

Supporting 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**

Family Caregivers: Backbone of the LTSS System

- **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

Taking Care of Family Caregivers: Policy Recommendations



Support During Hospital Transitions

Removing Barriers to Practice and Care

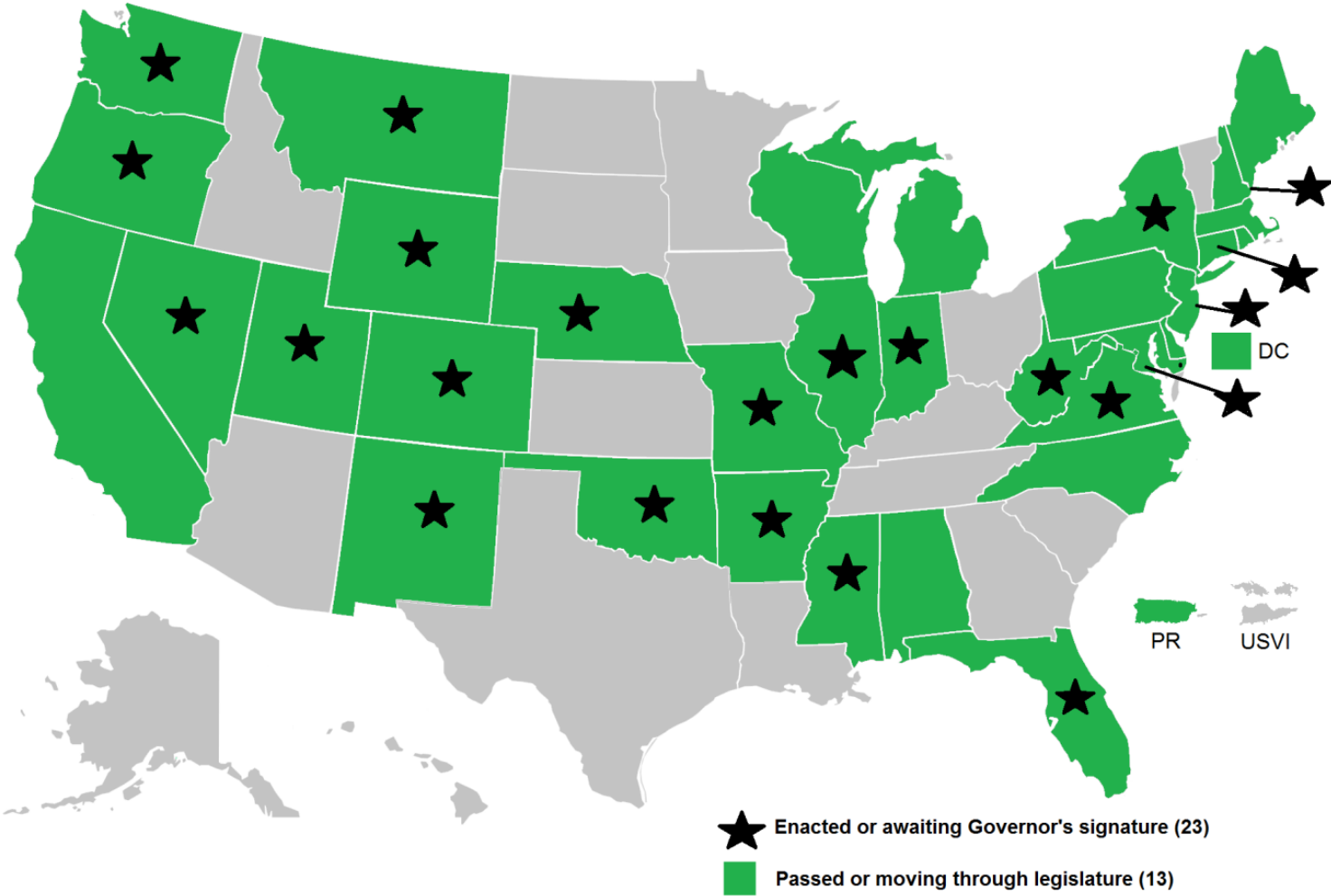
Respite Care

Workplace Flexibility

Uniform Guardianship and Power of Attorney Laws

Access to Direct Care Workers

Caregiving Legislation in the States



AARP's Home Alone Report

Findings:

- **Nearly 50%** of family caregivers perform complicated medical/nursing tasks and medication management
- **Most** do not receive training
- **69%** of care recipients do not receive home visits by health professionals
- **51%** of family caregivers performing medical/nursing tasks may prevent nursing home placement
- **More than 50%** of family caregivers report feeling down, depressed, or hopeless



