

Toward a Better Healthcare System

***If you build it, they will
come***

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Starting Questions

If you were chronically or terminally ill...

- **What would you want from your healthcare system?**
- **How optimistic are you that you could get it?**

More difficult question

**In thinking about the possibility
of chronic illness (or dying),
what do you fear?**

Objectives

- Discuss factors affecting healthcare for chronic and terminal illness
- Suggest personal strategies for obtaining better outcomes
- Suggest what might improve the system overall

Most people want it all...

- **Live forever (or at least a very long time)**
- **Be in good health – active, no pain**
- **Be at home (no doctors, hospitals or nursing homes)**
- **Pay nothing (or have someone else pay) for healthcare necessary to make this happen**

But, since you can't have it all...
What are your priorities?

Cure

Comfort/care

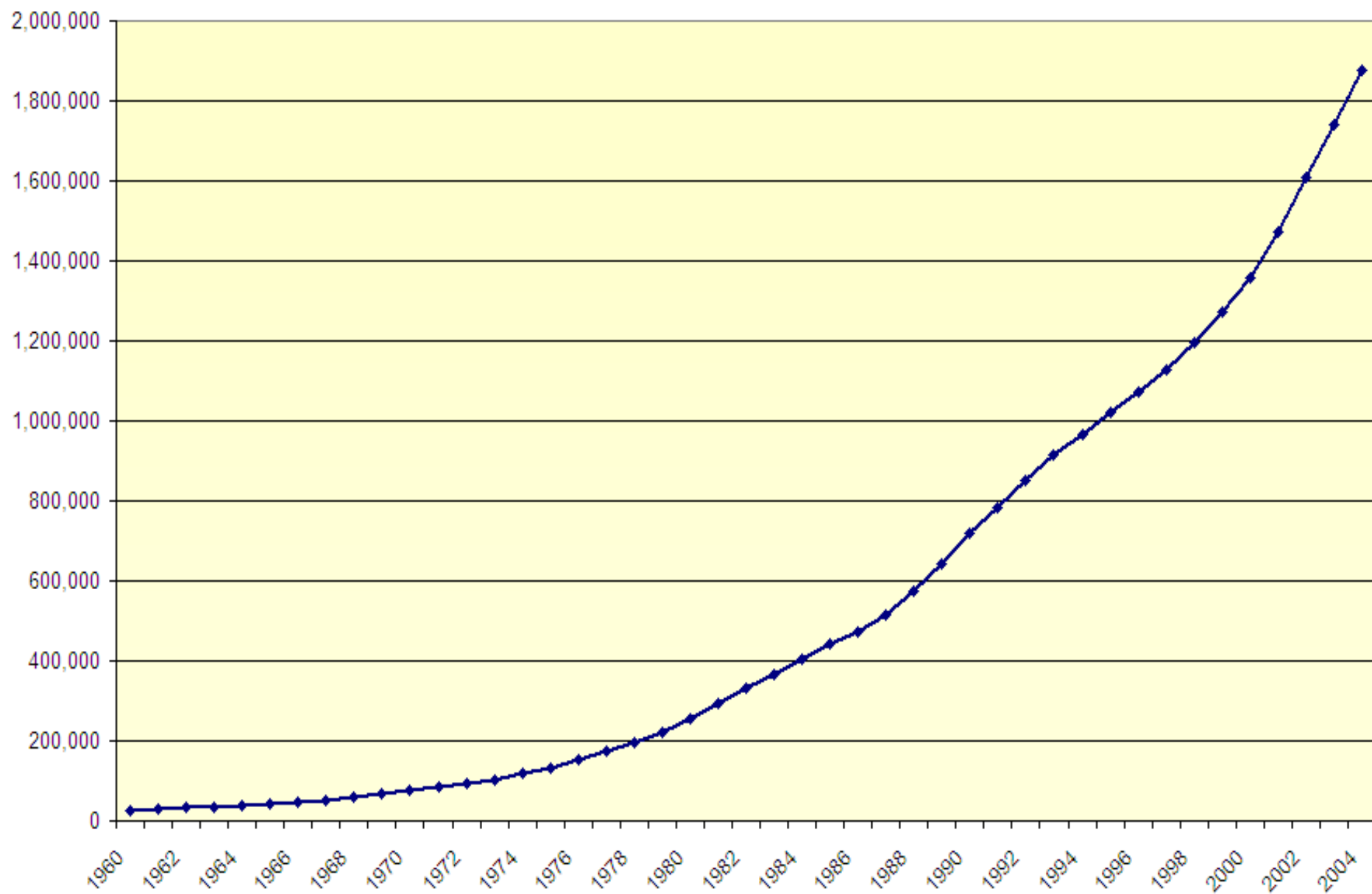


*And how would you
allocate either your \$ or
government \$ along this
spectrum?*

National Health Expenditures

(in millions of current dollars)

www.healthguideusa.org



Attributes	Patients	Bereaved Family Members	Physicians	Other Care Providers
Freedom from pain	3.07 (1)	2.99 (1)	2.36 (1)	2.83 (1)
At peace with God	3.16 (2)	3.11 (2)	4.82 (3)	3.71 (3)
Presence of family	3.93 (3)	3.30 (3)	3.06 (2)	2.90 (2)
Mentally aware	4.58 (4)	5.41 (5)	6.12 (7)	5.91 (7)
Treatment choices followed	5.51 (5)	5.27 (4)	5.15 (5)	5.14 (5)
Finances in order	5.60 (6)	6.12 (7)	6.35 (8)	7.41 (9)
Feel life was meaningful	5.88 (7)	5.63 (6)	5.02 (4)	4.58 (4)
Resolve conflicts	6.23 (8)	6.33 (8)	5.31 (6)	5.38 (6)
Die at home	7.03 (9)	6.89 (9)	6.78 (9)	7.14 (8)

*Attributes are listed in the mean rank order based on patient response. Numbers in parentheses are mean rank order, with lowest rank score (1) indicating most important attribute and highest rank score (9) indicating least important. Friedman tests were significant at $P < .001$, suggesting that rankings by each group were different than would be expected by chance alone.

