



Positive Aging: HIV Turns 30

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, ADMINISTRATION ON AGING, WASHINGTON DC 20201
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Agenda



Introduction/Housekeeping

Welcome

The Complications of Success

A Personal Perspective

Implementation in Community Settings

Area Agencies on Aging & HIV

Resources

Questions

Welcome



Kathy Greenlee Assistant Secretary for Aging

Presenters

Steve Karpiak, PhD, Director for Research, ACRIA -
AIDS Community Research Initiative of America and
New York University

Jane Fowler, Director, HIV Wisdom for Older Women

Doreen Bermudez, Training Coordinator, National
Resource Center for LGBT Aging/SAGE – Services &
Advocacy for GLBT Elders

Courtney Williams, Community Planner, District of
Columbia Office on Aging



The Complications of Success: The Aging HIV Population

Stephen Karpiak PhD
Associate Director for Research

AIDS Community Research Initiative of America (ACRIA)
ACRIA Center on HIV and Aging
New York University College of Nursing
NYU Medical Center for AIDS Research

ACRIA: AIDS Community Research Initiative of America

founded in New York City in 1991

Clinical Trials

- Antiretrovirals
- Side-effects management
- Comorbid treatments

Older Adults Research

- Social networks
- Depression management
- Multimorbidity management
- Service utilization
- Accessing caregivers
- Stigma
- Spirituality
- Sexual behavior and substance use

Education Health Literacy

- Staff/agency trainings on needs of aging HIV populations & those at-risk
- Technical assistance and capacity building
- Continuing education credits
- Materials in several languages
- Social messaging campaign
- HIV prevention



It Has Been 30 Years

By the end of 1990, just nine years from the start of the epidemic, approximately 160,000 Americans had been diagnosed with AIDS and 110,000 of them had already died

As of 2010 there are nearly 1.1 million Americans living with HIV

By 2015 the CDC estimates that one-half of Americans with HIV will be age 50 and older

September 2008: HHS Establishes
September 18 as an annual
National HIV/AIDS and Aging Awareness Day



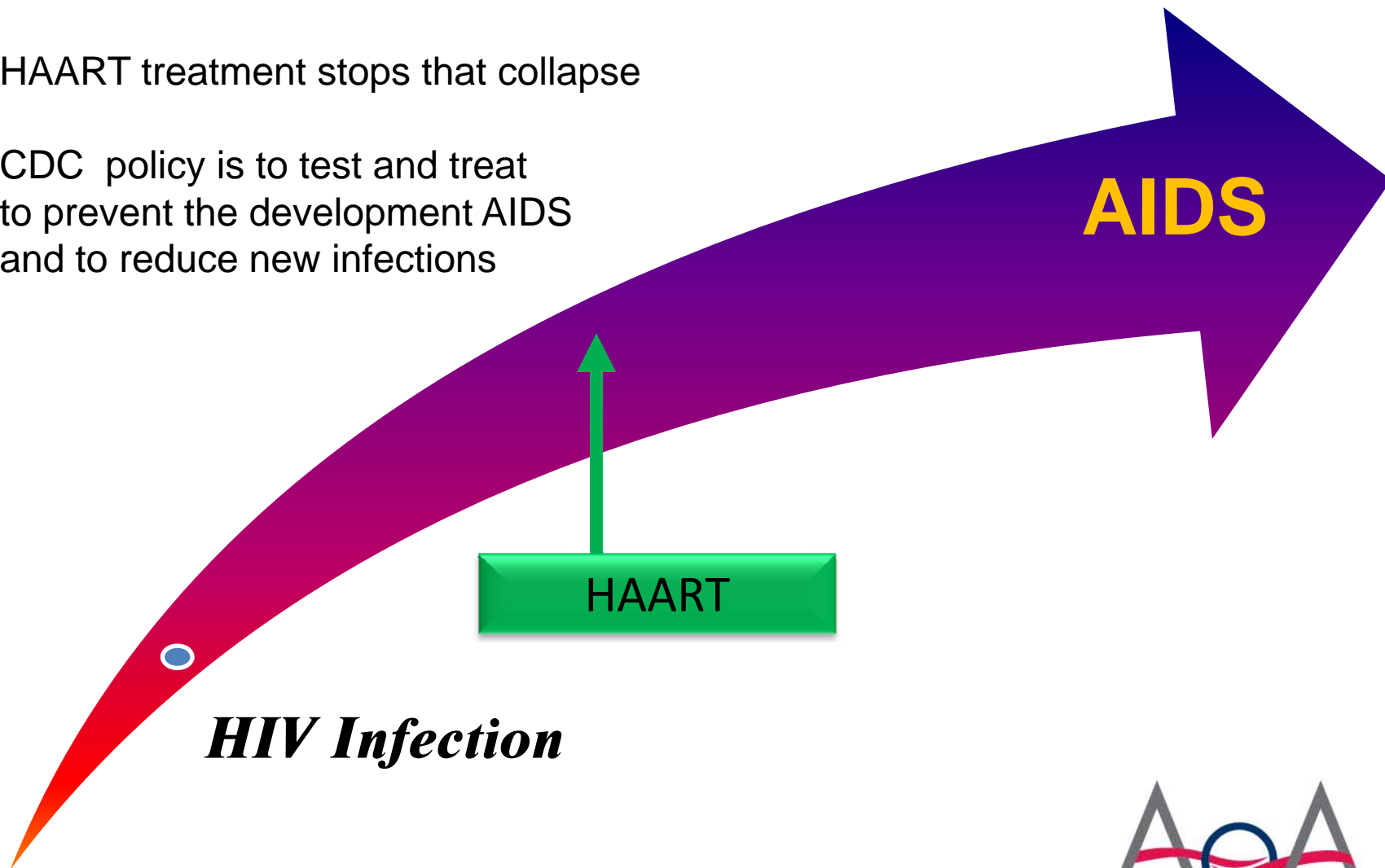
Oct 2010:
White House Office of National AIDS Policy convenes
a Special Meeting on HIV and Aging



