How to Irrigate the Deserts of LTC Policy, Programs, and Research in the U.S.?

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Elements

I. Introduction
II. The deserts
III. Why so dry?
IV. Hoping for better

I. Introduction

1. Among all the areas of health care, affordable equity is hardest to achieve in LTC (along with mental health)
   - Contrast with Rx, notionally the easiest
   - Once people are no longer independent, compensating for dependence takes lots of time and gets very expensive
2. LTC involves non-health matters where commitment to equity is absent
   - Housing, food, help, standard of living
   - Decency, freedom, right to least restrictive environment
3. LTC viewed by payers as financial bottomless pit
   - Outcomes hard to measure
   - Services perceived as desirable = fear of moral hazard
   - Lots of people needing lots of help for long time
4. So pay for what people don't want – parallel to poorhouse
5. History of moving the problem = "transinstitutionalization"
6. Ineradicable belief that "better is also cheaper"
7. If abandon business as usual, reason to hope we can do better

Rx

LTC or MH

II. The deserts

A. Sparse financing
B. Skewed care
C. Quality often terrible
D. Little innovation

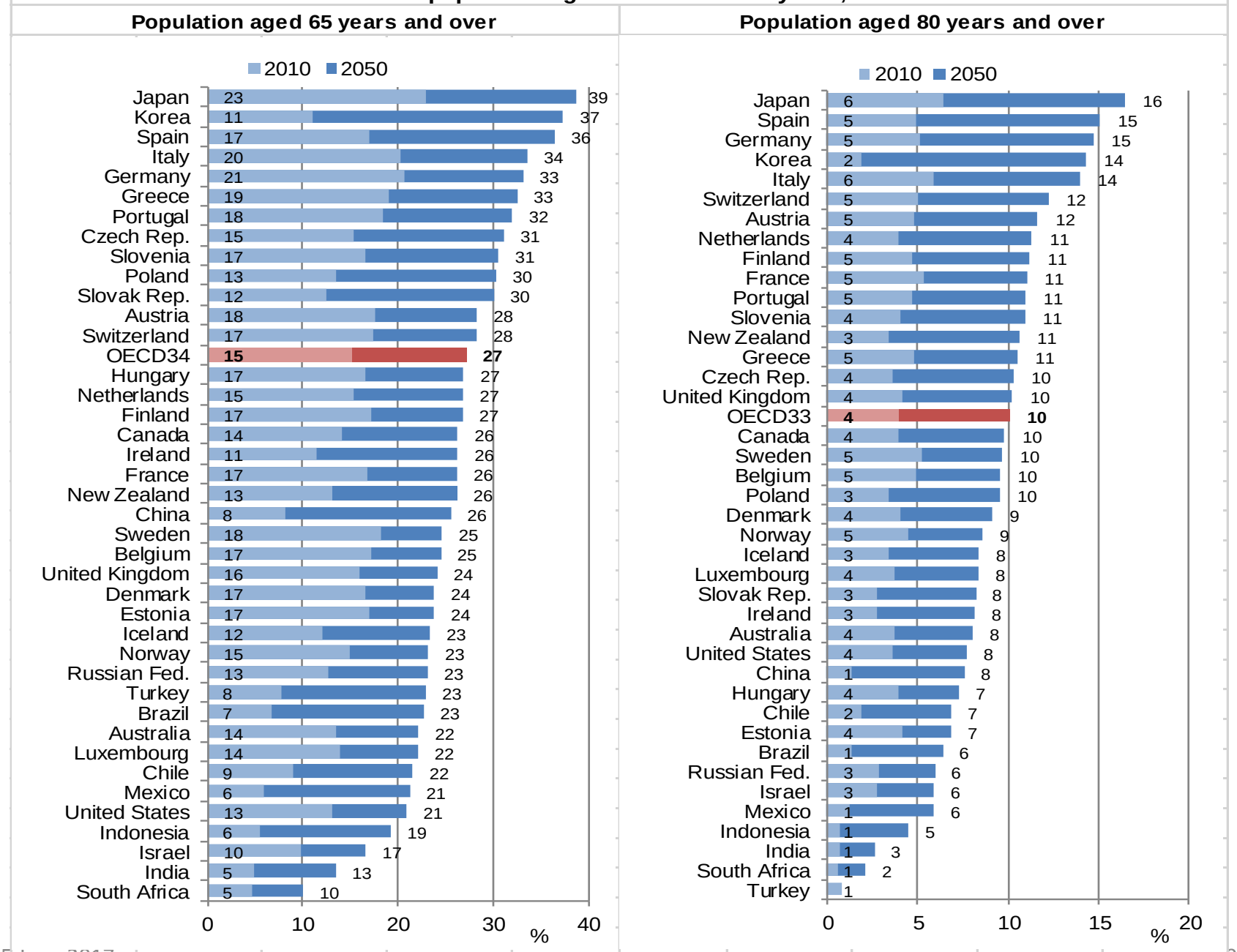
III. Why so dry?

