

The 17th Princeton Conference

**Examining End of Life Care: Creating Sensible Public Policies for Patients,
Providers, Providers, and Payers**

Session VII - Next Steps in Creating End of Life Policies May 20, 2010

**We Can't Fix the End of Life
by Merely Fixing Health Care**



Ira R. Byock, MD

Director of Palliative Medicine

Dartmouth-Hitchcock Medical Center

Dennis 83 yo man



- **Stable: CHF & ESRD on dialysis (3x/wk)**
 - **Admitted: Fall with facial laceration**
 - **Hypotension, severe dyspnea on exertion**
 - **New Dx: critical aortic stenosis**
 - **Lives alone**
 - **Church when has transportation, senior center, barber**
 - **Has Life Alert pendant**
 - **Needs med mgmt, Meals on Wheels, housekeeping**
-

**If all we do is improve medical treatment for dying
people...**



**...the best we will achieve is a better medical
experience of dying.**



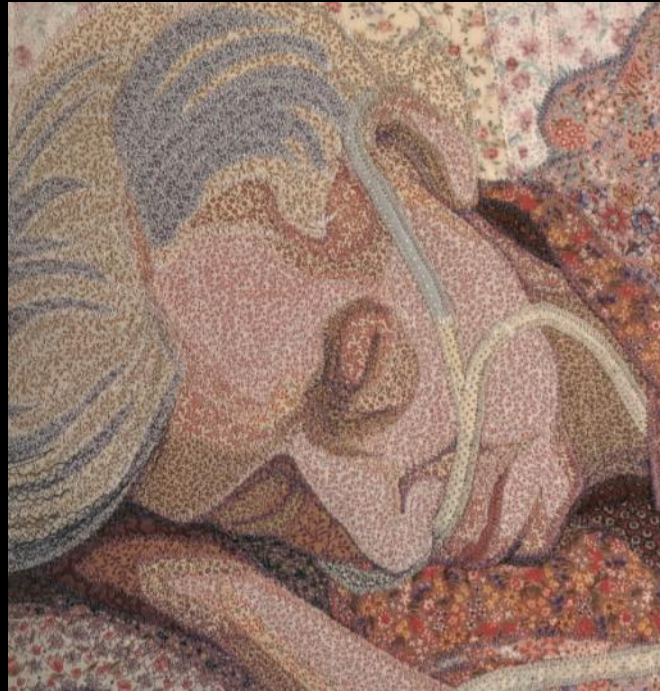
Patient-centered or Person-centered?



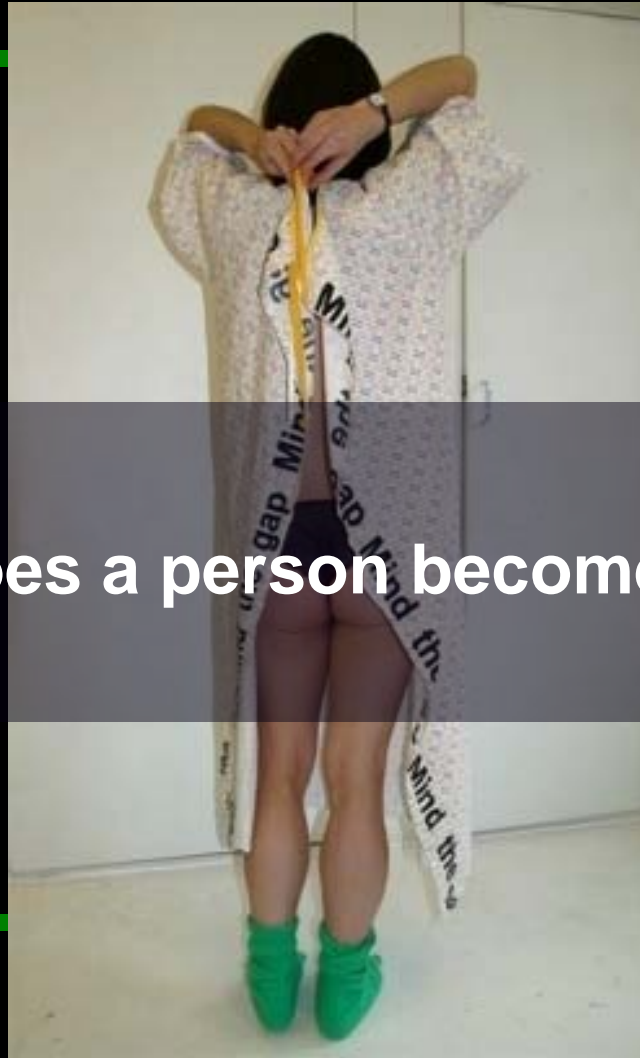
Dr. Mahlon Hoagland
Trina Schart Hyman, circa 1989-90