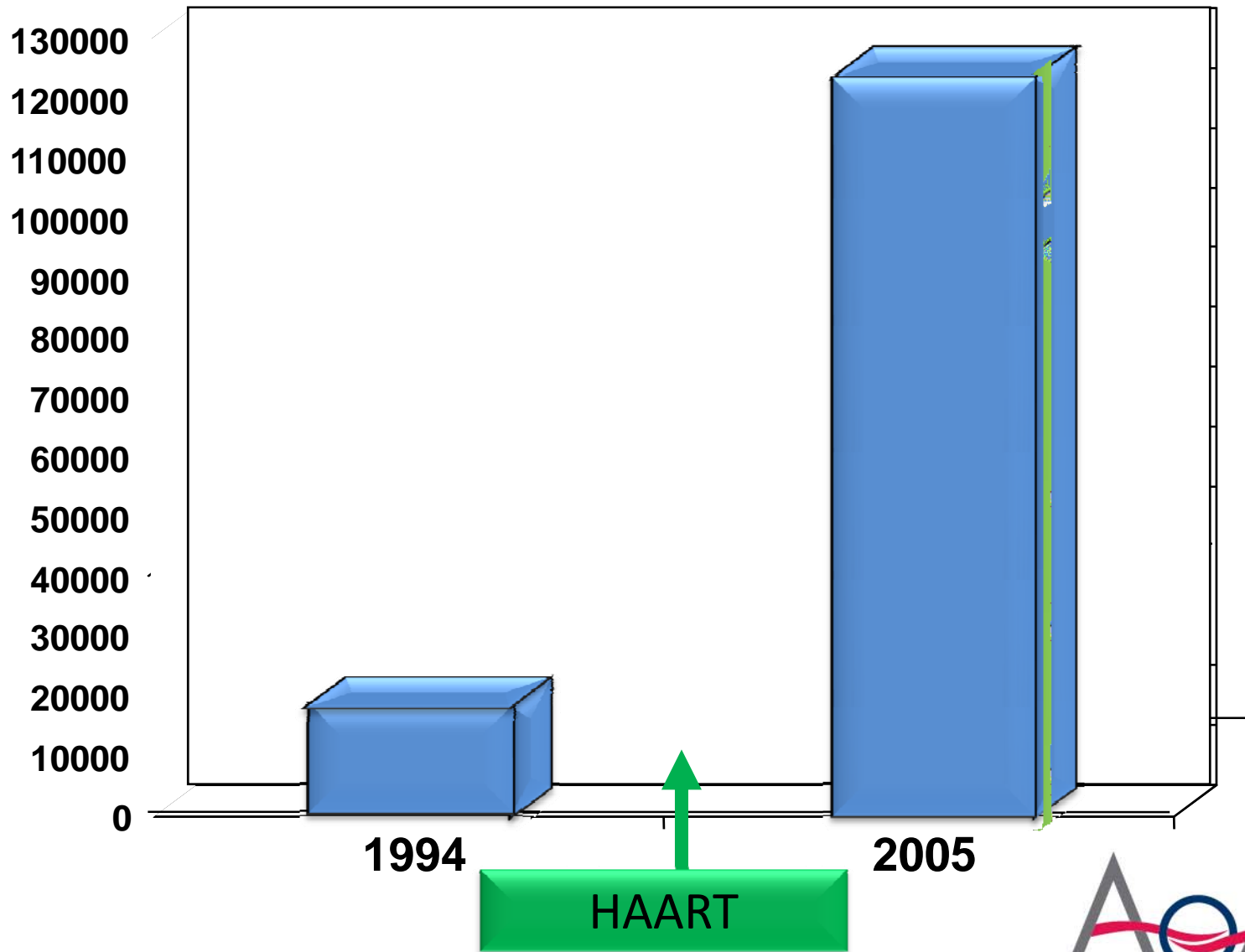
It takes 10 years for the virus to cause the collapse of the immune system resulting in AIDS

