

# Key Indicators and Goals for Successful Aging with A Disability

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“Our goal is for all Americans to live healthier,  
more prosperous, and more productive lives”  
–Kathleen Sibelius, Secretary of Health &  
Human Services, DHHS

# A long, healthy, glad, prosperous, participatory, and productive life

- Irish blessing: “May you live a long life, full of gladness and health, with a pocket of gold as the least of your wealth. May the dreams you hold dearest be those that come true, and the kindness you spread keep returning to you”
- longevity, life satisfaction, health, income adequacy, asset accumulation, life planning, life fulfillment, social participation, productivity, successful aging

# Aging

- Aging is heterogeneous—we age at different rates
- Aging is plastic—its progression can be slowed
- Genetics, behavior, and environment
- Pathologic versus normal aging
  - genetic: progeria
  - behavior: inactivity, eating poorly, unhealthy lifestyle choices (smoking excess, alcohol consumption), and lack of social participation
  - environmental: sunlight and skin cancer; poverty

# Elements of successful aging

- Living well **physically**, enjoying physical activity and feeling good physically
- Living well **psychologically**, without undue anxiety and depression, good cognitive functioning
- Living well **socially** in the community, with robust family and social networks, high social participation
- Living well **economically**, with sufficient income and assets to live comfortably

# Models of Successful Aging

- A popular formulation is Rowe & Kahn (1998)
- You can live well to a very old age if you work at it
- Successful aging is enjoying a low risk of disease and disease-related disability, maintaining high mental and physical function, continuing an active engagement with life

# Models of Successful aging

- One view of successful aging: compress morbidity and disability to the very end of the lifespan (Fries & Crapo, 1995)
- Like the proverbial “one horse shay,” after a century or so, everything fails at once and we just fall apart and cease to exist
- A lifespan spent in the absence of disease and disability

# Compression of morbidity

- Chakravarty and colleagues (2012) followed a cohort of college alumni who at baseline were 68 years old starting in 1986 for two decades.
- Those with low risk (nonsmokers, low BMI, and vigorous exercise) had onset of disability 8.3 years later than the high risk group.

# Compression of morbidity

- This is a sample of college alumni, mostly male
- Shows what can be achieved in an educated population
- Many studies of mortality and disability report an SES component (education and income), in addition to risk factors of diet, smoking, and exercise

# Successful aging

- Manton's dynamic equilibrium: the progression and severity of disease can be slowed, leading to improved longevity and reduced disability at older ages. Health care may not cure chronic disease, but it may reduce disability.
- Some research suggests that older Americans are aging more successfully over time: while the prevalence of many diseases is not being reduced, disability and mortality are being reduced (Freidman and Martin, 2000)
- In the older population, disability has declined more for well-educated, higher income, and younger populations (Schoeni, Freedman, & Martin, 2005), increasing disparities

# Unsuccessful aging

“The World is in the midst of a rising pandemic of mental disorders and associated chronic diseases and disabling conditions...rising at an alarming rate” (Kramer, 1980)

- Gruenberg “The Failures of Success”
- The idea is that health care prolongs life without curing disease, leaving people to live longer with cognitive and physical disabilities
- Basically, perspectives on successful aging do not consider aging with a disability to be a good thing

# Longevity gains for people with disabilities

- In the past, persons with certain severe early-onset disabilities—intellectual disabilities, spinal cord injury, cerebral palsy and others—did not survive long enough to experience aging.
- Longevity gains for persons with ID are especially large and some are now living beyond midlife and into older ages.
- Advances in medical treatment and management and rehabilitation have been essential contributors
- Improvements in the social and political environments of people with disabilities, including reduced institutionalization and increased social participation and the diffusion of public health knowledge have also contributed greatly.
- In the field of disability, aging with a disability is a desirable outcome, and one that can be improved

# Successful aging with a disability

- Trieschmann offered a model based on the perspective of persons aging with a disability in which maintaining health and function is seen as a “balancing act” that becomes more tenuous with age. Biological, psychological, and social variables affect this balance. It is an adaptive model in which individuals learn health and functional survival skills, and function better in supportive environments. A key emphasis in Trieschmann’s model is maintaining productivity and meaningful social participation as people with disabilities age
- Not so different from Baltes & Baltes model for successful aging in which age-related decrements are accepted and people learn to do the best with what they have

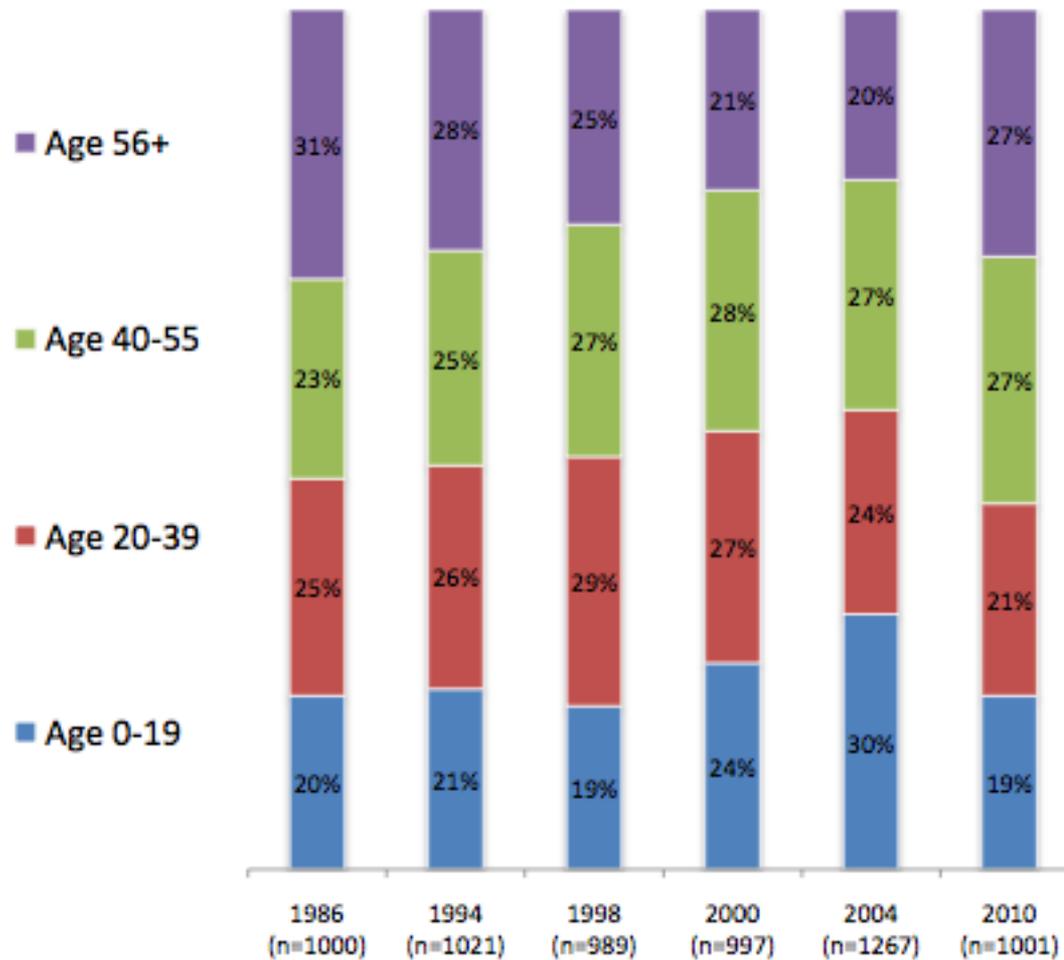
# Successful aging with a disability

- Kemp & Mosqueda note that the field of rehabilitation has stressed a “use it or lose it” approach to enhance function
- They note that a “use it or lose it” approach puts some people at risk as they age
- They suggest a “conserve it and preserve it” approach may be better in some cases

