Inclusion of Racial and Ethnic Minorities in Cognitive Research

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The Impact of Cognitive Impairment across Specialties

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Objectives

- Why is engagement of racial and ethnic minorities important in aging research?

- How should engagement of racial and ethnic minorities in aging research be conducted?

- What outcomes should be measured regarding engagement of racial and ethnic minorities in aging?

- What are potential pitfalls in engagement of racial and ethnic minorities in aging?

Why Diversity and Inclusion in Aging Research

# Figure 1. Life Expectancy at Birth, by Sex: 1900 to 2003.
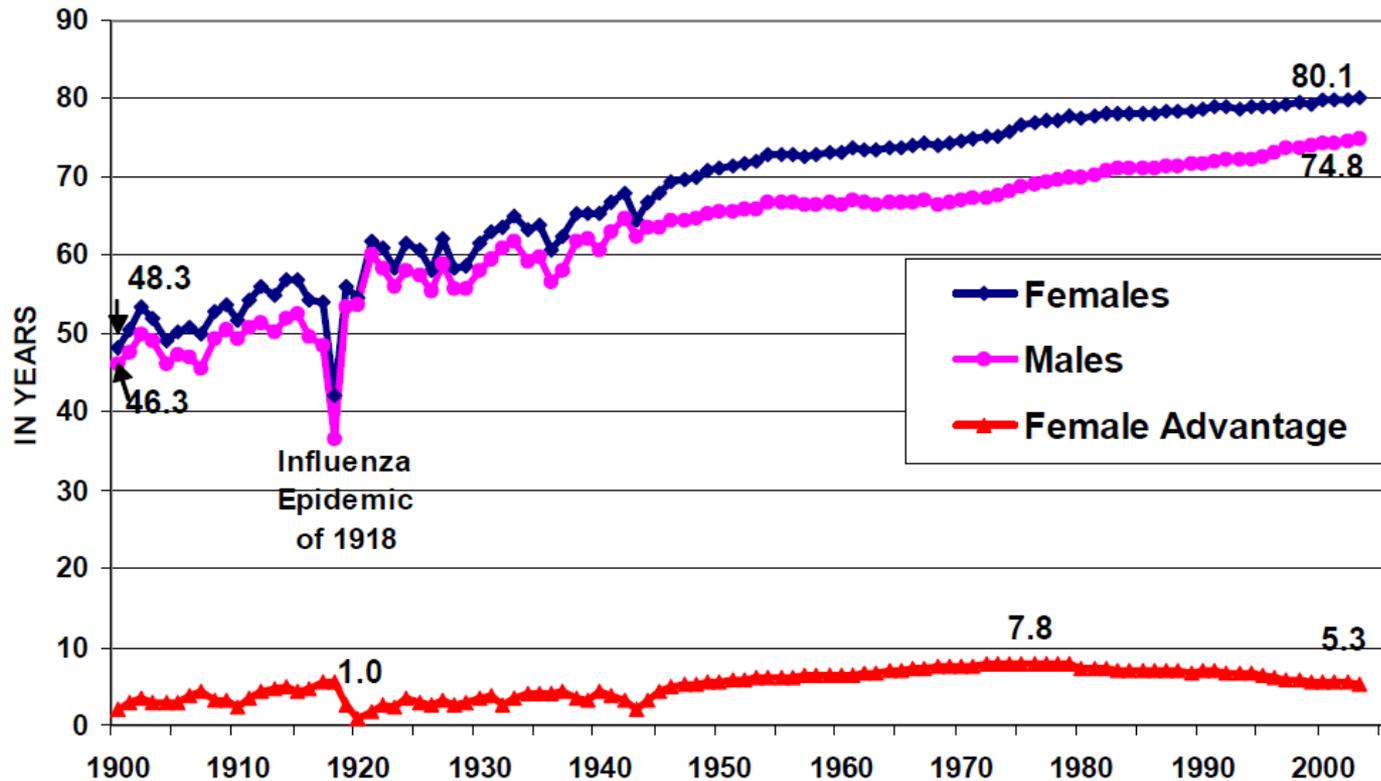
Source: For 1900-2002, CRS analysis based on data contained in NCHS, United States Life Tables, 2002, *National Vital Statistics Report,* vol. 53, no. 6, Nov. 10, 2004. For 2003, CRS analysis based on NCHS, Deaths: Final Data for 2003, *National Vital Statistics Report,* vol. 54, no. 13, Apr. 19, 2006.

