



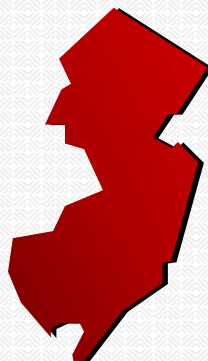
Rutgers Center for
State Health Policy

New Jersey Office of Legislative Services
Trenton, New Jersey
April 10, 2007



State Strategies to Support Family Caregiving

Susan C. Reinhard, RN, PhD



Background



- State focus on “Balancing LTC”, Choices for Independence, Money Follows the Person, Global Budget
- Informal support is the most important source of assistance for people of all ages with disabilities
- Must begin with consideration of family caregivers, the backbone of LTC
- Caregiver as both client and provider

Caregiver as Client



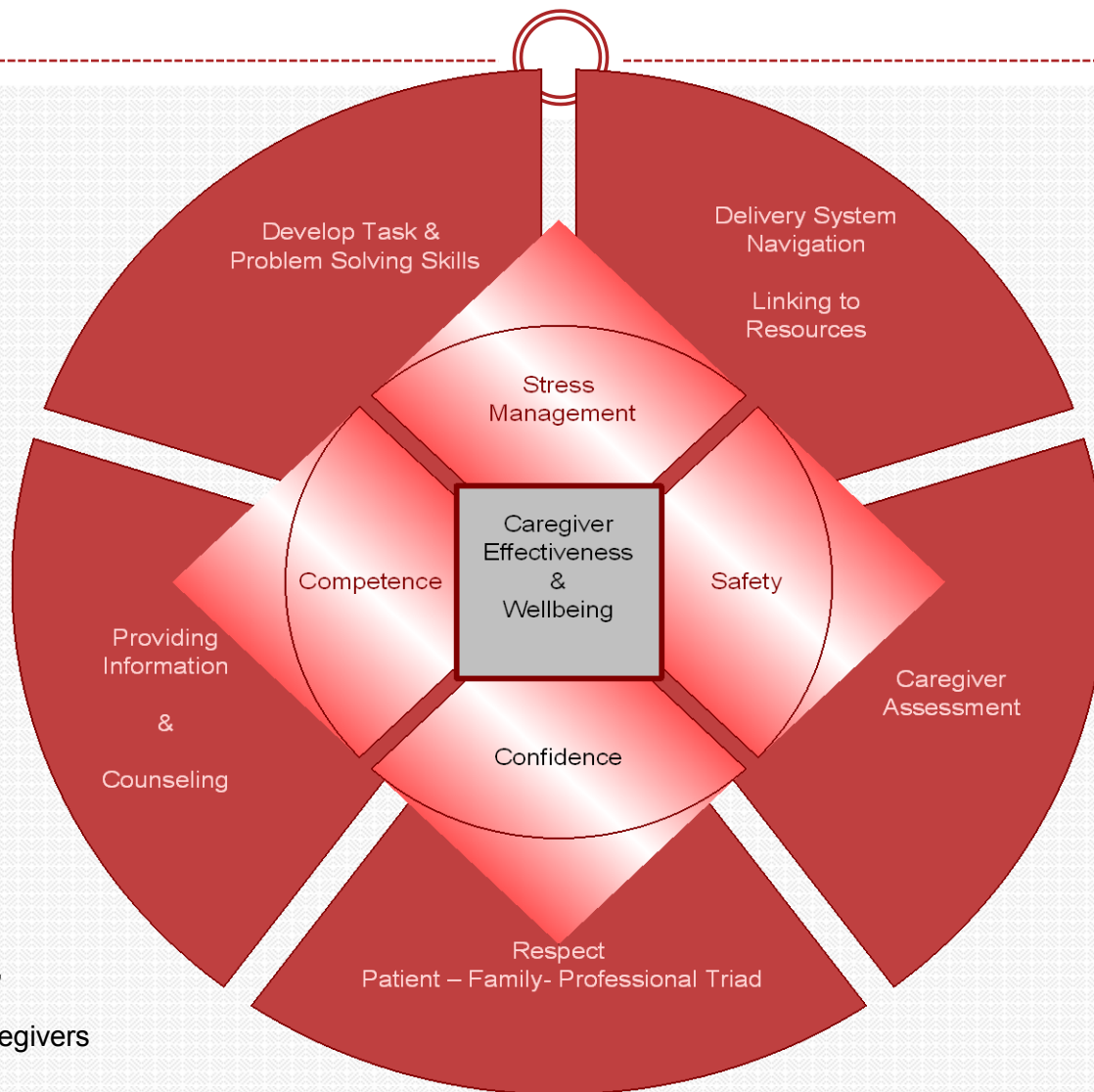
- Often referred to as “secondary patients” who need and deserve protection and guidance.
- Focus on how they are managing their caregiving responsibilities, which often place them at greater risk for injury and depression.
- Policy goal is to prevent them from becoming “patients” themselves.

