

# **Entering the World of Caregivers: Reducing Complexities**

Susan C. Reinhard, RN, PhD  
Senior Vice President,  
AARP Public Policy Institute

**5<sup>th</sup> International Carers Conference  
July 2010**

# Overview

- Caregiving in the United States
- An Intricate Web
  - Family Caregivers: The Backbone of the Long-Term Services and Supports System
  - Recognition and Support from Health Care Professionals
  - Direct and Indirect Costs to Employers

# Overview cont...

- The Delivery of Services and Supports in the U.S.
  - Transitional Care
  - Federal Programs
  - Employer Best Practices
- AARP's Role in Supporting Caregivers
  - Grant Initiatives
  - Other Resources

# Family Caregivers: The Backbone of the Long Term Services and Supports System

©Cartoonbank.com



*"Seventy-seven. How about yours?"*

# Family Caregivers: The Backbone of the Long Term Services and Supports System

- Help with essential daily activities
  - 58% of Caregivers provide assistance with Activities of Daily Living (ADLs)\*
- Managing difficult medication schedules and using sophisticated technology in the home
  - Oxygen equipment, catheters, intravenous medications
- Serve as translators, navigators, care coordinators, advocates, and more
- Economic value of caregiving estimated at **\$375 Billion\*\***

\*Source: Caregiving in the U.S. 2009 – A National Survey: National Alliance for Caregiving in collaboration with AARP funded by the MetLife Foundation; November 2009

\*\*Source: Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update

# Caregiving in the U.S.

- In 2009, an estimated 43.5 million caregivers age 18 and over provided unpaid care to an adult family member or friend who is age 50 years or older.
- The "typical" U.S. caregiver is a 48-year-old woman who works outside the home and spends more than 20 hours per week providing unpaid care to her mother for an average of 4.6 years.
  - 34% care for two or more people
  - 86% provide care for a relative



# Caregiving in the U.S.

- 78% of caregivers feel they need more help or information about caregiving topics
- The need for information increased with the age of the recipient and the level
- Top Sources of information –
  - 36% - health provider
  - 25% - internet (related to household income)
  - 20% - family, friends, other caregivers
  - 12% - aging or disease-specific organizations

# Caregiving in the U.S.

- Most caregivers are employed.
  - Among caregivers age 50-64, an estimated 60% are working full or part-time.
- Nearly 27% say they need help balancing work and family responsibilities or finding time for themselves.

