

Taking Stock of Where We Are (and Where We Might be Going)

“The future will be better tomorrow.”

Dan Quayle

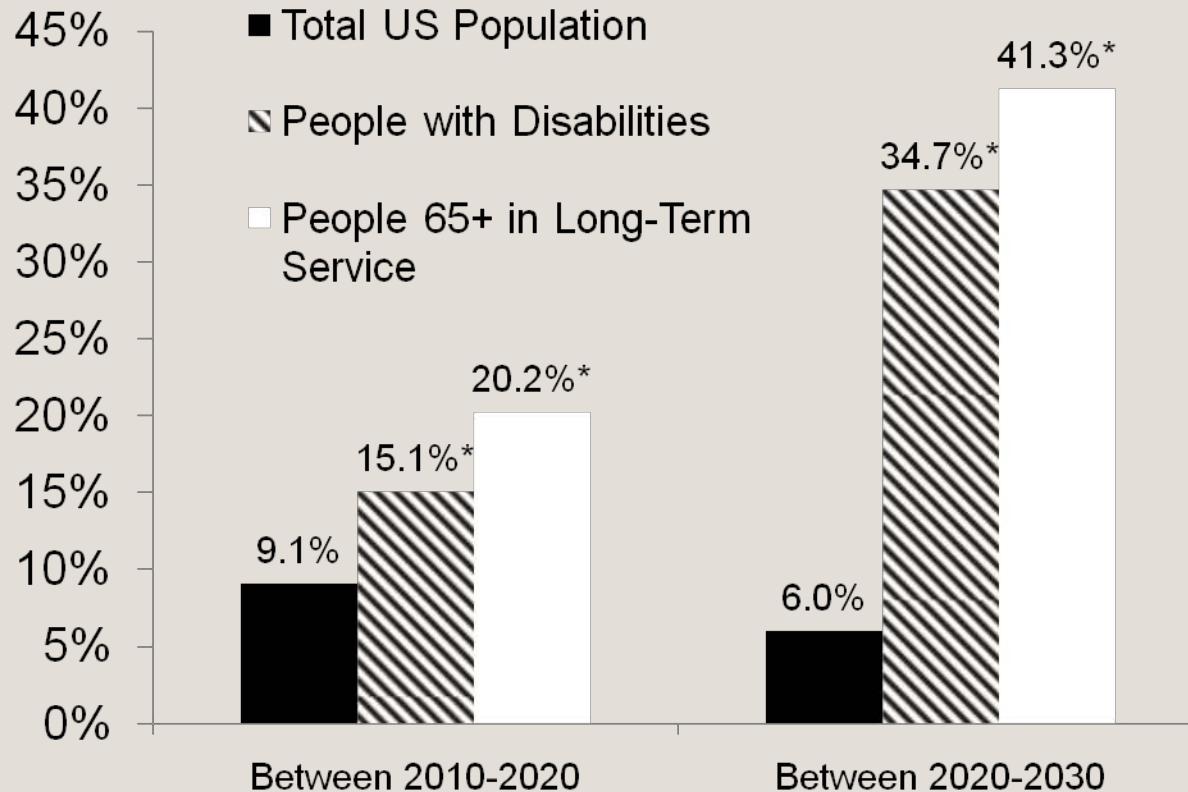
“The future ain’t what it used to be.”

Yogi Berra

If we were logical, the future would be bleak indeed. But we are more than logical. We are human beings, and we have faith, and we have hope.

Jacques Cousteau

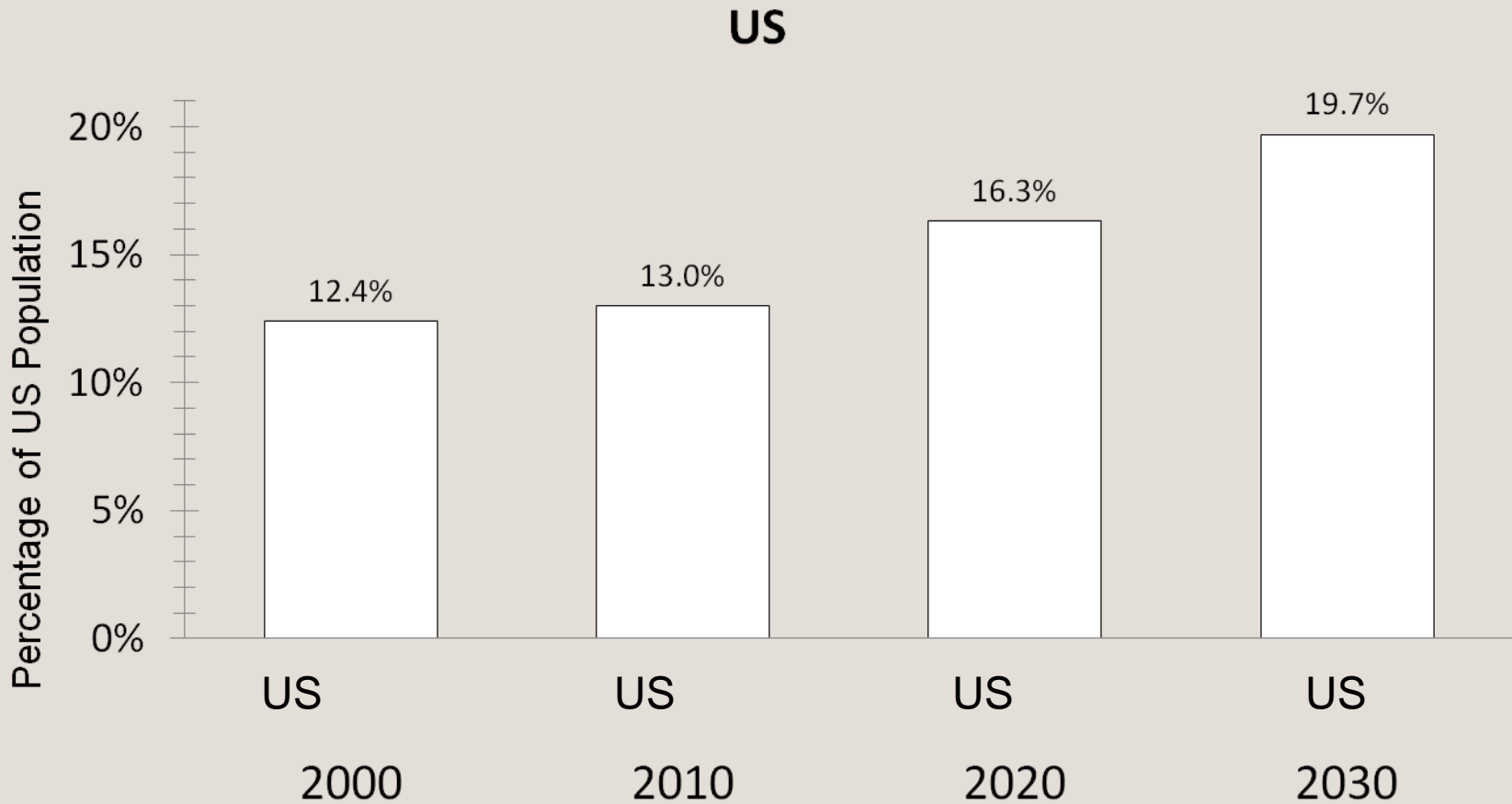
Population with Disabilities Will Grow at an Increasing Rate