# Aging with disability is common

- Aging with disability is quite common
- Larson and colleagues used the 1994/95 NHIS-D and estimated that 1.5 million adults ages 18 and older have ID/DD with onset before age 22
- This is consistent with more people with ID/DD surviving into adulthood

# Age of onset of disability in adults



Source: Harris surveys of adults with disabilities

# 13 million adults with early-onset disability

- I applied the Harris distribution of onset to the 2010 NHIS estimate of 32 million adults with complex activity limitation
  - 6 million adults with child-onset disabilities (ages 0-19)
  - 7 million adults with early adult-onset disabilities (ages 20-39)

# Goals

- What are the key goals for aging successfully with a disability?
- Existing models and research give us a starting point
- **Health & health promotion**
  - **minimizing health risk factors** of overweight, inactivity, and smoking
  - retaining **high cognitive and physical function** by using the mind and body (use it or lose it)
- maintaining **high life engagement** through active and extensive social networks

# 2005 Surgeon General Call to Action to Improve the Health & Wellness of People with Disabilities

- GOAL 1: People nationwide understand that persons with disabilities can lead long, healthy, productive lives.
- GOAL 2: Health care providers have the knowledge and tools to screen, diagnose and treat the whole person with a disability with dignity.
- GOAL 3: Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles.
- GOAL 4: Accessible health care and support services promote independence for persons with disabilities.

# Surgeon General 2012

- Lead healthier lives through better nutrition, regular physical activity, and improving communities to support healthy choices
- 2012 Report on Preventing Tobacco Use Among Youth and Young Adults

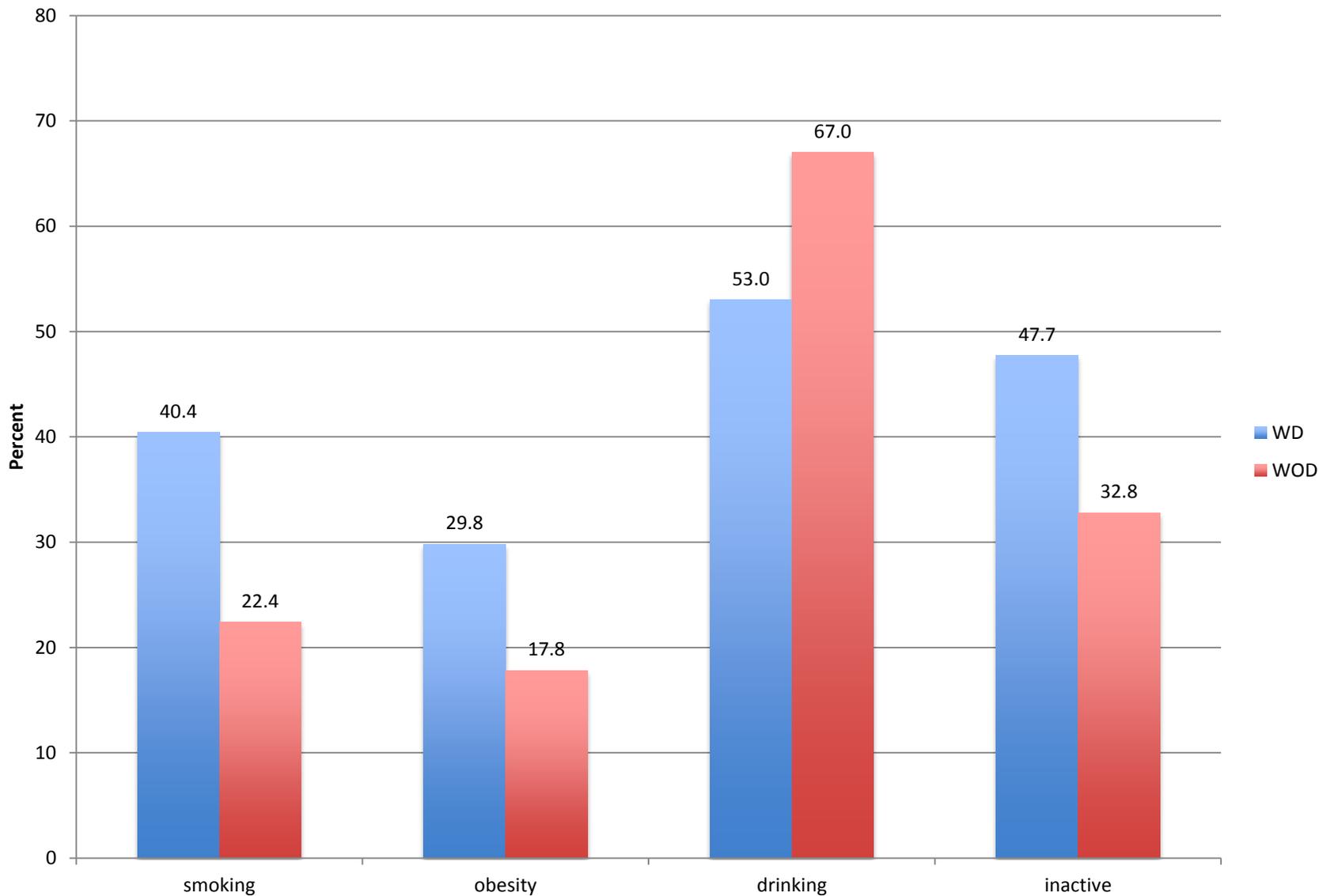
# Key goals

- Improve health & health promotion & access to care
- Improve participation in society
- Improve financial preparedness to avoid aging with too few financial resources
- Improve LTSS and aging in place
- Improve availability of assistive technology and accessible environments
- Reduce the social determinants of poor health and disability

# Absence of chronic disease

- Adults with disabilities ages 18-44 show little aging-related chronic disease (LaPlante & Carlson, 1996)
- Musculoskeletal impairments and conditions are the most common disabling conditions
- Majority have low back or joint pain

# Risk factors among adults 18-44, by disability. NHIS, 2001-2005



# Access to health care

- Some data suggests comparable access for young adults with disabilities
- young adults with disabilities ages 18-44 are more likely to have a usual source of medical care (83.8% vs. 78.4%,  $p < .001$ ) but slightly less likely for that to be a doctor's office (72.3% vs. 79.4%,  $p < .001$ ) (NHIS 2001-05)
- 22% are uninsured, same as those without disability

# Preventive care

- Young adults with disabilities are twice as likely to get flu shot (21.4% vs. 12.4%)
- Women slightly less likely to have had a pap test in past 3 years (79.5% vs. 84.3%)
- Equally likely to have had a mammogram in past 2 years (32%)