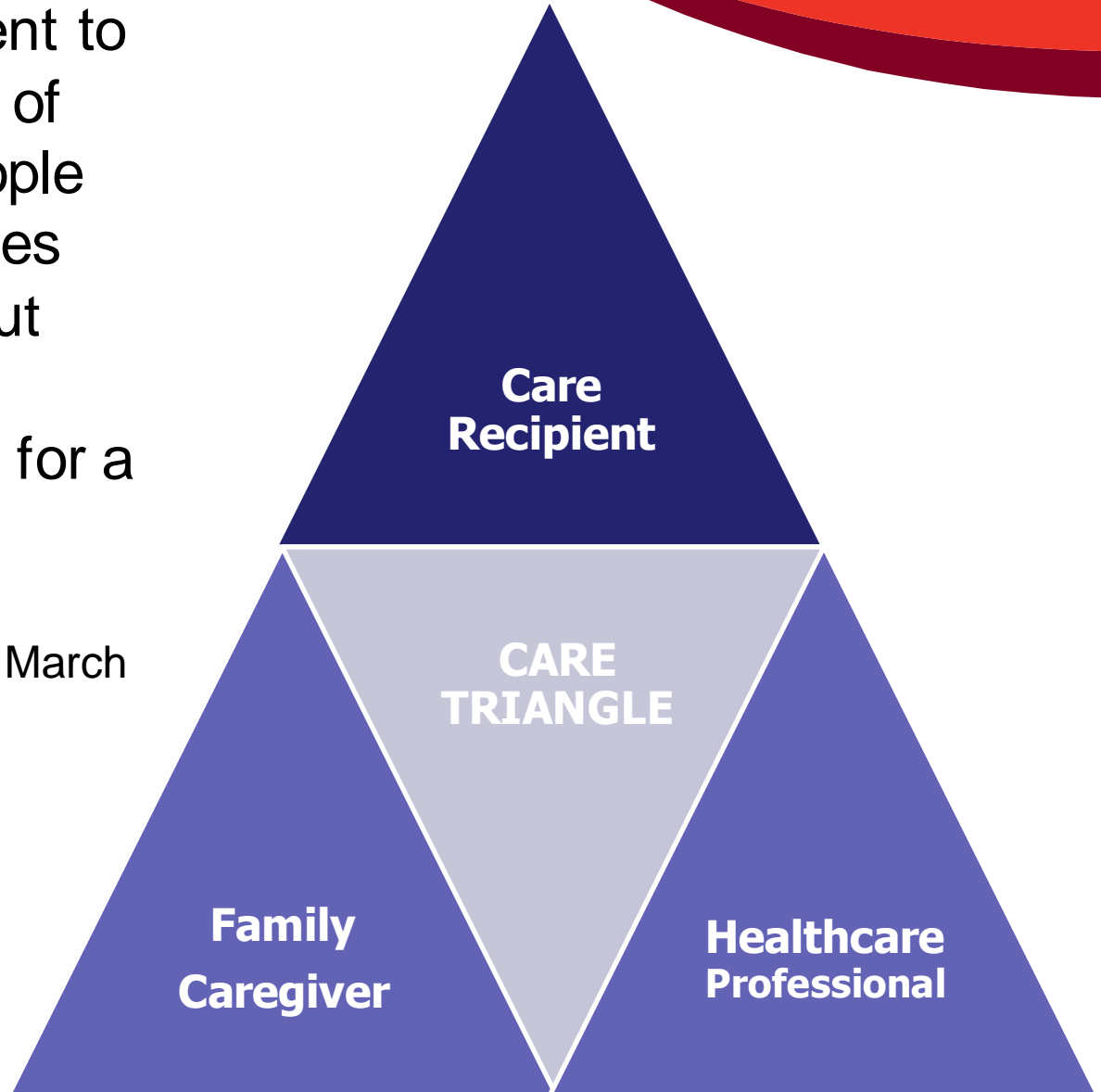


Source: Caregiving in the U.S. 2009 – A National Survey: National Alliance for Caregiving in collaboration with AARP funded by the MetLife Foundation; November 2009



“It will take a movement to join the three corners of the care triangle: people who need care, families who care for and about their members, and people who give care for a living.”

Deborah Stone, *The Nation*, March 13, 2008



# Caregivers Need More Recognition and Support from Healthcare Professionals

- Better communication
  - Interpretation of “privacy law” is a barrier
    - Health Insurance Portability and Accountability Act (HIPAA)
- More preparation for transitions across settings
- Assessment of the caregivers’ needs
  - Rarely are family caregivers asked “How are *you* doing? How are *you* managing?”
- Recognition as “team member”
  - Intimate knowledge of care recipient
  - Acquired care skills
  - Desire to be partners

# Example of Poor Communication

“Nobody told us anything. All they said to us was, “do you have all your things? Do you need another pair of socks?” We had our things and we didn't need socks, we needed information. And the person did not have the time to give it to us. ”

-----Jackie, cares for her 85 year-old husband Phillip

# Caregivers Report Problems with Transitions

Most frequent issues around transitions between hospitals (and other health care facilities) and home were:

- Finding resources, such as medical equipment and services
- Arranging for assistance in and around the home, both paid and unpaid
- Communication with doctors and other health professionals
- Finances/affordability

# Caregivers Report Problems with Transitions, cont...

- Uncertain expectations for their relative's or friend's recovery and/or prognosis
- Managing their relative's or friend's expectation
- Not enough time for competing demands (e.g., care coordination, job, children, self)
- Stress/emotional strain/guilt

# Health Effects on Caregivers and Related Costs

- Caregivers report having one or more chronic conditions at nearly twice the rate of non-caregivers (45% vs. 24%).
- The greater the burden of caregiving, the more likely caregivers are to report fair or poor health status.
- Health costs are higher for caregivers: caregivers are 50% more likely than non-caregivers to have medical bill problems or debt, and out-of-pocket health costs are higher for people who have a relative with a disability.