American Community Survey, 2006,

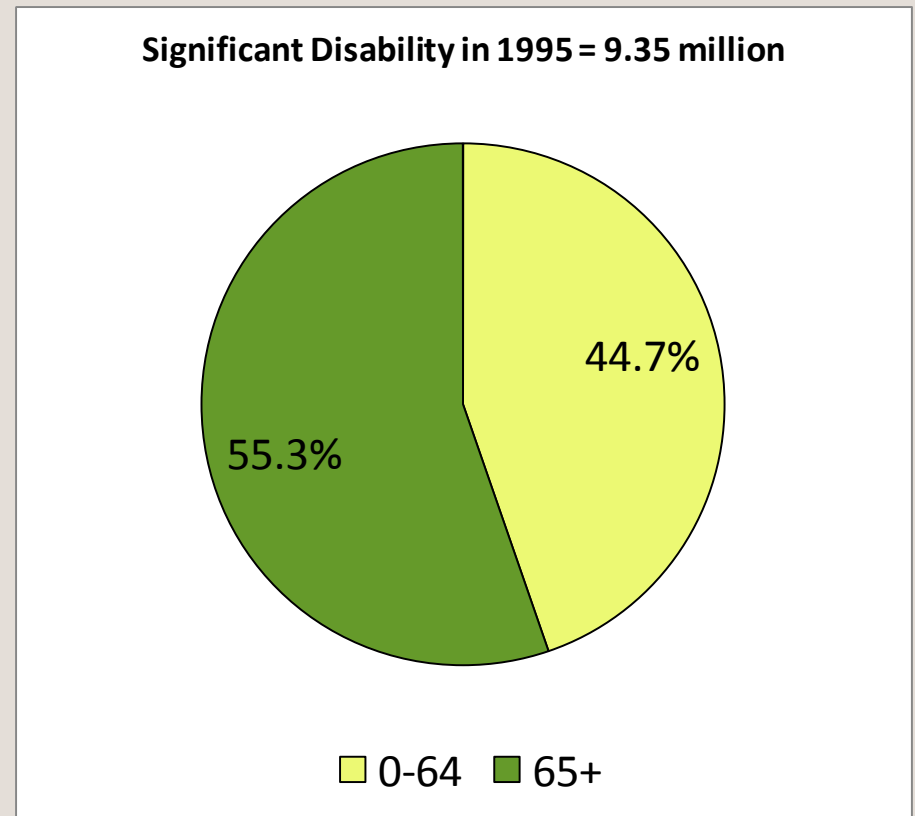
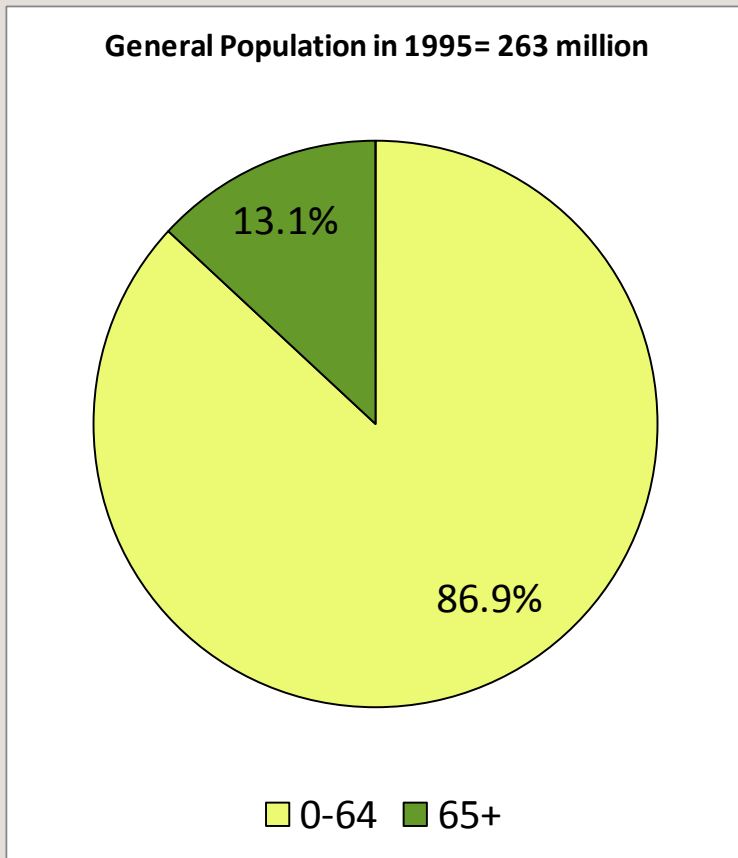
*Assume rates of disability and institutionalization remain the same as 2006

People with Disabilities Will Grow Primarily Because of the Growth in the US Population 65 Years and Older

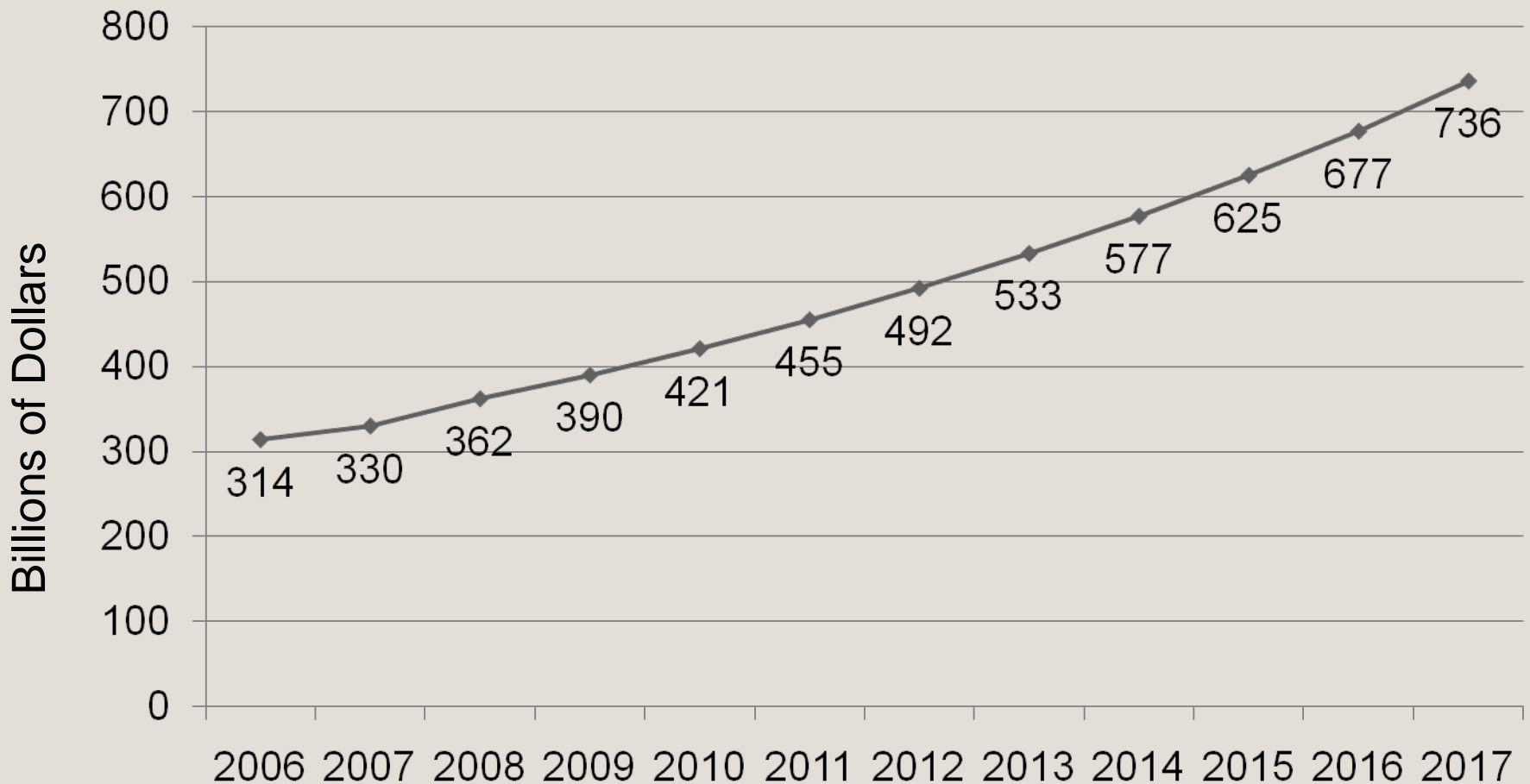


Source: US Census Bureau

People Who Are 65 and Older Are Much More likely to Needs Help from Others with Everyday Activities (ADLs and IADLs)

