Family Caregiving: Public & Private Sector Policies and Action

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Today’s Session

- Aging demographic
- Role of family caregivers
- Unaddressed needs & gaps
- Foundation-support activities
- Role of the Institute of Medicine (IOM)
New Strategies/Funding Areas:

- Models of Care
- Linking Education & Practice
- Tools & Measures for Quality
- Policy & Communications
- Leadership in Action
The Aging Demographic

- Happy birthday, Boomers
- Doubling of older adults
- Demographic skewing older
- Implications
Need for Family Caregivers

- Backbone of health care (IOM)¹
- 42 million caregivers
- Contributions exceed $450 billion/yr ²
- What happens when unsupported?

¹ Retooling for an Aging America, IOM
² Valuing the Invaluable, AARP
The 2030 Problem

• Caregiver support ratio—# of potential caregivers aged 45-64 to persons aged 80+
  – Caregiver Ratio today is 7:1
  – Drops to 4:1 by 2030
  – Becomes untenable by 2050 <3:1
What is it Caregivers Do?

- Hartford Foundation funded AARP/UHF report, *Home Alone: Family Caregivers Providing Complex Chronic Care*
- 46% providing “skilled care”
- 78% managing medications
Toll on Caregivers

• Negative effects on:
  – Financial situation & retirement security
  – Physical and emotional health
  – Social networks
  – Careers

• Greatest impact on caregivers of those w/ complex health, functional & cognitive impairments.
Hartford Foundation & Family Caregiving

- Review of evidence on family caregiving
- Led by AARP in partnership with:
  - Family Caregiver Alliance
  - Council of Social Work Education
  - American Journal of Nursing
- Funding partner: The Langeloth Foundation
Hartford Foundation & Family Caregiving

- Professional Partners Supporting Family Caregivers, Phase II (2010) -- AARP Fdn
- Partnerships w/ AoA/ACL, NASW, FCA
  1. Prototype Caregiver Support
  2. Social Work Practice Standards
  3. Increase Consumer Demand
  4. Inform Policymakers
NASW Standards: Social Work Practice w/ Family Caregivers of Older Adults

• Enhance social work practice
• Educate the public
• Advocate for family caregivers
• Free download: www.socialworkers.org/practice
Categories for Funders

- Direct Services
- Caregiver Education
- Innovations, Resources, & Tool
- Policy & Communications
- Health Reform Implementation
- Evaluation & Measures
- Technology
About TSF

• Mission/Vision

• How We Fund
  – Communications
  – Policy
  – Promising Programs
TSF & Family Caregiving

• “10 Things” series

• CHIS analysis of California’s caregivers

• Caregiver advocacy engagement
Your Turn…

- Using the index cards on your table, please share your Foundation’s work in the area of Family Caregiving.
- Remember to list your Foundation’s name on the card(s).
- Place the card(s) on the Boards.
Categories for Funders

• Direct Services
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Proposed IOM Study on Family Caregiving

• Full consensus committee study
• Focus on caregiving for older adults
• Committee of ~ 16 experts
• 22-month project: 18 months from start to release of pre-publication draft
• Product: analysis and recommendations of public and private sector policies and actions to support family caregiving
Current Status of Family Caregiving for Older Adults

Wide public awareness due to:

- Extensive survey data
- Reports on various aspects of family caregiving
- Communication initiatives
- Media attention
- Personal experiences & shared stories
Current Status of Family Caregiving for Older Adults cont.

Positive attitudes and statements:

• Gratitude for the help family caregivers provide

• Recognition of their value –
  “They are “irreplaceable”

• Concern about the difficulty of family caregiving and its negative impact on caregivers
Current Status of Family Caregiving for Older Adults cont.

Many different stakeholder groups & perspectives:

- What are the most important problems?
- What could/should be done?
- Who could/should do it?
Current Status of Family Caregiving for Older Adults cont.

• Lack of sufficient help for family caregivers

• Lack of societal consensus about fundamental issues -- roles and responsibilities

• Looming demographics: The ratio of potential caregivers to older adults who need caregiver help is better now than it will be for the next 40 years.
In Health Care

• Family caregivers
  – Say they feel invisible in health care settings
  – Lack training and support to provide the complex medical procedures they are now expected to provide at home

• Public programs, e.g., Medicare
  – are mandated to pay for the beneficiary - not the caregiver

• Health care providers
  – lack training to work effectively with family caregivers
  – Face difficult situations involving family caregiver decisions about the care recipient’s health care
In Long-Term Care / HCBS

• Family Caregivers
  – Lack information, training, and support for personal care tasks and ongoing medication management
  – Lack back-up for emergencies

• Public programs, e.g., Medicaid
  – are mandated to pay for the beneficiary - not the caregiver
  – often reduce payment/services if there is a family caregiver

• LTC / HCBS providers
  – may lack training to work effectively with family caregivers
Health Care and LTC / HCBS

- Family Caregivers
  - carry most of the responsibility in care transitions
  - lack help in navigating complex care systems

- New publicly funded models of integrated care
  - focus on coordinating medical and non-medical providers
  - lack explicit attention to family caregivers

- Electronic medical record software lacks even a space for family caregiver information
Health Care and LTC / HCBS cont.

• What should we do about family caregiver assessment?

• What should we do about family caregiver neglect or abuse?

• What should we do about family caregivers who don’t self-identify?
Family Caregiving and Employment

- Family caregivers
  - May reduce hours, come in late, leave early, conduct caregiving-related tasks at work, or quit entirely
  - Will lose income, health benefits, and retirement income

- Employers
  - Experience reduced worker productivity and incur replacement costs
  - Some employers have developed programs to assist their caregiver employees; these programs are frequently not used, and some employers have stopped providing them
Family Caregiving and Technology

Technology developers and marketers say:

- Technologies that could help family caregivers aren’t being used
- Or they are used too late, after the caregiver has reached a crisis point
- People don’t know how to find available technologies
- Access through the marketplace (e.g., Walmart and Brookstone) vs. health care/long-term care sources would reduce stigma and acceptability
Lack of Societal Consensus

We lack agreement about roles and responsibilities in family caregiving

- What are the roles and responsibilities of families, government, employers, technology developers and marketers, professional and paraprofessional associations, advocacy organizations, foundations, and others?

- Should there be any limit on what families are expected to do?

- Whose job is it to address questions and problems in family caregiving?
Family Caregiving Crosses Foundation Interest Areas

- Aging
- Assistive technologies
- Community
- Diversity
- Economic security
- Health care
- HIT
- Independence
- Intergenerational issues
- Home and community-based services
- Neglect / abuse
- Public health
- Quality measurement
- Social justice
- Safety
- Training and education
- Workforce
Your Turn…

• Using the index cards on your table, please share your ideas about
  – the most important issue(s) in family caregiving
  – high priority issues for an IOM study

• Remember to list your Foundation’s name on the card(s).

• Place the card(s) on the Boards.