# The Burden on Employed Caregivers is Costly to Business



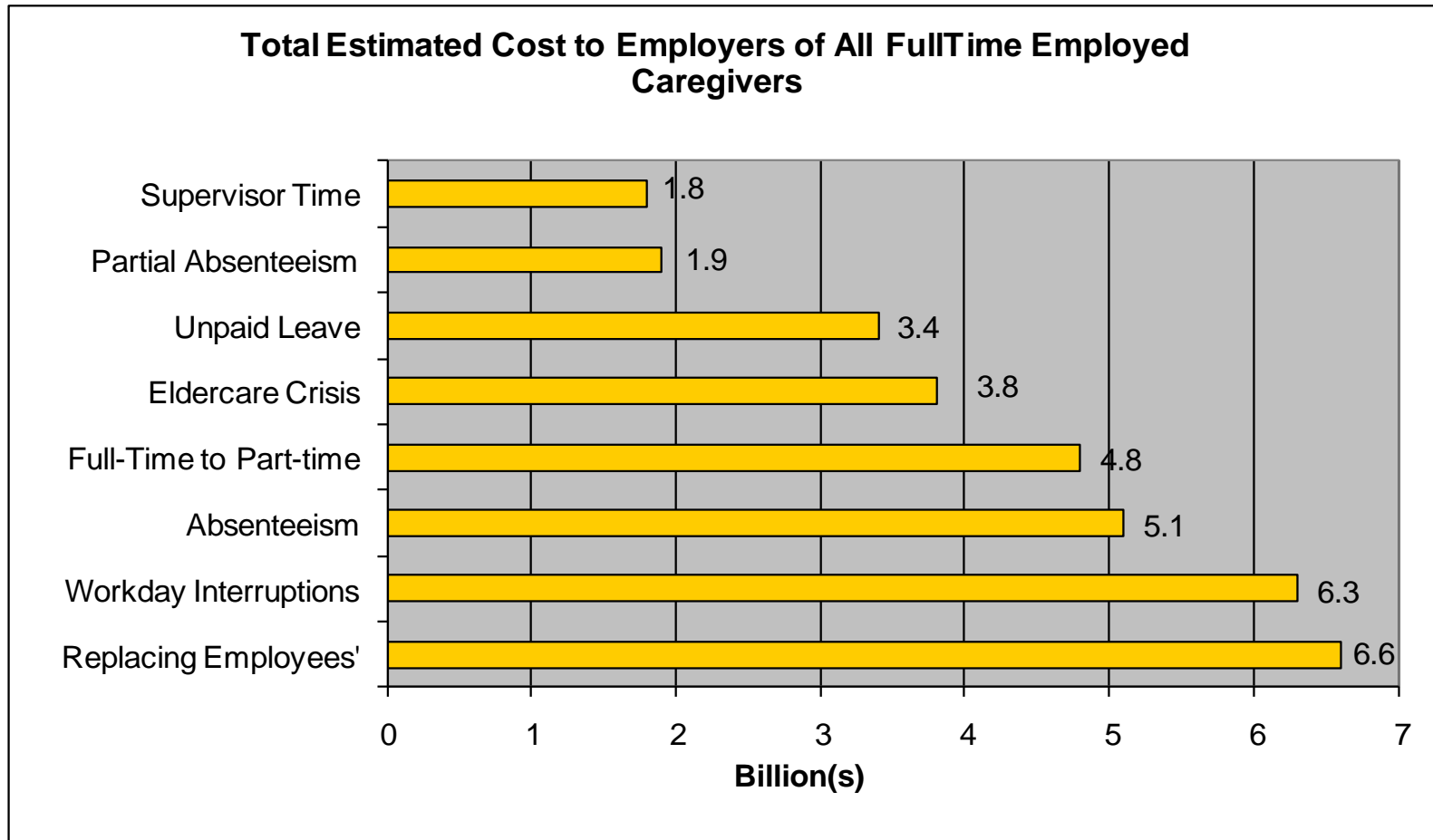
- Lower productivity— “Presenteeism”
- Lost time from work
- Lost career opportunities, lower future earnings, and retirement income