Caregiver as Provider



- Often need help to learn how to become competent, safe “workers” who can better support the individual and protect them from harm, such as a falling between the bed and the wheelchair
- Policy goal is to “keep them on the job”
 - Need to assess the caregiver’s learning needs for caregiver training
 - How to interact with the individual and professionals involved

Constellation of Goals and Approaches of Maximizing Caregiver Effectiveness and Minimizing Caregiver Stress



Source: Adapted from Reinhard, S., Given, B., Petlick, N. & Bemis, A. "Supporting Family Caregivers in Providing Care.,

New Jersey A Leader For Decades



- Statewide Respite Care Program
- Alzheimer's Adult Day Program—evidence base
- Caregiver Assistance Program
- Jersey Assistance for Community Caregiving
- Employed Caregivers

Promising Practices from States



- Care Coordination through Single Entry Point/Aging and Disability Resource Centers
- Consumer Direction
- Caregiver Tax Incentives
- Caregiver Training and Education
- Family and Medical Leave
- Caregiver Assessment

Care Coordination



- Michigan: Caregiver involvement in care planning through single entry points
- Hawaii: Funds for ADRC to coordinate family caregiver support

Consumer Direction



- Kansas: Offer individual choice, with focus on informal caregiver services
- Oklahoma: Allow hiring of family caregivers

Caregiver Tax Incentives



- Many states pending, none passed in 2004-2006
- New Jersey example; Allow \$5,000 income tax deduction
- New York example: Allow tax credit of \$1,500 to employer who provides or pays an agency to provide care for employee's adult dependents who are over 60 years of age

Caregiver Training and Education



- Hawaii (pending): Appropriate \$4 million to fund caregiver training and \$1,000 annual grants to family caregivers to alleviate burden

Family and Medical Leave



- Washington (pending): Provide up to 5 weeks paid leave, \$250 per week for employees who regularly work 40 hours

Caregiver Assessment



- Idaho: requires use of an established scale to assess the well-being of caregivers and determine their respite benefits
- Massachusetts

Why Assessment of Family Caregivers' Needs?



Are family members seen merely as “resources”, or as people with needs and rights of their own?

Lynn Friss Feinberg

Family Caregiver Alliance

Assessment of Family Caregivers' Needs



- We need to consider not only how the family caregiver can help the consumer, *but how we can help the family caregiver*
- Assessment is important for developing an individualized plan when the consumer chooses to seek family caregiver support in order to live in the community

Why Assessment?



- What is the “emergency back up” or “contingency planning” for a family caregiver who cannot provide the care that is assumed or stated in the “individualized care plan”? How would the state know unless there is a caregiver assessment?

Why Assessment?



- If the State is paying for the individual's care (state funded or Medicaid), and the plan for the individual relies on support from the family caregiver, the state should require and fund a caregiver assessment.
- Should be part of the “health and safety” review and “risk mitigation” that CMS requires.

Future Caregiver Initiatives Should Address



- Continual promotion and administrative oversight
- Expansion of consumer direction for caregivers
- Increased supports for caregivers of people with dementia
- More direct services to caregivers receiving respite
- More inclusion of middle income caregivers in services and supports