A. Sparse financing
B. Skewed care
C. Quality often terrible
D. Little innovation

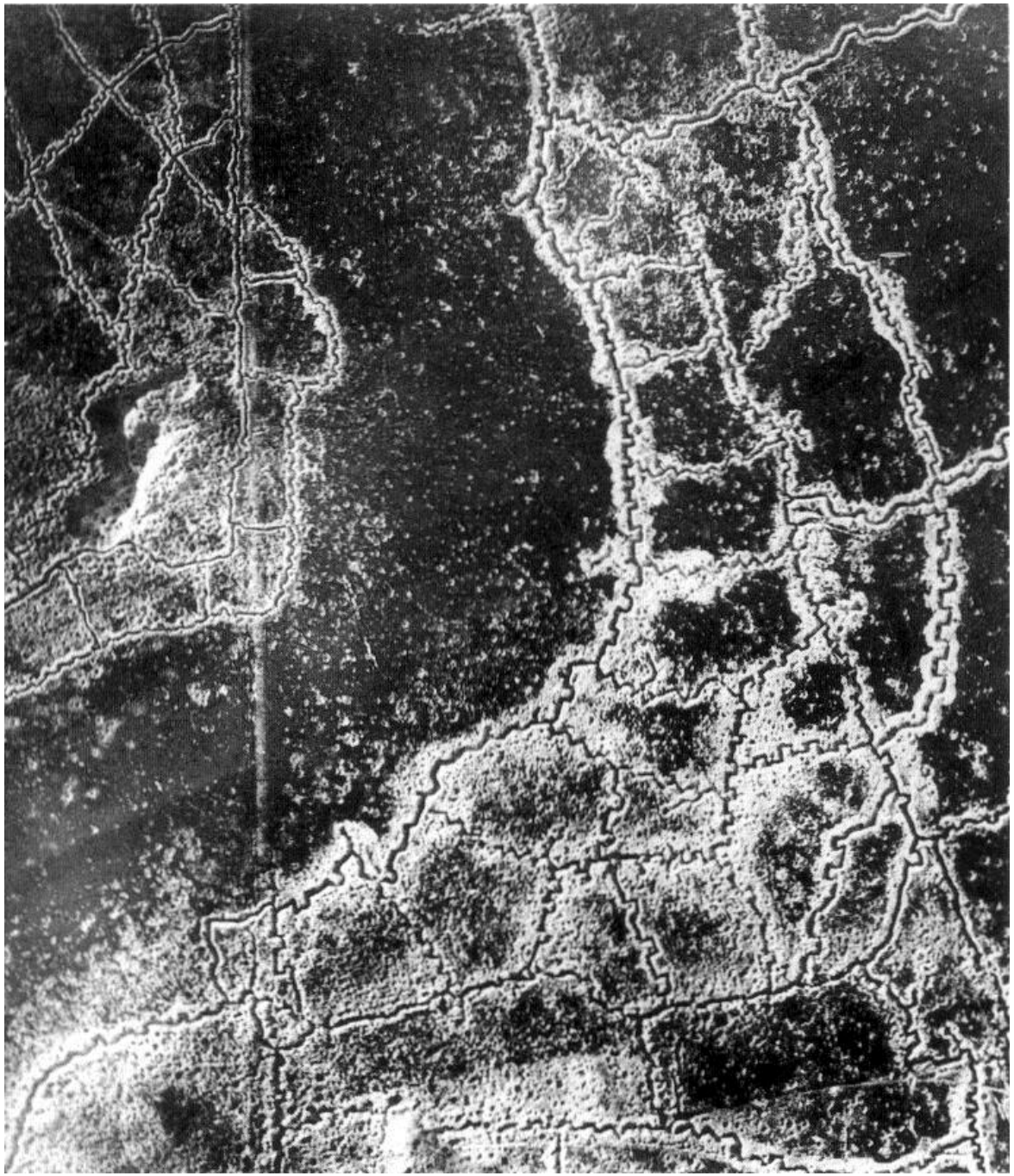
A. Sparse financing

1. Tight public financing
   - Acute care sponge (no serious cost controls)
   - Relatively few old voters (and their families)

