CCD Long-term Services and Supports Task Force
Annual Report for 2017

2017 ACTIVITIES

Preservation of Medicaid and Consumer Protections
We successfully advocated against significant threats contained in the American Health Care Act, Better Care Reconciliation Act, Obamacare Repeal Reconciliation Act and the Graham-Cassidy proposal. This resulted in maintaining Medicaid as an entitlement program and avoiding caps or cuts to the program, as well as preserving Medicaid expansion and the Affordable Care Act’s consumer protections (including those for people with pre-existing conditions). In conjunction with the Health Task Force, we effectively organized and carried out the work through Grassroots, Hill Meetings and Briefings/Publications Subgroups. This tremendous collaborative work included:

- At least 75 meetings on Capitol Hill;
- Numerous sign-on letters and several statements on the proposed legislation;
- Helping organize and participating in about a dozen rallies;
- Organizing 5 national call-in days;
- Development of resources including a fact sheet on why Medicaid per capita caps and block grants are devastating for people with disabilities, a fact sheet on why the Affordable Care Act’s consumer protections are important to people with disabilities, and toolkits for grassroots.

Medicaid Waivers
Monitored state-initiated Medicaid 1115 waivers that could have an impact on people with disabilities’ access to coverage through policies like work requirements and lock out periods.

Home- and Community-based Services Settings Rule
Reaffirmed the Task Force’s support of the rule, updated a fact sheet and held meetings on Capitol Hill about its importance to people with disabilities.

Tax Bill
In conjunction with the Health Task Force, sent letters to Capitol Hill expressing several concerns with the tax legislation—for instance, that it will lead to significant and dangerous cuts to Medicaid, Medicare and Social Security, as well as disproportionately impact people with disabilities who are overrepresented in the low-income bracket. While the individual mandate was repealed and the Orphan Drug Tax Credit weakened, through the letter and grassroots advocacy, we helped preserve the medical expense deduction, Disabled Access Tax Credit and Work Opportunity Tax Credit.
Other Legislation and Activities

- **Complex Rehabilitation Technology**: Achieved an administrative fix that keeps power Complex Rehabilitation Technology accessories out of Medicare’s Competitive Bidding Program. Sent Congress a letter urging passage of H.R. 3730 to ensure the same access for those needing manual Complex Rehabilitation Technology accessories.
- **Disability Integration Act**: The Disability Integration Act would ensure the rights of people with disabilities to live full and independent lives in their communities. We worked with bill sponsors to make changes favorable to people with disabilities. Subsequently, CCD sent this letter supporting the bill.
- **Money Follows the Person**: Worked with bill sponsors to introduce legislation that would reauthorize Money Follows the Person. In collaboration with the Disability and Aging Collaborative, sent a sign-on letter to Capitol Hill and held meetings on Capitol Hill supporting reauthorization of the program.
- **RAISE Family Caregivers Act**: Monitored and some CCD organizations weighed in supporting the enacted RAISE Family Caregivers Act which will establish a national plan to recognize and better support family caregivers.
- **National Quality Forum**: Monitored activities and work of the National Quality Forum.

**FUTURE ACTIVITIES**

- Continued focus on protecting 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 Medicaid 1115 waivers that could have a negative impact on access to coverage for people with disabilities.
- Continue to monitor and weigh in on LTSS-related legislation such as the Disability Integration Act, Money Follows the Person reauthorization, Complex Rehabilitation Technology legislation and caregiver-related legislation.
- Continue to monitor federal regulations impacting LTSS such as supporting strong implementation of the HCBS settings rule.
- Continue to monitor work of the National Quality Forum and engage as needed.

**CO-CHAIRS IN 2017:**

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

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

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

Sarah Meek, American Network of Community Options and Resources (ANCOR), smeek@ancor.org

Laura Weidner, National Multiple Sclerosis Society, laura.weidner@nmss.org