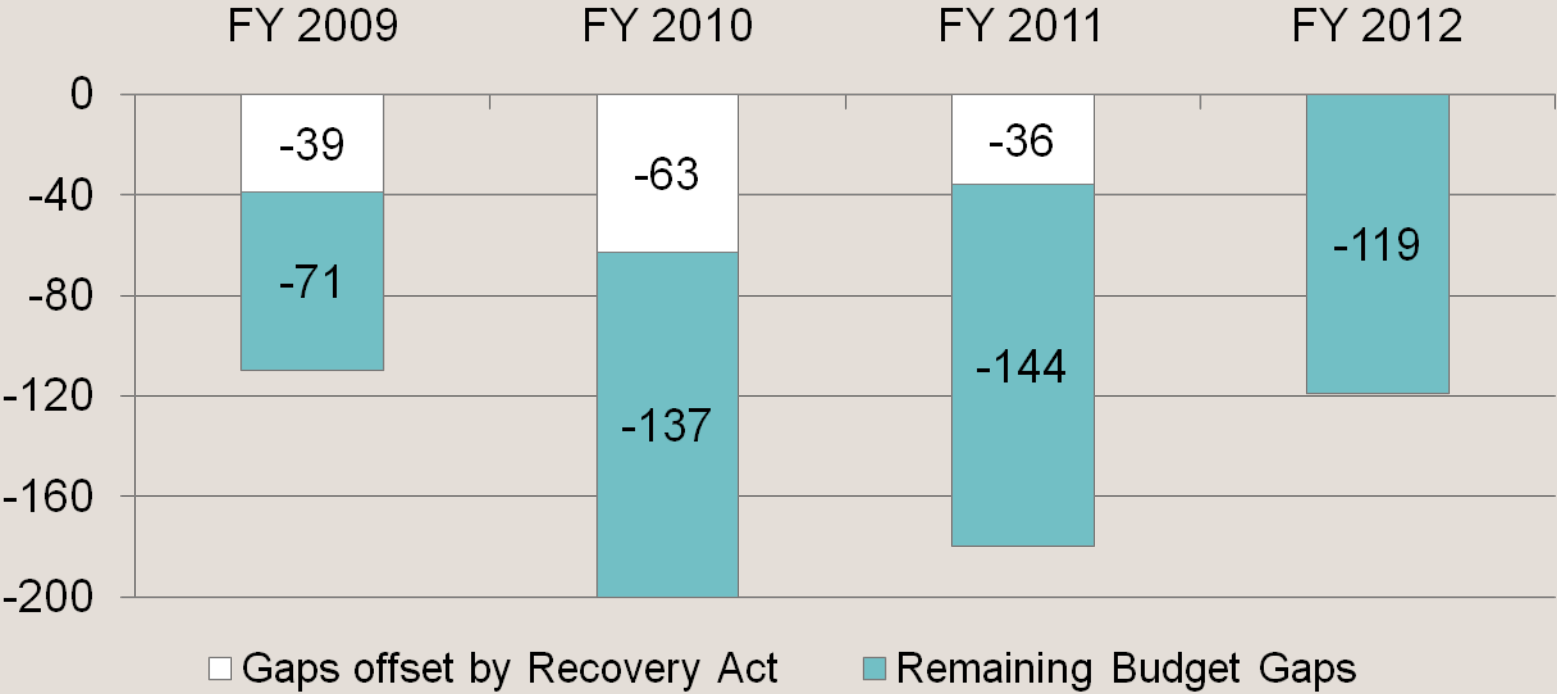


Because of the Demographic Trends Medicaid Spending is Projected to More Than Double Between 2008 and 2017



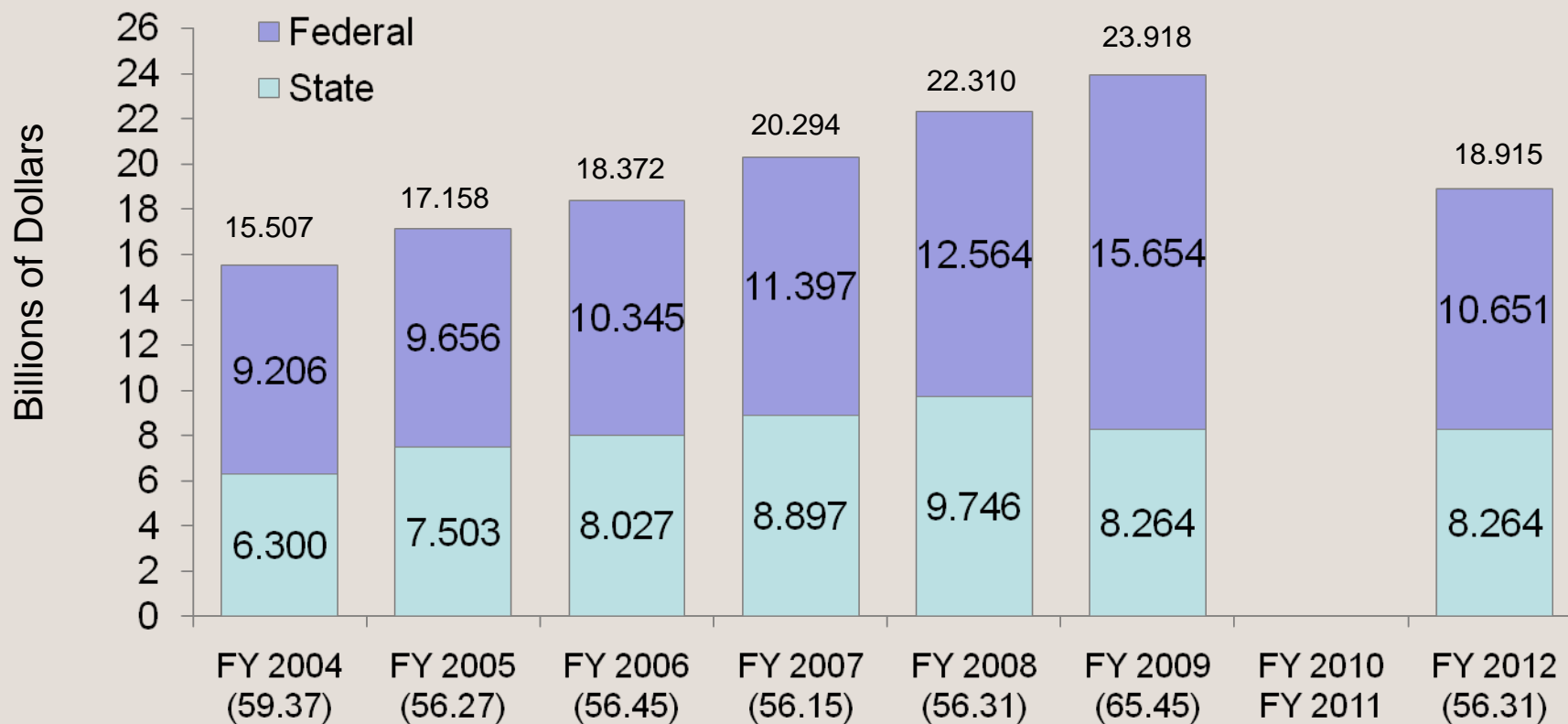
Source: Barbara Edwards, Health Management Associates (from CBO and CMS data)

But How Will States Pay for This with Total State Budget Shortfalls in the Hundreds of Billions?