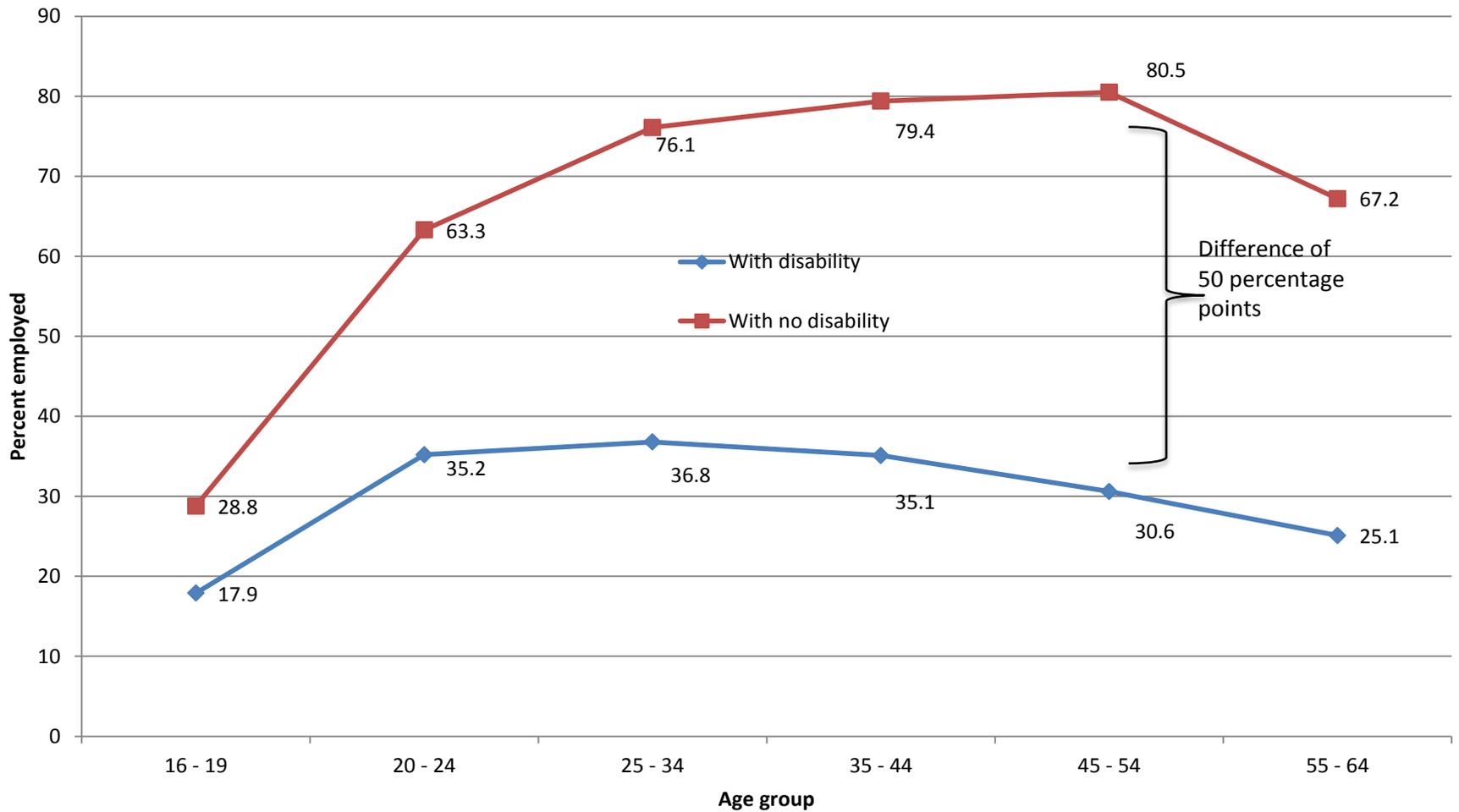
# Right medical advice

- Often, interactions with health professionals and attitudes they possess toward disability are problematic, resulting in young adults not getting the right medical advice, including not enough emphasis on health promotion and disease prevention, as discussed by Iezzoni (2011, Health Affairs)

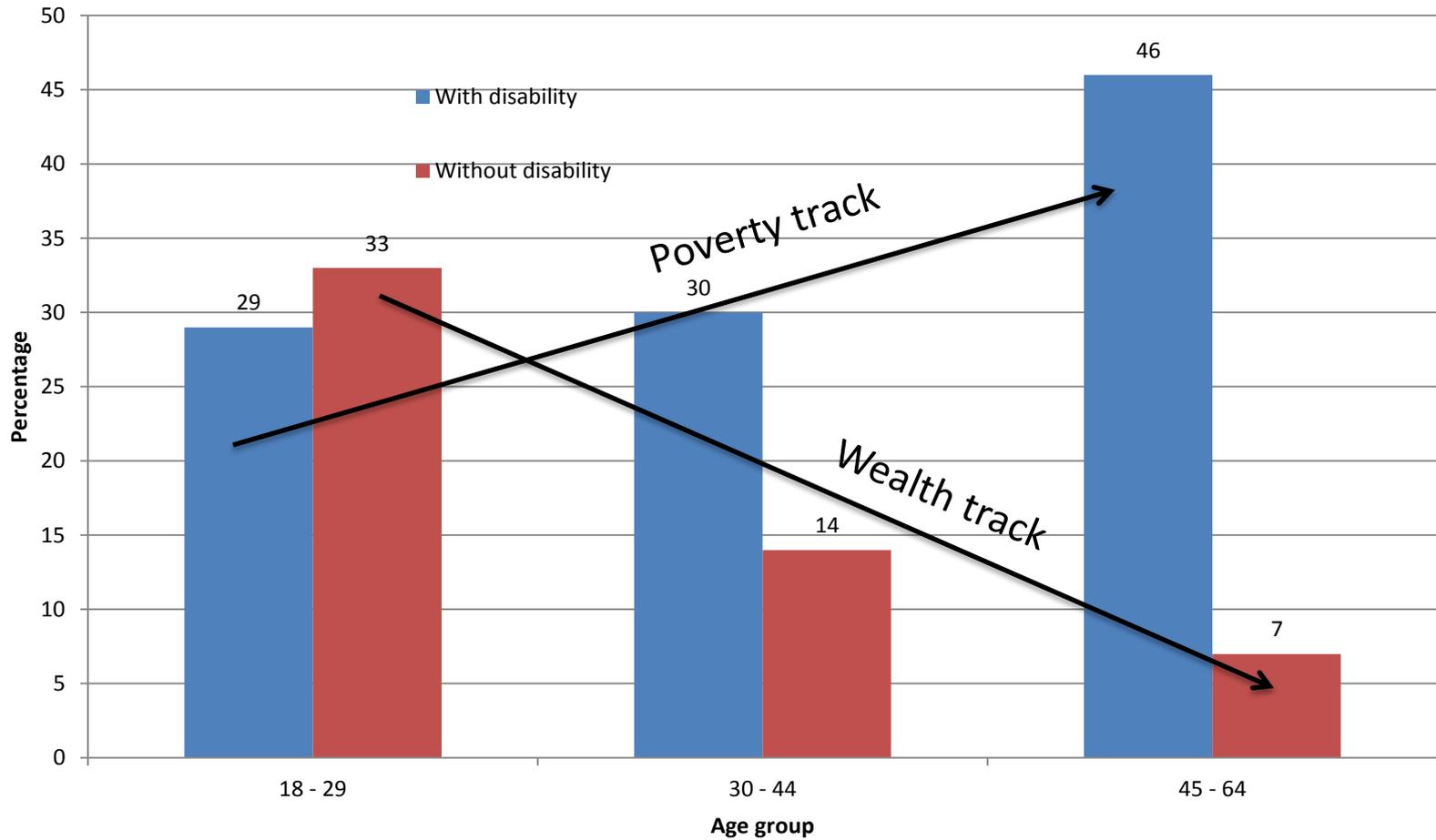
# Life engagement

- Work is an important way adults participate
- It is also the foundation for financial preparedness for aging