The CARE Act

- **Designation**

- Record the name of the family caregiver upon admission into the hospital

- **Notification**

- Contact the family caregiver(s) prior to discharge to another facility or home

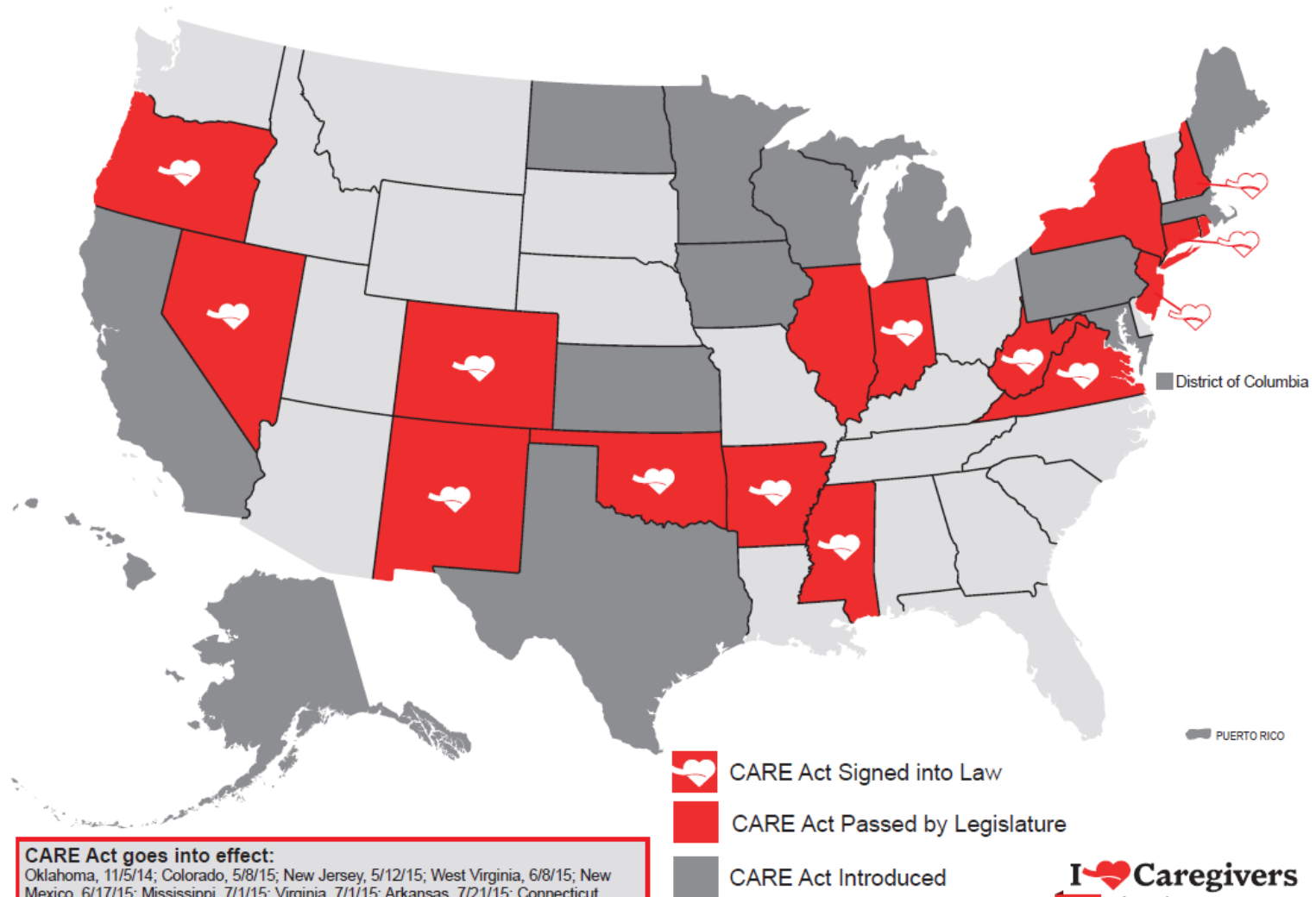
- **Consultation**

- Hospital consults with caregiver on discharge plan, taking into account the caregiver's capabilities and limitations

- **Training**

- Hospital gives caregiver the opportunity to receive instruction on all after-care tasks included in the discharge plan to be performed by the caregiver

Where is the CARE Act?



**Updated on 6/12/2015



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I Heart Caregivers



Gwen from DC  

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 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 totally 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 \$650 every two week 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 stepped 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.



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