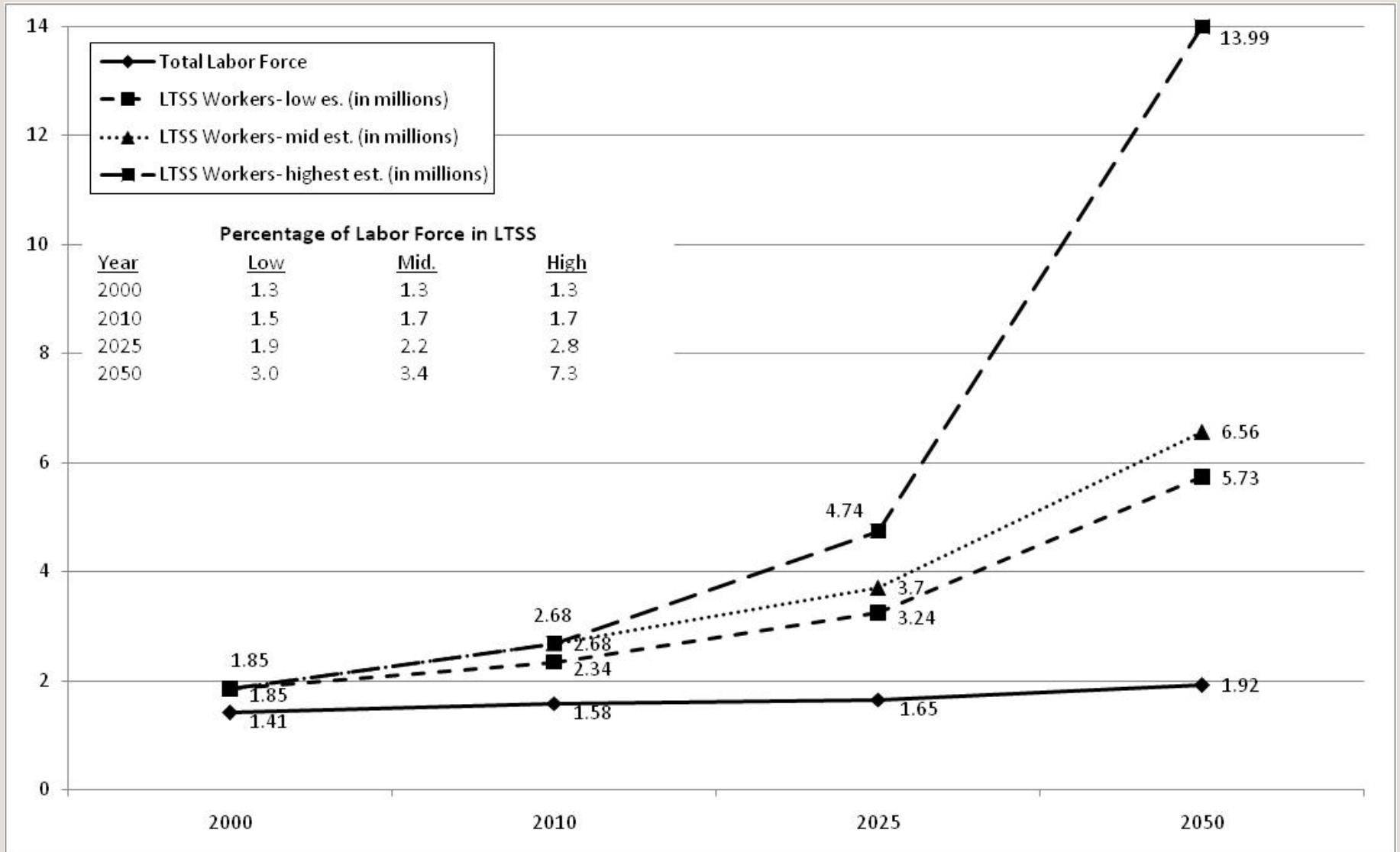


Estimate by Center on Budget and Policy P, June 29, 2010

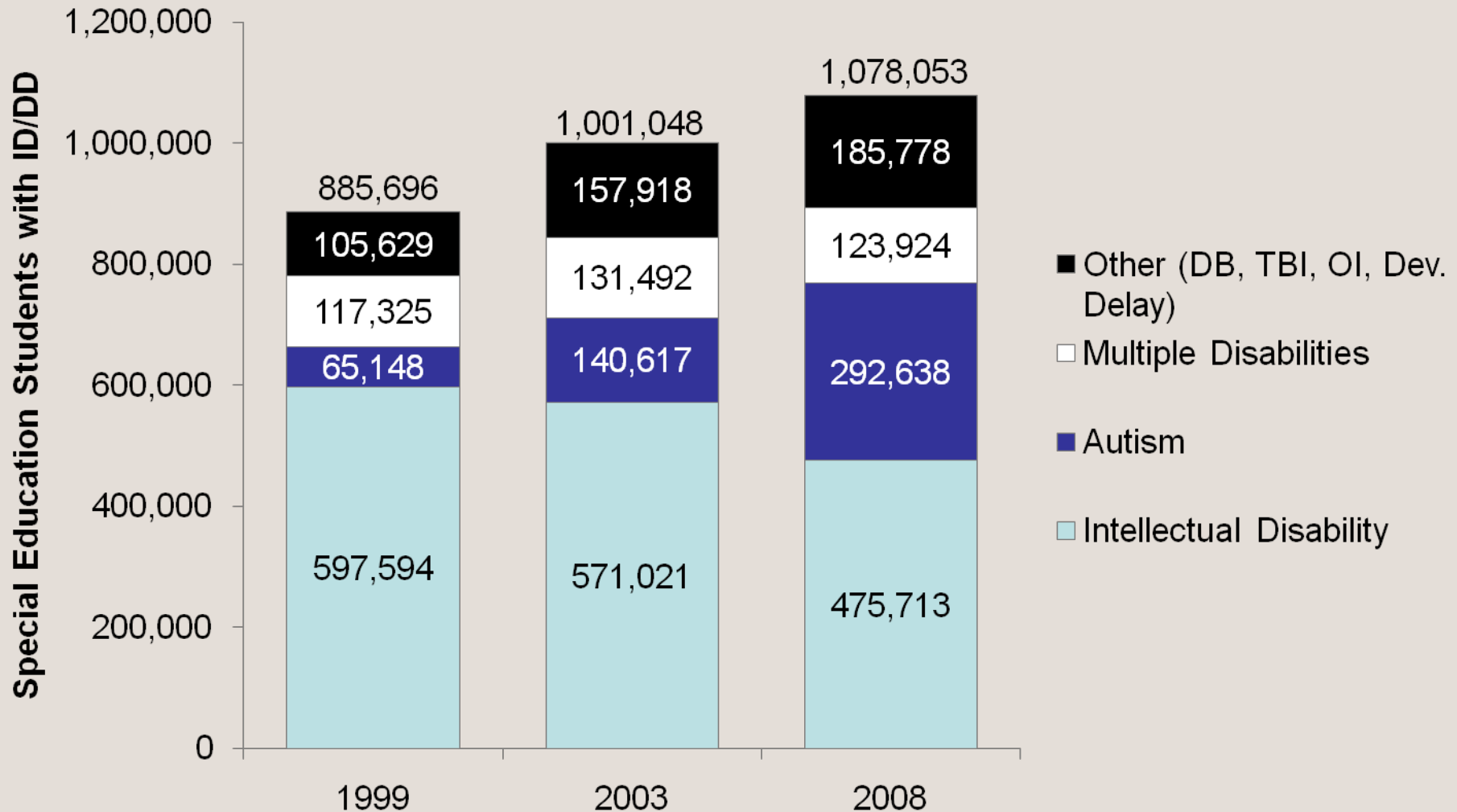
What Will Happen to Medicaid LTSS for Persons with ID/DD When Federal Cost-Share Returns to Normal?



And Who Will Provide the Support with Projected Growth in U.S. Labor Force (in hundred millions) and the Projected Demand for Persons to Provide Long-Term Services (in millions)?



What About the Increases in Children and Youth (6-21) Being Identified with Conditions Associated with ID/DD Services (+21.7% from 1999-2008)?



More and More People Are Waiting for Services

The Challenges of Financing Disability Services
May Not End with Recovery from the Great
Recession, But May Be:

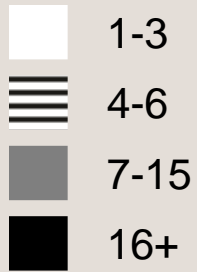
“The New Normal”

We Are Forced to Consider the Sustainability of Services We Have Developed

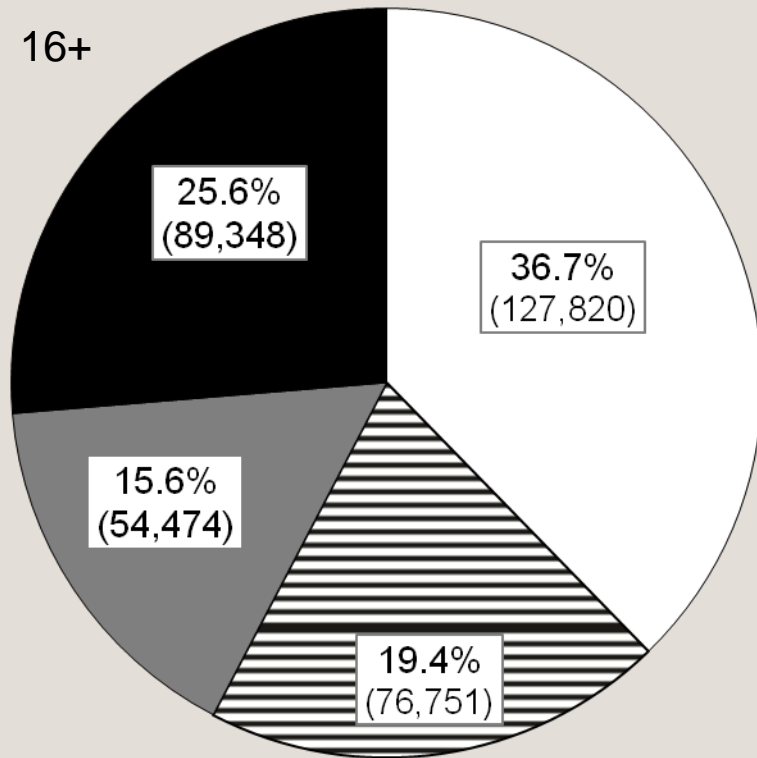
- What can we (and future generations) afford
- What can we justify based on:
 - Relative costs compared to others in need
 - Outcomes achieved for resources spent

What We've Done and Learned to Help Become More Sustainable

We've Moved Residential Services Recipients Out of Institutions to Homes in the Community