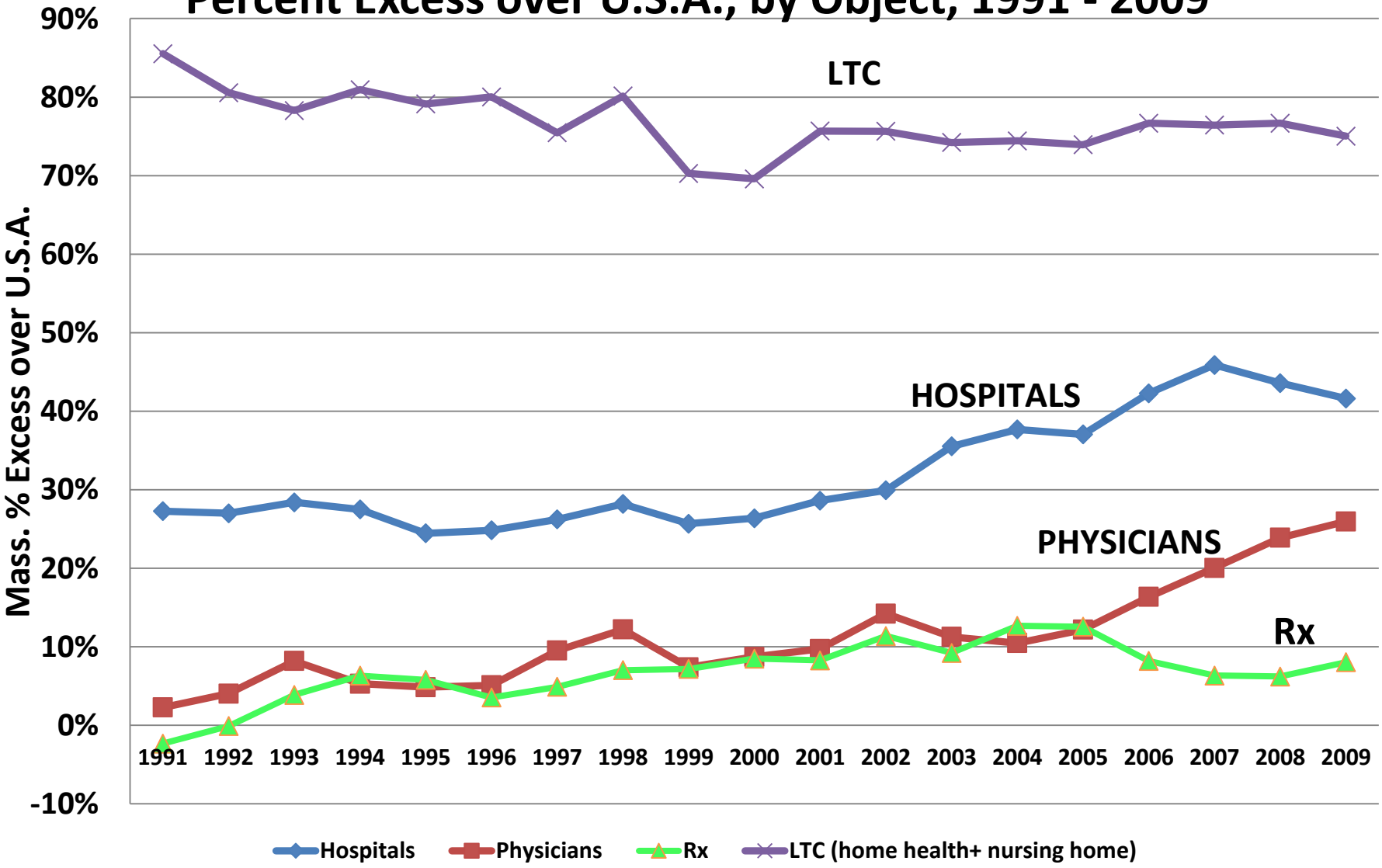
8.1.1. **Share of the population aged over 65 and 80 years, 2010 and 2050**



Source: http://www.oecd-ilibrary.org/sites/health_glance-2013-en/08/01/index.html?itemId=/content/chapter/health_glance-2013-71-en&mimeType=text/html



Massachusetts Personal Health Spending per Capita
Percent Excess over U.S.A., by Object, 1991 - 2009



Spending by state-of-residence

A. Long-term care overview

1. What is long-term care?
2. What are we trying to do? (Aims of LTC)
3. Who's protected? Who's not?
4. Where is care given? By whom?
5. Who pays?
6. Why is financing in LTC so inadequate and skewed?
7. Quality of care problems, causes, responses
8. What are the prospects for doing better?

1. What is LTC?

- Care you'll need for a long time, often indefinitely (hours/week, in your view?)
- Help with activities of daily living
- Help with instrumental activities of daily living
- Paid or unpaid
- Skilled or unskilled
- Where (configuration of care)
  - At home, in nursing home, and many other places

2. What are we trying to do?

- What are current aims? Can you find a public statement?
- What do you think the aims should be?
  - Promote subjective well-being—happiness?
    - Safe, adequate, dignified care—decency?
      - Avoid/prevent abuse, neglect, exploitation, theft?
    - Safeguard ***standard of living*** regardless of site?
      - Is that something to which we could commit ourselves?
  - Ensure medical security?
    - Right diagnosis and treatment
    - Slow deterioration and prevent acute destabilization
    - Avoid preventable harm like over-medication, bedsores, falls

3. Who's protected?

- Medicaid pays for very disabled and very poor
- Medicare home health and nursing home care are ***not LTC***—they are post-acute short-term
- Some Medicare hospice patients
- People with private LTC insurance
- People with assets and income
- People with family members and friends who are available, able, and willing to help

4. Where is care given? By whom?

- Nursing homes
- Assisted living facilities
  - What care do they give?
- Continuing care retirement communities
  - What care do they give?
- Home care
- Adult day health
- Housing-centered arrangements like
  - Nursing home without walls
  - Congregate, communal, or supportive housing

The disjunction

- Great share of elders/disabled people want to live at home but the great share of public $s pay for institutional care
  - How explain that disjunction in a democracy?