Number of Persons over 65

Figure 1: Number of Persons 65+, 1900 – 2060 (numbers in millions)
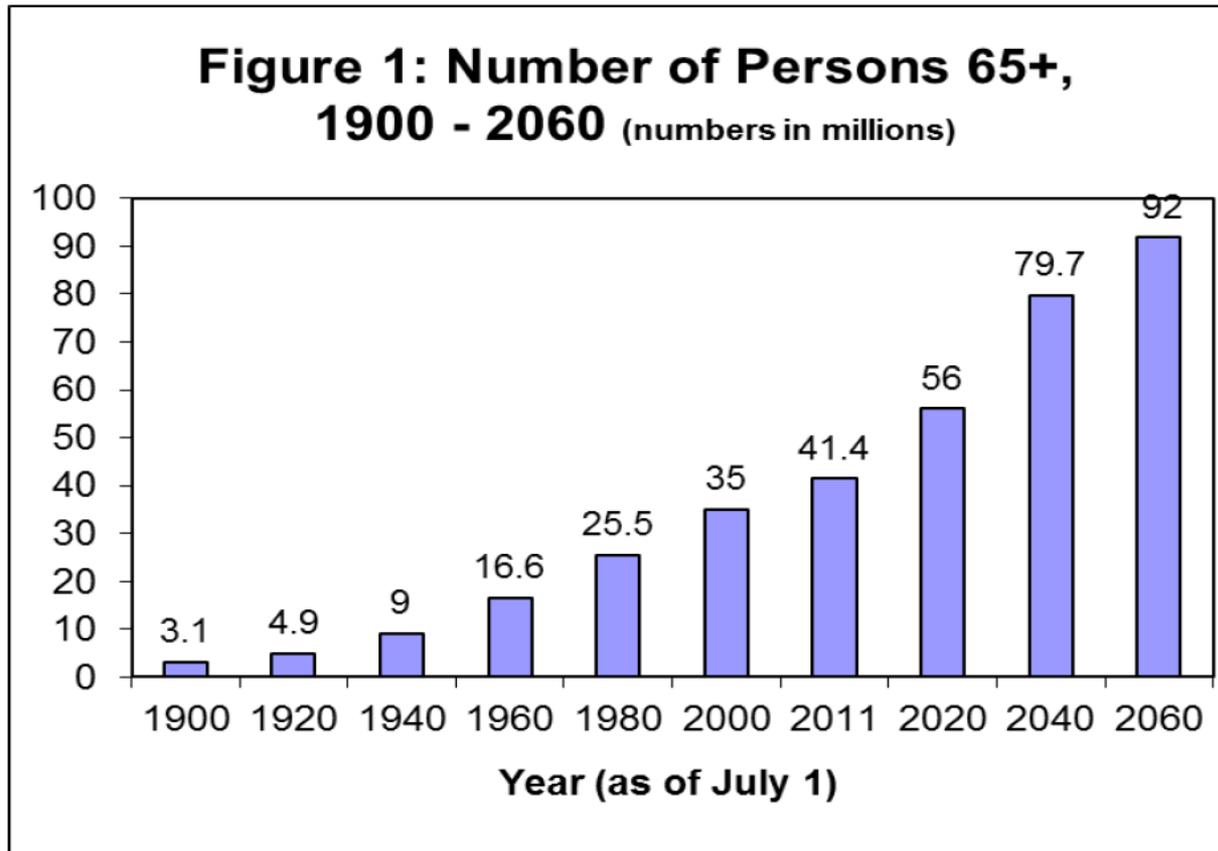
Note: Increments in years are uneven.
(Based on online data from the U.S. Census Bureau's 1) Population Estimates and Projections; 2) Table 1. Projected Population by Single Year of Age (0-99, 100+), Sex, Race, and Hispanic Origin for the United States: July 1, 2012 to July 1, 2060, Release Date: 2012; and 3) Table 5. Population by Age and Sex for the United States: 1900 to 2000, Part A. Hobbs, Frank and Nicole Stoops, Census 2000 Special Reports, Series CENSR-4, Demographic Trends in the 20th Century.)

U.S. Life Expectancy (All, White, and Black Races)
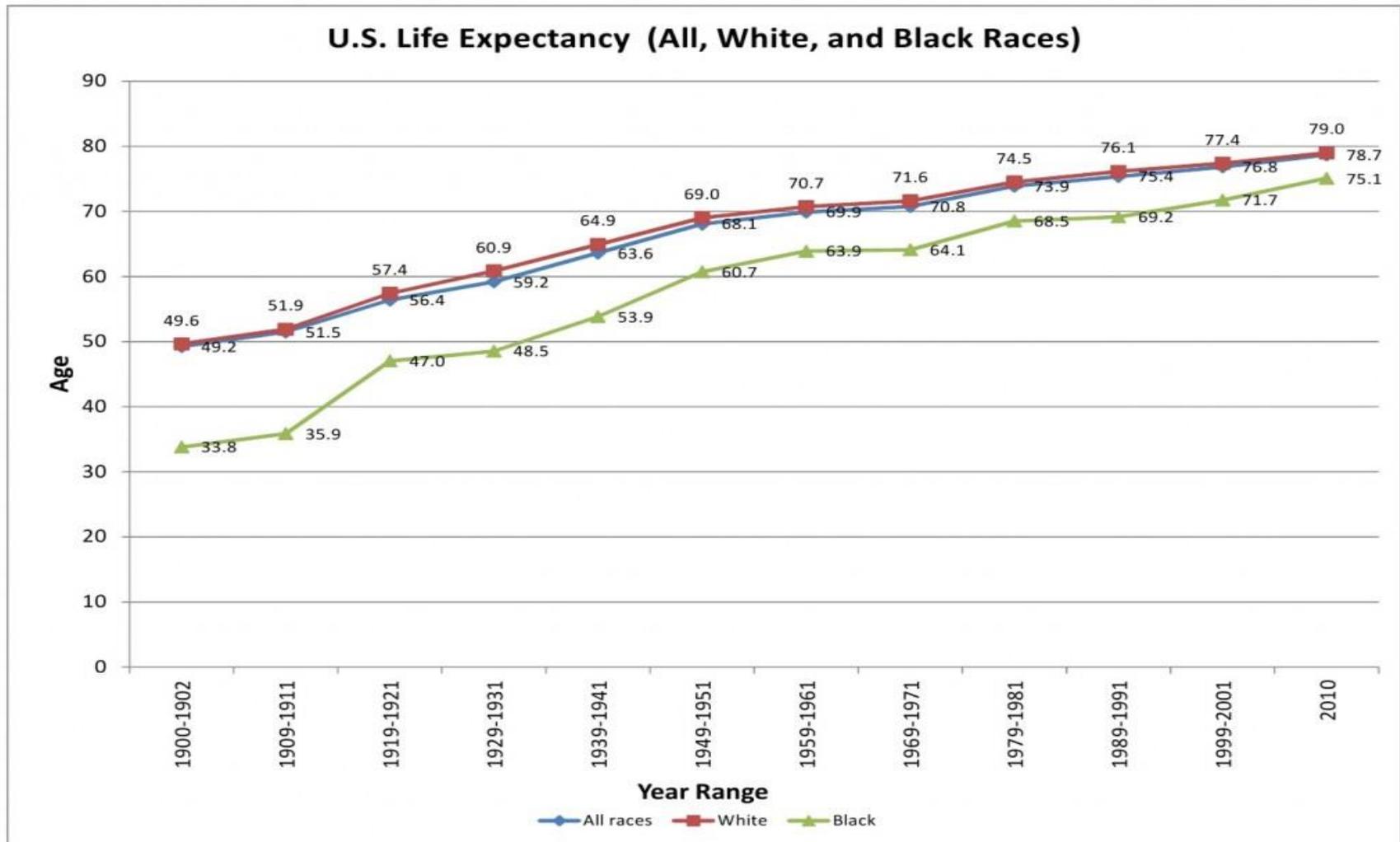
Source: National Center for Health Statistics, 2011