Steinhauser K et. al. , Factors considered important at the end of life by patients, family, physicians, and other care providers JAMA, 2000; 284(19):.2476-2482

So, what factors affect what you will get in terms of healthcare?

■ You

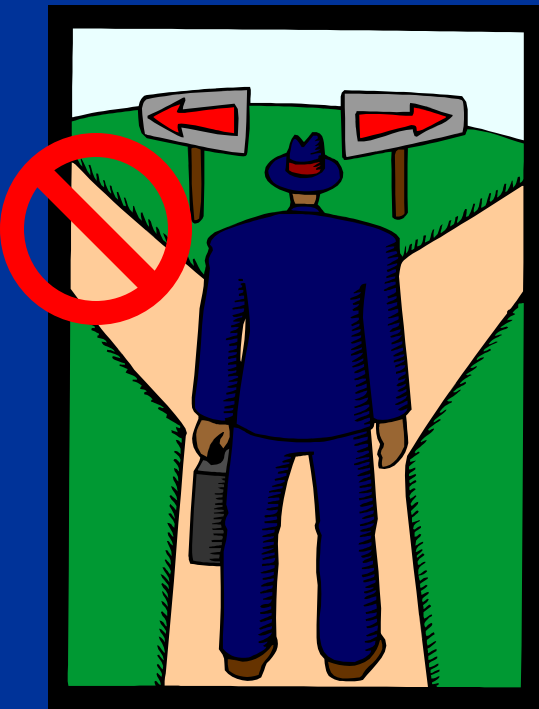
- Insurance
- Socioeconomic Status
- Age
- Race
- Disease
- Other factors – where you live

■ The System

- Accessibility
- Relative capacity of care venues
 - Clinic, Home Care, Acute, NH

What about what you *want*?

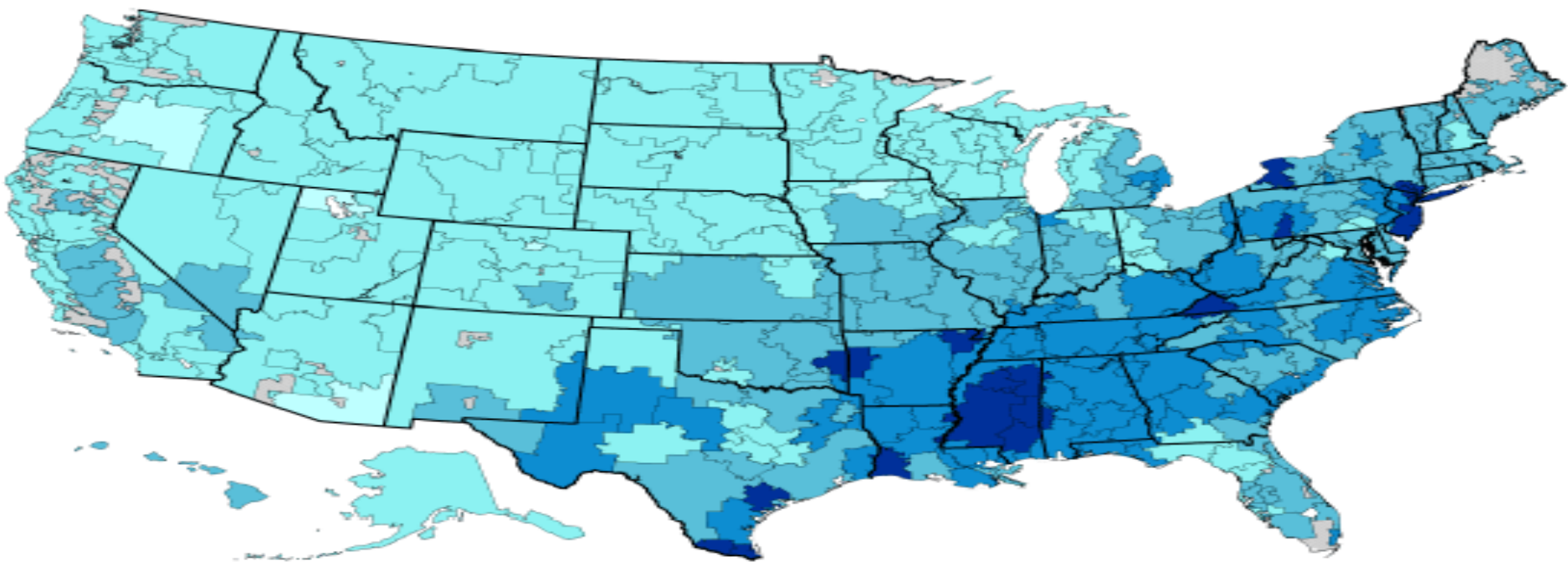
Bad news – With advancing illness, what you *get* is more determined by what they *got* than by what you *want*



Patient Preferences for Site of Death Home vs. Hospital or Nursing Home

“Whether people die in the hospital or not is powerfully influenced by characteristics of the local health system but not by patient preferences or other patient characteristics.”

Pritchard, R. S., E. S. Fisher, et al. (1998). "Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment." J Am Geriatr Soc 46(10): 1242-50.

