



CONSORTIUM FOR CITIZENS
WITH DISABILITIES

CCD Long-term Services and Supports Task Force Annual Report for 2016

2016 ACTIVITIES

Legislation and Capitol Hill Work

- **Opposition to Block Granting, Placing Per Capita Caps and/or Significant Cuts to Medicaid:** Sent a [letter](#) to Capitol Hill expressing opposition to block granting, setting of per capita caps and/or significant cuts to the Medicaid program.
- **Long-term Services and Supports Financing Proposals:** Released a [Statement](#) and held related Capitol Hill meetings to weigh in on the recent reports on long-term care financing, express our support for Medicaid improvements, and support the emerging consensus on the need for a public insurance program.
- **Chronic Care Workgroup:** With the CCD Health Task Force, submitted [feedback](#) to the Finance Committee's Bipartisan Chronic Care Working Group Policy Options Document.
- **Money Follows the Person:** Sent a [letter](#) urging reauthorization of Money Follows the Person and held approximately 30 related Capitol Hill meetings.
- **Complex Rehabilitation Technology (CRT):** Sent a [letter](#) urging passage of S. 2196/H.R. 3229 by year's end to protect access to CRT manual and power accessories—which helped achieve six months more protected access to CRT power accessories.
- **Program of All-Inclusive Care for the Elderly (PACE):** Some CCD LTSS organizations worked with the National PACE Association to produce an Adapted PACE Protocol that was delivered to the Center for Medicare & Medicaid Innovation (CMMI) to help ensure that any upcoming PACE pilots will adequately serve younger people with disabilities and held a related webinar. Also submitted [comments](#) to CMS that the home- and community-based services (HCBS) settings regulation should be applied to PACE programs.
- **Disability Integration Act (S. 2427):** Sent [an endorsement letter](#) to Senator Schumer.
- **Caregiving:** Supported funding for the Lifespan Respite Care Program in FY 2017 and stayed apprised on caregiving legislation such as the RAISE Act (H.R. 3099/S. 1719).

Regulations

- **HCBS Regulation:** Continued to monitor implementation of the updated definition of HCBS under Medicaid 1915(c), (i) and (k).
- **Medicaid Managed Care:** Evaluated the LTSS and quality provisions of the final Medicaid managed care regulation issued in April 2016 that CCD had previously commented on.

National Quality Forum (NQF)

- NQF finalized ACL funded “Quality in Home and Community Based Services To Support Community Living.”
- NQF endorsed the CMS-AHRG developed, CAHPS trademarked Home and Community-Based Services Experience Survey.
- NQF finalized its report to CMS – “Promoting Community Connections Through Quality Measures for” Persons Dually Eligible for Medicare and Medicaid.
- Agency for Healthcare Research and Quality (AHRQ) initiated public input into efforts to enhance person understanding, navigation, engagement, and self-management.

FUTURE ACTIVITIES

- A significant focus in 2017 will be advocating for protection of Medicaid as an entitlement program and opposing block granting, setting of per capita caps and/or significant cuts to Medicaid.
- Continue to monitor and weigh in on LTSS-related legislation such as the Disability Integration Act, Transition to Independence Act, Complex Rehabilitation Technology legislation and caregiver-related legislation.
- Continue to weigh in on the Senate Finance Committee’s work around care for people with chronic conditions.
- Continue to ensure that any PACE demonstration projects properly serve younger people with disabilities.
- Continue to monitor federal regulations impacting LTSS such as the HCBS settings rule.
- Continue to monitor work of the National Quality Forum and engage as needed.

CO-CHAIRS IN 2016:

*Alison Barkoff, Center for Public Representation, abarkoff@cpr-ma.org

Dan Berland, National Association of State Directors of Developmental Disabilities Services (NASDDDS), dberland@nasdds.org

*Nicole Jorwic, The Arc of the United States, jorwic@thearc.org

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**New LTSS Co-chair as of November 2016*

***Served as LTSS Co-chair from January 2016 – October 2016, but no longer part of CCD*