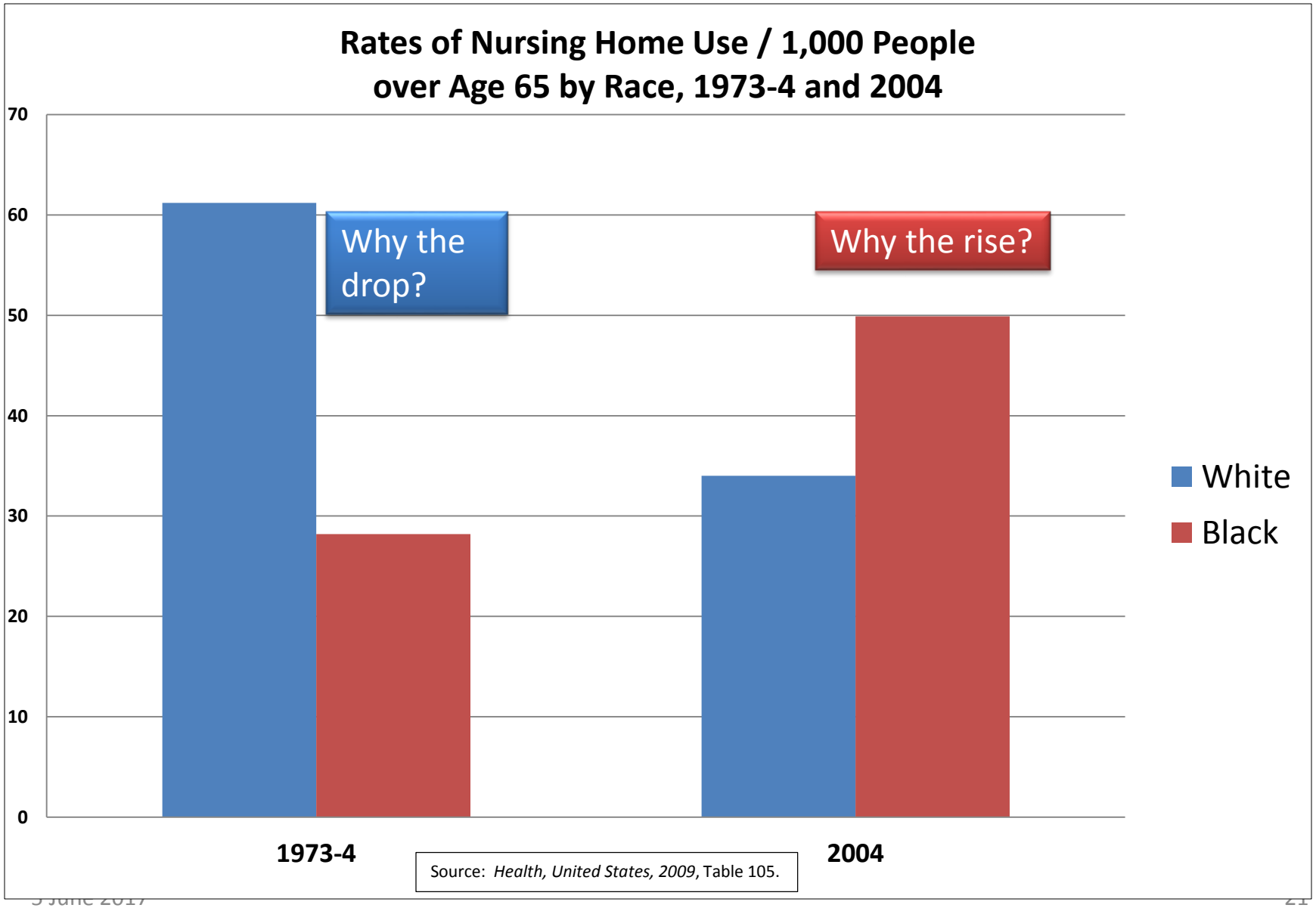
Missing the target

- We promote de-institutionalization but often end up with transinstiutionalization (***Why?***)
  - From geriatric wards of state mental hospitals to nursing homes
  - Promoted by Medicaid policy to pay for nursing home care but not for state mental hospitals
  - Many states are pushing Medicaid LTC dollars to pay for “home and community-based services”
    - Are group homes “home and community-based services”?
      - Sometimes

Family help

1. Unpaid family/friends provide about 80% of LTC
   - In future, families may become less
     - Available
     - Able,
     - Or willing to help
2. A small drop in the 80% share → a large proportionate rise in publicly-financed share
   - If family share drops by 4 percentage points and
   - If it is replaced by paid services
   - Paid share rises from 20% to 24%
     - (A 20 percent rise in cost!)