HAART treatment stops that collapse

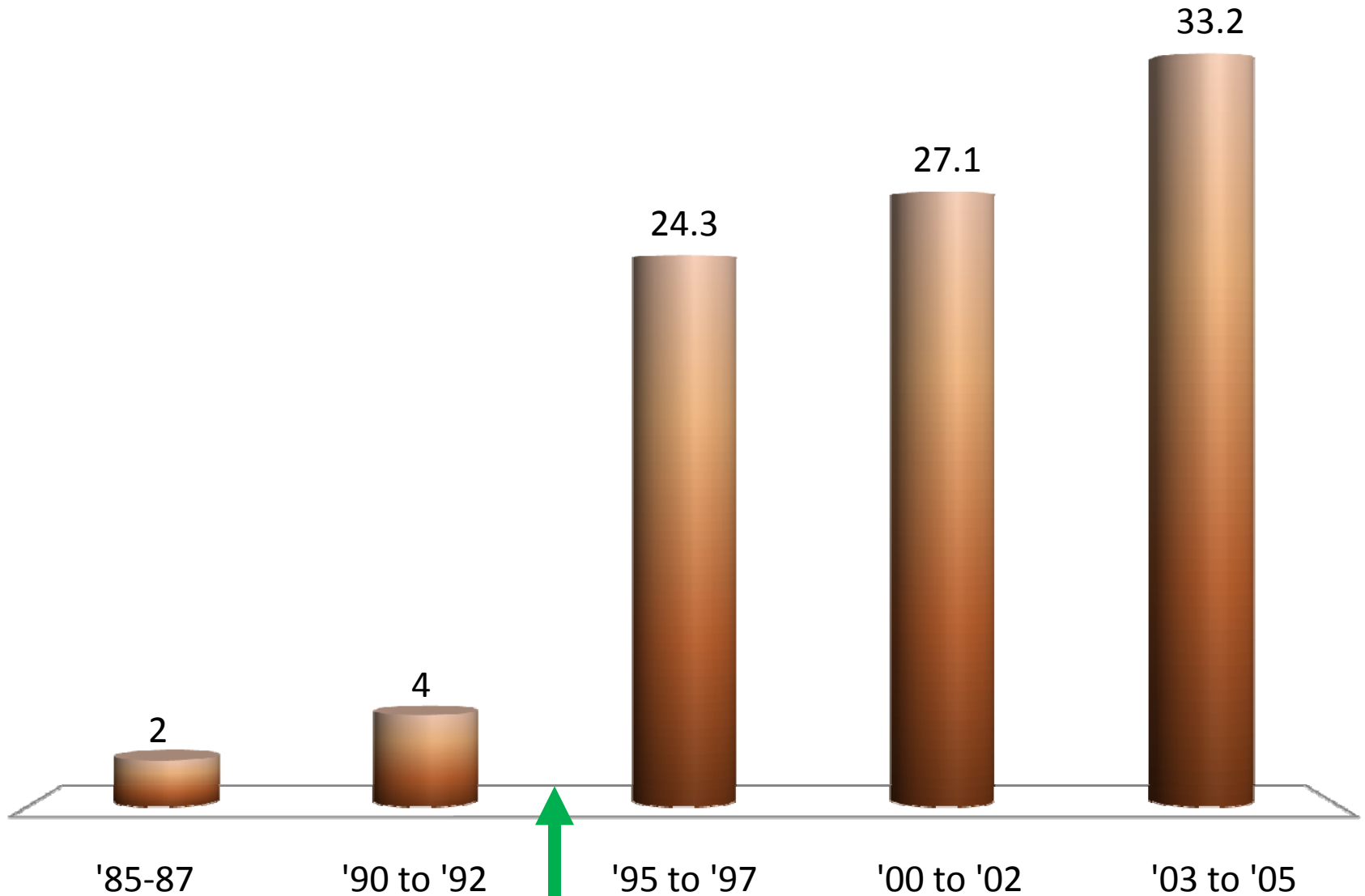
CDC policy is to test and treat to prevent the development AIDS and to reduce new infections