**Figure 2. Employment rates of adults with and without disability, 2009  
(CPS)**



**Figure 3. Percentage with family income under \$15,000 (Harris 2010)**



# LTSS & aging in place

- Do better at supporting the care needs of persons with disabilities and their caregivers
- Many states are not using the options available under Medicaid to provide LTSS
- These tend to be the poorer southern states
- Hopefully, more states will use the Community First Choice option under health care reform

# Assistive technology & accessibility

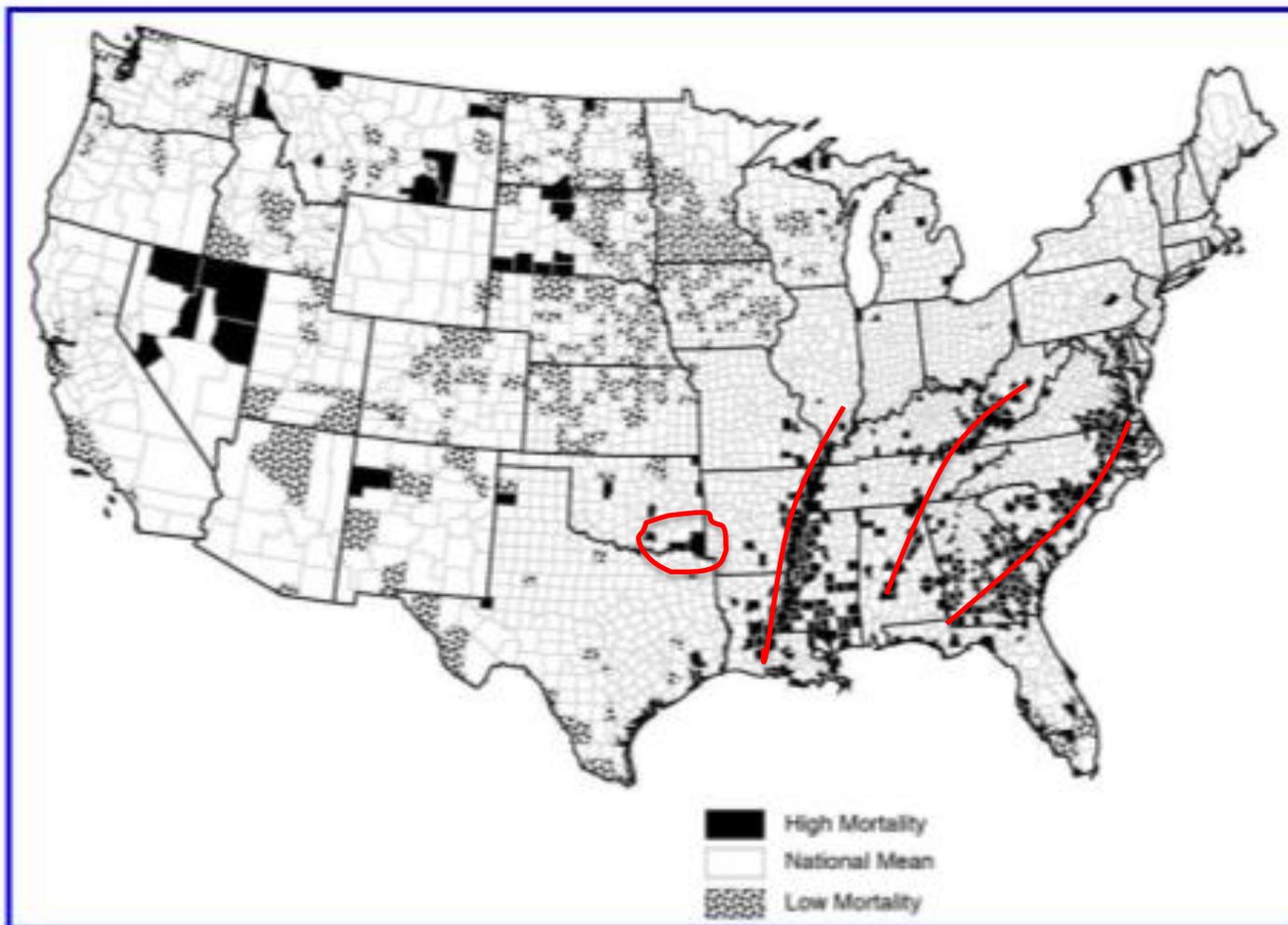
- AT/home modifications are key for independence but are underfunded
- Difficult for people with disabilities to afford them

# Social determinants

- Baltes & Baltes (1990) reminds us: aging takes place in a social context, and an ecological perspective is useful
- Consideration of individual characteristics are important, but the social determinants of these characteristics need to be addressed
- Living conditions vary, and people can adapt to them to some degree, but living conditions set limits on successful aging



# Persistent mortality patterns

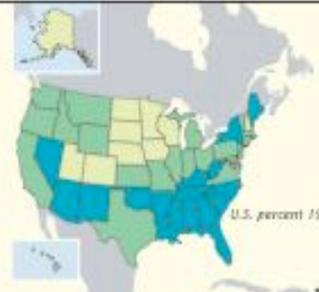


US counties with high or low age-adjusted mortality rates in at least four of seven 5-year periods from 1968 to 2002. (Cossman et. al, 2007). High is  $>1$  SD above national mean; Low is  $>1$  SD below.