# The Burden on Employed Caregivers is Costly to Business

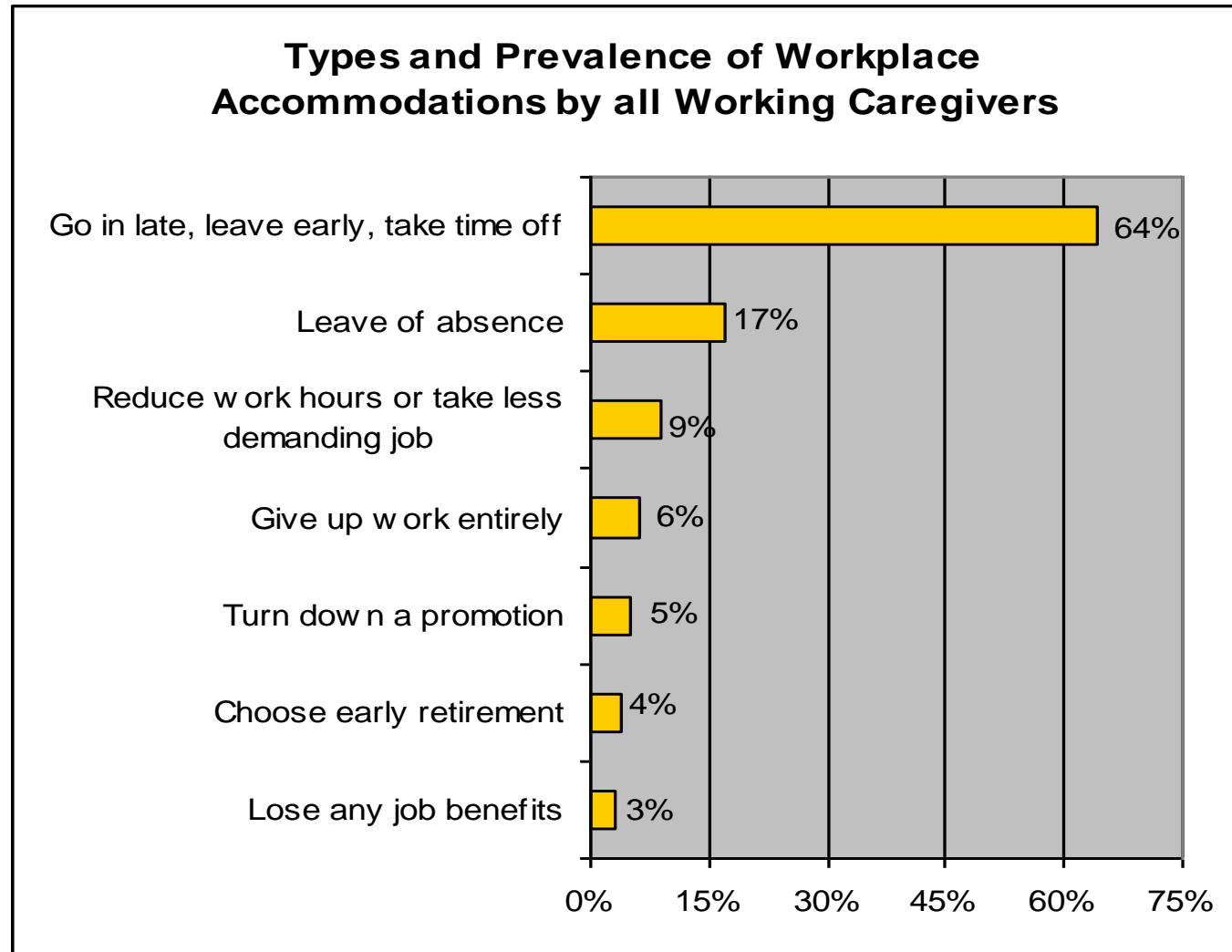
- 10% to 31% of working caregivers leave their jobs as a result of caregiving responsibilities.
- Productivity losses to U.S. businesses for full time employees who are caregivers= **\$33.6 billion**.
- Average cost per caregiver employee= **\$2,110**.