USA AIDS Cases Over Age 50 - CDC



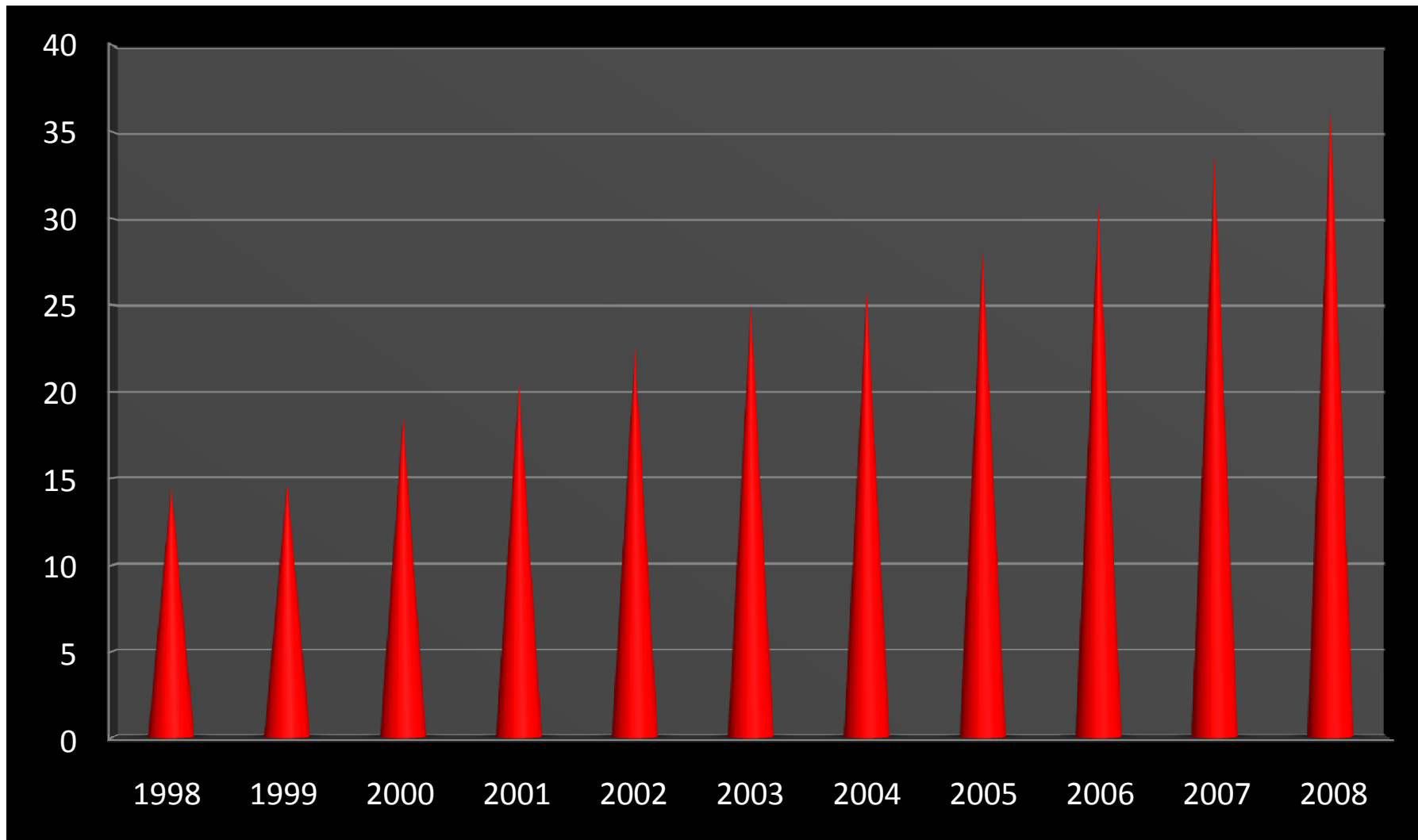
Median Life Years at Age 20 with HIV and in Care



HAART

% OF PEOPLE LIVING WITH AIDS DIAGNOSIS OVER AGE 50 IN US

CDC SURVEILLANCE DATA



U.S. Department of Health and Human Services, Administration on Aging, Washington DC 20201 PHONE 202.619.0724 | FAX 202.357.3555 | EMAIL aoainfo@aoa.gov | WEB <http://www.aoa.gov>