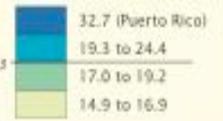


**Figure 5.**  
**Disability Status: 2000**

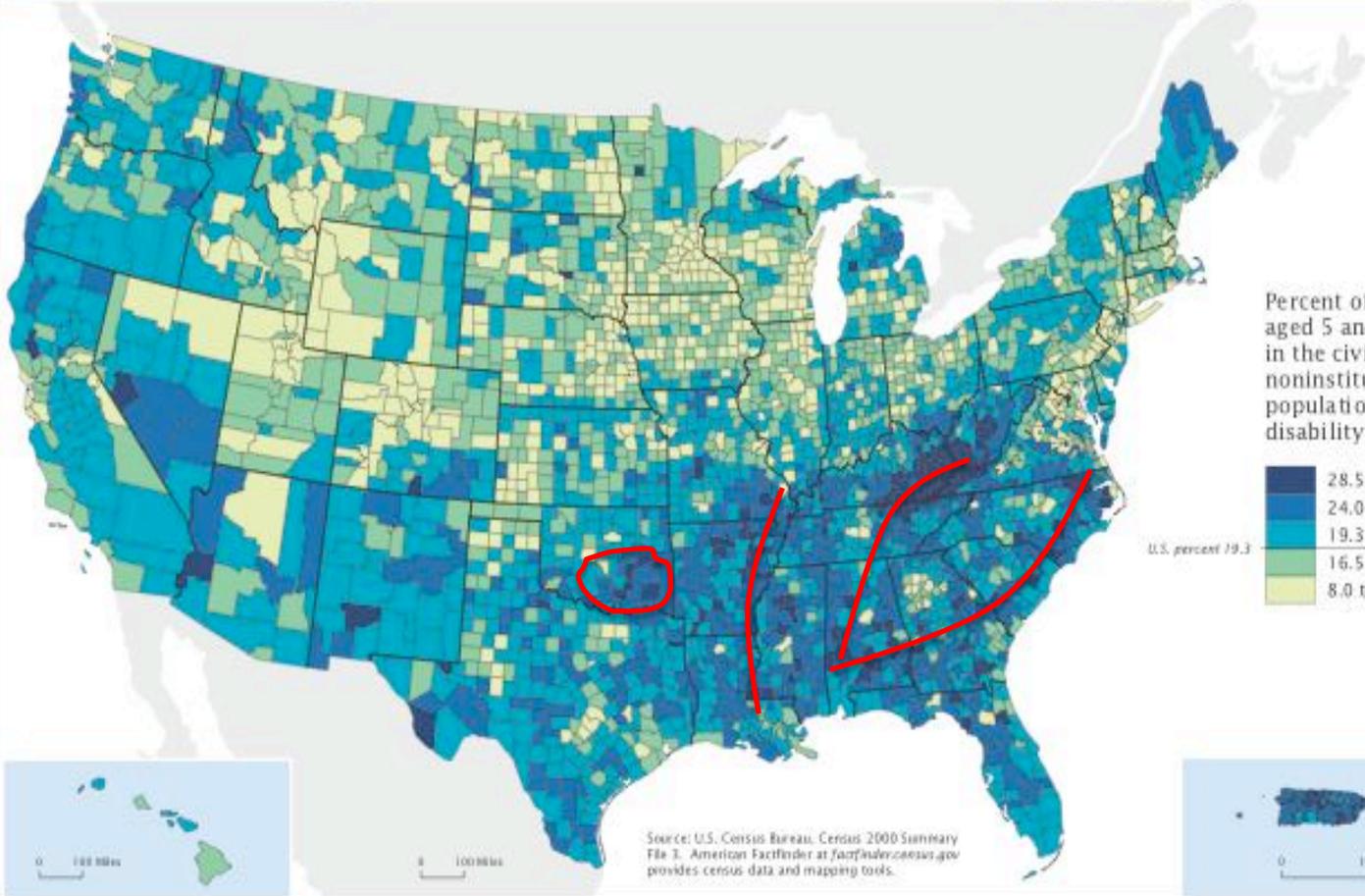
*(For information on confidentiality protection, sampling error, nonsampling error, and definitions, see [www.census.gov/prod/cen2000/abc/rf3.pdf](http://www.census.gov/prod/cen2000/abc/rf3.pdf))*



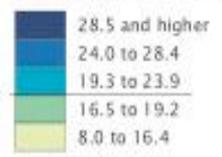
Percent of people aged 5 and older in the civilian noninstitutionalized population with any disability by state



U.S. percent 19.3



Percent of people aged 5 and older in the civilian noninstitutionalized population with any disability by county



U.S. percent 19.3

Source: U.S. Census Bureau, Census 2000 Summary File 3, American Factfinder at [factfinder.census.gov](http://factfinder.census.gov) provides census data and mapping tools.

# Disability and premature death rates are geographically correlated

- A fairly high correlation exists between the 2000 Census disability rate for the total noninstitutional population ages 5 and older and the rate of years of potential life lost ( $r=0.695$ )  
YPLL counts deaths prior to age 75, weighted by the age of death, for the total population (per 100,000 persons)
- This suggests that successful aging is less likely for many persons with disabilities in areas with high disability rates

# Geographic variation in disability is related to socioeconomic disparities

- The worst places for successful aging would appear to be Appalachia and the South, the best places appear to be the plains states and the pacific region
- An ecological model that I have developed using the 2008-2010 ACS explains 90 percent of the variation in disability rates across 2,069 PUMAs by demographic and socioeconomic characteristics including educational attainment and per capita income

# Conclusions

- Need to find ways to reduce the substantial geographic disparities in disability and longevity
- Ecologically based approaches are needed combining efforts of people with disabilities, families, organizations and communities, relevant government and non-government health, education, vocational, social and other services
- There needs to be a focus on well-being over the life course for children and young adults with an emphasis on early intervention in many domains: educational attainment, health knowledge, and employment participation

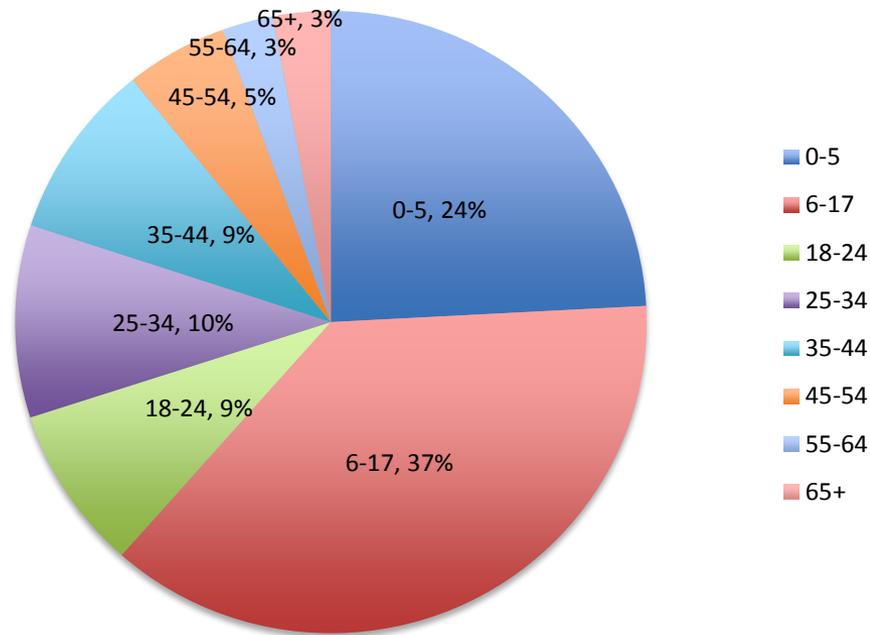
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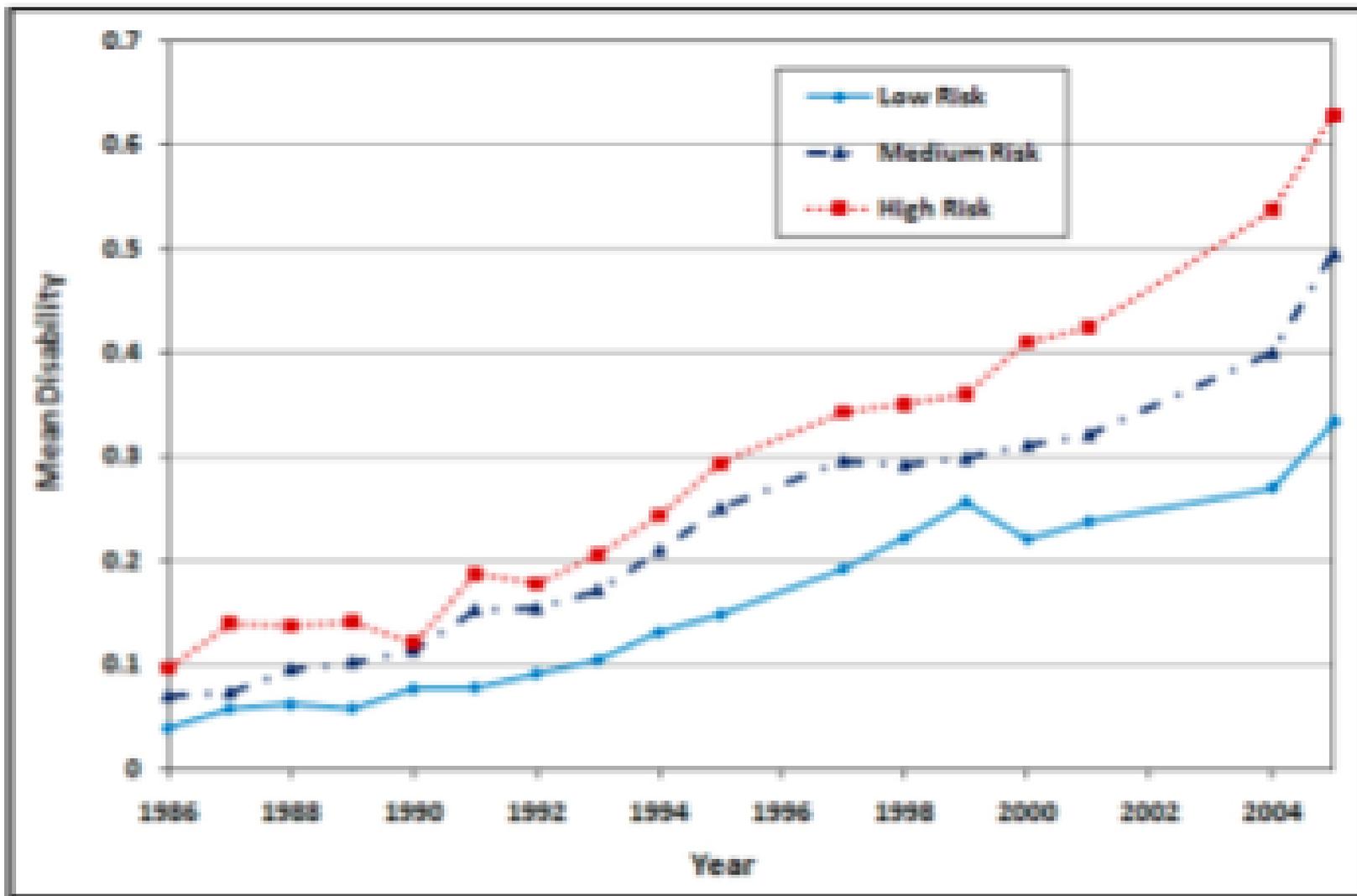
**Figure 1. Age distribution of persons with intellectual and developmental disabilities, US 1994/95. Source: Larson et al., 2001.**