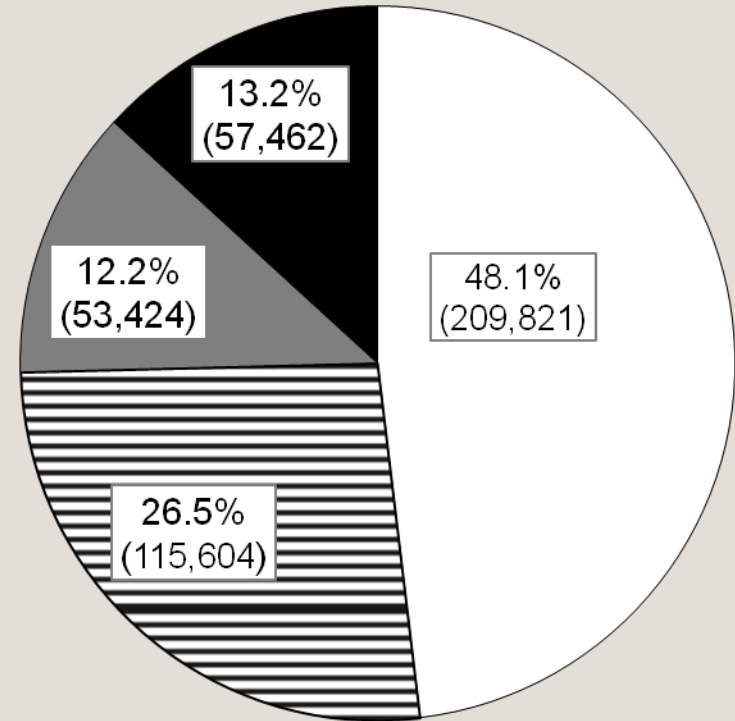


1998



Total = 348,393

2008



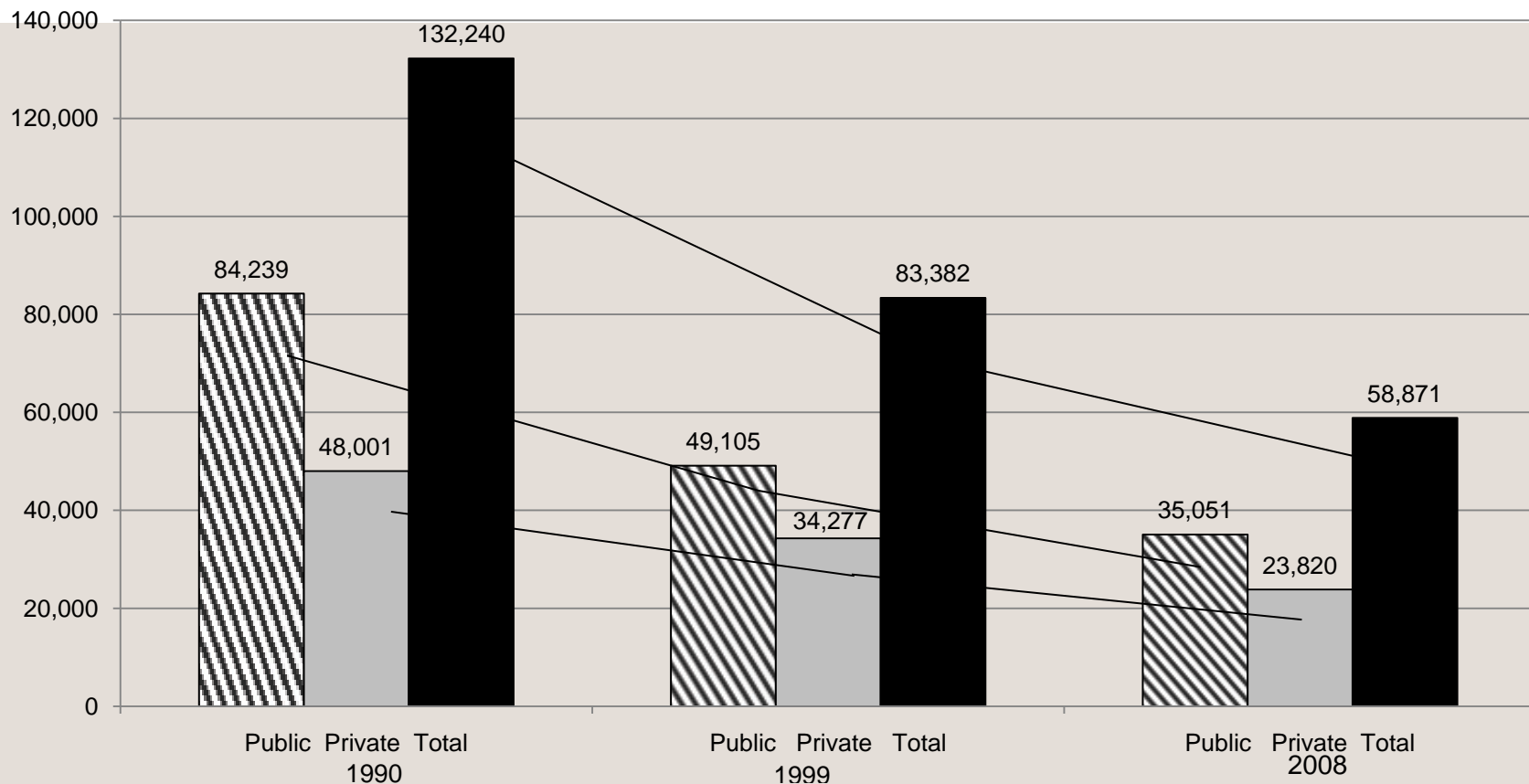
Total = 436,311

CDC/National Center on Birth Defects and Developmental Disability (2001):

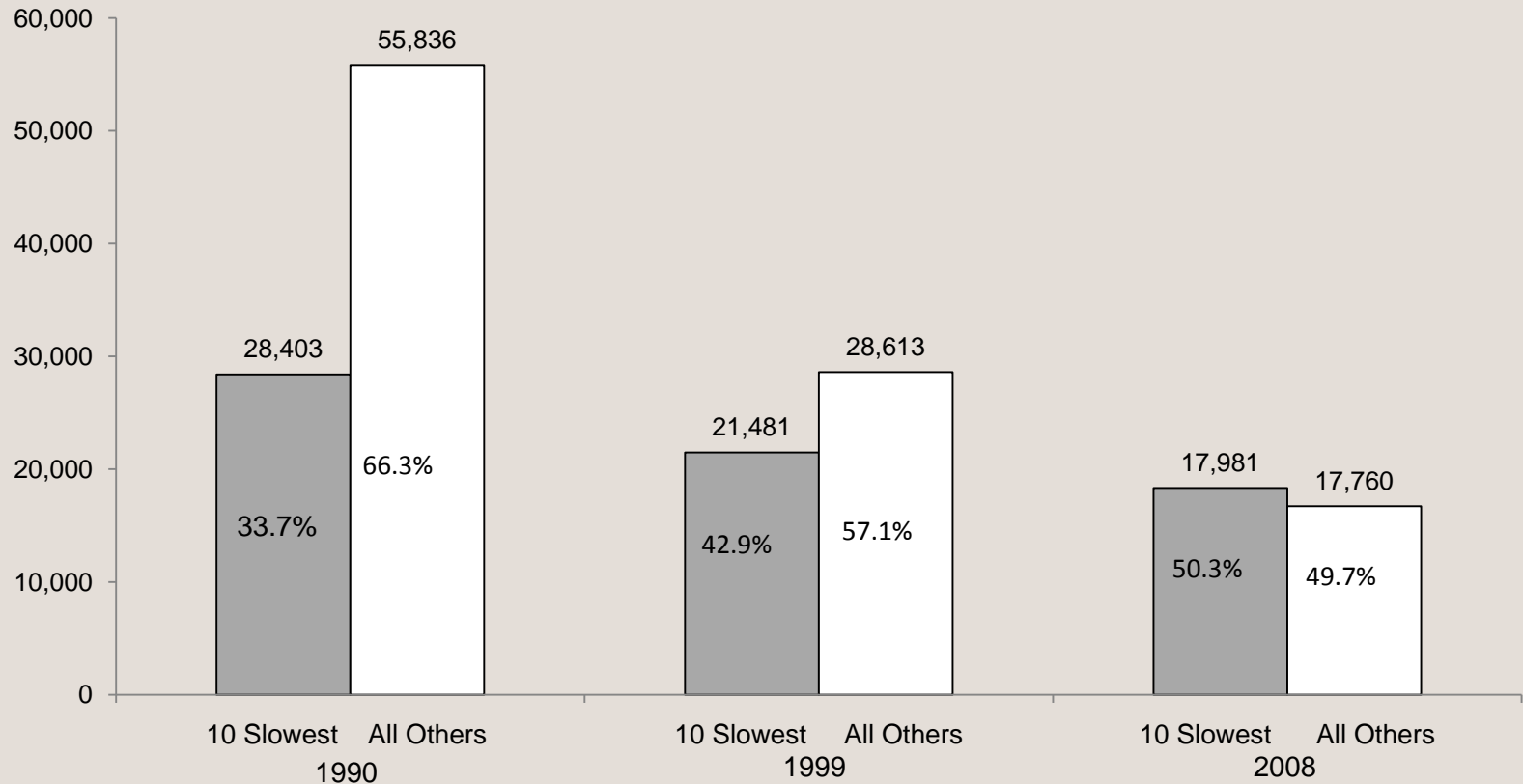
“Institutions and other forms of congregate care are inconsistent with positive public health policy and practice. They diminish people’s opportunities to realize the essential features of human well-being: choice, control, ability to establish and pursue personal goals, family and community interaction, privacy, freedom of association, and the respect of others.”

National Center of Birth Defects and Developmental Disabilities (2001, December.)
Healthy People 2010, Chapter 6: Vision for a decade. Atlanta: Centers for Disease Control and Prevention.