Etymology of Patient *(from Latin)*

One who suffers



When does a person become a patient?



Improving the End of Life

Dying is personal



Improving the End of Life

It Takes a Family



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An individual receives a diagnosis...



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...a family gets the illness.



Definition of Family



“For whom it matters...”

Caregiving in U.S. – NAC & AARP

53.4 million caregivers in the United States – more than one in five adults – provide unpaid care to people with disabilities and chronic illness.

National Alliance for Caregiving and AARP 2004

www.caregiving.org

SUPPORT – *The Family Impact Study*

- **29% loss of most – or all – of their major source of income**
- **31% reported loss of most – or all – family savings**
- **20% a family member made a major life change**



**Covinsky KE, Goldman L, Cook EF, et al.
The Impact of Serious Illness on Patients' Families
JAMA December 21, 1994 - Vol 272, No 23. pp 1839-1844**

Caregiver Health

Family caregivers who report mental or emotional strain associated with the chronic stress of caregiving had mortality risk 63% higher than non-caregiving controls.

Schulz and Beach
The Caregiver Health Effects Study
JAMA. 1999; 282:2215-2219

What Families Value

- Ensuring the “best care possible”



What Families Value

- Ensuring the “best care possible”
- Feeling that preferences were followed



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- Honoring and celebrating the person in his/her passing



What Families Value

- Ensuring the “best care possible”
- Feeling that preferences were followed
- Knowing the person was treated in a dignified manner
- A chance to say and do the things “that matter most”
- Honoring and celebrating the person in his/her passing
- A chance to grieve together



