

# Collaborative Leadership to Advance Disability Policy

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## About NCOA

### Who We Are:

NCOA is a respected national leader and trusted partner to help people aged 60+ meet the challenges of aging



### Our Mission:

Improve the lives of millions of older adults, especially those who are struggling

## Disability and Aging Collaborative

Informal coalition of more than 40 national aging and disability groups working together to advance LTSS policy

One of the first successful efforts to bring together aging and disability organizations



## Disability and Aging Collaborative

- American Association on Health and Disability
- American Association of People with Disabilities
- AARP
- ADAPT
- Alliance for Retired Americans
- Altarum institute
- AFSCME
- ANCOR
- The Arc of the United States
- Association of University Centers on Disabilities
- Alzheimer's Association
- Bazelon Center for Mental Health Law
- Caring Across Generations
- Center for Medicare Advocacy
- Community Catalyst
- Dana & Christopher Reeve Foundation
- Direct Care Alliance
- Disability Rights Education & Defense Fund
- Easter Seals
- Families USA
- Health and Disability Advocates
- Leading Age
- Lutheran Services in America
- National Association of Area Agencies on Aging
- National Association of Councils on Developmental Disabilities
- National Academy of Elder Law Attorneys
- National Association for Home Care and Hospice
- National Committee to Preserve Social Security and Medicare
- National Council on Aging
- National Council on Independent Living
- National Consumer Voice for Quality Long-Term Care
- National Disability Rights Network
- National Health Law Program
- National PACE Association
- National Senior Citizens Law Center
- Paralyzed Veterans of America
- Paraprofessional Healthcare Institute
- SEIU
- United Cerebral Palsy
- United Spinal Association
- VNAA –Visiting Nurse Associations of America

# Disability and Aging Collaborative

Formed in 2009  
 Goal: Ensure LTSS Was Part of Health Reform

- Successful advocacy led to ACA passage with:
- Community First Choice
  - Balancing Incentives Program
  - 1915(i) improvements
  - Money Follows the Person extension
  - Funding for ADRCs
  - HCBS Spousal Impoverishment Protections
  - CLASS Act

**Long Term Services and Supports Must be Part of Health Care Reform**

**THE FACTS**

- 40 million people lack insurance for their health care.
- 200 million people lack insurance for their long-term services and supports.
- 10 million Americans daily need long term services and supports. Forty percent are under age 65.
- 40 million Americans provide care daily for adults, many of whom are disabled.
- Nearly every American family will face the need to provide long-term services and supports for someone with a disability.
- Vulnerable adults of all ages with disabilities cannot afford or access the services they need in the setting of their choice.
- Families work multiple jobs and drain their bank accounts to pay for their loved ones' care.
- We must take the pressure off of State Medicaid expenditures and improve access to home and community-based services.
- Homelessness is on the rise and productivity is declining.

**THE TIME TO ACT IS NOW**

- We must take the pressure off of State Medicaid expenditures and improve access to home and community-based services.
- Homelessness is on the rise and productivity is declining.

**Health care reform without long term services and supports will fail to solve this crisis.**

**SPONSORING ORGANIZATIONS**

**We call on Congress to provide real health security by including long term services and supports in health care reform legislation.**

This problem can be solved in a financially sound way for families and taxpayers. We can make it affordable to care.

# Issues and Focus Over Time

- Regulations
- CFC and 1915(i)
  - HCBS Settings rule
  - Medicaid managed care

Visibility of need for LTSS financing reform

- Duals Integration and Managed LTSS
- Consumer Protections
  - Capacity of State Advocates
  - Quality Measures

**Medicaid cuts and caps hurt US**

1 in 5 Americans relies on Medicaid to stay healthy and independent. Medicaid cuts and per capita caps mean less care, lost jobs, and greater hardships for families, especially in rural areas.

**Congress: Don't cut and cap Medicaid**

**Supporting Organizations**

A list of numerous organizations including: American Health Care Association, American Public Health Association, American Society on Aging, etc.

## Functioning Over Time

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
My organization benefits from being involved in the DAC.					
Year 1	31.3	50.0	12.5	6.3	0.0
Year 2	50.0	50.0	0.0	0.0	0.0
Year 3/4	66.7	33.3	0.0	0.0	0.0
The level of commitment among DAC participants is high.					
Year 1	6.3	62.5	25.0	6.3	0.0
Year 2	16.7	66.7	16.7	0.0	0.0
Year 3/4	50.0	41.7	8.3	0.0	0.0
People in the DAC communicate openly with one another.					
Year 1	12.5	50.0	31.3	6.3	0.0
Year 2	22.2	72.2	5.6	0.0	0.0
Year 3/4	45.8	37.5	16.7	0.0	0.0
The views of my organization are listened to by the DAC in formulating priorities and policy positions.					
Year 1	33.3	46.7	20.0	0.0	0.0
Year 2	38.9	61.1	0.0	0.0	0.0
Year 3/4	58.3	37.5	4.2	0.0	0.0
What we are trying to accomplish with the DAC would be difficult for any organization to accomplish by itself.					
Year 1	25.0	50.0	12.5	12.5	0.0
Year 2	44.4	33.3	22.2	0.0	0.0
Year 3/4	47.8	43.5	8.7	0.0	0.0

## Disability and Aging Collaborative

- 1) **Collaboration Takes Time and is Messy**
  - Mistrust, assumptions, stereotypes, negative past experiences
  - Egos, self-interests, funding silos
- 2) **Find Common Ground**
  - Not going to agree on everything, needs to be mutual benefit
- 3) **Openness to Learning**
  - Promising practices, be respectful of language
- 4) **Infrastructure Support is Critical**
  - Schedule/lead meetings, communication
- 5) **When it Works it Works!**
  - More powerful impact together