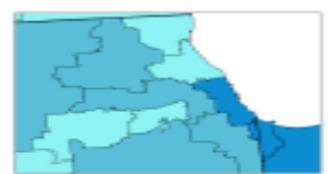


**Percent of Medicare Deaths
Occurring in Hospitals**
by Hospital Referral Region (1995-96)

40 or More	(24)
35 to < 40	(67)
30 to < 35	(102)
20 to < 30	(108)
Less than 20	(5)
Not Populated	



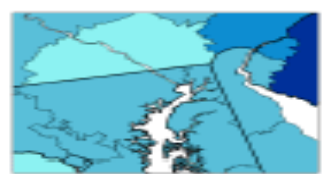
San Francisco



Chicago



New York

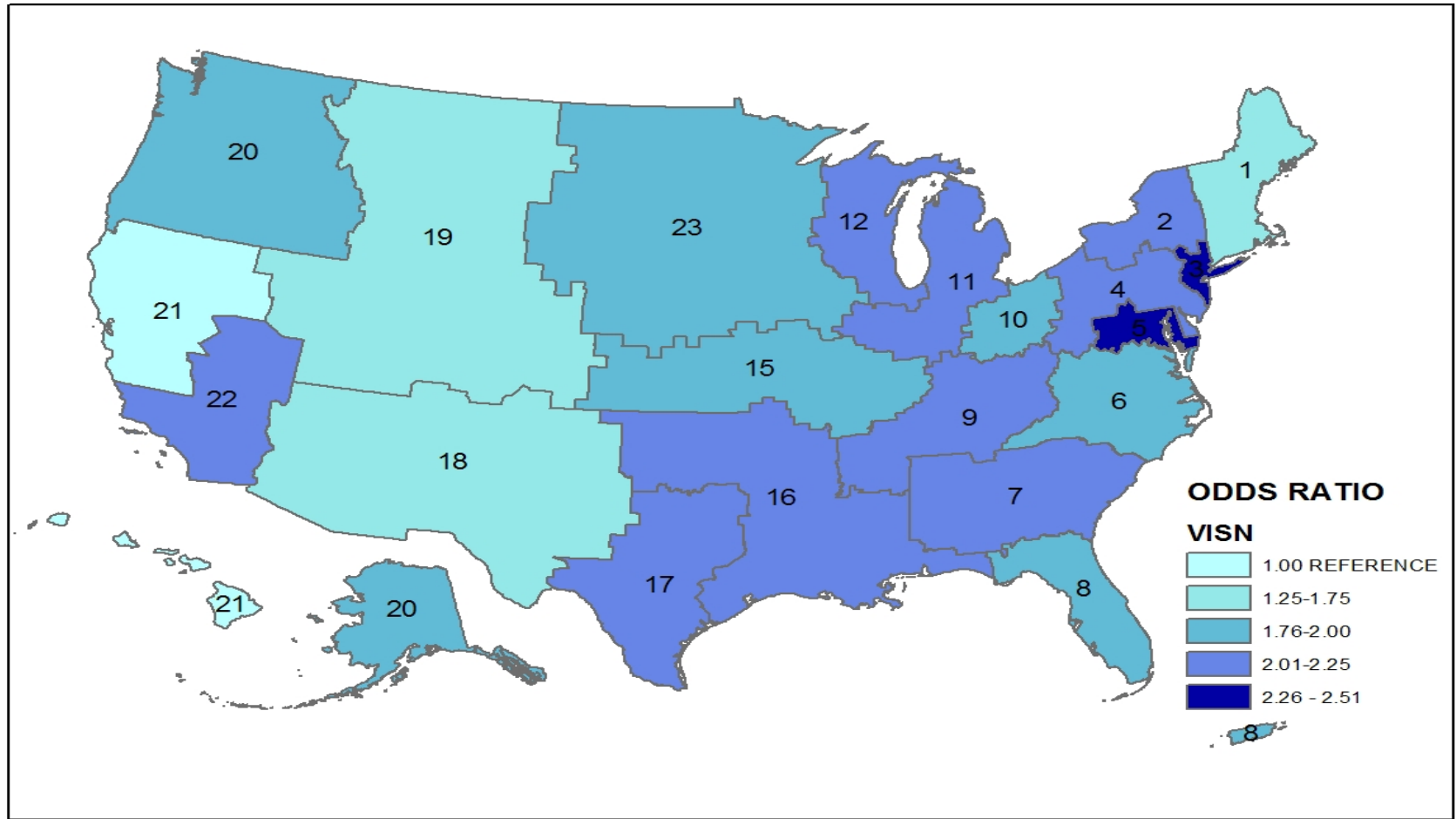


Washington-Baltimore



Detroit

ADJUSTED ODDS RATIO DYING IN ICU VS. ELSEWHERE



Controlling for Charlson Co-morbidity Index,
HCUP/CCS Diagnosis-based Risk adjustment, Age,
Sex, Race and Distance Nearest VA