We Continue to Make Progress in Reducing People Living in Public and Private Institutions of 16+ Residents (but more slowly)

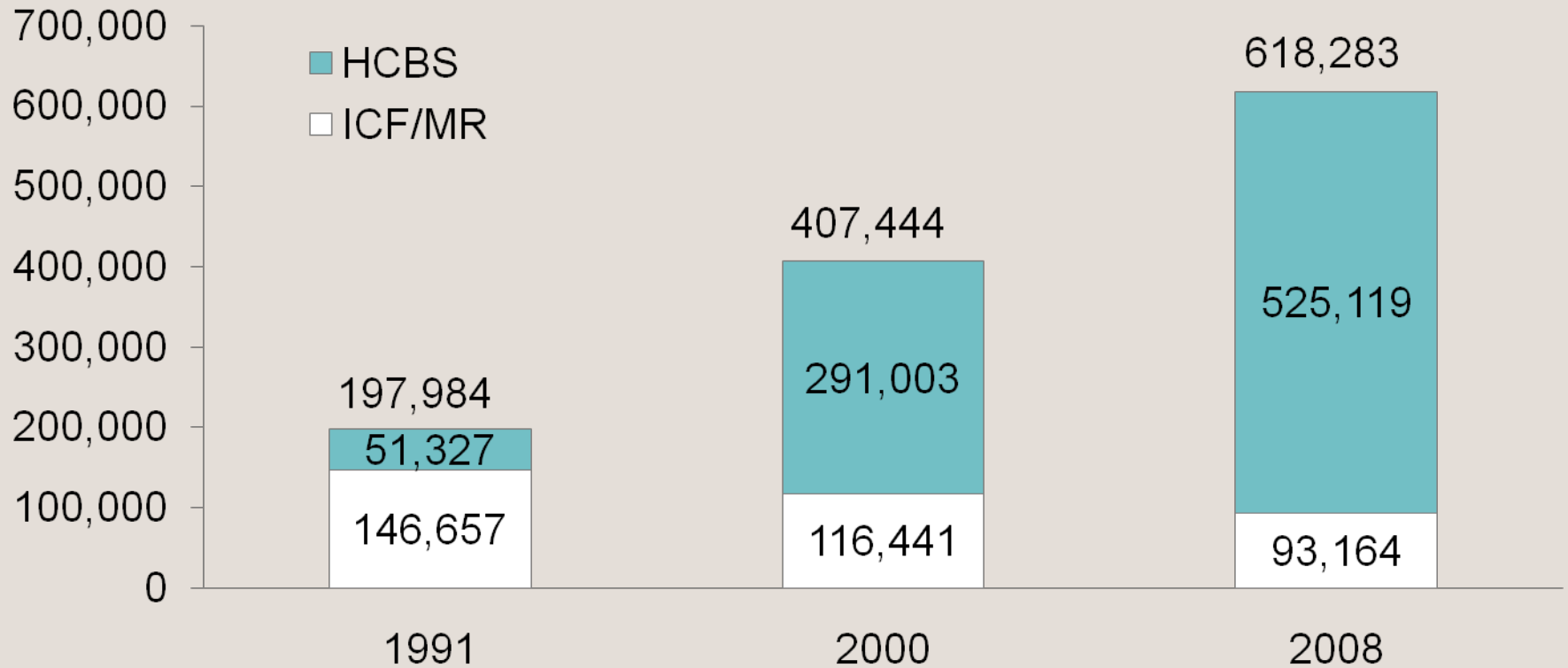


The Slowest Moving States Have Become the Primary Factor in Public Institution Depopulation (and DOJ has noticed)

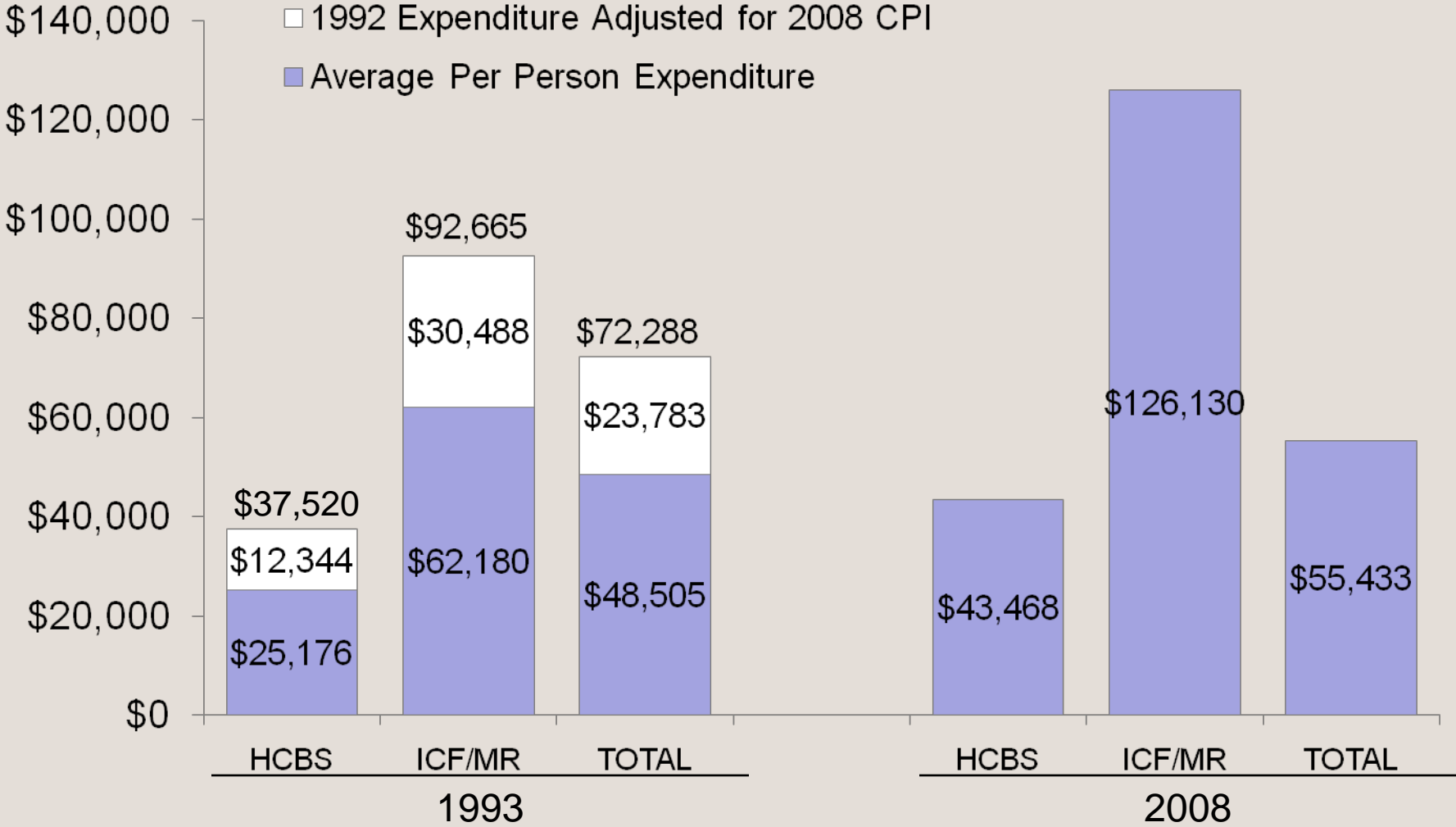


Slowest: AR, FL, IL, IA, MS, NE, NJ, NC, OH, TX

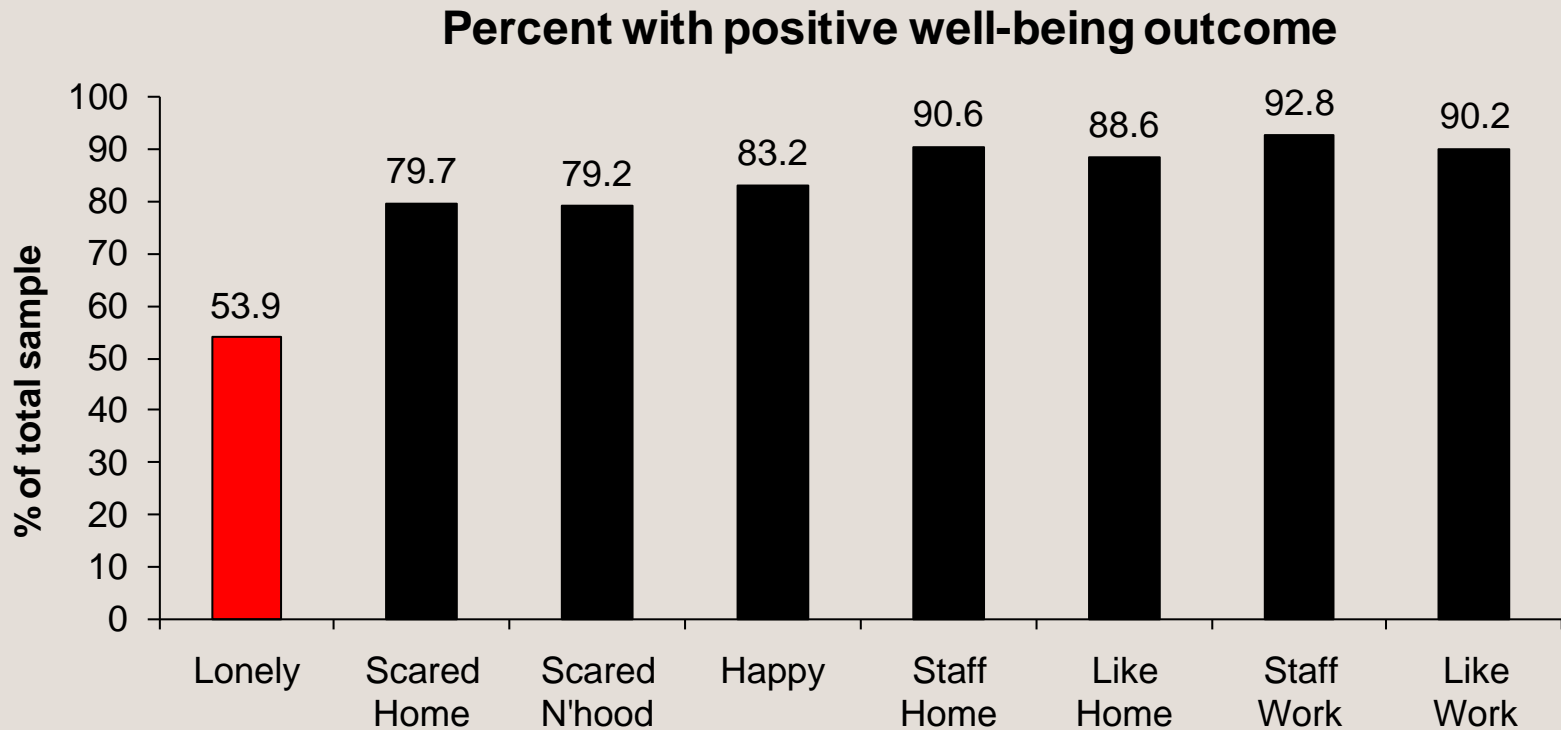
We've Moved People from Medicaid ICFs/MR to Home and Community Services and Greatly Increased HCBS



