



Family Caregiving in the 21st Century: Policies for a Crumbling Infrastructure

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Why family caregivers matter

- **Family caregivers provide most of the care to elderly, disabled, and chronically ill individuals**
- **They provide care over years...and years...and years**
- **They are (largely) unpaid**
- **If paid at a modest rate, their labor would add an additional \$350 billion to the health care system's costs (AARP estimate)**



What's new about family caregiving

- **Greater policy emphasis on home and community-based care, which largely means family care**
- **More and older patients being treated at home with ongoing complex care needs**
- **More medical and managerial tasks assumed by family caregiver**
- **Fewer available family members**



What do family caregivers do?

Family caregivers as “disenfranchised care contractors”

Responsible for all or most of the following:

- Medication management, including pain medications**
- Symptom control**
- Operation of medical equipment**
- Record keeping**
- Personal care**



What do family caregivers do?

- ❑ **Financial and legal management**
- ❑ **Coordination of services**
- ❑ **Nutrition**
- ❑ **Mobility**
- ❑ **Communication with health care professionals**
- ❑ **Household management**
- ❑ **Not to mention jobs, children, other responsibilities....**



What makes family caregivers vulnerable?

- **Long-term caregivers at risk for physical and mental health problems, including:**
 - **Immune system deficiencies**
 - **Joint and muscle problems**
 - **GI problems**
 - **Sleep deprivation**
 - **Depression**
 - **Anxiety**
 - **Isolation**
 - **Death**



Caregiving Stress and Nursing Home Placement

- **Caregiver physical strain and financial hardship, as well as care recipient behavior, are important predictors of caregiver stress.**
- **Reducing stress would avoid or defer nursing home entry and is needed to underpin current efforts to return nursing home residents to community-based care.**
- **Source: HHS, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy, January 2007**



Family Caregiving and Public Policy: Odd Bed(side) Fellows

- **Recent initiatives and advocacy (Family Caregiver Support Program, Lifespan Respite, and several others)**
- **Though important, they cannot change the basic fragmented system in which:**

Policies are based on individual beneficiary, not family unit (with the exception of hospice)

Benefit of investment by one sector (e.g., hospitals) goes to another (e.g., home care); where's the incentive?



Family Caregiving and Public Policy: Odd Bed(side) Fellows

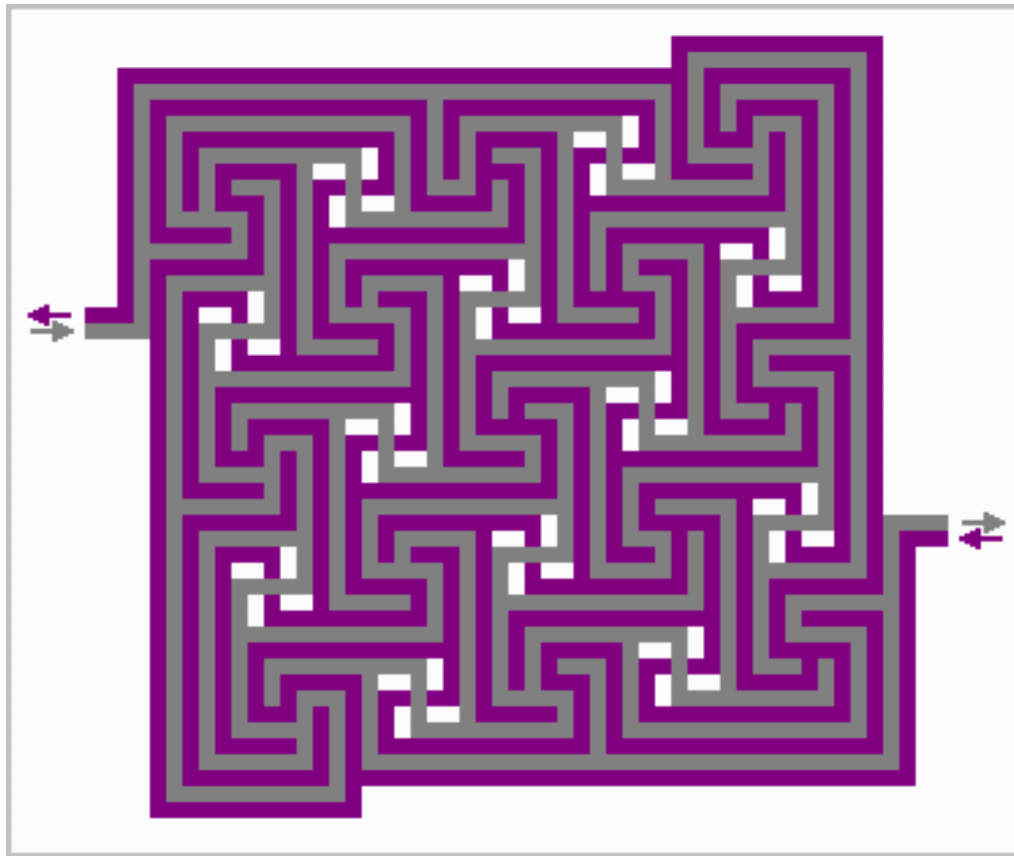
- ❑ **Policy world almost totally ignores middle-class family caregivers—i.e., most Americans**
- ❑ **Artificial separation of aging services and health care**
- ❑ **Different cultures: Policy world deals with systems and regulations; family caregiving is based on intimacy and intangibles**
- ❑ **Policy world is often incomprehensible to outsiders**