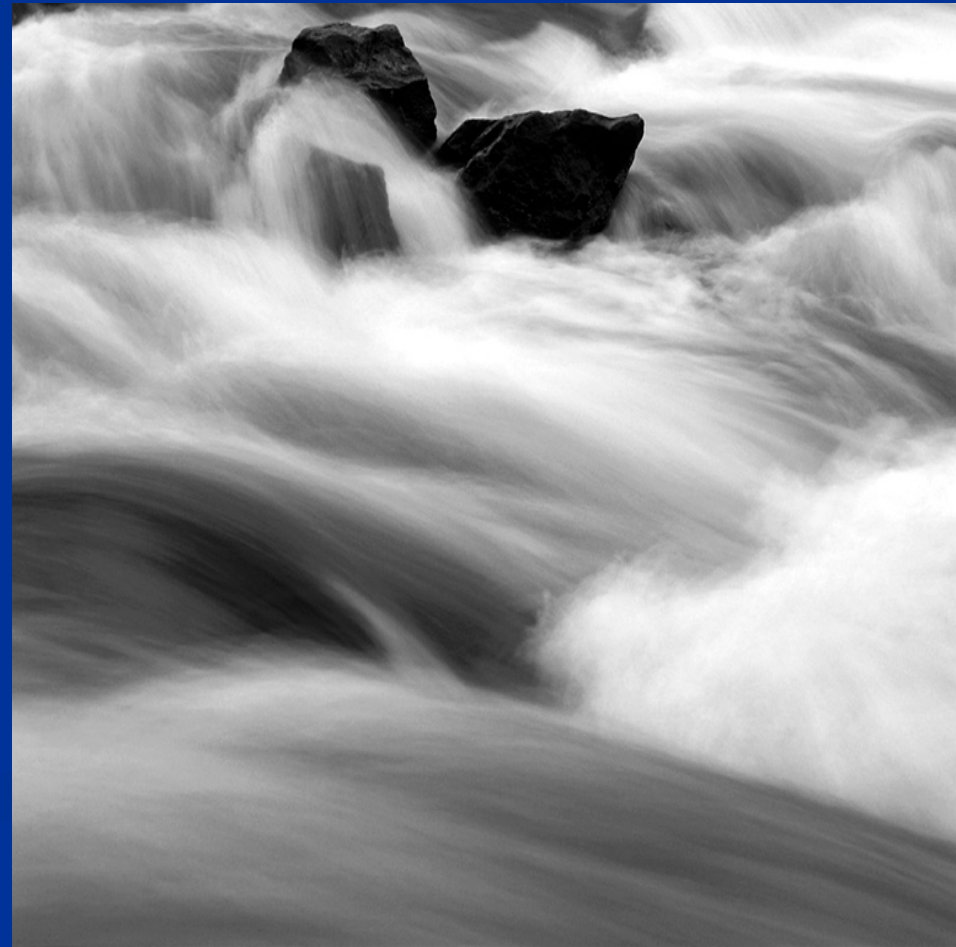
What are major determinants of whether you die in an ICU?

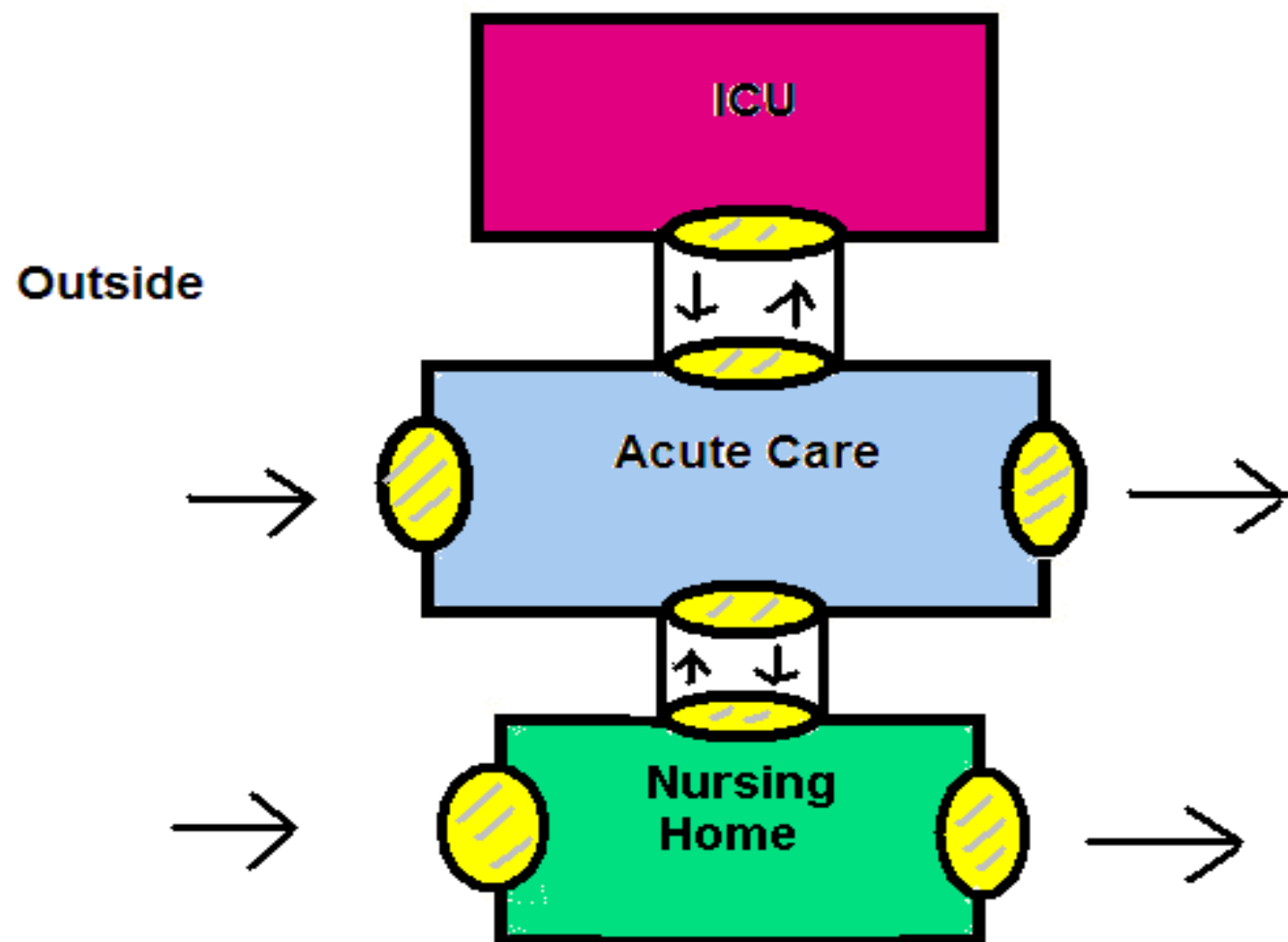
- Access to ICU
 - 911 system
 - Proximity to the hospital
- # ICU Beds
- Availability of alternative places to go