# The Bottom Line



# Workplace Accommodations Due to Caregiving



Source: National Alliance for Caregiving/AARP (November 2009). Caregiving in the U.S.: Findings from a National Survey

# Examples of Transitional Care Models

Care Transitions Intervention – Eric Coleman, funded by the The John A. Hartford Foundation and based at the University of Colorado.

Provides individuals and their caregivers with tools and support to encourage them to participate more actively in their care transitions.

# Examples of Transitional Care Models

## Transitional Care Model (TCM)

- Targets older adults with two or more risk factors, such as poor self-health ratings, multiple chronic conditions, or a history of recent hospitalizations.
- Central to the model is the master's-prepared advanced practice transitional care nurse, well versed in national standards of care delivery and experienced in providing comprehensive care and acute and community-based services. (Naylor, 2006)

# Federal Programs – U.S. Administration on Aging

- The National Family Caregiver Support Program (NFCSP)
  - Offers five types of services:
    - information to caregivers about available services,
    - assistance to caregivers in gaining access to the services,
    - individual counseling, organization of support groups, and caregiver training,
    - respite care
    - supplemental services, on a limited basis
- Aging and Disability Resource Centers (ADRCs)

# Providing Support to Caregiving Employees – Benefits

- Dependent life insurance
- Long-term care insurance covering spouse and parents/parents-in-law
- Flexible spending accounts/dependent care accounts
- Cash subsidies for services for older relatives
- Access to Employee Assistance Programs (EAP's) for counseling and support

# Providing Support to Caregiving Employees – Policies

- Paid sick leave that can be used to care for relatives or friends who are ill
- Paid family leave that can be used to care for ill relatives or friends
- Flexible work arrangements (flextime, part-time hours, compressed work weeks, job-sharing)
- Employee leave-sharing - employees can donate a portion of their leave time to others who have eldercare responsibilities

# Providing Support to Caregiving Employees – Policies

- Companies with 50 or more employees must comply with the *Family and Medical Leave Act* (FMLA), which allows for up to 12 weeks of unpaid leave to care for a seriously ill parent, spouse or child, while protecting job security.
  - Smaller firms can use the FMLA guidelines to provide support for individual employees.
- Sabbatical Leave



# AARP Caregiving Initiatives

- Professional Partners Supporting Family Caregivers – Phase II
  - Funded by The John A. Hartford Foundation
  - In partnership with the U.S. Administration on Aging, Family Caregiver Alliance, National Association of Social Workers (NASW)
- Objectives
  - Establish standards of practice for social workers working with family caregivers
  - Seek to improve public policies related to support of family caregivers
  - Raise consumer expectations for caregiver support
  - Develop a caregiver assessment aimed at increasing caregiver skills
  - Develop a caregiver intervention that will train nurses and social workers to provide tailored information and referrals to caregivers.

# AARP Caregiving Initiatives

- Professional Partners Supporting Family Caregivers In Diverse Settings
  - Funded by The Jacob & Valeria Langeloth Foundation
  - In partnership with the New York University/Hartford Institute for Geriatric Nursing's *Nurses Improving Care for Healthsystem Elders (NICHE)* program and the American Journal of Nursing.
- Objectives
  - Produce a qualitative research report highlighting the unique experiences of nurses, social workers and family caregivers in diverse communities.
  - Develop culturally relevant educational materials to help nurses and social workers adopt best practices in partnering with family caregivers in diverse communities
  - Develop a web-based family caregiving toolkit for healthcare professionals (specifically nurses)

# Resources

AARP Resources

[www.aarp.org/research/ppi](http://www.aarp.org/research/ppi)

[www.aarpinternational.org](http://www.aarpinternational.org)

[www.aarp.org/caregiving](http://www.aarp.org/caregiving)

U.S. Administration on Aging

[www.aoa.gov](http://www.aoa.gov)

Family Caregiver Alliance

[www.caregiver.org](http://www.caregiver.org)

# Questions?

Susan C. Reinhard  
[sreinhard@aarpp.org](mailto:sreinhard@aarpp.org)  
202-434-3840