New York City is the U.S. HIV Epicenter

There are approximately

120,000

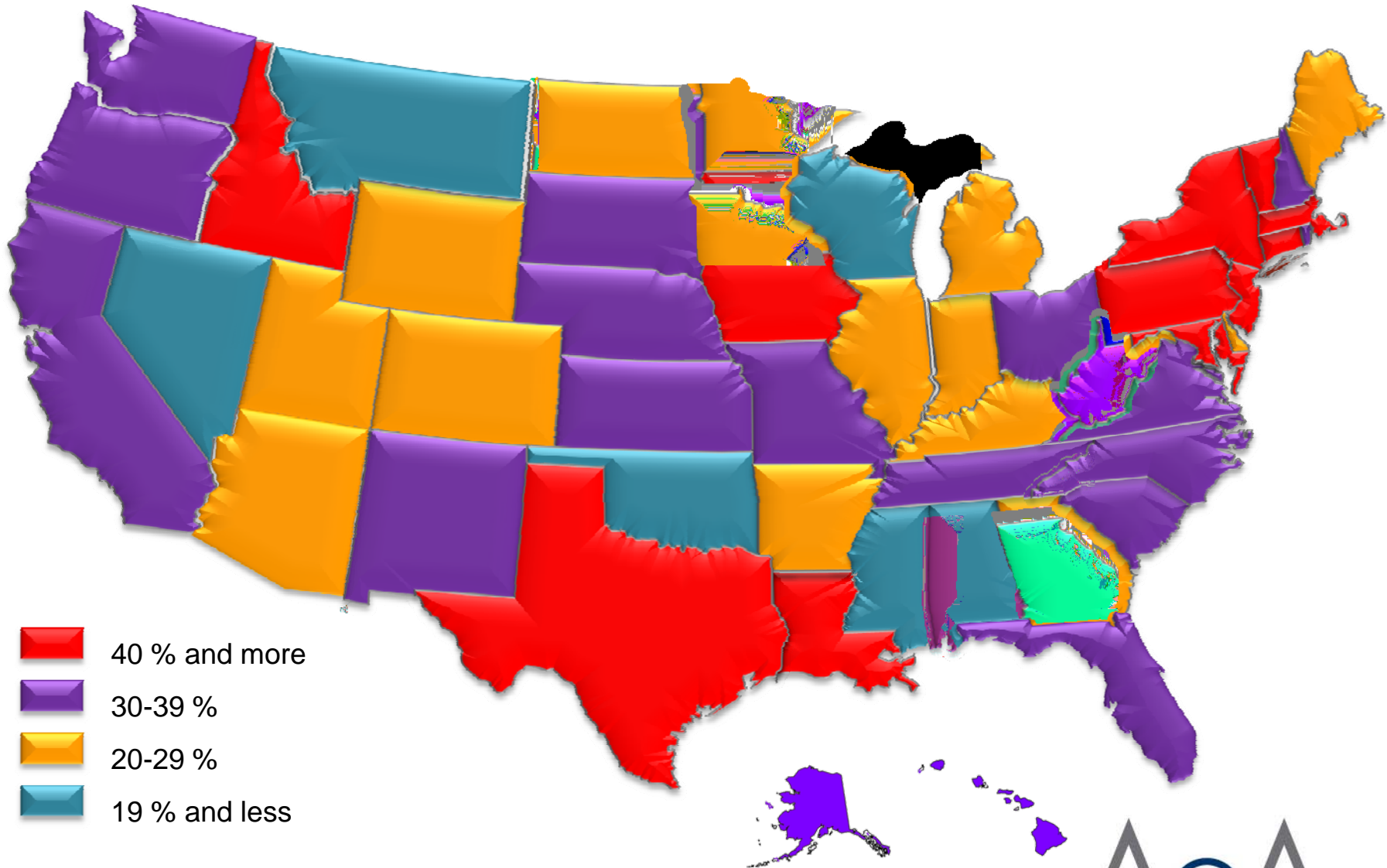
people living with HIV

42% are over age 50

and

75% are over age 40

% of People with HIV Age 50 and Older 2009-2010



- 40 % and more
- 30-39 %
- 20-29 %
- 19 % and less

Please refer to the [image description](#) found on page 64 for an accessible version of this map.

Why is the HIV Population Growing and Graying?

CARE

- Drugs to treat HIV are effective thereby transforming a diagnosis from a death sentence to a long life span

CARE

- The overwhelming majority of older adults with HIV were infected before age 50

Prevention

- Almost 1 in 6 new HIV infections occur in people 50 and older

Prevention

- New HIV infections have been largely ignored HIV Prevention efforts have not targeted older adults

ACRIA Funded Initial Studies On HIV and Aging in 20



WHO

Are These Older Adults
Living with HIV?

