Policies and Family Caregiving

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Family Caregiver –
Broad Definition

• Any relative, partner, friend or neighbor who has a significant relationship with, and who provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition.

• The “average” U.S. caregiver is a 49-year-old woman who works and spends nearly 20 hours/week providing unpaid care to her mother for nearly 5 years.
Characteristics of Family Caregivers

- One in five adults
- More than 8 in 10 are caring for relative/friend age 50+
- Predominantly female (2 in 3)
- Typically wife or adult daughter
- 46% perform medical/nursing tasks and help with tasks of daily living
- 61% working at paid jobs
  - About 3 out of 4 have worked while caregiving
Valuing the Invaluable

• About 42.1 million family caregivers in the U.S. provide an estimated 40 billion hours of care to an adult with limitations in daily activities at any given point in time.

• The estimated economic value of their unpaid contributions was about $450 billion in 2009 – from an estimated $375 billion in 2007.

Family Caregiving in the “Old Days”
Family Caregiving – “The New Normal”
What’s Different About Caregiving Now Than in the Past?

• Longer duration of caregiving
• Greater complexity of family caregiving role
  – Both “care coordinators” and “service providers”
    • Navigating the fragmented health care and long-term services and supports (LTSS) systems
    • Providing complex chronic care
      – Many carry out ADLs and IADLs and do medical/nursing tasks in the home
• More women in the workplace
  – Nearly half today, up from 33% in 1960
What’s Different About Caregiving Now Than in the Past?

• Changing composition of families and households
  - More long-distance caregiving
  - Increasing diversity
  - Delayed marriage and childbirth
  - High rates of divorce
    • Divorce rates of 50+ pop. doubled between 1990 and 2010
  - Fewer adult children (smaller families)
    • The % of frail elders (age 85+) without any surviving children is projected to increase from 16% in 2000 to about 21% in 2040
  - Increasing numbers of childless women
    • Nearly 20% of women are childless today; 10% in 1970
Costs of Caregiving: Families At Risk

- Family caregiving comes at substantial costs to the caregivers themselves

- A vulnerable and at-risk population that the health care and LTSS systems neglect
  - Physical health risks
  - Emotional strain/mental health problems (depression)
  - Social isolation
  - Financial burdens
  - Workplace issues
  - Retirement Insecurity

- Caring for persons with chronic conditions or disabilities is now viewed as a public health concern
Policy Context

• Serious illness or disability affects the family as well as the person

• Most people with serious, chronic illness cannot manage their care on their own—they rely on their family (broadly defined)

• Yet, family caregivers are the “invisible workforce” in health care and in long-term services and supports (LTSS)
  - Lack of recognition
  - Lack of respect for the work that family caregivers do
  - Focus on the “beneficiary” in payment and service delivery, rather than addressing the concept of person- and family-centered care
The Paradox

- Policy direction toward more home and community services and away from nursing home care
  - What most Americans value and want
  - Depends greatly on family caregivers
Current Federal Policies that Recognize and Support Family Caregivers

- **Medicare’s Hospice Benefit** *(made permanent by Congress in 1986)*
  - Addresses the patient’s and the family’s needs
  - “Unit of care” is the family, not just the patient

- **Family and Medical Leave Act** *(1993)*
  - Guarantees up to 12 weeks of job-protected *unpaid* leave for worker’s own health needs or for certain family care (child, spouse, parent)

- **Older Americans Act, National Family Caregiver Support Program** *(2000)*
  - Caregiver as client – culture change in the aging network
  - Provides caregiver support services (e.g., family counseling, support groups, training, respite care)
  - Funding level: $155 million
Current Federal Policies that Recognize and Support Family Caregivers

• **Lifespan Respite Act** (2006)
  - Expands and enhances respite services in the states
  - Funding level: $2.5 million

• **Patient Protection and Affordable Care Act (ACA)** (2010)
  - Law mentions the term “caregiver” 46 times and “family caregiver” 11 times.
  - Promotes new models of care to improve care transitions, coordinate care, and test concurrent care for Medicare beneficiaries
    • Opportunities exist, but little attention, to date, to family caregiver needs specifically
New Policy Initiatives

1. Conduct an IOM study on family caregiving

2. Assure that federal health care and long-term services and supports (LTSS) programs implement *person-and family-centered* assessment and support protocols as a condition of receiving federal/state funds
   - Patient-Centered Medical Homes, Community Care Transitions Programs, Medicaid HCBS waiver programs, Center for Medicare & Medicaid Innovation (CMMI) demos

3. Modify reimbursement policy in Medicare and Medicaid so that provider identification, assessment and communication with family caregivers is rewarded
   - Identify family caregivers in electronic health records
   - Encourage primary care providers and other health care professionals to routinely identify Medicare beneficiaries as part of Medicare’s annual wellness visit
New Policy Initiatives

4. Increase and preserve funding for the National Family Caregiver Support Program

5. Incorporate end-of-life and support for families in care transitions policy and practice as an essential element in quality of care

6. Increase the reach of the Family and Medical Leave Act (FMLA)
   - Expand the relationships covered by the law to include domestic partners, parents-in-law, grandparents, and siblings
   - Require employers to protect workers in businesses with fewer than 50 employees
   - Cover bereavement leave
     • Employees shouldn’t be afraid of losing their jobs when they are dealing with a death in the family
New Policy Initiatives

7. Adopt policies at the state level that exceed the current federal eligibility requirements for the FMLA
   - Current state laws do not address bereavement, although many businesses do have a bereavement leave policy

8. Promote access to paid leave
   - CA and NJ lead the way

9. Adopt policies at the state and local levels to prohibit discrimination of workers with caregiving responsibilities, including requirements to provide reasonable accommodations for working caregivers
   - Employment discrimination due to family caregiving responsibilities is a growing issue and a particular challenge to mid-life and older workers
“What we need... is for our nameless problem to be plucked out of the realm of the personal and brought into full public view, where help can find us.”

Questions?

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