Transinstitutionalization



Transinstitutionalization

- Why were 1,000,000 beds built in assisted living facilities after about 1980?
  - States encourage –mobilize private $s for LTC
  - Private patients (residents) live better until need NH
  - State can pay for fewer LTC days in NH through Medicaid
- Results
  - Patient segregation in nursing homes
    - More disabled, confused, incontinent
    - Income and racial mix changes
  - Greater average disability than previously
  - Unless Medicaid pays more per patient-day, quality falls

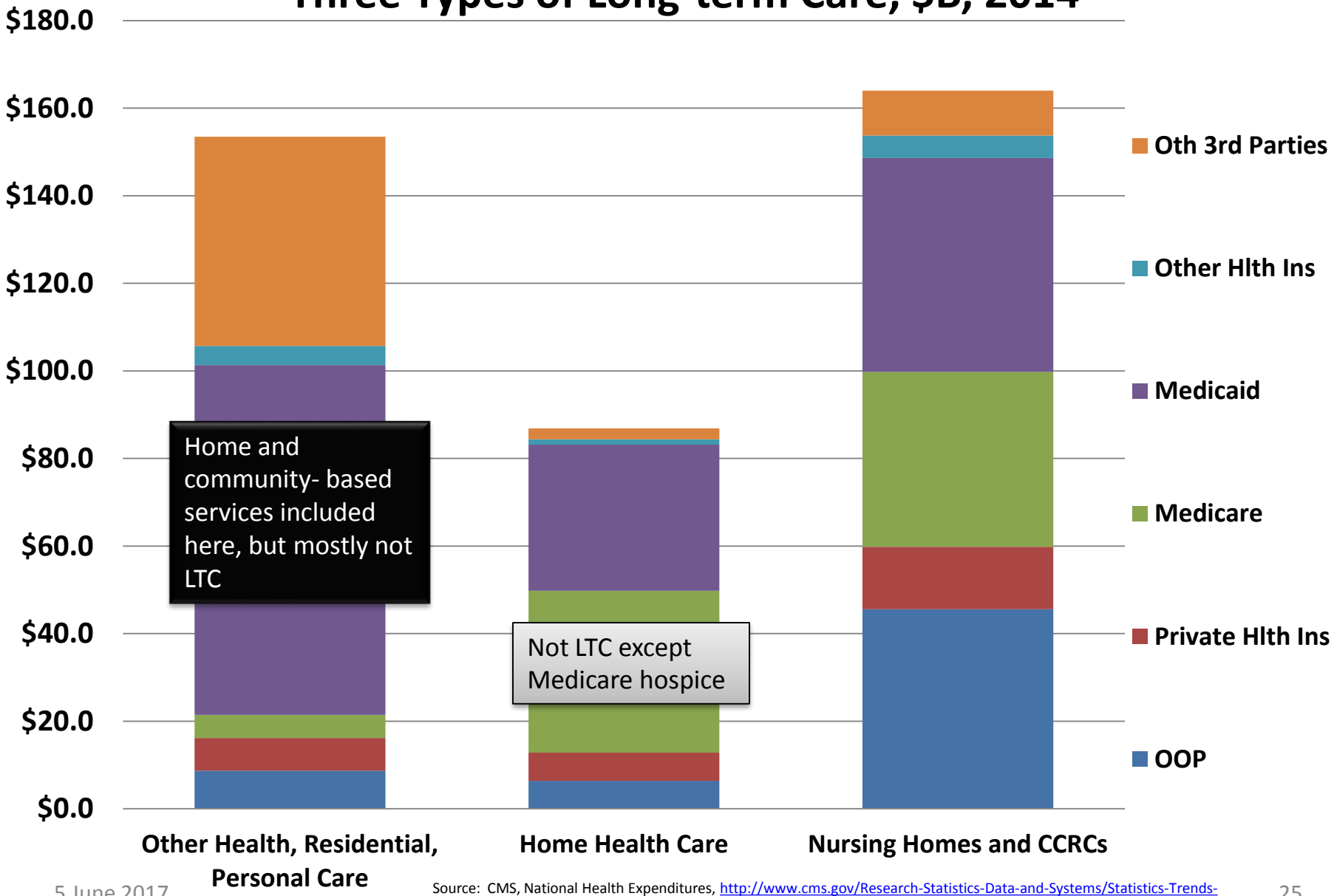
5. Who pays for LTC?

