

VOICE OF THE RETARDED

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Voice of the Retarded Opposition to H.R. 1811, the revised version of the Family Opportunity Act

VOR strongly supports the original version of Family Opportunity Act (FOA). However, VOR joins many other advocates and consumers who are unable to support H.R. 1811 because of the inclusion of a harmful offset and the provisions of the Money Follows the Person (MFP) proposal.

In its original form in the House and in the Senate-passed bill, FOA sought to allow moderate-income families to purchase Medicaid coverage for children with severe disabilities. VOR wholeheartedly supported this version of FOA. Recently, however, the MFP proposal was added (costing \$1.75 billion over five years) along with a cut to Medicaid-supported targeted case management to offset the total cost of H.R. 1811, including the MFP program.

This offset has sparked tremendous opposition from the disability community, as well as great controversy among Members of the House, including sponsors of the bill. VOR agrees with the opposition of previous House sponsors as well as many advocates and consumers. The Medicaid offset would require we rob Peter to pay Paul, which satisfies no one; neither Peter nor Paul will be well served.

Furthermore, the addition of the MFP proposal poses a threat to the concept of bringing much needed medical assistance to moderate income (i.e. working poor) families who struggle on a daily basis to keep their children with severe disabilities at home.

VOR also takes exception to the assertion that the system needs rebalancing in favor of community-based services, as is the main intent of MFP (see *"The Myth of an Institutional Bias in Medicaid for Persons with Mental Retardation,"* attached). The expansion of one Medicaid program cannot be justified at the potential expense of the extremely needy and vulnerable individuals living in Intermediate Care Facilities for the Mentally Retarded (ICFs/MR). The \$1.75 billion price tag also makes it more difficult to find the necessary offset to pay for the FOA.

Regrettably, the Family Opportunity Act has morphed into something that VOR cannot in good conscience support. A reasonable Congress will reinstate the Family Opportunity Act (Dylan Lee James Act) in its original version so that desperately needed assistance can be provided to working families with special needs children.

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The Myth of an “Institutional Bias” in Medicaid for Persons with Mental Retardation and Developmental Disabilities

Often it is alleged that 70% of all Medicaid long-term care dollars pay for institutional care. Globally, this is true. Specifically, related to the mental retardation and developmental disabilities (MR/DD) population, it is not true. The Medicaid program for long-term care spends more dollars and supports more people with MR/DD in the community, including in the Home and Community Based Services (HCBS) waiver program, than for those in Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR).

What then, is the basis for the 70% myth? The answer lies in the fact that the Medicaid program covers more than people with MR/DD; it also covers people who reside in nursing facilities (NF), most of whom are elderly¹. The so-called institutional bias in the numbers occurs because Medicaid defines “institutional care” to include all Medicaid-eligible populations, the vast majority of whom reside in NFs. The facts are far different when one separates the MR/DD and elderly populations.

The “institutional bias” of Medicaid myth as applied to services for persons with MR/DD can have dangerous consequences for our most fragile citizens. For example, proposals such as Money Follows the Person (MFP) and the Medicaid Attendant Services and Supports Act (MiCASSA) are motivated by a desire to “rebalance” the system by increasing community supports at the expense of “institutional” (including ICF/MR) options. In this process, ICF/MR care may become uneconomical and extinct, risking the health, safety and very lives of people with severe and profound mental retardation if these facilities close. While there is a great need to expand community-based options, it should not be done at the expense of another Medicaid population. Focus on expansion must address the areas of greatest need for people with MR/DD – the provision of quality community options, including ready access to health care services, and helping those on waiting lists for services.

Here are the facts about the Medicaid program:

- Nearly 70% of the Medicaid funds for long-term care (for both people with MR/DD and the elderly) are spent for services provided in “institutional” settings. However, only 20% of this funding is for people with MR/DD who reside in ICFs/MR (Table 1).
- When one looks at only Medicaid expenditures for persons with MR/DD who reside in ICFs/MR and in HCBS, it turns out that Medicaid spends more for community services (55%) than for institutional care (45%). (Table 2). Note: NF expenditures for MR/DD residents, who are only 2.4% of the NF population, are excluded from Table 2 because reliable data could not be located.

Table 1²

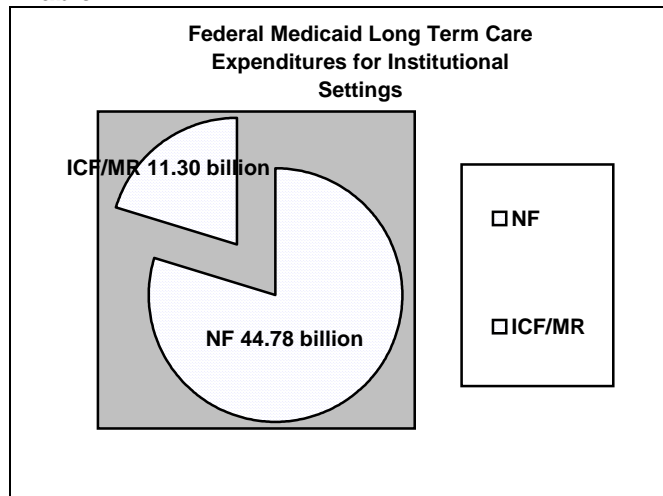
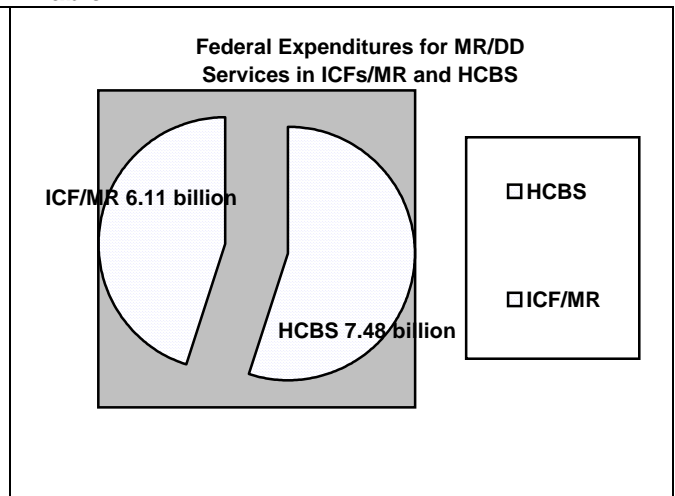