In this study people were more likely to die in an ICU if their hospital had a lot of ICU beds and less likely if they had a lot of nursing home beds

Systems of Care and Patient Flow

- 911 to ER
- Healthcare system organized around acute care hospital
- 24/7 Availability of acute care
- No “911 Hospice,” home Care, nursing home care





A look to the future

California's Population Is Aging

**Californians
Age 65 and Older (millions)**

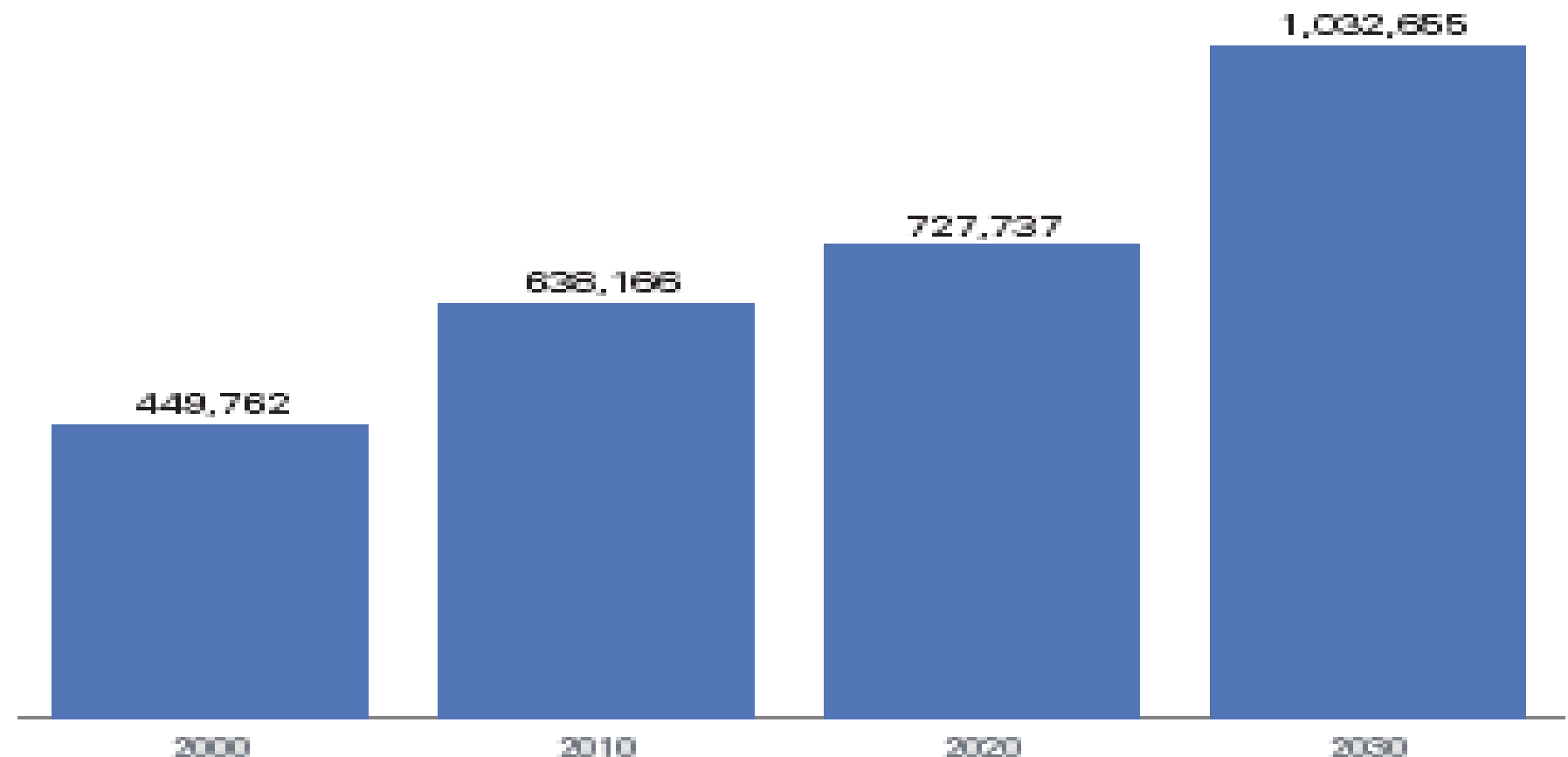
**U.S. Residents
Age 65 and Older (millions)**



Source: U.S. Census Bureau, 2003: State Population Projections and Population Projections Program, Population Division.