Nearly 1,000 NYC Adults Over Age 50



RESEARCH on OLDER ADULTS with HIV

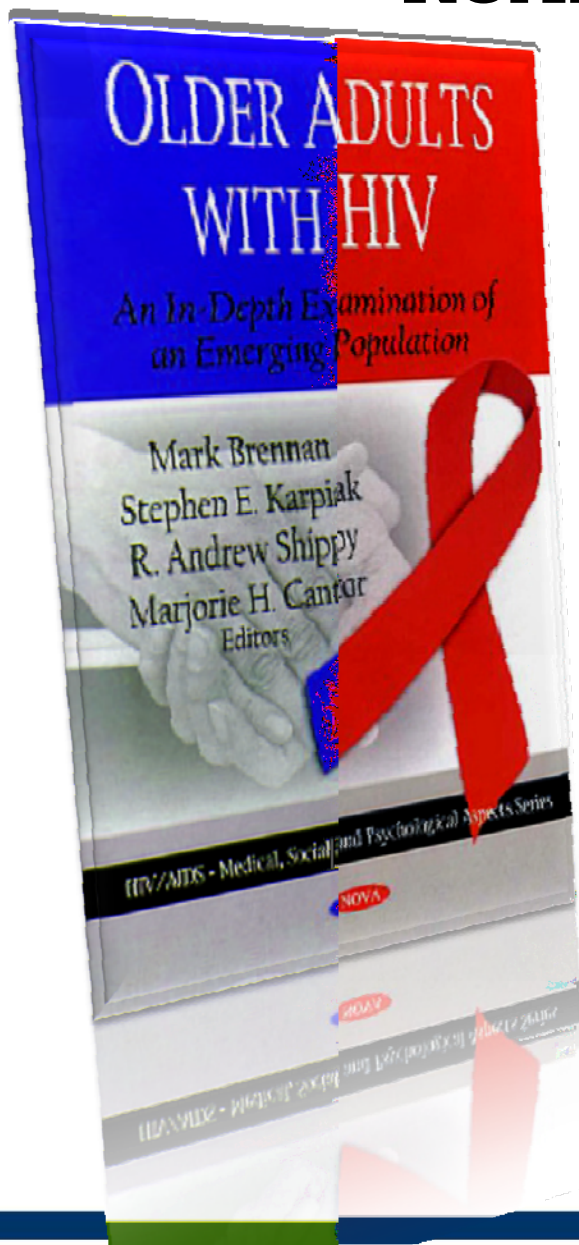
Stephen E. Karpiak, PhD

Mark Brennan, PhD

Principal Investigators

ACRIA Center on HIV and Aging

ROAH is COMPREHENSIVE



Demographics

Sexual Behavior / Substance

Use Social Networks

Psychological Well-Being

Distress - Depression

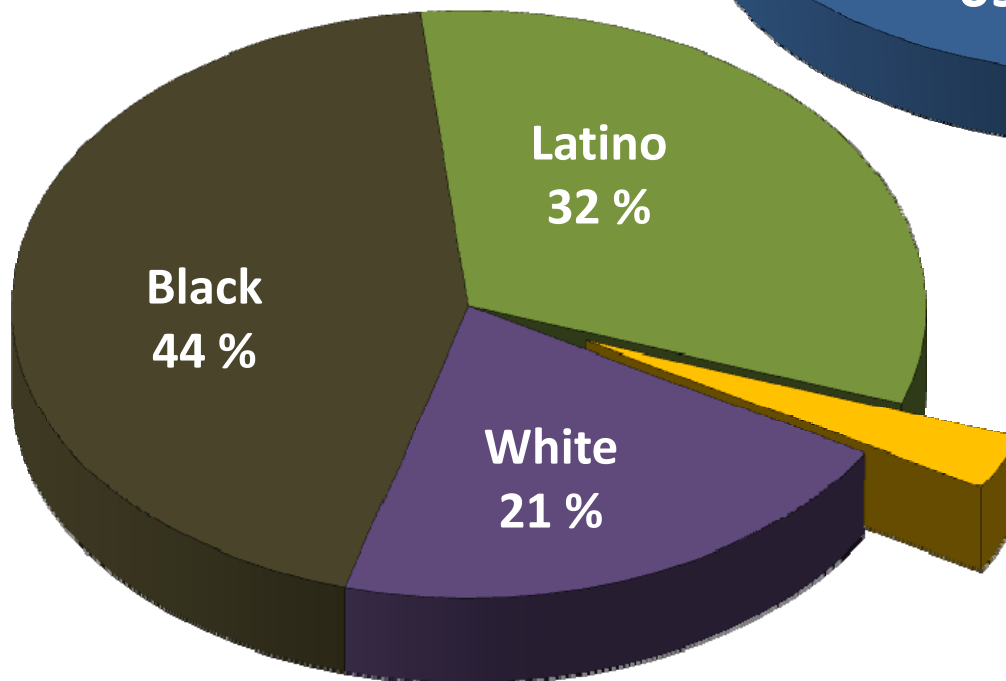
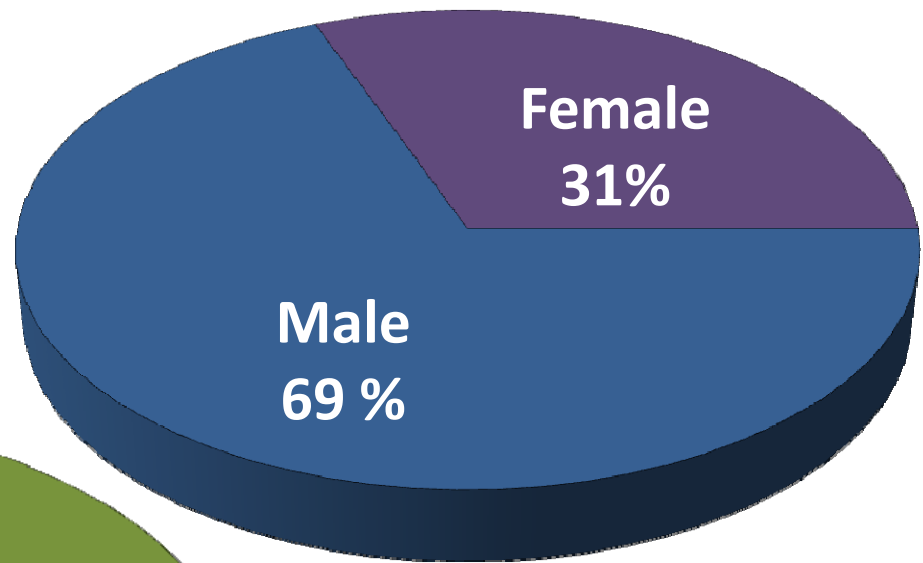
HIV Status/Health