Diversity in Aging

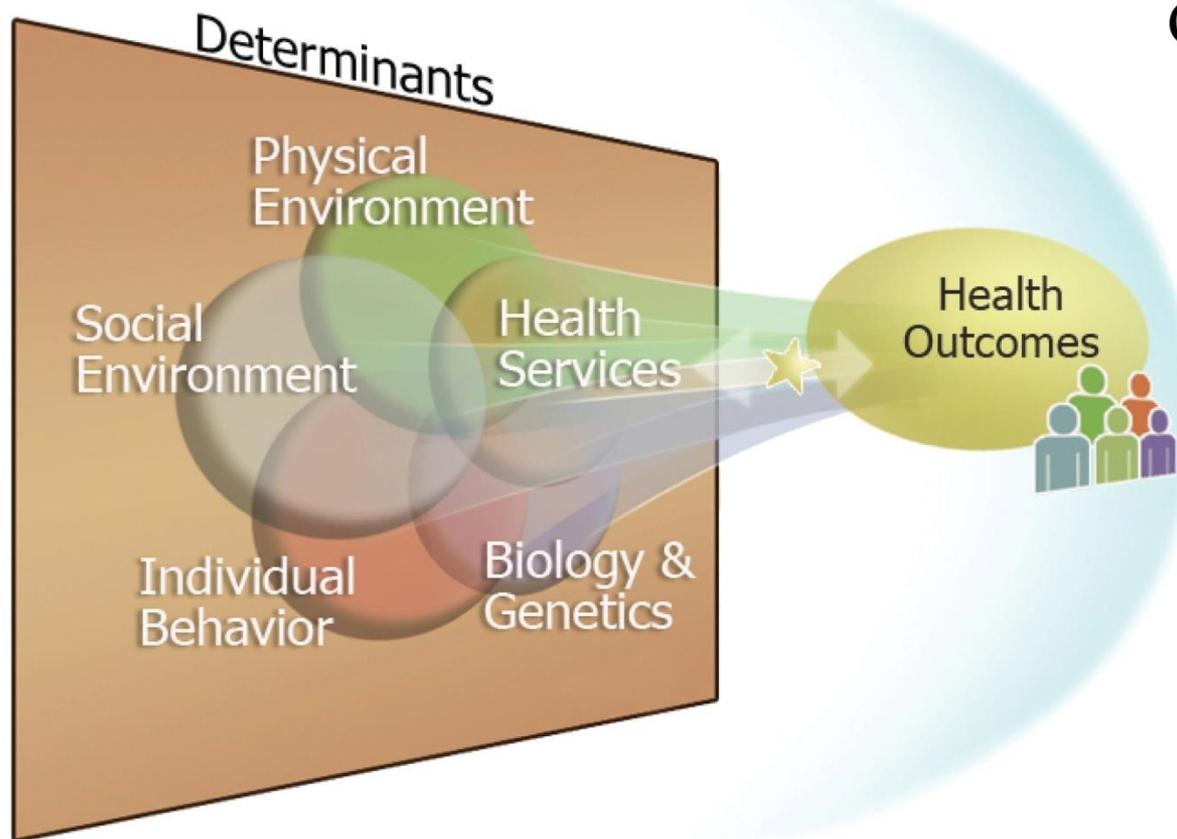Population age 65 and over, by race and Hispanic origin, 2014 and projected 2060
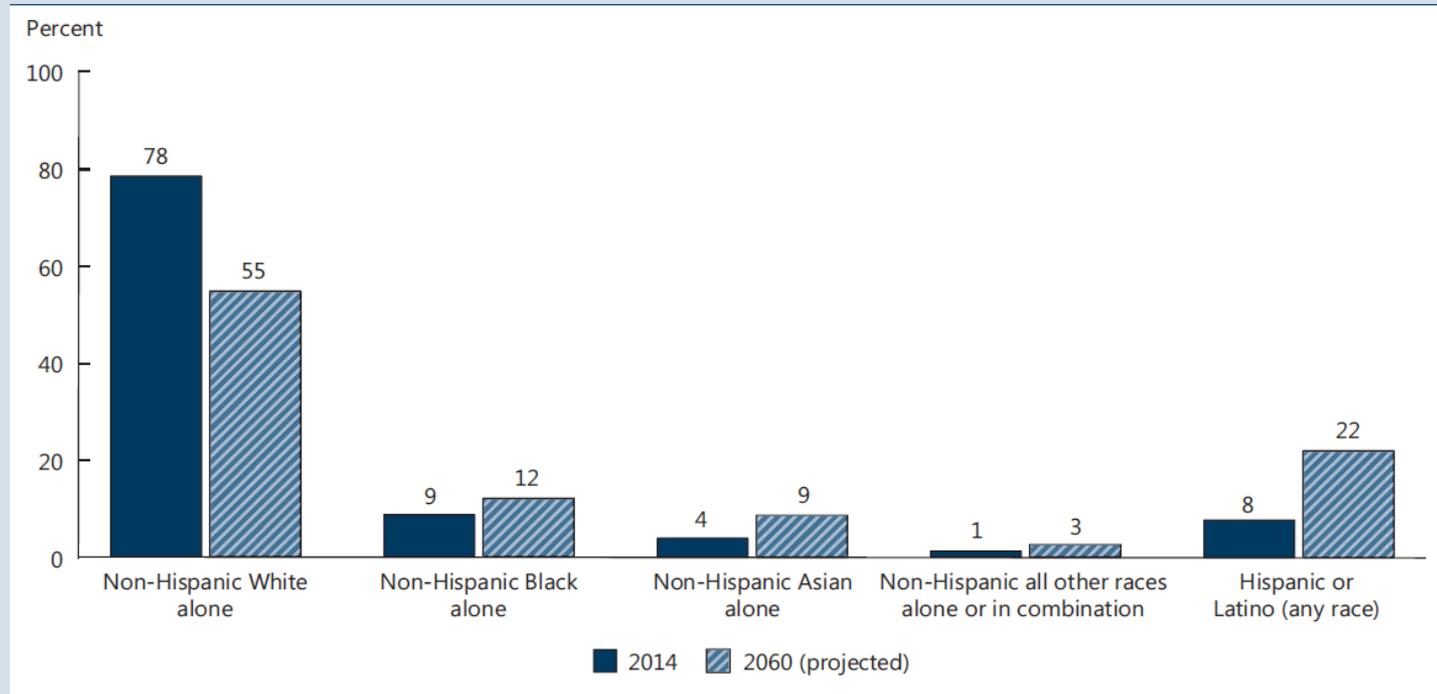
NOTE: The presentation of racial and ethnic composition data in this table has changed from previous editions of *Older Americans*. Unlike in previous editions, Hispanics are not counted in any race group. The term "non-Hispanic White alone" is used to refer to people who reported being White and no other race and who are not Hispanic. The term "non-Hispanic Black alone" is used to refer to people who reported being Black or African American and no other race and who are not Hispanic, and the term "non-Hispanic Asian alone" is used to refer to people who reported only Asian as their race and who are not Hispanic. The use of single-race populations in this chart does not imply that this is the preferred method of presenting or analyzing data. The U.S. Census Bureau uses a variety of approaches. The race group "non-Hispanic All other races alone or in combination" includes people who reported American Indian and Alaska Native alone who are not Hispanic; people who reported Native Hawaiian and Other Pacific Islander alone who are not Hispanic; and all people who reported two or more races who are not Hispanic. "Hispanic" refers to an ethnic category; Hispanics may be of any race.