More Frail Elderly, More Care Needed

Californians, Age 85 and Older



Source: California State Department of Finance, Demographic Research Unit, CDC Life Expectancy.
www.cdc.gov/nchs/data/healthdata/2003/031hau027.pdf

Predictions

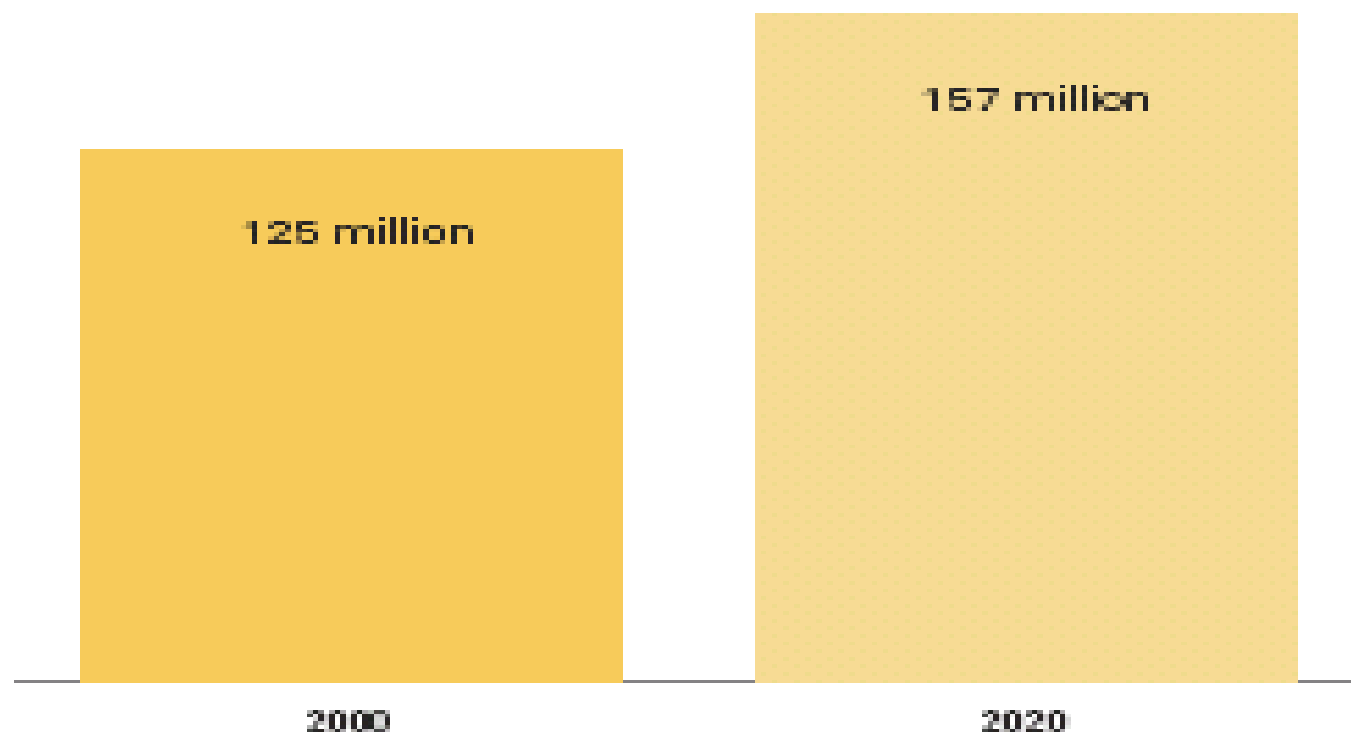
- Ratio of Elders in need of care / Available Caregivers will grow dramatically
- Continuing shift in locus of care for chronically ill patients *out* of hospital and *into* the community

WHO *WILL* PROVIDE CARE?

Often, ethnic “others”...

**With different values and ways
of managing chronic and life-
limiting illnesses**

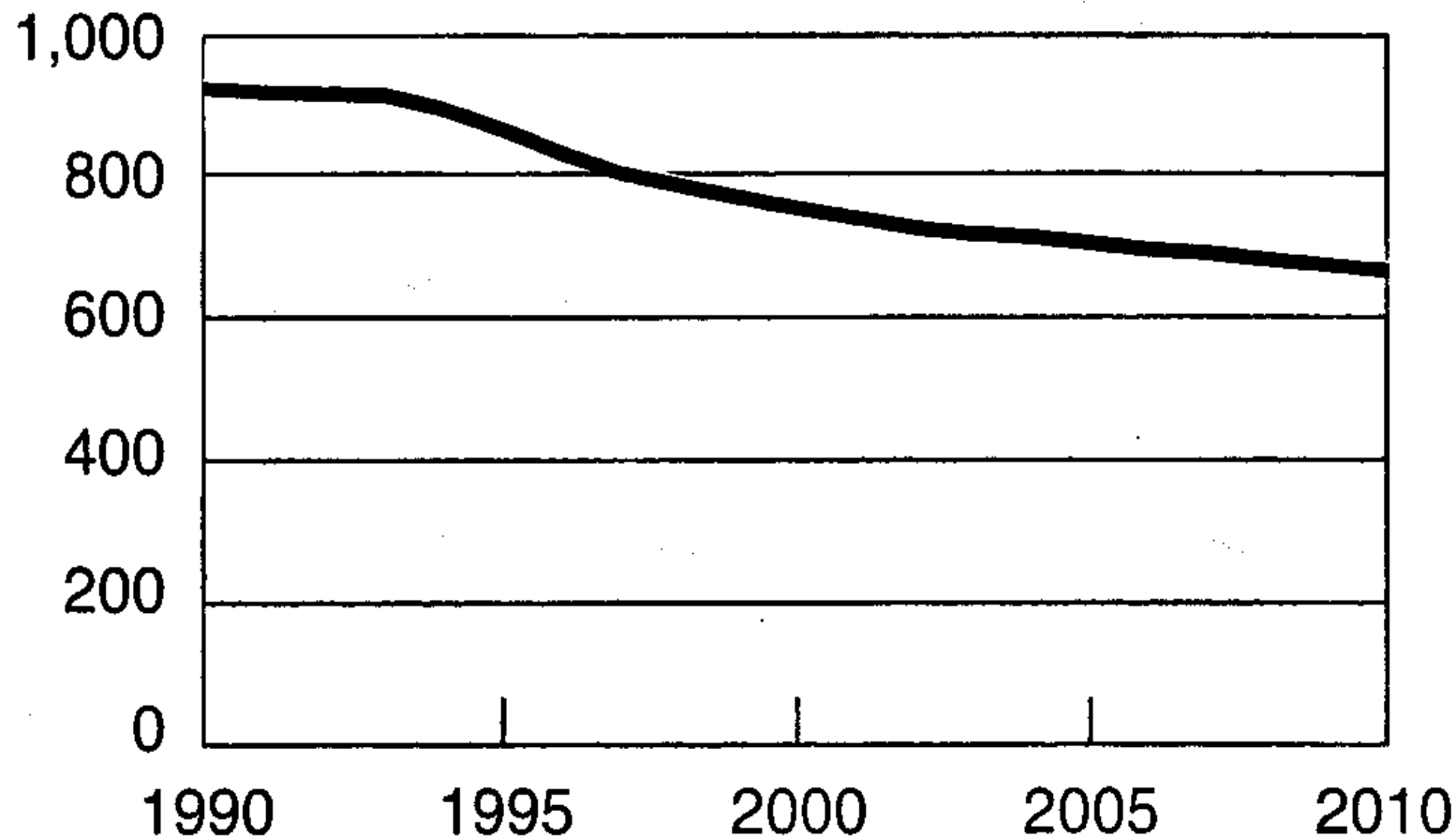
Americans with Chronic Conditions, 2000 vs. 2020 (projection)