Religiousness & Spirituality

Loneliness Among Older Adults

HIV Stigma and Disclosure

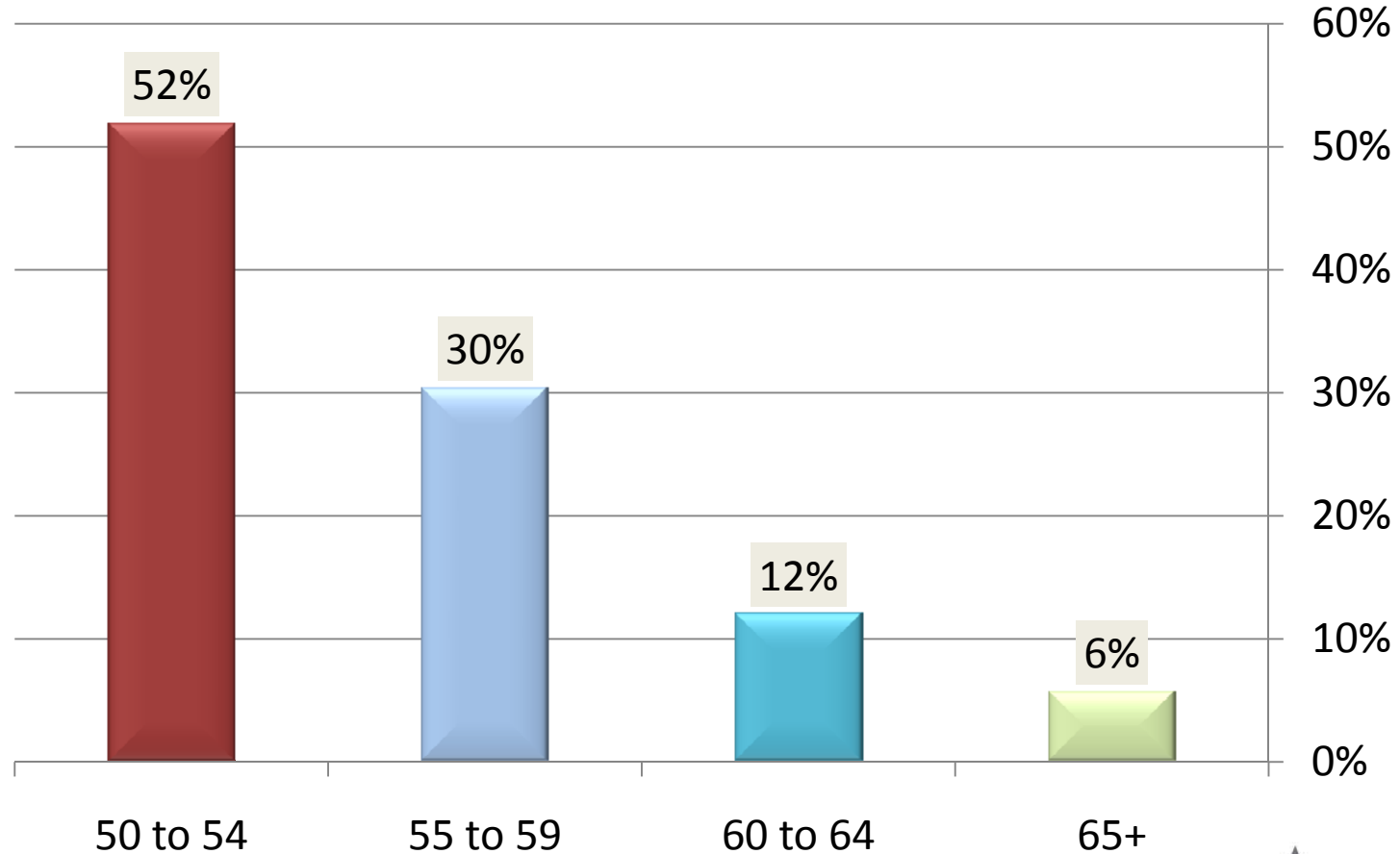
ROAH Mirrors the HIV Population of NYC and US