By Shifting from ICF/MR to HCBS, Average Real Dollar Per Person Annual Expenditures for Medicaid Long-Term Services and Supports Decreased by 30% between 1993 and 2008



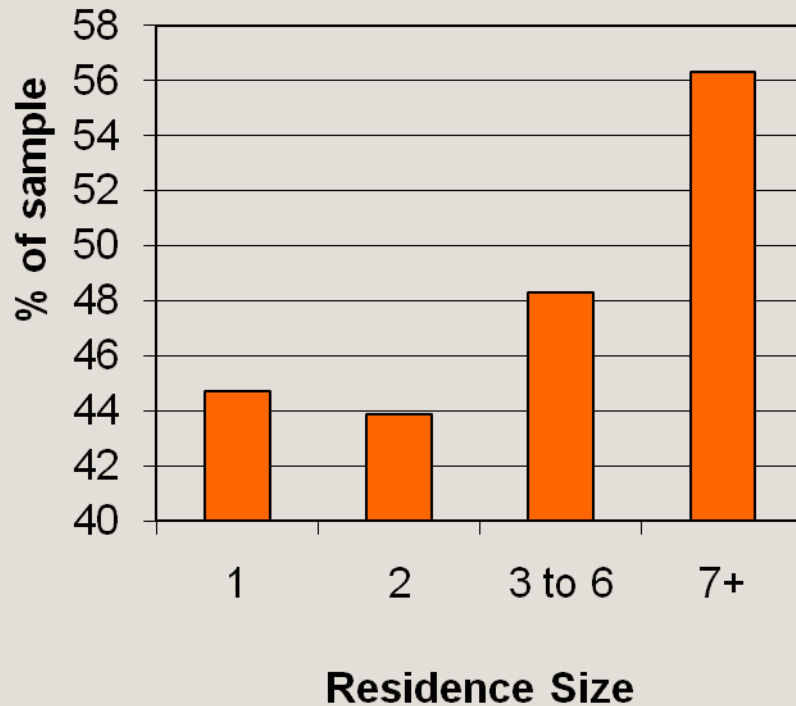
People with ID/DD Are Generally Positive About Their Well-Being in Places of 15 or Fewer Residents; Loneliness is the Most Widespread Problem.



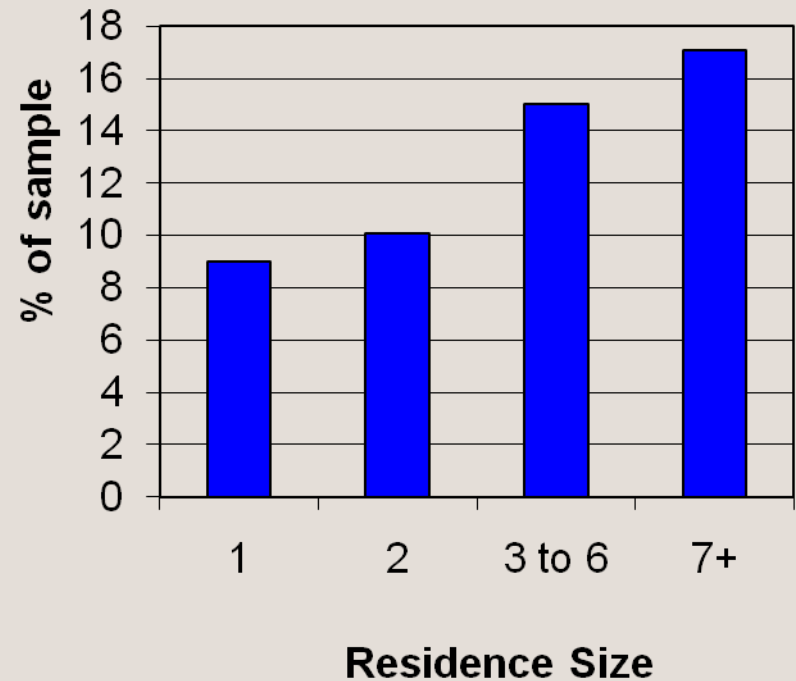
Source: National Core Indicators; 6 States