1.5 million adults ages 18 and older have ID/DD with onset before age 22

# Disability belt

- The disability belt (or belts) exists for children, working age, and older persons
- In Appalachia, children have 75% higher rate of disability than in the Pacific region, for working age adults disability is 210% higher, for elderly persons disability is 21% higher



Source: Chakravarty et al. (2012)

# Successful aging with disability

- What are the essential conditions for successful aging with a disability?
- How can a child with a disability age successfully if work attachment is low, wages are low? How can a child with a disability avoid the “poverty trap?”
- Poor access to preventive care, including diagnostic screening.

# Successful aging

- Healthy aging, positive aging, optimal aging, aging well

# Congenital and early acquired conditions/disabilities

- Post-polio
- Cerebral palsy
- Muscular dystrophy
- Intellectual and other developmental disabilities
- Spinal cord injury
- Brain injury

# Adult onset disabilities

- SCI & TBI
- Diabetes
- Alcohol & drug addiction
- HIV and AIDs
- Cancer

# Static versus progressive

# Service barriers

- Inaccessible medical services
- Restricted access to PAS, causes reliance on family

# Risk factors

- The underlying nature of disability: static or progressive
- Access to rehabilitation
- Access to preventive health care
- Access to exercise (Rimmer)
-

# Goal transformation

- Aging successfully with a disability emphasizes a broader goal than managing morbidity and disability
- The broader goal is living healthier, more prosperous, and more productive lives

- We manage what we measure—Social Science Research Council

# Measuring success

- Longevity
- Function (physical, social, cognitive)
- Life satisfaction
- Wellness (absence of bad days)
- ALE, DALYs are not appropriate on considering aging with a disability (Unless the weights are derived from people with disabilities).

# Key indicators of successful aging with a disability

- Percentage of persons with disabilities living in the least restrictive settings; i.e., in the community
- Percentage receiving adequate LTSS—lack of unmet need for personal assistance with IADL/ADL
- Access to needed assistive technology
- Healthy lifestyles
  - Good weight
  - Smoking
  - Diet
  - Exercise

# Indicators

- Access to preventive health services; exam rates comparable to (or better than) people without disabilities
- Access to rehabilitative services
- Rate of meaningfully engagement in work or other productive activity
- Rates of community participation
  - Cultural events
  - Religious services

# Indicators

- Life satisfaction, HRQL

# Birth defects

- Major structural or genetic birth defects affect approximately 3% of births in the United States
- major structural or genetic birth defects as conditions that 1) result from a malformation, deformation, or disruption in one or more parts of the body, a chromosomal abnormality, or a known clinical syndrome; 2) are present at birth; and 3) have a serious, adverse effect on health, development, or functional ability
- Boys are 13 percent more likely than girls to have birth defects

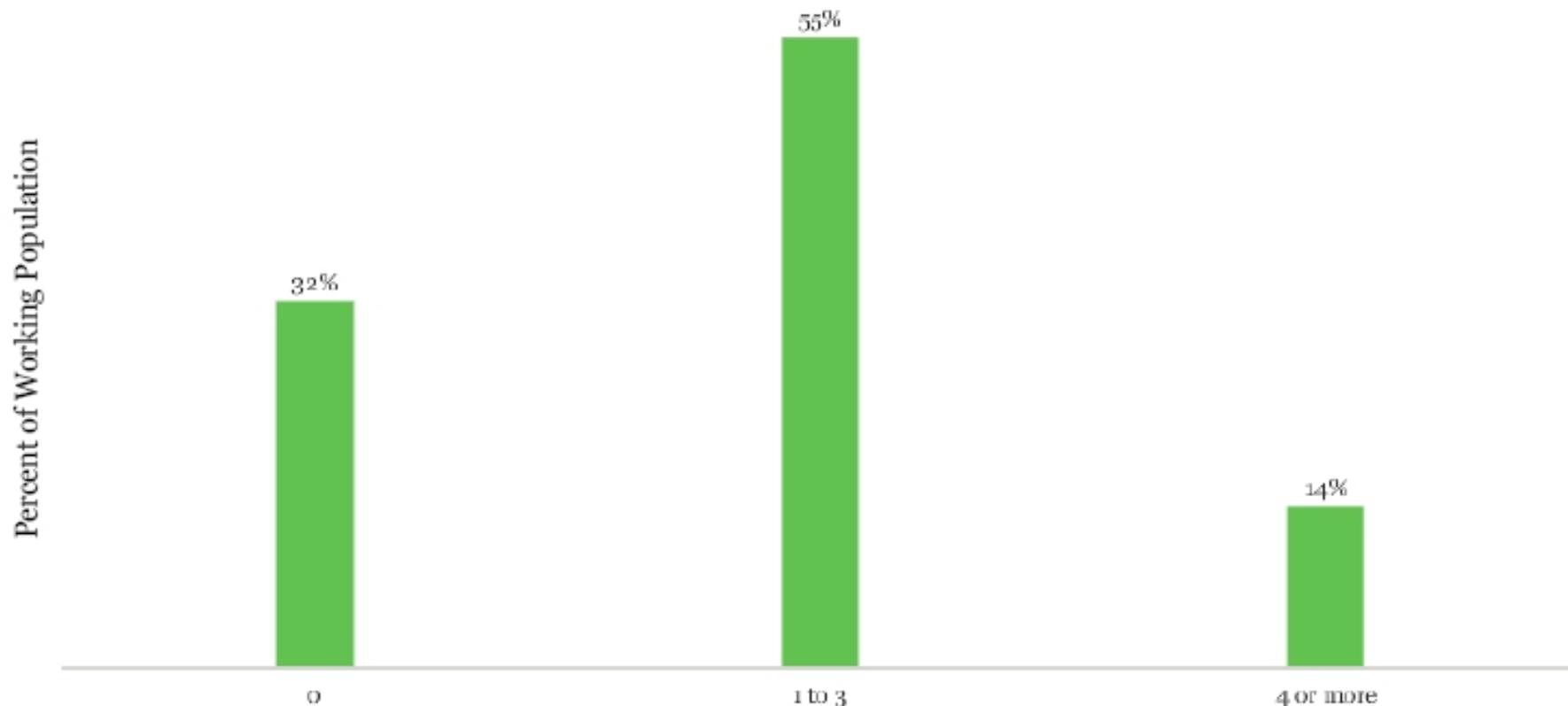
# Most adults have one or more chronic illnesses