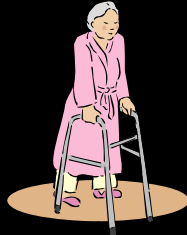
Improving the End of Life

It Takes Community

The Shrinking Pool of Caregivers

1990

11 to 1



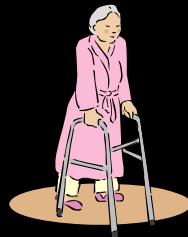
2010

10 to 1



2030

6 to 1



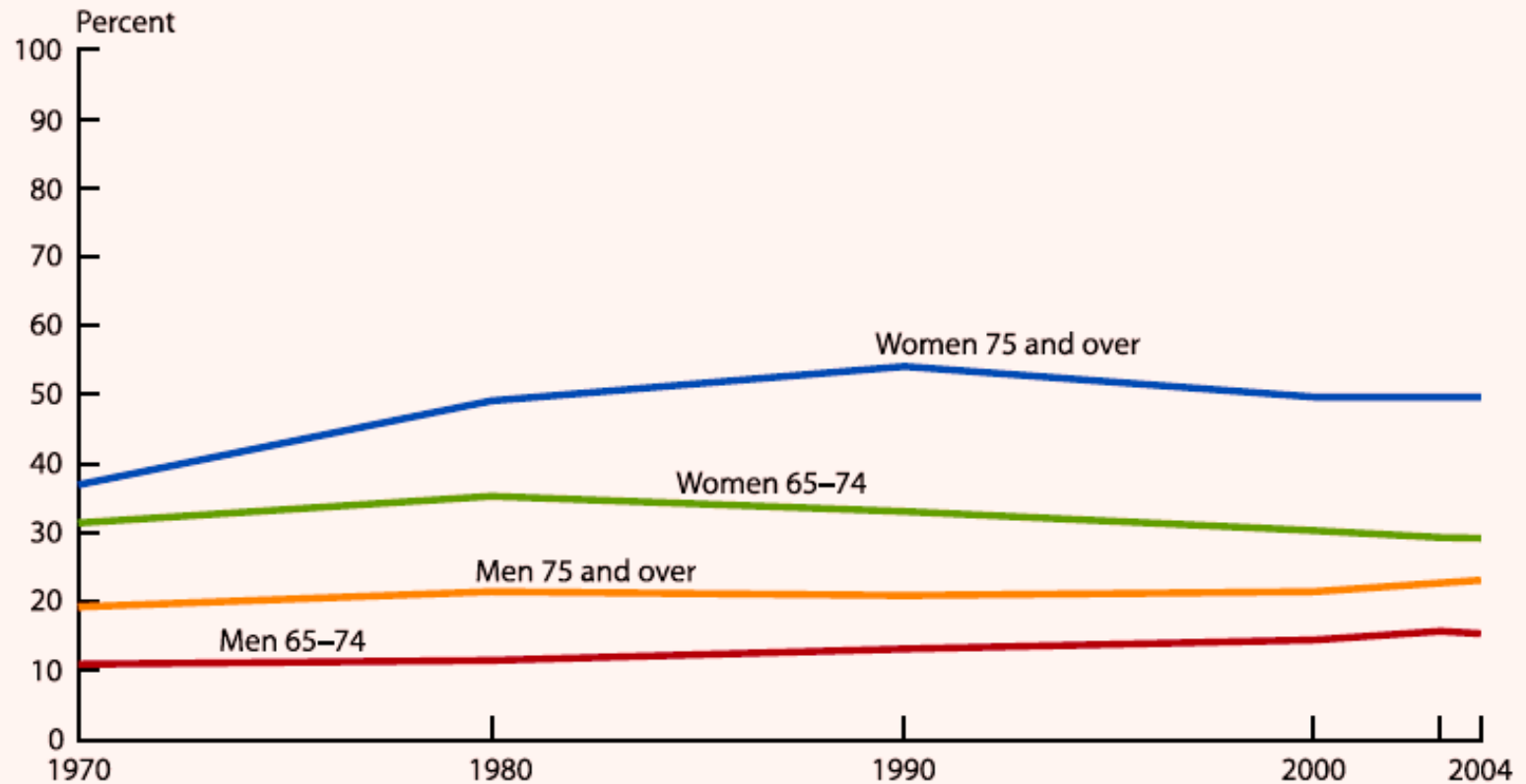
2050

4 to 1



Old Alone

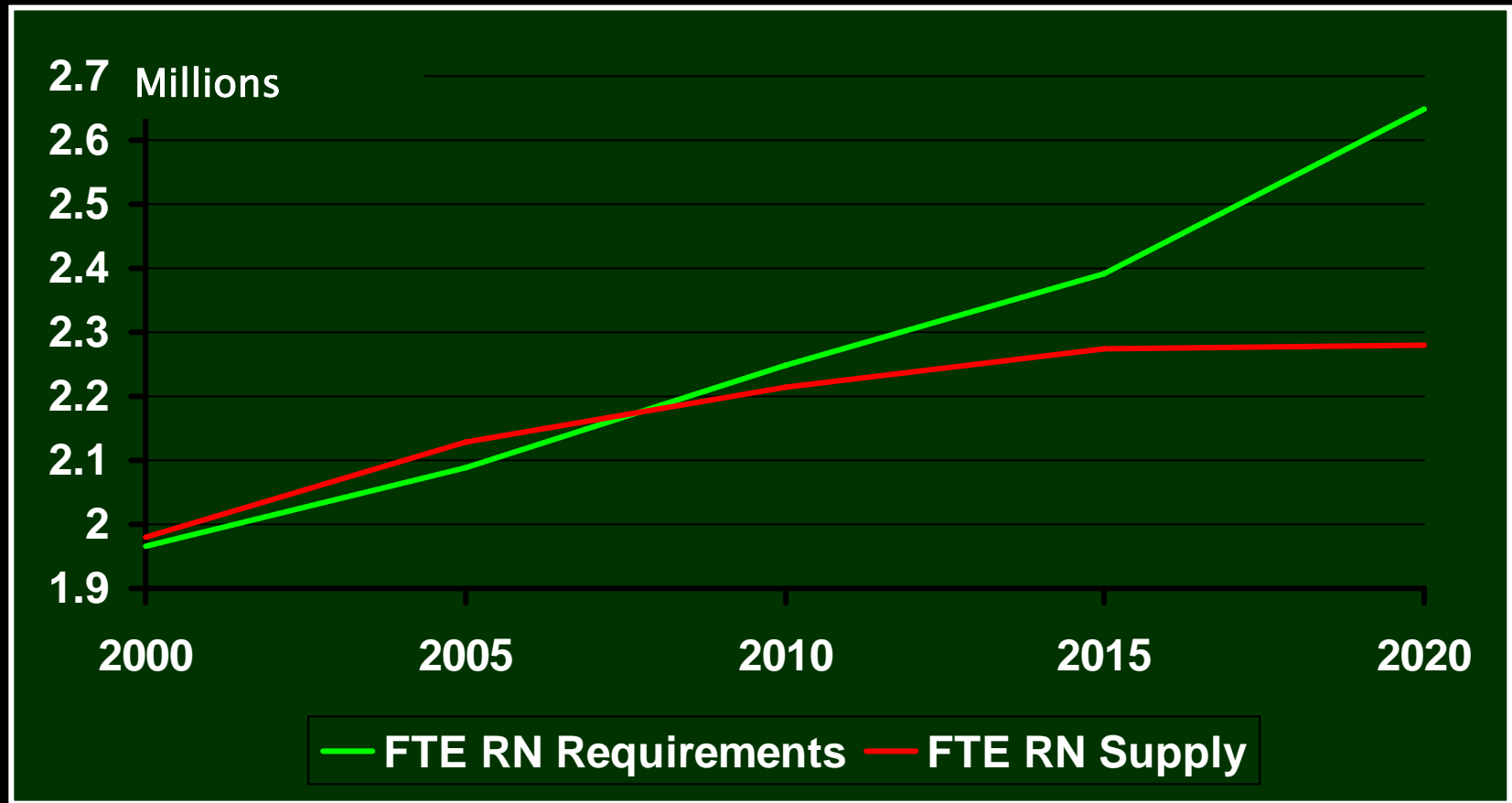
Population age 65 and over living alone, by age group and sex, selected years 1970-2004



Reference population: These data refer to the civilian noninstitutionalized population.

Source: U.S. Census Bureau, Current Population Survey, Annual Social and Economic Supplement.

The Current & Coming Crises in Nursing



Source: Projections by Division of Nursing BHP, HRSA, USDHHS, 1996

Why Community?



- **Volunteerism**
 - **Engaged local leaders**
 - **Innovative approaches**
 - **Local solutions**
 - **Community-based surveillance**
 - **Quality improvement initiatives**
-

Community



- **Congregations / Faith communities**
 - **Neighborhoods or apartment buildings**
 - **Workplaces**
 - **Schools**
 - **Non-profit agencies** (food banks, shelters)
 - **Service groups** (Lions, Kiwanis, Elks, Junior League)
 - **Youth groups** (Scouts, 4H, FFA)
 - **Social clubs**
 - **Fire and Police**
-

Caring for One Another

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Parish Nursing



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Center for Community Health Ministry

The Center for Community Health Ministry and the Parish Nurse Institute brings the elements of physical, mental, ...



Video Library

Beyond Four Walls is an introduction to Parish Nursing from the Center for Community Health Ministry at Florida Hospital.



Congregational Spotlight

There are many congregations throughout Florida that have vibrant health ministries. Some of these congregations ...