Reference population: These data refer to the resident population.

SOURCE: U.S. Census Bureau, Annual Estimates of the Resident Population by Sex, Age, Race, and Hispanic Origin for the United States and States: April 1, 2010, to July 1, 2014 (PEPASR6H); U.S. Census Bureau, Table 1. Projected Population by Single Year of Age, Sex, Race, and Hispanic Origin for the United States: 2014 to 2060 (NP2014_D1).
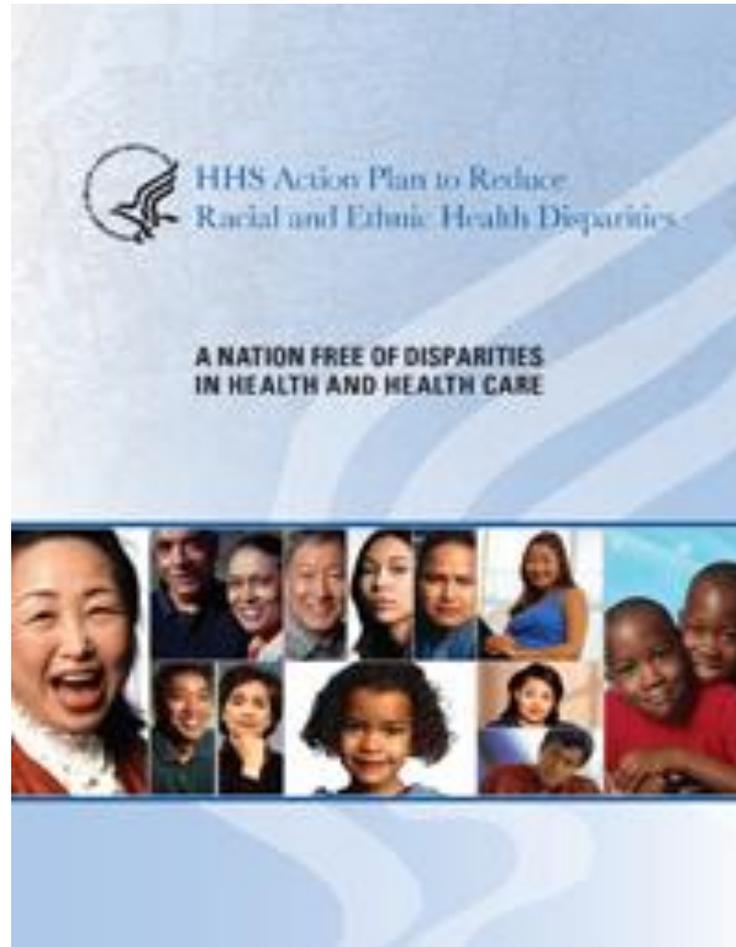
Healthy People 2020

A society in which all people live long, healthy lives

Determinants

Physical Environment

Social Environment

Health Services

Individual Behavior

Biology & Genetics

Health Outcomes

Overarching Goals:

- Attain high quality, longer lives free of preventable disease, disability, injury, and premature death.