Source: Gerard F. Anderson, PhD., Johns Hopkins Bloomberg School of Public Health, Partnership For Solutions, <http://www.partnershipforsolutions.org/statistics/prevalence.html>.

*Figure 4–14. Hospital Beds Will Keep Slowly Disappearing
(Total beds in community hospitals)*

Thousands of beds

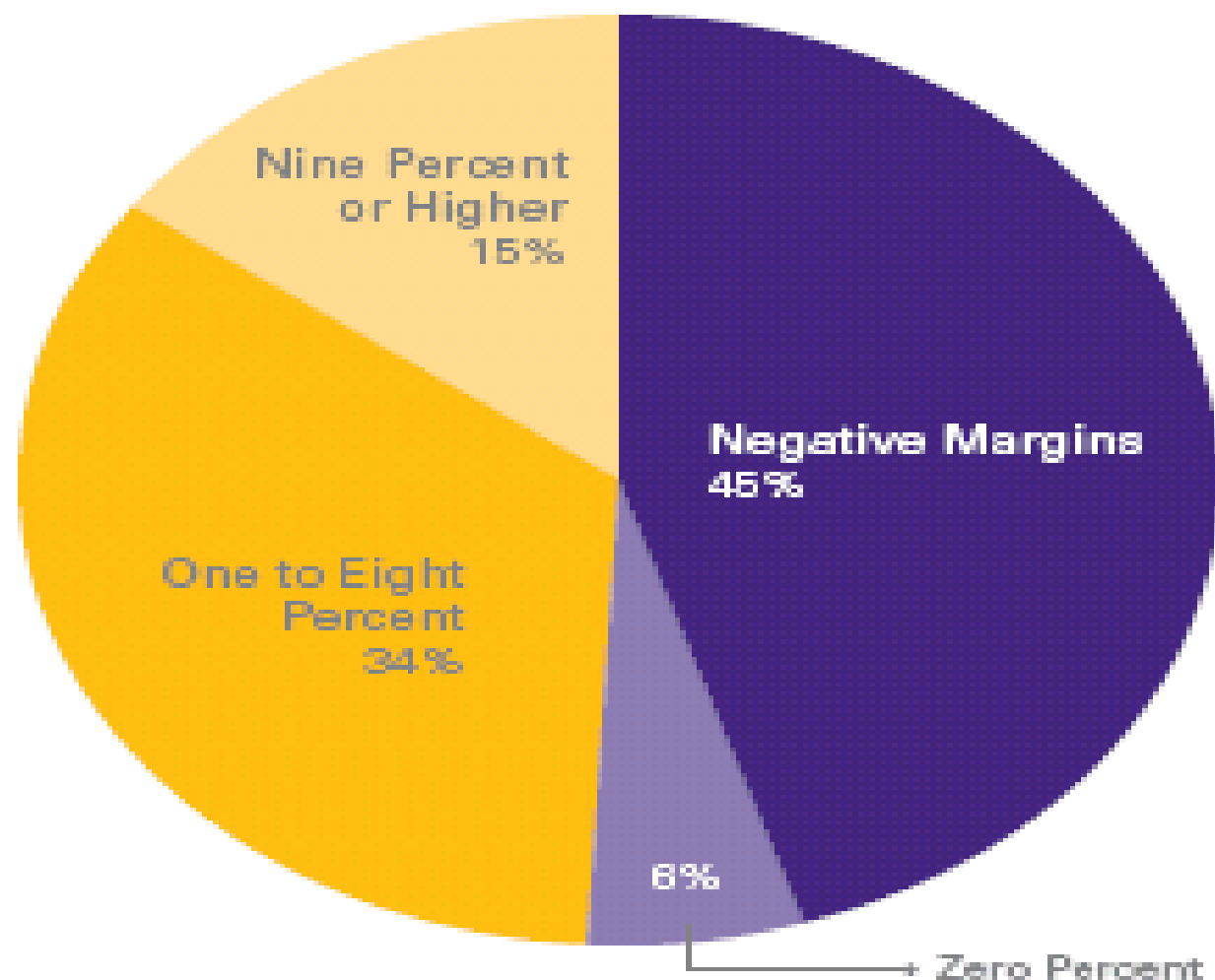


Source: IFTF

Nursing Home Facts in California...