We've Learned That Home Size Affects Perceptions of Well-Being

% Lonely Sometimes or Often

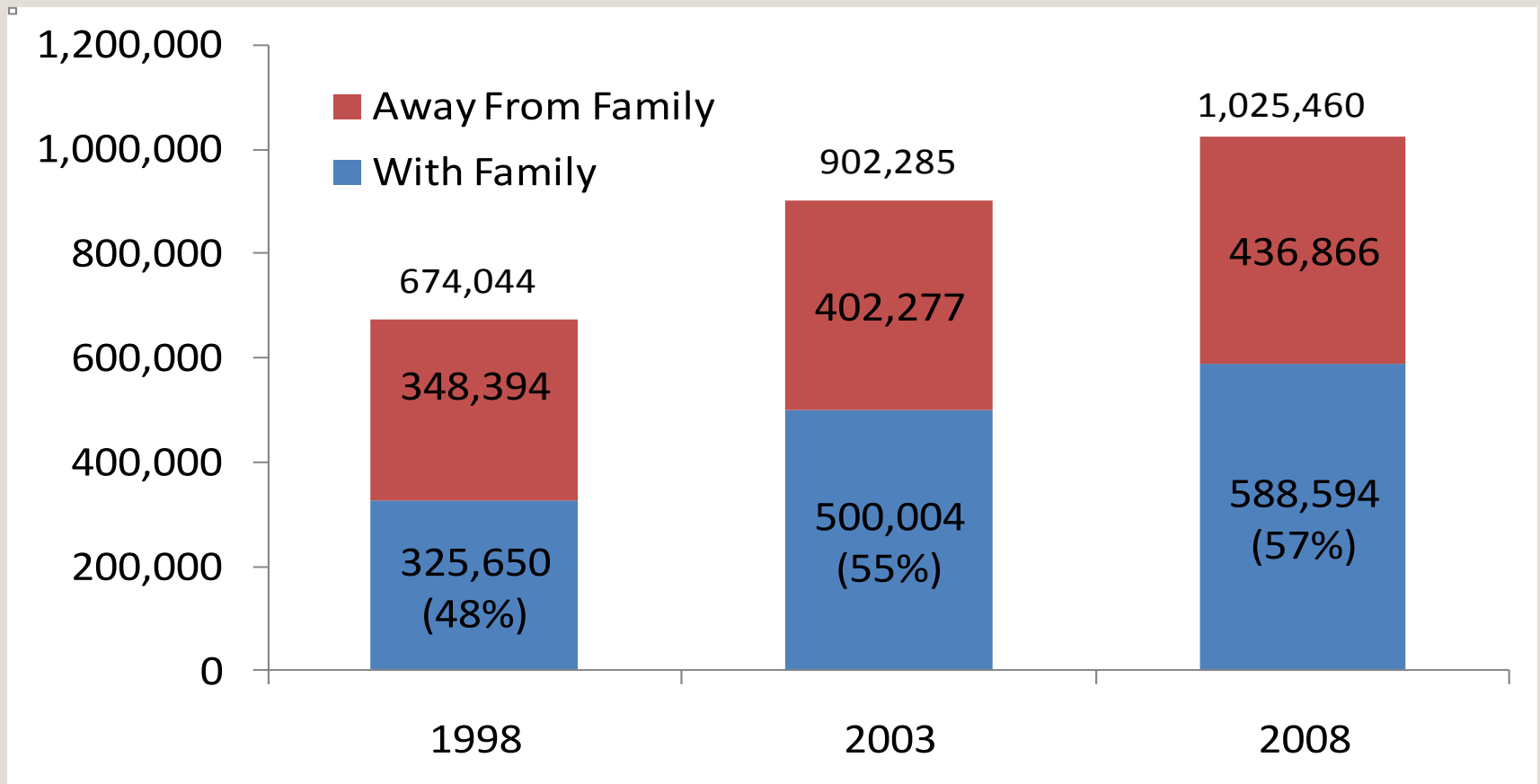


% Like Home? No or In-Between

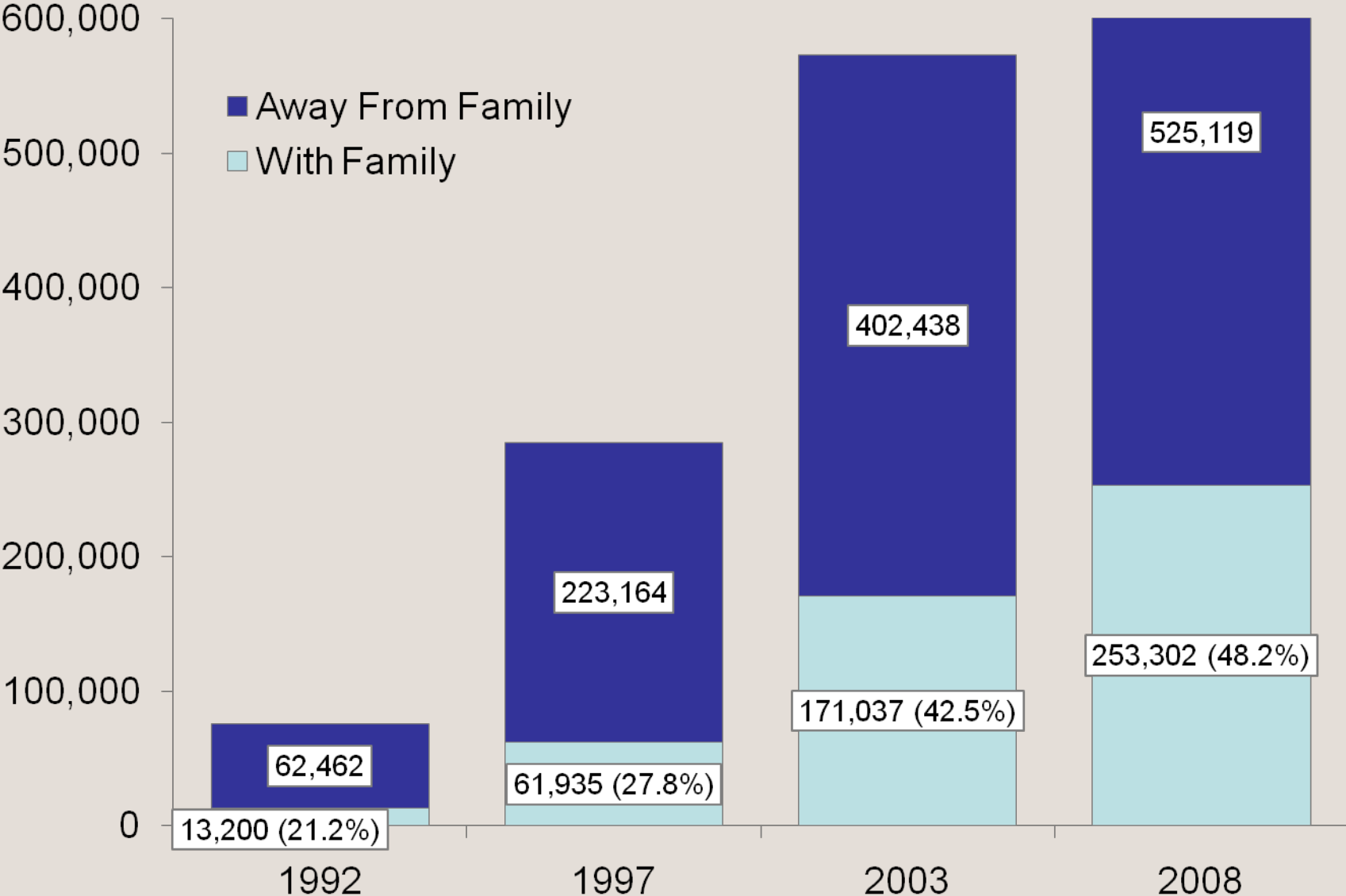


Source: National Core Indicators; 6 States

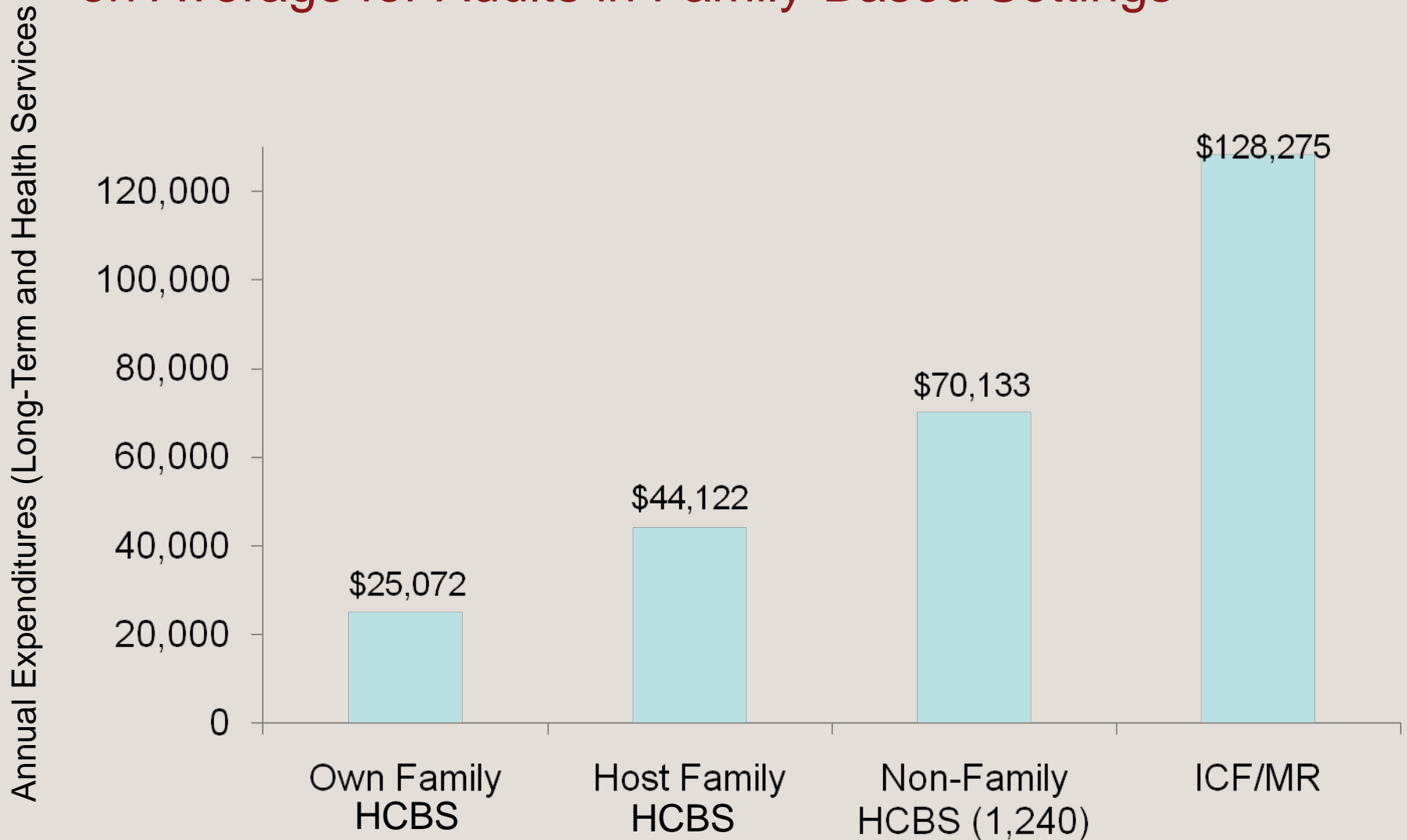
We Have Increased the Number of People Receiving ID/DD Services and Supports While Living with Family



We've Supported A Rapidly Growing Number and Proportion of HCBS Recipients Who Are Living with Family Members



We've Found That Medicaid Expenditures Are Much Lower on Average for Adults in Family-Based Settings



Source: MSIS and NCI data from 4 states (1,240 Individuals)

We've Seen That Adults Report Good Quality of Life Outcomes While Living with Family (6 States)

- No difference on:
 - Feeling afraid in your neighborhood
- Better results for those NOT living with family on:
 - Home staff nice & polite
- Better results for those living with family on:
 - Loneliness
 - Feeling afraid at home
 - Feeling happy
 - Liking home

Source: National Core Indicators

“Taking Stock with Where We Are:” How Well Do We Reflect Basic Qualities of Sustainable Systems?

- Sustainable systems are economically viable for the long term.
- Sustainable systems carry out functions valued in the society.
- Sustainable systems have active and mobilized constituencies.
- Sustainable systems avoid demanding ever greater shares of public resources by being efficient and effective.
- Sustainable systems have built-in capacities to gather, analyze, report and use data to improve performance.
- Sustainable systems are flexible and change to new demands.
- Sustainable systems accommodate shifting priorities within society.
- Sustainable systems effectively develop future generations.