- Achieve health equity, eliminate disparities, and improve the health of all groups

- Create social and physical environments that promote good health for all.

- Promote quality of life, healthy development and healthy behaviors across all life stages.

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HHS Action Plan to Reduce Racial and Ethnic Health Disparities

A NATION FREE OF DISPARITIES IN HEALTH AND HEALTH CARE

"It is time to refocus, reinforce, and repeat the message that health disparities exist and that health equity benefits everyone."
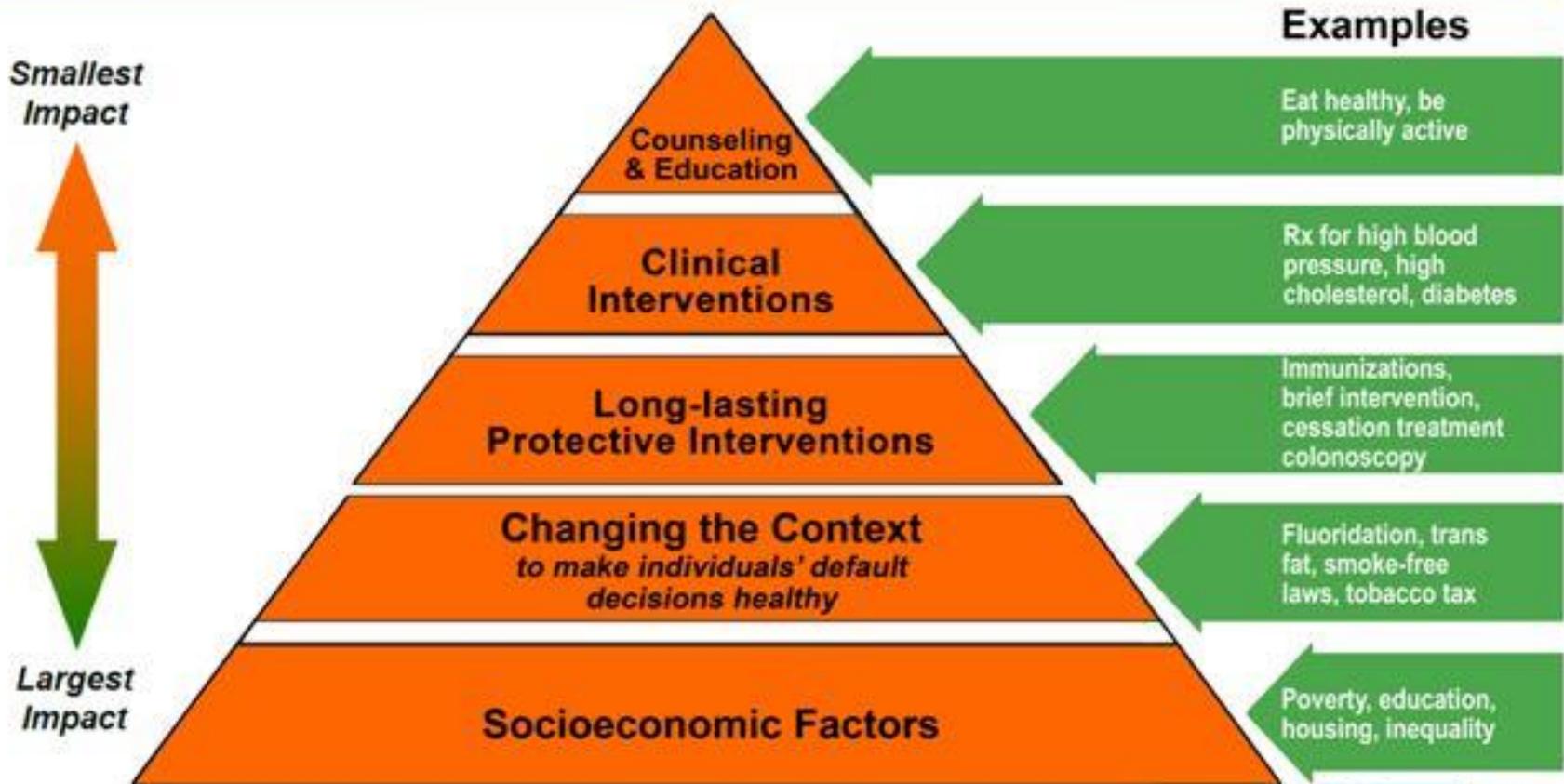– Kathleen G. Sebelius, Secretary, Health & Human Services

"A nation free of disparities in health and health care."