- More than half of adults have at least one chronic illness. Sources: NHIS, Gallup
- That is the case even among working age adults

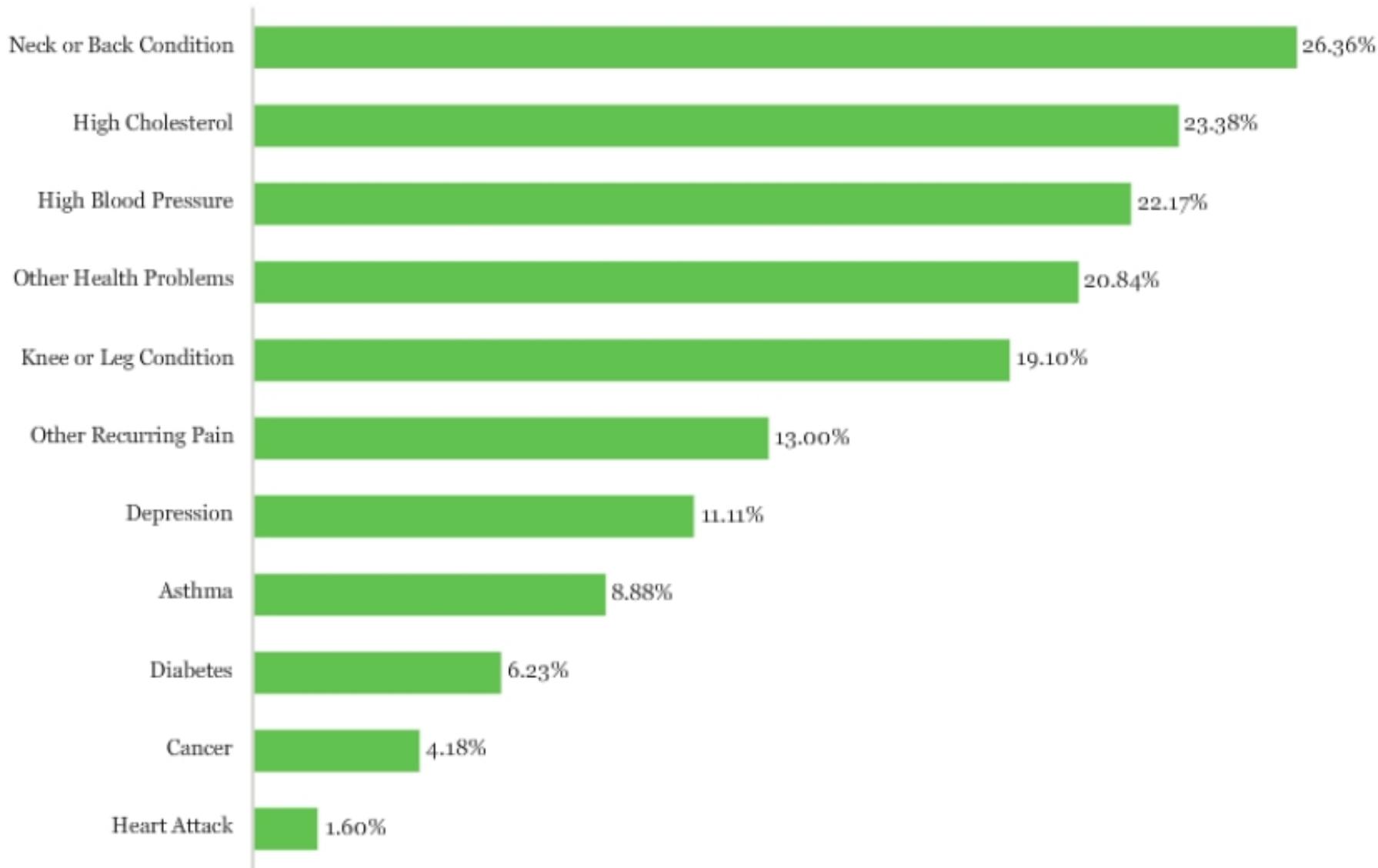
# The Working Population

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*Number of Disease Conditions*



