



CCD LONG TERM SERVICES AND SUPPORTS TASK FORCE ANNUAL REPORT

As the 108th Congress comes to a close, FY 2004 left a lot of our issues still on the table. Thus, we will be revisiting a lot of the same issues in the new 109th Congress.

2004:

The Task Force spent significant time working to prevent the Medicaid program from being block granted or capped, including through administrative approval of Section 1115 waivers. The Task Force worked with the Health Task Force and larger coalitions to oppose the approval of several state-proposed Section 1115 Medicaid waivers which would result in significant cuts in services and protections for people with disabilities.

The Lifespan Respite Care Act (HR 1083, S. 538) authorizes competitive grants to states to make quality respite available and accessible to family caregivers, regardless of age or disability. The bill allows grantees to identify, coordinate and build on federal, state and local respite resources and funding streams, and would help support, expand and streamline planned and emergency respite, provider recruitment and training, and caregiver training. House and Senate Republican champions of the bill have promised to have the bill reintroduced in the next Congress.

In addition, the full text of S. 538 has been incorporated into the omnibus "Ronald Reagan Alzheimer's Breakthrough Act," (S. 2533, H.R. 4595). This legislation enjoyed the support of 62 members of the Senate. The bill also contains tax provisions to assist family caregivers and those purchasing long-term care insurance. But the larger focus is on NIH Alzheimer's Research. The bill was not acted on by the House or Senate.

Direct Support Professional Fairness and Security Act of 2004 (H.R. 5197) Legislation was introduced by Representatives Lee Terry (R-NE) and Lois Capps (D-CA) on September 28, 2004 with 13 other co-sponsors. It will amend Title XIX of the Social Security Act (Medicaid) to provide funds to states to enable them to increase the wages that private providers pay to direct support professionals in supporting certain individuals with disabilities through specific state Medicaid services. While acknowledging the recruitment and retention crisis and low wages of direct support workers across all long-term support options, H.R. 5197 is designed to eliminate wage inequities for those who provide private supports to targeted individuals with disabilities—those individuals, regardless of age, who are eligible for and receiving Medicaid 1915(c) home

and community-based waiver services, 1115 waiver services, personal care, rehabilitative services, home health care services, and ICF/MR services.

The Au Pair Program Expansion Act of 2004 (H.R. 3998) was introduced March 18, 2004 by Representative Jim Cooper (D-TN). H.R. 3998 proposes to expand the Au Pair exchange visitor program to include the provision of in home independent living services for adults with disabilities. This would allow participants in the Au Pair program to serve as live-in personal care assistants for adults with disabilities.

Money Follows the Person Act of 2003 (S.1394) was introduced by Senators Tom Harkin (D-IA) and Arlen Specter (R-PA) on July 11, 2003. The bill is a demonstration project that would require the federal government to reimburse the state for 100% of the first-year costs of home and community based services for individuals on Medicaid who move to the community from nursing homes or other institutions. In year two, the state match returns to the original rate. The bill was referred to the Senate Finance Committee, had a hearing but was never marked-up.

President Bush's FY 2003-04 budgets called for \$1.75 billion for a Money Follows the Individual Rebalancing Demonstration Project. CMS and Senate Finance staff did not agree on a bill for introduction. In the House of Representatives, an amendment to the Family Opportunity Act (H.R. 1811) was proposed in late June to include Money Follows the Person. The amended version was on the "suspension" calendar and about to be voted upon when concerns about offsets in Medicaid to fund the legislation led to disagreements about how to proceed. H.R. 1811 was pulled from the suspension calendar and has not been acted upon since.

2005:

The Task Force will place a high priority on protection of the rights of people with disabilities and access to necessary services and supports in the federal/state Medicaid program. The Task Force will work to oppose the expected efforts to block grant the program and reduce protections for people with disabilities who depend on Medicaid services. This will include work during the budget resolution process and the budget reconciliation process.

The Task Force will work with sponsors, staff, and the administration for passage of the legislation that was not enacted in 2004.

Other Issues the task force will work on in the 109th Congress include continuing to look at implementation of the U.S Supreme Court's decision in *Olmstead*, the New Freedom Initiative Grants, the Medicaid Community-Based Attendant Services and Supports Act (MiCASSA), the National Governors Association consideration of a resolution on MiCASSA, and working with the Health Task Force and others on the White House Conference on Aging.