Parish Nursing @ Florida Hospital

Since 1994, Florida Hospital's Parish Nurse training programs have prepared over 500 nurses for their role as Parish Nurses ...

The Doula Program

The New York Times

New York, Sunday, January 25, 2004

In Death Watch for Stranger, Becoming a Friend to the End

By N. R. KLEINFELD

That first day, Bill Keating hoped that Lew Grossman was not a weeper. Anything else he thought he could handle, but, please, not someone who cried.

In a nursing home bed, still as stone, Mr. Grossman looked awful. A bedraggled, brittle-looking man, 77, he was able to move only his left arm. He had a large nose and protruding ears. He had sunken jowls, and all but five teeth were gone, victims of too much affection for sweets. Wispy white hair erupted from his head.

The doctors didn't imagine he had much longer. Too many things wrong.

An odd time to meet someone, when that person's life is about gone. That was the point. It was supposed to be handshakes on death's doorstep.

Lew Grossman lived at the Isabella Geriatric Center, a sprawling, well-tended nursing home on Audubon Avenue in Washington Heights. For the most part, his days were spent cloistered in his room. No friends, no visitors. His companions were the TV and his memories. The TV was always tuned to Channel 7. He was a stickler about that. "They've got good stuff on



Bill Keating, a volunteer, paid regular visits to Lew Grossman, who otherwise would have died alone.

Channel 7," was his explanation. In the next bed was a roommate who nodded and smiled but never spoke, not one word.

In May 2002, when they met, Bill Keating didn't know a thing about Lew Grossman. Mr. Keating was no social worker or minister or anything like

that. He was a retired corporate lawyer in his mid-60's, recruited into a new program that paired volunteers somewhat enlightened in the particulars of death (they were called "doulas") with terminally ill people alone with their mortality. After all, there's no rental agency for friends, for when you're

Robby Wainwright/The New York Times

The Doula Program

The New York Times

New York, Sunday, January 25, 2004



Andy Wachsmann/The New York Times

Bill Keating, a retired corporate lawyer, had doubts when he joined the Doula volunteer program, which provides companionship for the terminally ill. But he got into the spirit of it, considering it a way to express his gratitude for being prosperous, happy and healthy. He broke the ice with Lew Grossman by taking lox and cream cheese, big-band recordings and other treats to him at the geriatric center. Mr. Grossman died quietly on Jan. 2.

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Policy Matters Thinking Beyond Health Care



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- Senior Centers

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How do you stay young

- By experiencing new things
- By following the example set by my grandchildren and letting my "inner child" out
- By maintaining a positive attitude
- By maintaining an active and healthy lifestyle
- All of the above

Make Grandma's Day



Gifts for Grandparents Day don't have to be complex. In fact, of all the holidays that children participate in, Grandparents Day is one of the simplest for which to create a gift. The first ...

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Financial Planning for the Elderly



It's no surprise that with age, seniors often experience increased limitations, the loss of certain abilities and that they require more assistance with the activities of daily living. It is equally ...

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New Hampshire Agencies Related to PAS

The following is background and contact information about state agencies involved with Personal Assistance Services.

- > [Medicaid Agency](#)
- > [Mental Health Services](#)
- > [State Unit on Aging](#)
- > [Protection and Advocacy Agency](#)
- > [Home Health Agencies](#)
- > [State Personal Care Agencies](#)
- > [State Independent Living Council and Centers for Independent Living](#)

Medicaid Agency

Medicaid is health insurance that helps many people who can't afford medical care pay for some or all of their medical bills. Medicaid is paid for by Federal and State funds. There is an organization in each state government that is responsible for administering Medicaid in that state. Each state sets its own guidelines regarding who can receive services (eligibility) and what services are covered under Medicaid.



Improving the End of Life

It Will Take

Advocacy and Activism

Advocacy and Activism

National Association of Attorneys General



**Drew Edmondson
Attorney General
Oklahoma**

“Attorneys General in each state are charged with protecting constituents in matters affecting the public interest, including consumer protection of those who are dying.”