- Financing for real LTC services
  - Current sources of nursing home $s
    - **Exclude** Medicare post-acute nursing home + rehabilitation
  - Current sources of home health $s
    - **Exclude** Medicare home health
    - Add in Medicare hospice > x days?
- Private (money to live + LTC services)
  - Savings, Social Security, pensions + retirement accounts
  - Family help
  - Private LTC insurance
  - Reverse annuity mortgages – but ***be very careful***!
- Housing-based programs with some LTC help
  - Assisted living buildings/communities
  - Continuing care retirement communities
  - Supported public housing with some services

Another euphemism

- Doughnut hole
- Skin in the game
- Spending down (to Medicaid eligibility for LTC)

Sources of Revenue for Three Types of Long-term Care, $B, 2014



Source: CMS, National Health Expenditures, http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/index.html

A common financial sequence

a. A human problem becomes to big and too politically important to ignore
b. A program is created and financed to address the problem
c. A share (small?) of caregivers financially exploit the program via gaming or stealing
   - Patients are often harmed by diversion of dollars needed for care
   - Campaign contributions from caregivers buffer effective responses
d. Political outrage builds (or seems to build)
e. Payments to all caregivers are cut, often below levels adequate to finance good care
   - More patients are harmed

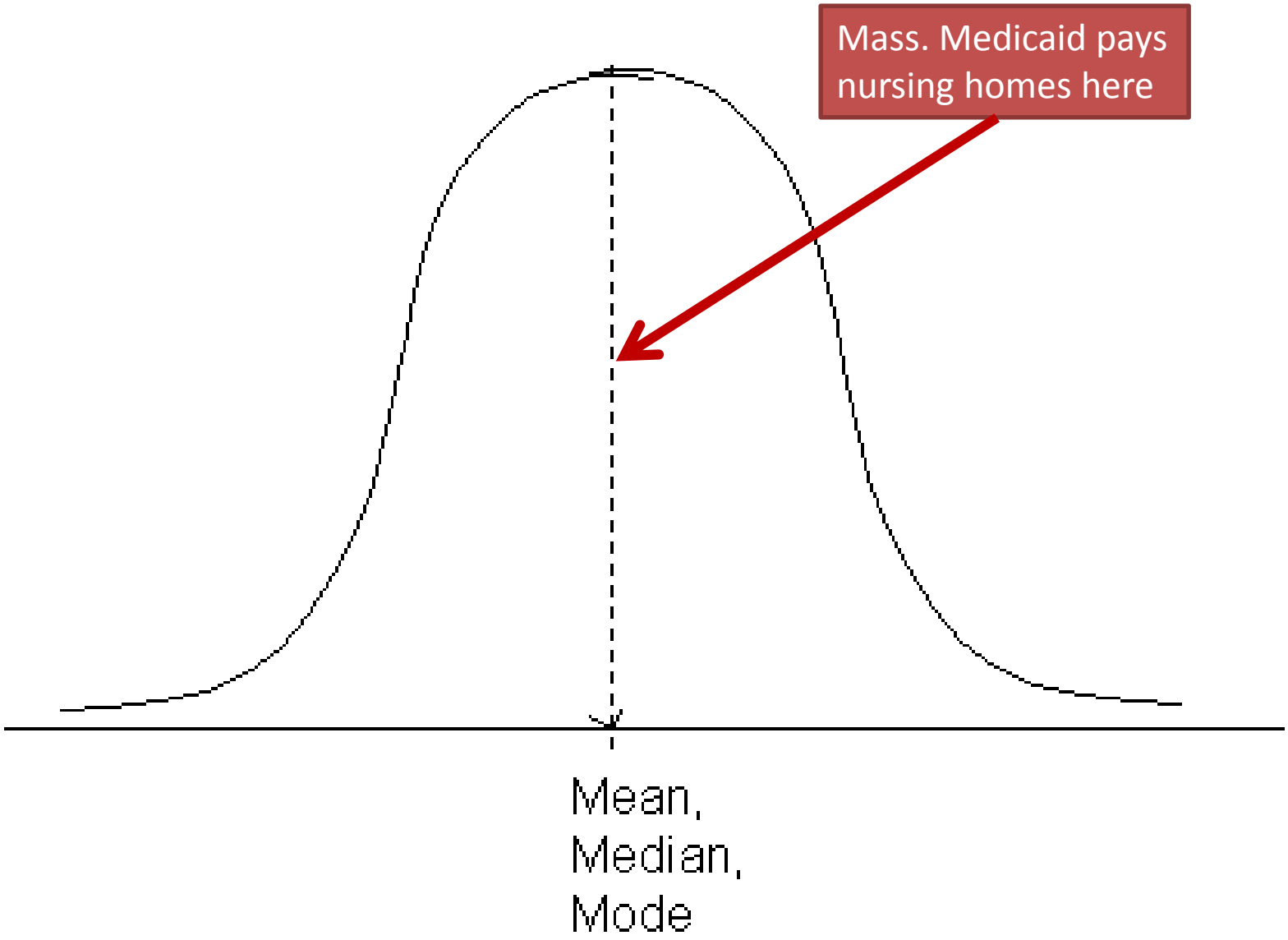
- Examples
  - Physician visits to nursing home residents
  - Medicaid payment rates to nursing homes
  - Medicare payment rates to hospices (not yet, but possible)

→ ***How could we do better?***

Does Medicaid pay enough?

