2002 data from the Medicaid Statistical Information System Summary File, they found that Medicaid long-term care users accounted for 7 percent of the Medicaid population in 2002 but over half of total program spending. Three quarters of this spending went toward long-term care and 25 percent was devoted to acute care and other supportive services. Beneficiaries dually eligible for Medicare and Medicaid accounted for two-thirds of Medicaid enrollees who used long-term care and a similar share of Medicaid spending. Apart from the elderly and disabled, about 400,000 non-disabled children and 1.1 million non-disabled adults under age 65 used long-term care services in 2002. Entire Report <http://www.kff.org/medicaid/7576.cfm>.

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- 2. Medicaid Commission Update: Panel Calls for Big Changes in Medicaid

Summary: The panel said Congress should rewrite the Medicaid law to encourage the use of home care and community services, instead of nursing homes and other institutions. In an interview, Angus King, the former Maine governor who is the panel's vice chairman, said: "We need to reverse Medicaid's institutional bias. Community care that's what people want. It's better for beneficiaries. And it's less expensive." The panel urged the Bush administration to study a novel idea: increasing federal subsidies for low-income groups added to the Medicaid rolls, while scaling back subsidies for higher-income people added to the program. The panel said this would help achieve "Medicaid's core purpose," serving low-income people. For more Medicaid Commission issues, see <http://www.aapd.com/News/commission/indexmedcomm.php>.

Panel Calls for Big Changes in Medicaid
by Robert Pear
The New York Times Nov. 22, 2006

WASHINGTON, DC - A federal advisory panel says that long-term care for aging baby boomers threatens to bankrupt Medicaid, and it recommends sweeping changes to rein in costs, including greater use of managed care for the sickest Medicaid recipients. The proposals set up a likely clash between the new Democratic Congress and the Bush administration, which has sent strong signals that it will seek big savings in Medicaid next year.

Panel members adopted the recommendations last week, by a vote of 11 to 1, and are drafting a report to be submitted next month to Michael O. Leavitt, the secretary of health and human services. Mr. Leavitt created the panel in May 2005 and is receptive to many of its proposals.

The panel, known as the Medicaid Commission, said states should have more freedom to alter benefits and eligibility for the program, which serves more than 50 million low-income people. Moreover, it said states should be allowed to enroll some of the sickest Medicaid recipients, including nursing home residents and people with disabilities, in managed care plans. The panel said such plans "would provide a medical home and better coordinated care" for people entitled to both Medicaid and Medicare. Care is often fragmented now because Medicaid pays nursing homes while Medicare is the primary payer for doctors and hospitals, and in many cases "clinical data is not shared," the panel said.

People enrolled simultaneously in the two programs account for 13 percent of Medicaid recipients, but more than 40 percent of Medicaid costs. Medicaid, which is financed jointly by the federal government and the states, covers two-thirds of the nation's 1.6 million nursing home residents. "The anticipated costs for long-term care services in this country threaten the future sustainability of the Medicaid program," the panel warned. It recommended that the federal government and the states provide new tax incentives for people to buy private insurance covering the costs of long-term care, so they would not rely so much on Medicaid. "Public policy should promote individual responsibility and planning for long-term care needs," said the panel, led by former Gov. Don Sundquist of Tennessee, a Republican.

More generally, the panel said states should be free "to consolidate or redefine eligibility categories" and should be given "greater flexibility to design Medicaid benefit packages." The proposals drew a swift negative response from Democrats who will be responsible for Medicaid in the new Congress. Representative John D. Dingell of Michigan, who is in line to become chairman of the Energy and Commerce Committee, dismissed the panel as "a hand-picked commission stacked against working families." Senator Max Baucus of Montana, the Democrat in line to lead the Finance Committee, said many of the proposals would make it more difficult for "the most vulnerable Americans" to get comprehensive care. John C. Rother, policy director of AARP, the lobby for older Americans, said, "In some states, flexibility means cutting benefits."

But Christina Pearson, a spokeswoman for Secretary Leavitt, said, "He definitely supports more flexibility for states to meet the needs of different population groups." Grace-Marie Turner, a commission member, said, "People who rely on both Medicaid and Medicare are the most vulnerable beneficiaries, but in most cases, nobody is coordinating their care." Even if a state wants to place them in managed care, it may take months or years to get federal approval, said Mrs. Turner, who is president of the Galen Institute, a research center focusing on health policy.