*Prevalence of Disease Conditions in the Working Population*

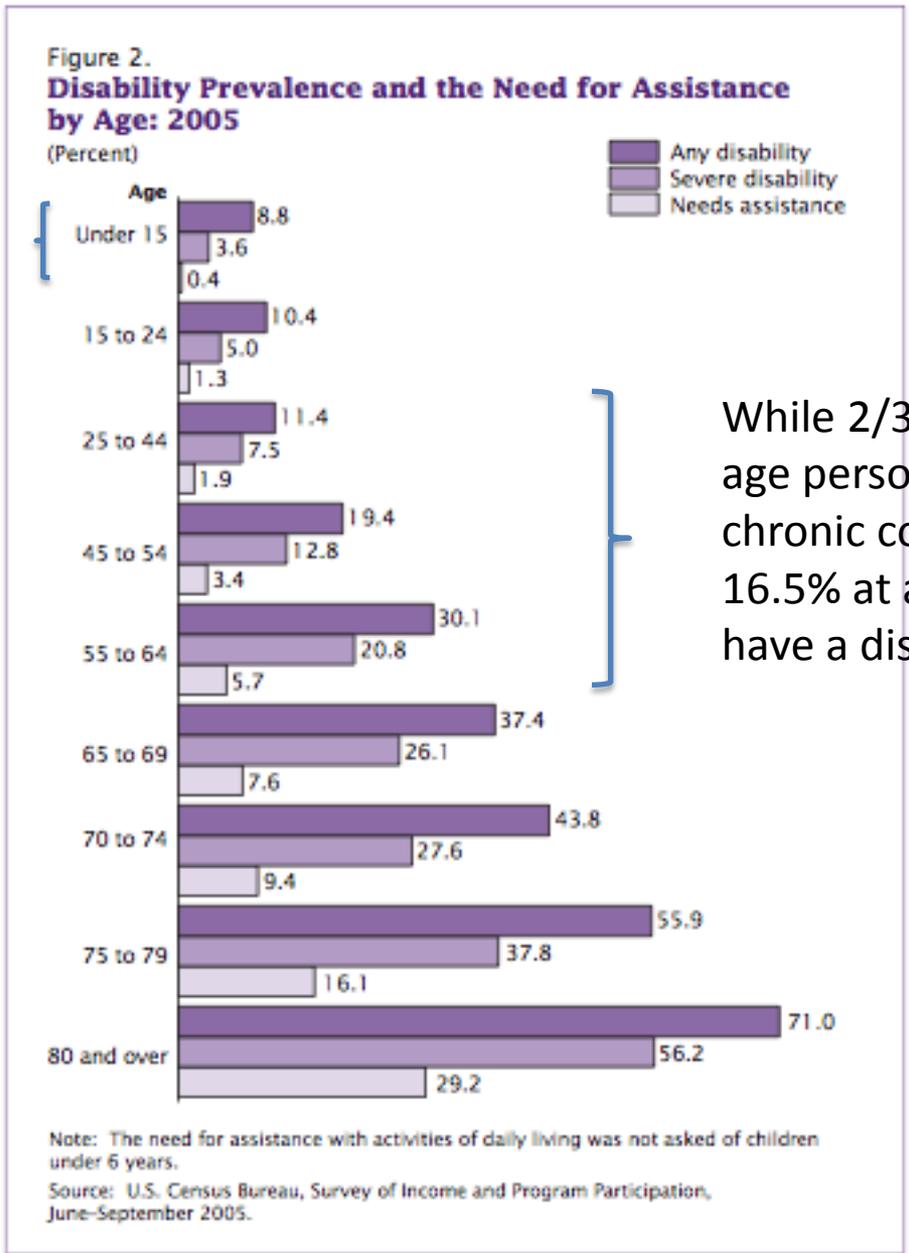


# Prevalence of disability, 2005 SIPP

- 18.7 percent of the total noninstitutionalized population has a disability—either an impairment or difficulty with an activity
- 12.0 percent have a severe disability—generally an activity they cannot perform

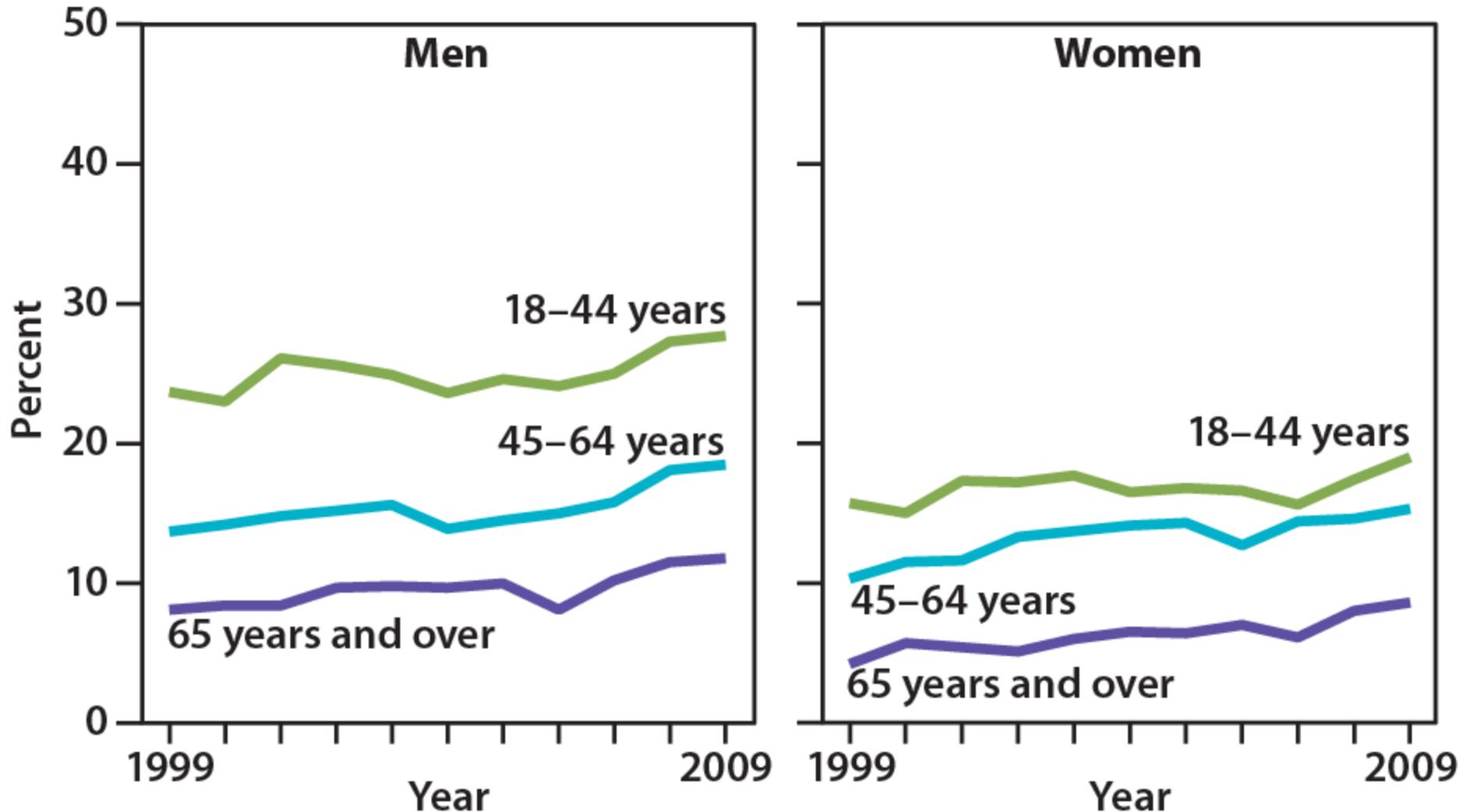
At ages <3, 2% have developmental delay, at ages 3 to 5, 3.8% do.

At ages 6-14, 12.8 percent have a disability (3.6% with DD)



While 2/3 of working age persons have chronic conditions, 16.5% at ages 21-64 have a disability

# Participation in aerobic and muscle-strengthening activities\*



NOTE: \*Activities that meet the 2008 federal guidelines available at: <http://www.health.gov/paguidelines/default.aspx>.

SOURCE: CDC/NCHS, *Health, United States, 2010*, Figure 12. Data from the National Health Interview Survey.

# Some good news

- A good part of this is preventable

# Aging with disability

- How will a child with a disability age? For example, a child with severe asthma that limits activity?
- How will a young adult with a disability age? For example, a 23 year old athlete with a spinal cord injury?
- How will a middle age adult age, who is diagnosed with HIV?

# Chronic disease

- Diabetes epidemic
- Asthma epidemic is still with us: prevalence increased from 2001 to 2010 and is now at its highest level—8.4 percent (Akinbami, 2012)
- It is not clear how to prevent asthma from developing and there is no cure. Yet the means to control and prevent exacerbations in persons who have asthma are well established in evidence-based clinical guidelines