- In Massachusetts, the state sets the rate at which Medicaid pays nursing homes
  - That's the payment per patient-day
- These have changed little since 2005
- State says there are lots of empty NH beds as patients seek care outside NHs, so there's no reason to hike the price paid by Medicaid
- But what if seek care elsewhere because NH quality has deteriorated?

– Erin Ailworth, "State, Nursing Homes Face off over Medicaid Funds," *Boston Globe*, 19 May 2014, 4 pp, www.bostonglobe.com/business/2014/05/18/facing-closures-nursing-homes-seek-boost-medicaid-funding/AYStZ90nezURPQBC3mGM9I/story.html


Mass. Medicaid pays nursing homes here
Mean,
Median,
Mode

But

- If the rate of use of nursing homes has dropped, who's still using nursing homes?
- Do remaining patients need more help, on average?
- Is this an example of the distillation effect?
- If so, should the Medicaid rate rise?

6. Why is financing so inadequate and skewed?

a. Cheaper to offer to pay for what people don't want—nursing home—they'll probably use less of it
b. Payers think it's risky to promise to pay for something that might seem attractive (moral hazard!)
   - Even though most people seem to value their privacy more than they value in-home help
c. Paying for long-term non-institutional care for lots of people can be financially scary
   - Open-ended people for open-ended time
   - But if pay mainly for nursing homes, can control use by regulating number of beds, and number of patients eligible for payment
d. Costly acute care sponges up available dollars
e. Long-term care isn't prestigious—will anyone win a Nobel Prize in medicine for work in LTC?

7. NH Quality problems, causes, remedies

Quality problems	Causes	Remedies
Restraints, physical, chemical	Patients often cognitively impaired Cheaper than adequate staffing, especially if revenue is low	Boost Medicaid payments (how?)
Abuse, neglect, theft	Workers under-paid (low Medicaid rates?) Job is hard, often unrewarding Patients not getting better Patients often ungrateful Isolated patients—lacking sustained family presence to protect patients	Boost Medicaid payments Boost family involvement (how?)
Failure to provide needed care	Families lack time, strength Caregivers under-paid Residents not getting better	Improve coverage and support families; mobilize time
Dependence, fear, alienation, anger, depression, boredom	Physical, cognitive declines Incontinence NH run like institution, not like home Lack of resources to individualize care	Higher staffing levels, providing more to do, and more interaction?
Circular finger-pointing between payers and nursing homes	We can't pay you more until you improve quality. How can we improve our quality if you won't pay us more? No one's accountable!	Public ownership and accountability for adequate $s + private management?

If we can't improve nursing homes

- Should we just close them?
- And find better ways to care for their 1.5 million (or so) residents?

And what about places where people with developmental disabilities reside?

And what about Alabama hospices? Why are they so much worse than the one in Boston described by Gawande?

What are the quality problems, their causes, and their remedies?

Will home care be kinder, safer, and preferred by people?

- Most people prefer to remain at home
- Family members provide most of the help
- Paid workers often important
- What's the risk of abuse, neglect, theft?

- Nursing homes' quality is very uneven
- Most feel more like institutions than homes
- Risk of abuse, neglect, theft by workers and other residents

Some LTC and MH overlaps

- A large share of people needing LTC also suffer cognitive or emotional impairment
- About half of nursing home residents are considered too cognitively impaired to give informed consent to flu shots
- Alzheimer's!
- A large share of older people removed from state mental hospitals in 1960s and 1970s were transferred to nursing homes
  - Medicaid paid in NH but not in mental hospital!

8. What are the prospects for doing better?

a. How would you improve the safety, adequacy, and dignity of care for residents of nursing homes?
   - How to protect dependent, vulnerable, and often frightened people from abuse or neglect?
   - Any positive aims you'd like to pursue?
     - Peace, love, kindness, security, pleasure?

b. How are other nations able/willing to more broadly and generously finance non-institutional LTC?

c. Why is there so little innovation in LTC?
   - That can be overcome

An international look

- U.S. elder population share ~13%, while many rich democracies are approaching 20%
- Why do most of them provide broad public financing for LTC while we don't?
  - Political pressure from lots of elder/family voters
  - They spend much less on acute care so have money left over

LTC innovation - financing

- Very little innovation in LTC financing or delivery
  - Less cure and more care?
    - Integrate acute and long-term care $s → more $ for LTC?
      - Dual eligible demonstrations merge M'care + M'caid $s
  - Medicare hospice program—is it LTC? Some? Mostly?
  - Private LTC insurance—sometimes helpful, very often financially unstable, always expensive
  - Housing supports, multi-generational living
  - Reverse annuity mortgages = cash out home equity
    - Looked good but great risk of bad deals!
    - Check the fees and the real payouts!
    - Threw Federal Housing Administration into first-ever deficit!