The commission said states should be able to place all types of Medicaid recipients in managed care without getting "a waiver or any other form of federal approval." But, it said, individuals should be able to "opt out" of managed care. Gwendolyn G. Gillenwater, a commission member who is policy director of the American Association of People with Disabilities, an advocacy group, voted against the report. "People with disabilities have not had good experience with managed care," Ms. Gillenwater said. "We need federal protections and safeguards. People with disabilities should at least have a choice of two managed care plans. And what are your choices if you opt out of managed care? The alternatives are getting more and more limited."

The panel said Congress should rewrite the Medicaid law to encourage the use of home care and community services, instead of nursing homes and other institutions. In an interview, Angus King, the former Maine governor who is the panel's vice chairman, said: "We need to reverse Medicaid's institutional bias. Community care that's what people want. It's better for beneficiaries. And it's less expensive."

The panel urged the Bush administration to study a novel idea: increasing federal subsidies for low-income groups added to the Medicaid rolls, while scaling back subsidies for higher-income people added to the program. The panel said this would help achieve "Medicaid's core purpose," serving low-income people.

3. VOR Rebuttal: What (MR/DD) Institutional Bias??

Summary: The following testimony was delivered by Robin Sims, VOR's second vice president, at the final Medicaid Commission hearing in November in Arlington, Virginia. VOR participated

in a total of 5 Medicaid Commission meetings, providing testimony relating to the need for a full array of residential options, including facility-based care, community quality concerns, the potential of the Community Resource Center model, and the myth of an institutional bias. Special thanks to Irene Welch (Georgia), Nancy Ward (Texas), Patricia Bennett (Virginia), Mary Reese (Maryland), and Robin Sims (New Jersey) for representing VOR at these meetings.

VOR Statement to the Medicaid Commission
November 2006
by Robin Sims, Second Vice President

DISPELLING MEDICAID MYTHS

I. INTRODUCTION

My name is Robin Sims.

I am the First Vice President of VOR, a national nonprofit advocacy organization for people with mental retardation and their families. I hope that by now, VOR and our perspective is familiar to you. You have heard from VOR representatives in Atlanta, Georgia; Irving, Texas; and twice before today in Arlington, Virginia.

As with the VOR representatives who have testified before me, I come today as a volunteer. Our support for VOR's perspective is motivated by our common link: We all have family members with mental retardation who need Medicaid services.

In my case, I have 2 children with disabilities. Although their needs are very different, both are thriving in their own way Heather is 23 years old and has a regressive form of autism. She has lived in an ICF/MR in Clinton, NJ called the Hunterdon Developmental Center for the past 8 years. She needs constant supervision and assistance with all her self-care needs. She has violent outbursts and requires the expertise of a trained staff to keep her from hurting herself and others. While she has made some improvement since her admission to Hunterdon, it is due to the consistency and predictability of the environment. Without her Medicaid-funded ICF/MR placement she would not have survived. Benny is now 20 years old and has Fragile X Syndrome. As he ages out of school services it is unknown what kind of work or programming will be appropriate for him. His father and I have seen many other kids like Benny with no services after transition and the results have been from severe depression, regression and even death.

II. MY FOCUS TODAY -- WHAT INSTITUTIONAL BIAS?

My focus today will be the myth of an institutional bias, with regard to Medicaid expenditures, for persons with mental retardation and developmental disabilities.

It is critically important to me and VOR that each Commissioner understand the very different populations receiving Medicaid long-term care and do not, in addressing an alleged bias, inadvertently negatively impact people with mental retardation who have nothing to do with the institutional bias.

VOR has a legitimate reason to be concerned. At a recent meeting, a member of this Commission stated publicly that the Commission had agreed unanimously to eliminate the institutional bias.

I'm hopeful that my brief remarks today, along with VOR's written presentation received by Commissioners in advance of this meeting, will help explain why the allegation of a Medicaid institutional bias for people with MR/DD is simply not true.

There is no Medicaid "Institutional Bias" for Persons with Mental Retardation and Developmental Disabilities (MR/DD)

The origin of this myth relates to two factors.