Frameworks

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CDC Health Impact Pyramid
Factors that Affect Health

Examples

Smallest Impact

Counseling & Education — Eat healthy, be physically active

Clinical Interventions — Rx for high blood pressure, high cholesterol, diabetes

Long-lasting Protective Interventions — Immunizations, brief intervention, cessation treatment colonoscopy

Changing the Context to make individuals' default decisions healthy — Fluoridation, trans fat, smoke-free laws, tobacco tax

Largest Impact

Socioeconomic Factors — Poverty, education, housing, inequality

Check the Tarrant County Public Health Web site to learn more.
http://health.tarrantcounty.com

CDC

NIA Health Disparities Research Framework
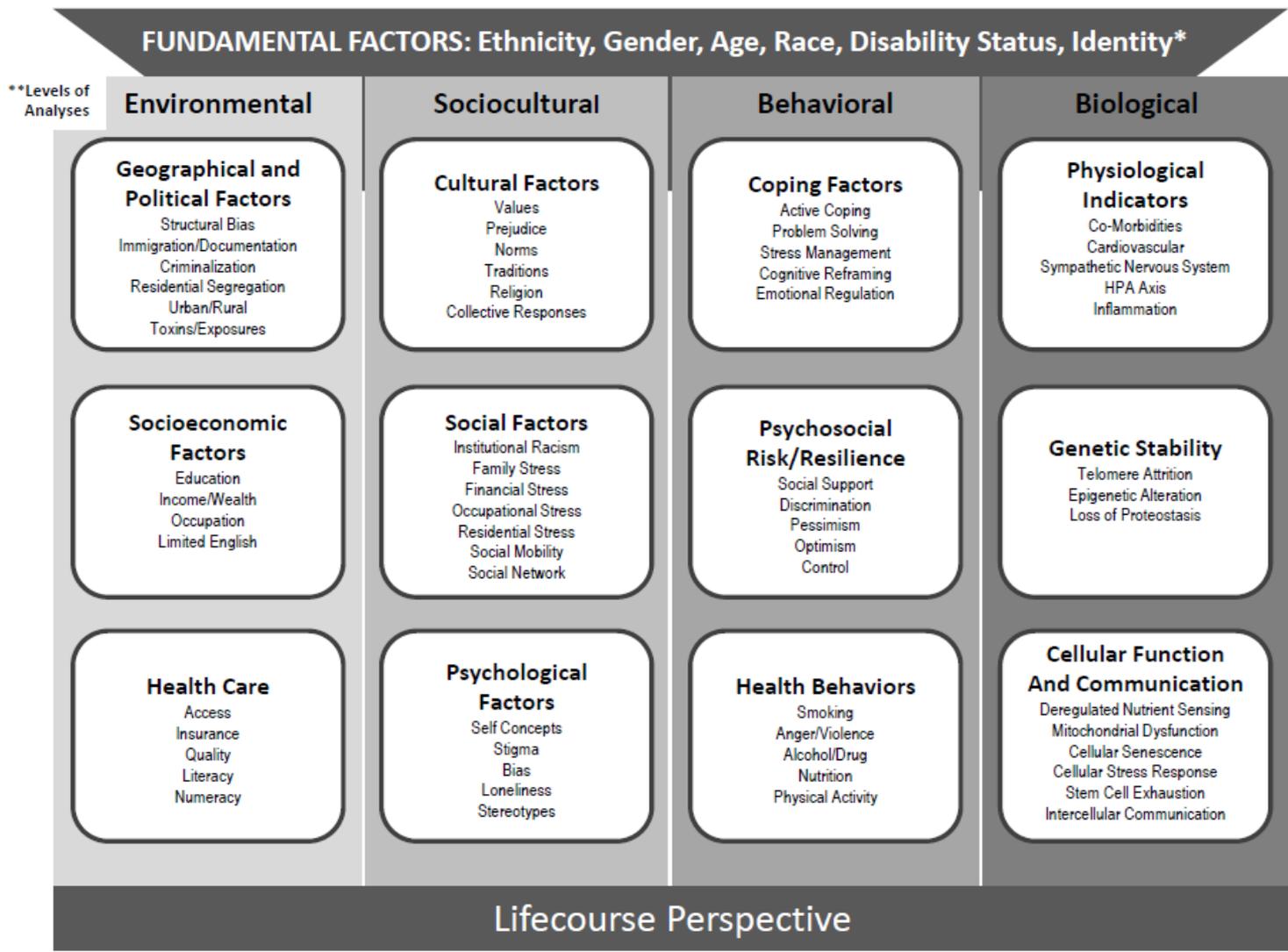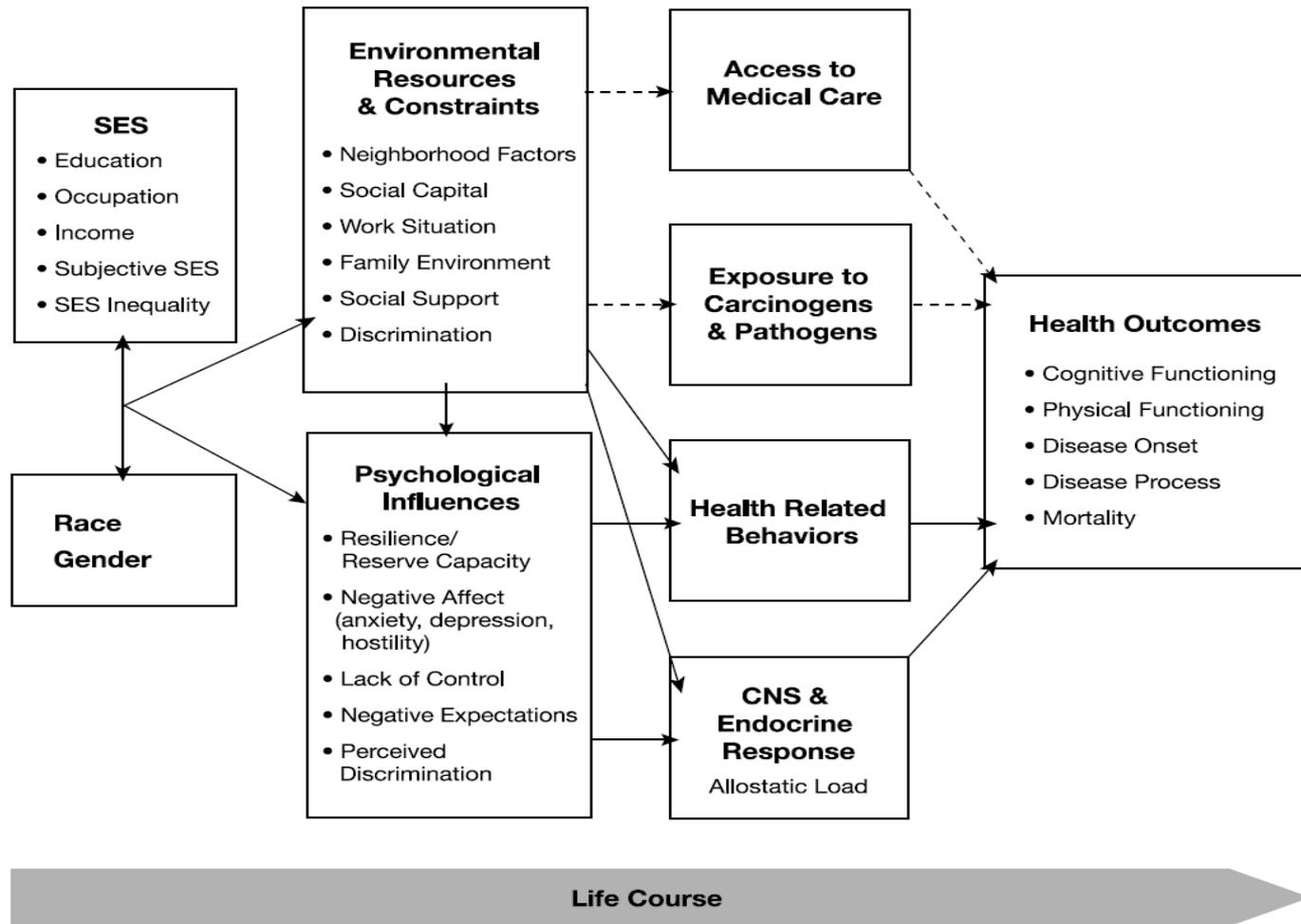