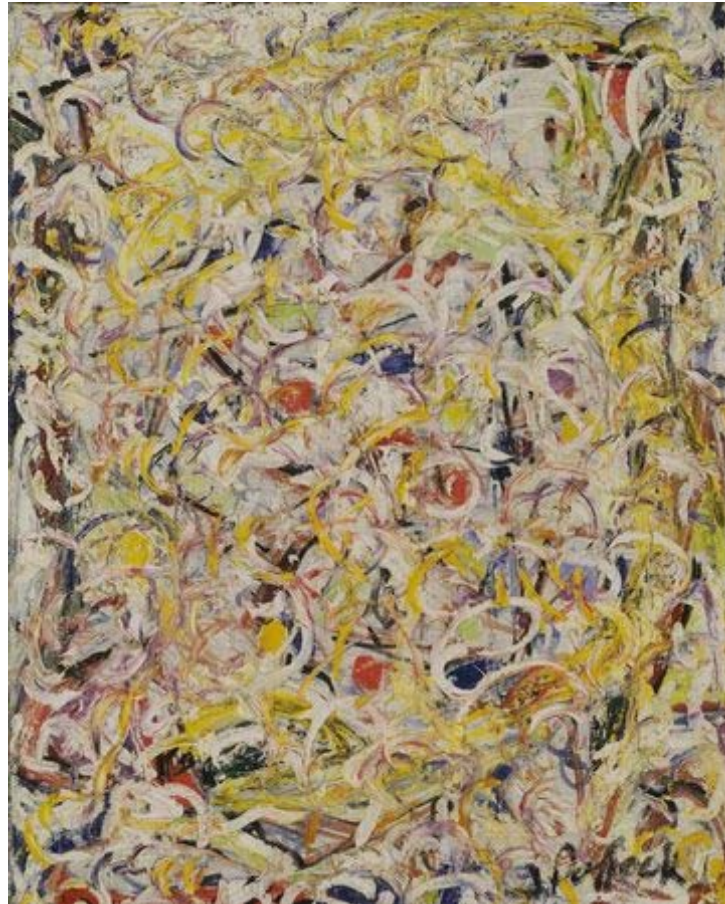
Examples of Insider Terminology

- ❑ **Informal caregiving**
- ❑ **Medical home**
- ❑ **Medication reconciliation**
- ❑ **Hospitalist, proceduralist, surgicalist**
- ❑ **Handoffs**
- ❑ **Skilled and unskilled care**
- ❑ **Medically necessary**
- ❑ **Custodial care**
- ❑ **Respite services**

A journey through the health care system – as I saw it in 1990



A journey through the health care system –as I see it today



Jackson
Pollock,
"Shimmering
Substance,"
MOMA



A Place to Begin: Transitions in Care Settings

- Move from one care setting to another has serious potential for error and miscommunication with cost implications**
- Family caregiver essential source of information about patient and responsible for follow-up care**
- Yet family caregivers seen as “nuisances”**
- UHF review of 200 articles on transition care found only 2 or 3 references to involving family caregivers**



Caregiving Transitions and Culture Shock

- Each transition confronts the patient and caregiver with a new culture, defined broadly as set of assumptions, rules, expectations, and worldviews.
- Each profession and setting has its own culture, which often confuses family caregivers.
- In each setting, family roles are different and are seldom explained as caregivers move from one setting to another.
- See Carol Levine and Thomas H. Murray, *The Cultures of Caregiving: Conflict and Common Ground among Families, Health Professionals, and Policy Makers* (Johns Hopkins University Press, 2004).



United Hospital Fund “Campaign for Family Caregivers”

- Campaign focuses on transitions**
- Addresses admissions and discharges in hospitals, nursing homes, and Certified Home Care Agencies**
- Three elements:**
 - 1. Awareness**
 - 2. Commitment**
 - 3. Taking action**



Health Care Provider Tools

- **Responding to issues identified in self-assessment surveys (providers and caregivers)**
- **Examples:**
- **HIPAA statement (in plain language)**
- **Caregiver needs assessment**
- **Performance improvement plan**
- **Medication reconciliation**



Family Caregiver Navigation Tools

Help family caregivers be better prepared to support patients through transitions and beyond

□ Examples

□ Navigating the ER

□ HIPAA privacy rules

□ Understanding home care

□ Medication management/reconciliation



Timetable for “Campaign for Family Caregivers”

- Health care leaders/caregiver engaged in refining tools and signing on to Campaign –Fall 2007**
- Launch planned for early 2008**
- Surveys and tools will be widely disseminated through a cutting-edge website and other means**

Website: www.uhfnyc.org