Advocacy and Activism



National Association of Attorneys General

Will my pain be managed?

Will my wishes be known and honored?

Will I receive competent care?

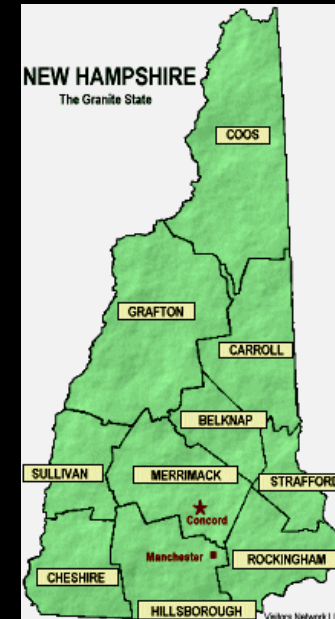


Will my family be supported?

What We Want Policymakers to know



8 Citizens Forums throughout New Hampshire



www.ReclaimTheEnd.org

What We Want Policymakers to know



www.ReclaimTheEnd.org

Key Findings



> 80% said it was very or extremely important to have:

- **Dignity respected**
- **Preferences honored**
- **Pain controlled**
- **Not leave family with debt.**

Byock IR, Corbeil YJ, Goodrich ME.
Beyond Polarization: Public Preferences Suggest Policy Opportunities
to Address Aging, Dying, and Family Caregiving.
Am J Hospice & Palliative Care 2009

Key Findings



> 80% strongly endorsed

- **Palliative care requirements for clinical licensure & reimbursement**
- **Expansion of family caregiver leave**
- **Respite care**
- **Bereavement support**

< 50% strongly endorsed

- **Being kept alive as long as possible**
 - **Being prayed with**
 - **Being prayed for**
-

Byock IR, Corbeil YJ, Goodrich ME.

Beyond Polarization: Public Preferences Suggest Policy Opportunities to Address Aging, Dying, and Family Caregiving.

Am J Hospice & Palliative Care 2009

Key Findings



Conclusion

By avoiding actions which elicit strong divergence of opinion and focusing on actions on which consensus exists, public officials and candidates can respond to problems and improve care and experience for frail elders, dying Americans, and their families.

Byock IR, Corbeil YJ, Goodrich ME.
Beyond Polarization: Public Preferences Suggest Policy Opportunities
to Address Aging, Dying, and Family Caregiving.
Am J Hospice & Palliative Care 2009

Policy Levers

- **Eliminate statutory-regulatory distinction between curative and palliative care**
 - **Require insurers to include hospice & palliative care as benefit similar to Medicare**
 - **Publish clinical standards for professionals and institutions**
 - **Publish “reasonable expectations” for consumers and citizens**
 - **Make data public in “report card” fashion**
 - **Expand funding Senior Centers & Aging Services**
-

Policy Levers

- **Require adequate (evidence-based) staffing of aides in SNF, LTC, ALF**
 - **Require living wages for aides in SNF, LTC, ALF**
 - **Est. standards for training of physicians, nurses & allied clinicians – as a condition for certification and public financial support**
 - **Fund health service research into delivery of continuum of care**
 - **Resolve political barriers to effective pain management**
 - **Public “report cards” and bulletin boards of all health services (a public “Angie’s List”)**
-

Policy Levers

Older Americans Act

- **Coordination and Planning to charge of Senior Services**
- **Case management, housing services, advance care planning**
- **Direct Care workforce initiatives**
- **Family caregiver support initiatives**

State government:

- **Licensure requirements for physicians, nurses**
 - **Insurance coverage for hospice and home care**
 - **Evidence based staffing levels in SNF, LTC, ALF**
-

Policy Levers

Grants to civic and faith-based organizations for home care to frail elders and ill people

Expanded family leave and caregiving support

Health insurance coverage for family caregiving

Tax deductions for family caregiving expenses

Expanded NIH / AHRQ supported research in

- **Family caregiving**
 - **Secondary prevention**
 - **Community-based services**
-

