Promising State Programs to Support Family Caregivers

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Family Caregivers:
Backbone of the LTSS System

- Family caregiver is an **unpaid** relative, partner, friend, or neighbor who has a significant relationship with and who provides a range of assistance for an older adult or an adult with a chronic or disabling condition(s).

- **Average U.S. caregiver** is female, 49 years old, working outside the home and spends nearly 20 hours/week providing unpaid care to her mother for about five years.

- In 2009, 42 million family caregivers in the United States provided an estimated **$450 billion** in unpaid care.
Vast majority (74%) of family caregivers have worked at some time during their caregiving experience and over half (58%) are employed full or part time.

Significant majority of employed caregivers make work accommodations because of caregiver responsibilities and need job and financial security protections.

Family caregivers face bewildering array of tasks and responsibilities as well as stress, physical strain, competing demands and financial hardship.
The Disconnect

- Family members are providers, coordinators, and receivers of services and supports
- Lack of understanding
- Family members are often invisible in the care process
Taking Care of Family Caregivers: Policy Recommendations

- Support During Hospital Transitions
- Removing Barriers to Practice and Care
- Respite Care
- Workplace Flexibility
- Uniform Guardianship and Power of Attorney Laws
- Access to Direct Care Workers
Caregiving Legislation in the States
Where is the CARE Act?

CARE Act goes into effect:
- Oklahoma, 11/5/14; Colorado, 5/8/15; New Jersey, 5/12/15; West Virginia, 6/6/15; New Mexico, 6/17/15; Mississippi, 7/1/15; Virginia, 7/1/15; Arkansas, 7/21/15; Connecticut, 10/1/15; Nevada, 10/1/15; Indiana, 1/1/16; New Hampshire, 1/1/16; Oregon, 1/1/16

**Updated on 6/12/2015**
No one will ever understand the heartache, helplessness and hopelessness that come with caring for a loved one when there are no resources available. I will never forget that dreadful day in December 2009 when my mom had her first stroke. Our lives have never been the same. If you have ever had to take care of a loved one who is unable to care for themselves you will understand my pain.

Mom had no retirement, no savings, and no medical benefits; all she had was a social security check that was slightly over $1000 a month. This monthly income did not allow her to receive benefits from the state; she was over the income to receive assistance, mom was totaled dependent on me.

Mom needed round the clock care and assistance with everything, she could not even take herself to the bathroom. The first two years I depleted my savings and was working on my 401K just to purchase her medication. I paid $550 every two weeks for someone to care for her in my home and while I went to work.

I am so grateful to the staff of Legal Counsel for the Elderly who steered in and assisted me in getting an EPD Weaver and other resources for my mom to make her caregiving a little easier.

No one prepares you for this job but it is a job that some of us are required to do. The only reward is knowing that at the end of the day I have done everything I can to care for my mother and to make her remaining days as comfortable as possible.