Figure 2. NIA Health Disparities Research Framework
* Sexual and gender minorities.
** Text within boxes represents examples of related factors.

Adler, et al 2010

How to Approach Engagement of Diverse Older Persons in Research

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The NGAGE Model

Network
Give First
Advocate for Research
Give Back
Evaluate

1. Network

2. Give first

Design

Execution

Prioritization

Dissemination

Questions

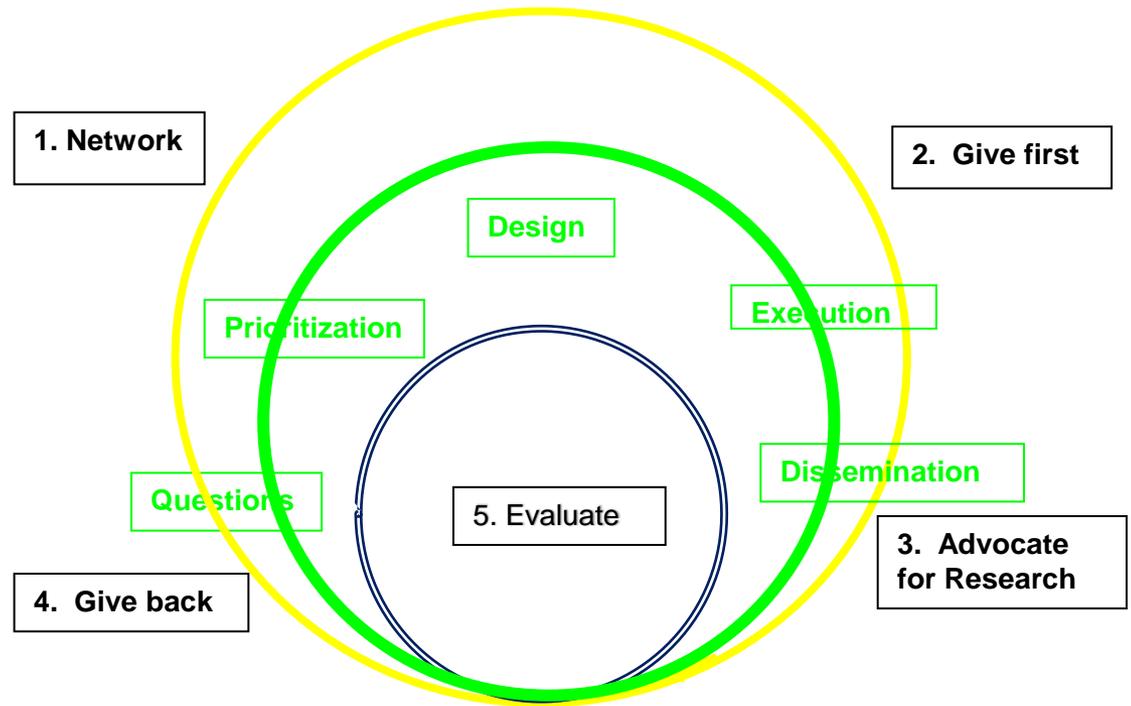5. Evaluate

3. Advocate for Research

4. Give back

Figure 1. Integration of Activities at Community and Individual Study Levels. Outer circle represents community activities, middle circle represents participant input on research, and inner circle represents individual study activities.