Table 2³



- HCBS recipients comprise 72% of MR/DD residents in Medicaid-funded long-term care settings. ICFs/MR recipients make up just 21% and the remaining 7% reside in nursing facilities (Table 3).
- Medicaid-funded HCBS and other community residences, as compared to ICFs/MR, comprise 95% of the residential placement options for persons with MR/DD (Table 4). These figures exclude individuals with MR/DD receiving services in the family home or their own home, which represents an additional 482,479 people receiving non-residential community-based services, although it is unclear what percentage of this amount is Medicaid-supported.

Table 3⁴

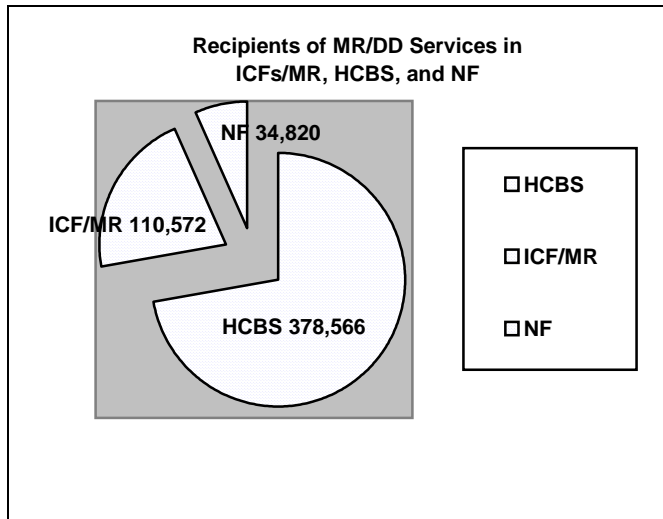
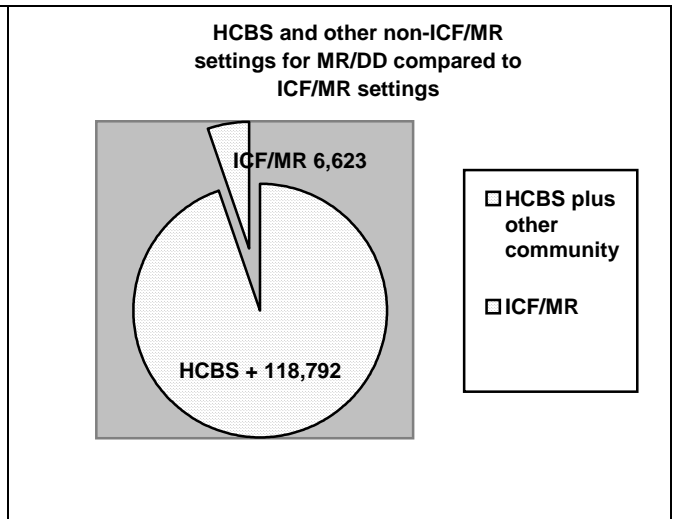


Table 4⁵



- 79.7% of individuals who reside in ICFs/MR have severe and profound mental retardation and require 24-hour around-the-clock care for their safety. Nearly half (47%) of these same residents have two or more additional conditions, and nearly all need help walking, toileting, eating, dressing and/or communicating verbally. By sharp contrast, the vast majority of people with MR/DD who reside in the community are far higher functioning individuals with little or no need for intensive care services.
- A 2003 peer-reviewed study by Kevin Walsh, Ph.D., concluded that “From the studies reviewed here, it is clear that large savings are not possible within the field of developmental disabilities by shifting from institutional to community placements.” Thus, if more funds were spent to move people from ICFs/MR, little or no money would be saved, unless the quality of the lives of the clients were reduced through lesser quality care and services.

¹ Trend in the cost of Operating a Nursing Home: Analysis of Medicare Cost Reports for Skilled Nursing Facilities, Health Services Research and Evaluation, American Health Care Association (January 26, 2004)(Total number of residents in nursing facilities (2003) was 1,450,319, including 34,820 residents with MR/DD (see Table 3)).

² Steve Gold, “Medicaid 2003 Expenditures,” Information Bulletin #68 (May 26, 2004).

³ Residential Settings for Persons with ID/DD served by State and Nonstate agencies on June 30, 2002. In R. W. Prouty, Gary Smith & K.C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2002*, University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, <http://rtc.umn.edu/risp02/risp02.pdf>, Tables 3.4 (p. 96) and 3.7 (p. 103).

⁴ *Id.*, Tables 3.12 (p. 113), 3.13 (p. 114), and 3.2 (p.90).

⁵ *Id.*, Tables 2.1 (p.64) and 3.1 (p. 88) (figure for HCBS plus other community settings derived by taking the total state and nonstate residential settings for persons with MR/DD, from Table 2.1, and subtracting total ICF/MR settings from Table 3.1).