The first is the historical combining of figures for the nursing facility program with the ICF/MR program to comprise a total figure for "institutional spending." This co-mingling of people and services throws together people with MR/DD and the services they require with the much larger physically-disabled demographic -- including the elderly -- and the services they require.

The second is labeling all "institutional" services as mandatory and all community services as "optional." As a matter of fact, nursing facility care is mandatory but ICF/MR care and community care are both optional Medicaid services.

Separating out ICF/MR funding from nursing home care "institutional" figures and comparing just the funding for people with MR/DD leads to dramatically different conclusions.

A) ICFs/MR comprise only 20% of total Medicaid "institutional" spending. Nursing Facilities (NFs) (also called "nursing homes") account for 80% of total Medicaid "institutional" spending.

B) Furthermore, when funds for persons receiving MR/DD services are separated out, only 25.8% of total Medicaid dollars goes to ICFs/MR (MR/DD institutions) while 74.2% is spent for MR/DD community-based services. Stated another way, we spend almost 3 times as much on Medicaid home and community-based services, and compared to MR/DD institutional services.

C) From 1977 to 2004, overall fiscal commitment ("fiscal effort") to community programs, as measured by the total amount spent from state and federal sources for MR/DD services per \$1,000 of citizens' personal income, increased by 486%. In contrast, institutional spending declined by 51% (Figure 3).

III. A NOTE ABOUT MEDICAID EXPENDITURES

On a related note, it is important also for Commission members to recognize that ICFs/MR are not the cause of rising Medicaid costs. The ICF/MR program is a tiny and falling percentage of all Medicaid funding and a good investment for both the federal government and the states to care for their most needy citizens. I know; my daughter is a benefactor of the good care

received in a state ICF/MR. There is no doubt in my mind that the availability of ICF/MR supports saved her life and brought sanity and peace to my family home.

Consider these figures, relating to Medicaid expenditures. From 1995 through 2005 --

- * Medicaid increased by 98.28%
- * Community increased by 267.5%
- * ICF/MR increased by only 25.9%

IV. CONCLUSION

The myth of an "institutional bias" in Medicaid -- spending more on institutional services than community services -- coupled with Medicaid "rebalancing" initiatives, as applied to services for persons with MR/DD, can have dangerous consequences for our most fragile citizens.

Federal and State efforts to "rebalance" the system by increasing community supports at the expense of "institutional" (including ICF/MR) options, places at risk the ICF/MR option. ICFs/MR may become uneconomical and extinct, risking the health, safety and very lives of people with severe and profound mental retardation.

The most fragile people of the MR/DD population are not going away. Their specialized care needs will continue to exist at the same or greater level into the future. Their care will continue to be expensive regardless of where they are being served; some studies suggest the cost of care could be higher in community settings for the most disabled and medically-fragile of our society.

While there is an ongoing need to expand community-based options, it is short-sighted and morally indefensible to do so at the expense of an exceedingly fragile population.

Thank you for your time today.

4. Give the gift of VOR! A great way to honor your loved ones with a meaningful gift, while also benefiting a great organization - VOR!

A donation in someone's honor makes a perfect Holiday gift, or give the gift of VOR membership.

A Tribute donation of any level will result in your honoree's name being included in the next issue of The Voice, in the Tribute Donation section. VOR also now offers special tribute categories allowing you to dedicate an entire issue of a VOR Weekly E-Mail Update (\$100), or an issue of the quarterly newsletter, The Voice (\$1000). With your gift of \$100 for a Weekly Update, or your gift of \$1000 for a printed issue of The Voice, the issue will be prominently

dedicated to the person of your choice and a small article about that person will be included in the issue. This is a great holiday gift idea; they will feel special!

The gift of a VOR membership - just \$25 - is also a great holiday gift. Soon after the receipt of your gift, the new member will receive a copy of the latest newsletter, along with a note sharing that they are receiving this membership due to your generosity.

These are great holiday gift ideas that also benefit VOR. Use the form at the end of this weekly update or contact Tony Padgett, VOR's Director of Resource Development at anthonypadgett@sbcglobal.net, or 847-253-6020 with any questions.

Thank you for your support and HAPPY HOLIDAYS!!!

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
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)

City St Zip

Phone Fax

E-Mail

Family/Professional Organization Affiliation (if applicable)

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