NGAGE Activities

Step	Examples of Activities
Network	One-on-one leader meetings Community board meetings
Give First	Partner in community aging events Healthy Aging presentations
Advocate for Research	Community presentations Telephone/in-person follow-up
Give Back	Study Finding Review w/ Participants Community Research Updates
Evaluate	Enrollment Funnel Pre- and post-presentation surveys Reasons for repository participation

Figure 1. The Evolution of Community Member Engagement in Research
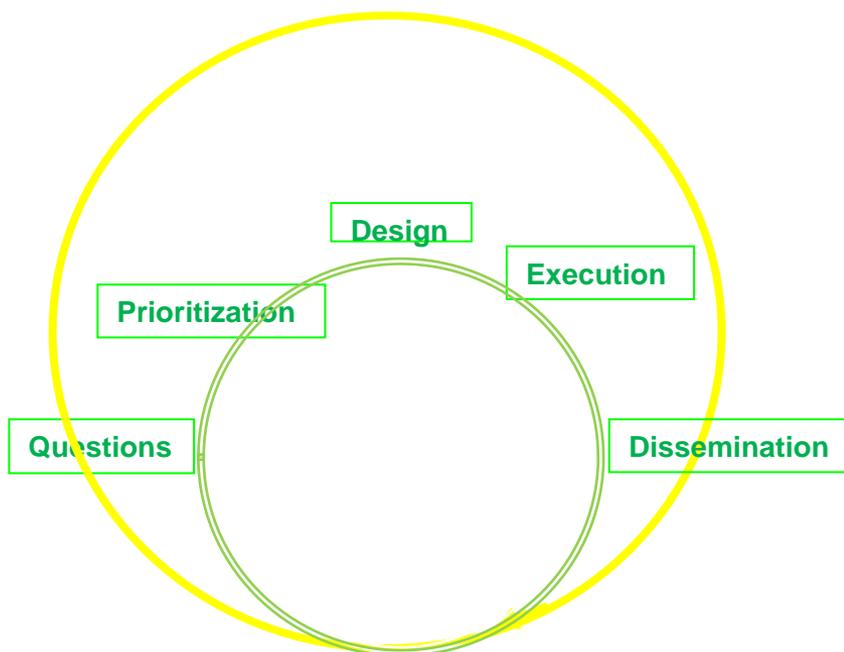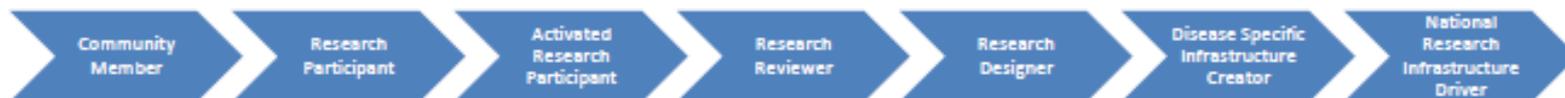
Step	Examples of Activities
Questions	Wordle Exercise in ROS and generation of manuscript ideas
Prioritization	Pilot Grant Review
Design	Study materials for Latino Core
Execution	Ways to engage in study procedures
Dissemination	Formatting of Annual RADC Newsletter to participants

What Outcomes to Evaluate regarding Diverse Engagement in Older Adults

Evaluation – Recruitment

Sponsor Category	Study (Examples)	Potentially Eligible	Consented
Rush ADC Center	Clinical Core Latino Core Religious Orders Study	935	269
ADC Associated	ADNI/ADNI-3 DOD-ADNI ADCS ADC Pilots	196	19
NIH Associated	NIA Non-NIA	831	78
Non-Federally Funded	Foundation Industry	177	17

Participants That:	White	Black	Hispanic	Other	Total
Recommended research to another person	31 (42%)	37 (50%)	15 (20%)	6 (8%)	89
Wrote a newsletter article	1 (100%)	0	0	0	1
Requested a talk	0	0	0	0	0
Participated in a talk	0	0	0	0	0
Reviewed a research proposal	1 (25%)	1 (25%)	2 (50%)	0	4
Assisted with designing a new research proposal	1 (100%)	0	0	0	1
Reviewed a funding proposal or funding request for an advocacy group	0	0	0	0	0
Reviewed a national funding proposal	0	0	0	0	0

Evaluation – Outreach

Event or Activity (n=355)	# Participants	Audience Breakdown or Target Group(s)		
		Whites, %	Blacks, %	Hispanics, %
Network	2,448	84	15	72
Give First	9,103	63	36	56
Advocate for Research	1,777	71	28	64
Give Back	1,310	59	37	34
TOTAL	14,638	67	32	57

Pitfalls

How Engagement Can Go Wrong

- Not considering important scientific questions that require diversity
- Not switching the "control" group occasionally
- Not considering engagement
- Not appreciating the history of prior engagement in the community
- Not offering team membership to persons from the diverse community.
- Not engaging again after first attempt.
- Not willing to share in decisions and information
- Not considering long-term engagement
- Not being curious about diverse life experiences
- Not setting up systems in advance to measure important engagement outcomes.

- Diversity and inclusiveness is important in aging research.
- One reason why is to understand the mechanisms to achieve health equity during the lifespan.
- Engagement requires careful planning and execution.
- Setting up systems to measure outcomes important.

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