



CONSORTIUM FOR CITIZENS
WITH DISABILITIES

Long Term Services and Supports Task Force Annual Report for 2013

2013 ACTIVITIES

Protection of Medicaid as an Entitlement Program

Working in conjunction with other CCD Task Forces, the LTSS Task Force advocated with Congress and the Administration to ensure that people with disabilities are not hurt by any proposed changes or cuts to Medicaid. In mid-June, the CCD LTSS and Health Task Forces sent a letter to Rep. Bill Cassidy expressing concerns with his reintroduction of the Medicaid Accountability and Care Act (H.R. 1853) which would remove the individual entitlement of Medicaid and shift it to a per capita caps structure. Rep. Upton and Sen. Hatch were cc'ed, as per capita caps were included in their blueprint to reform Medicaid. The LTSS Task Force also conducted visits to offices on Capitol Hill to express its concerns with the Medicaid per capita caps proposal.

While Medicaid was exempted from sequestration in the Budget Control Act, when a Budget Conference Committee was established in October 2013, alteration of and/or cuts to the Medicaid program were back on the table for negotiations. The LTSS Task Force sent a letter to all Budget Conference Committee members on November 5 urging them to continue protecting Medicaid as an entitlement program for vulnerable Americans including those living with disabilities. Medicaid was not disturbed by the budget agreement negotiated by Senator Murray and Rep. Ryan.

The Long-term Care (LTC) Commission

When the Community Living Assistance and Supports (CLASS) program was repealed as part of the fiscal cliff deal, a bipartisan Commission was established to propose long-term care reform and financing solutions to Congress. The LTSS Task Force attended LTC Commission hearings and in conjunction with the Leadership Council of Aging Organizations (LCAO), developed and submitted principles for LTSS to the Commission. LTSS Task Force members also worked to gather signatures to an online petition urging Congress to establish more flexible, affordable LTSS options for Americans. The petition garnered over 9,700 signatures. With the LTC Commission having issued its final report, the CCD LTSS Task Force remains involved with LCAO to try and determine next steps on LTSS reform including identifying congressional champions.

National Quality Forum

The CCD LTSS Task Force tracked work of and weighed in with the National Quality Forum (NQF), through the representation of Clarke Ross. For instance, when evaluating approximately 400 quality measures for people dually eligible for Medicare and Medicaid, five of CCD's six recommendations were included that are sensitive to the needs of people with disabilities.

The CCD LTSS Task Force also hosted a presentation by Beth Mathis, Vice President for Business Development and Customer Relations, The Council on Quality and Leadership (CQL) on CQL's Personal Outcome Measures. This presentation was made in relation to CMS looking to the NQF to endorse/encourage quality measures that states can use in their duals projects and managed care.

Monitoring Implementation of the Affordable Care Act

The CCD LTSS Task Force continued to monitor implementation of the Affordable Care Act (ACA), most notably states choosing to expand Medicaid and take up the ACA's home- and community-based services options.

Letter to OMB on Companionship Exemption Regulation

Some CCD LTSS Task Force members sent a letter to the Office of Management and Budget (OMB) on non-controversial aspects of its companionship exemption regulation including the possible impact on family caregivers.

Letter to CMS in Response to Disability Competent Care Self-Assessment Tool

The CCD LTSS Task Force sent a letter in response to the disability competent care self-assessment tool that was developed for CMS by the Lewin Group and Institute for Healthcare Improvement. The letter generally supported the tool but provided recommendations that could further support people living with disabilities including more sensitivity in use of the word "care" and clarification on when individuals may need support from family caregivers and the like when developing their plan.

Lifespan Respite Care Program

CCD LTSS Task Force members were encouraged to activate their grassroots to help get members of Congress to sign on to Rep. Langevin's Dear Colleague letter, urging the House Appropriations Committee to provide \$2.5 million for the Lifespan Respite Care Program in Fiscal Year 2014. The Lifespan Respite Care Program provides grants to states to better coordinate and deliver quality respite care to our nation's more than 60 million family caregivers. The letter had more signers than ever before—34—and was bipartisan.

FUTURE ACTIVITIES

- Continuing to protect Medicaid from proposed structural changes or cuts that would harm services for people with disabilities;
- Encouraging implementation of the Affordable Care Act LTSS programs;
- Responding to proposed regulations from CMS and other agencies;
- Monitoring state efforts to save money through comprehensive changes to Medicaid LTSS including managed care, health homes, dual eligibles, and other integrated financing and delivery system models;
- Urging Congress to tackle LTSS reform and provide more flexible, affordable LTSS options for Americans; and
- Continuing to focus on quality of care for those dually eligible.

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