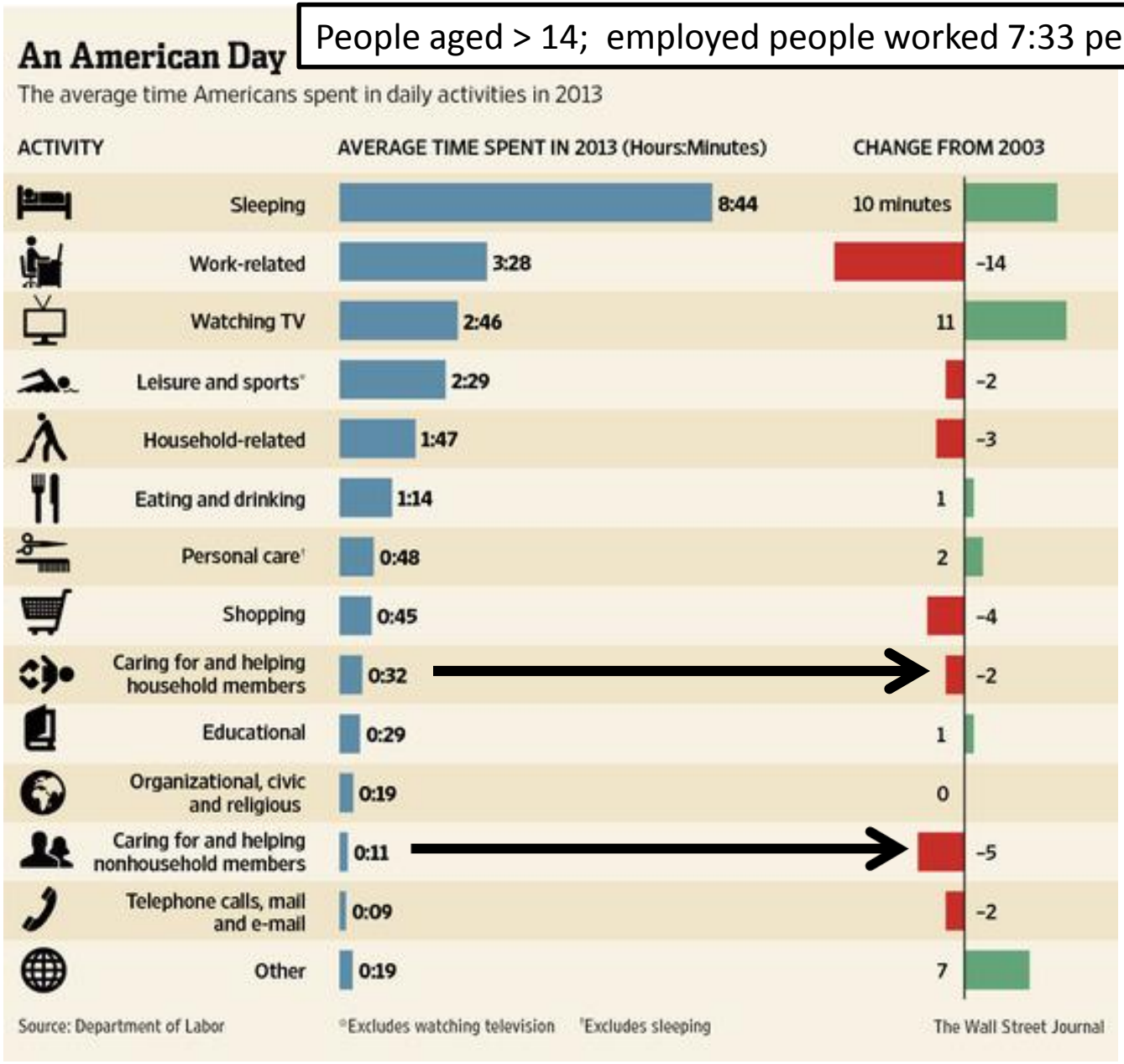
Two sides of stone bridge buttress one another

LTC means needing much help (time) from other people

Paid and unpaid help are complements, not alternatives

- Mobilize volunteers' time by banking it—when **able**, and get help when **needed**
- Create a parallel economy of reciprocity, of good deeds
- And social insurance for in-home and institutional care, often including payments to family members
  - Easier for other rich democracies
    - Since their income distributions are more balanced
      → There's a more solid floor under living standards
    - And they spend so much less on acute health care

People aged > 14; employed people worked 7:33 per day on the job



Source: Eric Morath, "Aging Americans Sleep More, Work Less, Survey Finds," *WSJ*, 19 June 2014, http://online.wsj.com/articles/aging-americans-sleep-more-work-less-survey-finds-1403121530#printMode, from BLS, *American Time Use Survey, 2013 Results,* 18 June 2014, http://www.bls.gov/news.release/pdf/atus.pdf.