- **No growth in nursing homes capacity over 10 years**
- **About 50% of nursing homes loosing money**
- **Projected need: 60% growth (to 67,000 beds) by 2020**

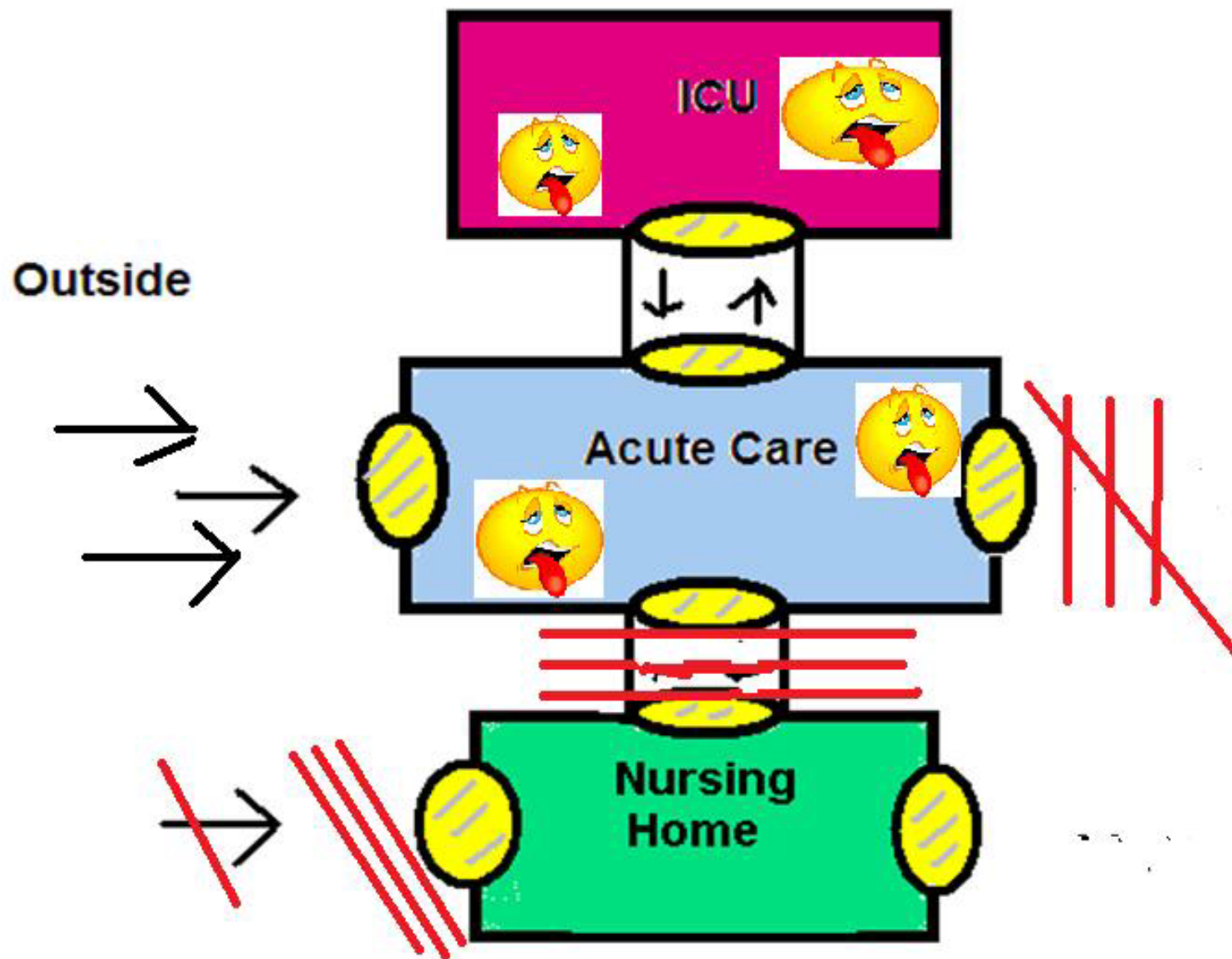
Profit Margins for Freestanding California Nursing Homes, 2003



Source: Justin O'Meara and Charlene Harrington, University of California, San Francisco. Calculations provided using Office of Statewide Planning and Development, 2004; long-term care annual financial data, 2001 and 2003.

Net Effect

*More chronic illness + less
acute care beds + no
growth in
community/nursing home
support = systematic
impaction*



This will affect us all

What you can do

Finances/Insurance

Assume a prolonged period of disability

- Review current coverage for home care, hospice care and nursing home care
- Consider purchasing additional coverage (if possible), if coverage is poor
- Discuss financial impact of illness on:
 - Employment/income
 - Savings

Trade-offs

- Where to live?
- Moving in with family members?
- Will someone have to stop work to provide care?

Difficult Discussions

- Advance Directives
- Priorities in care
- Where to receive care

Do's and Don'ts

■ Do

- Talk about problems that are likely to arise
- Talk about goals and trade-offs in priorities
- Consider the impact of decisions on all involved stakeholders

■ Don't

- Make promises you can't keep

I promised Dad I would never take him to a nursing home...

Find Allies

- Disease-specific advocacy groups
- Patient “navigators”
- Use the Web

What about Changing the System?

- Advocate for a change in priorities
 - Better nursing homes
 - More emphasis on care
 - Improved access for care

But be honest – what are you willing to give up to get these?

SUMMARY

- **Bad News – The current system is not well designed for care of chronic or terminal illness**
 - If you passively depend on the “system” to get you to the right place, you will likely be disappointed
- **Good News – There are a lot of us in the same boat! If we “row” together, we may be able to get what we need**