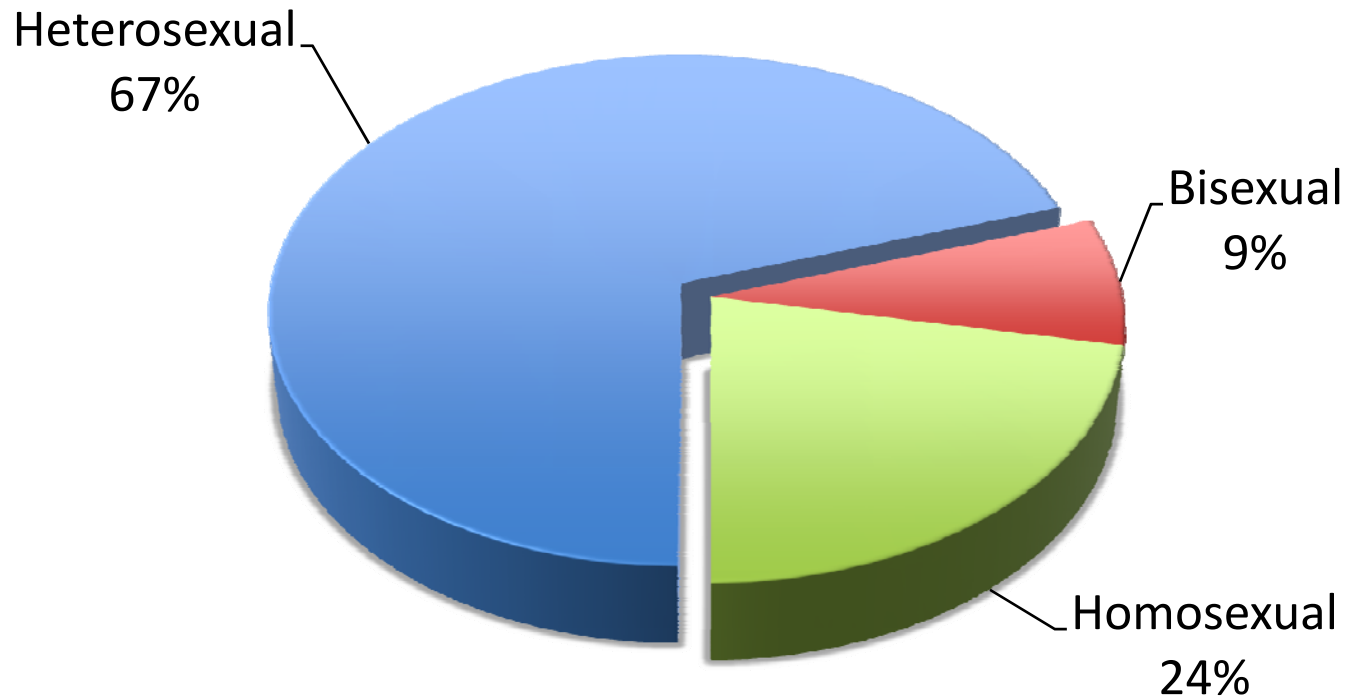
API / Am. Indian 3 %

ROAH: Age Distribution

Mean Age = **55.3** / Age range 50-78



ROAH: Sexual Self-Identification

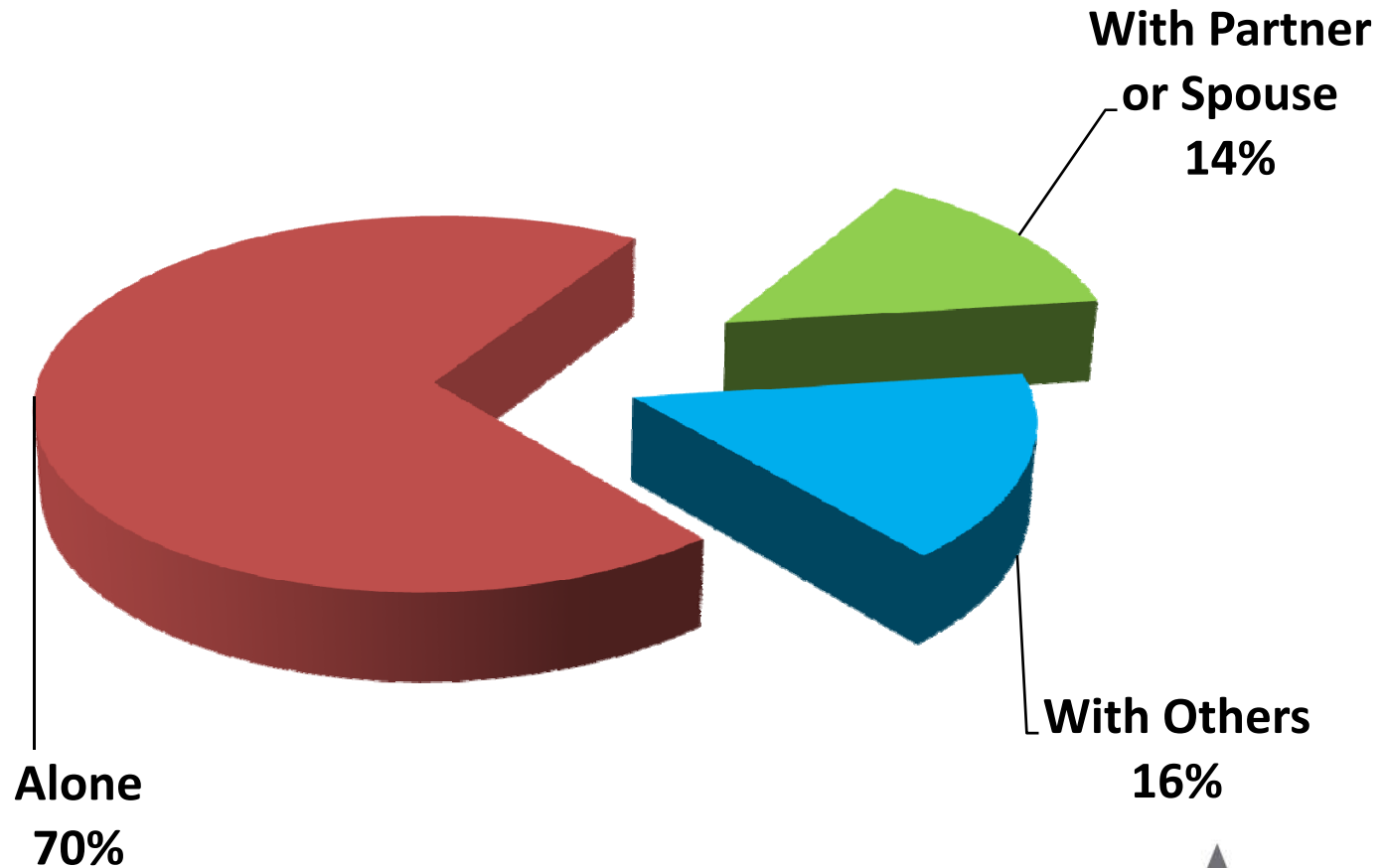


ROAH:HIV Treatment and Care

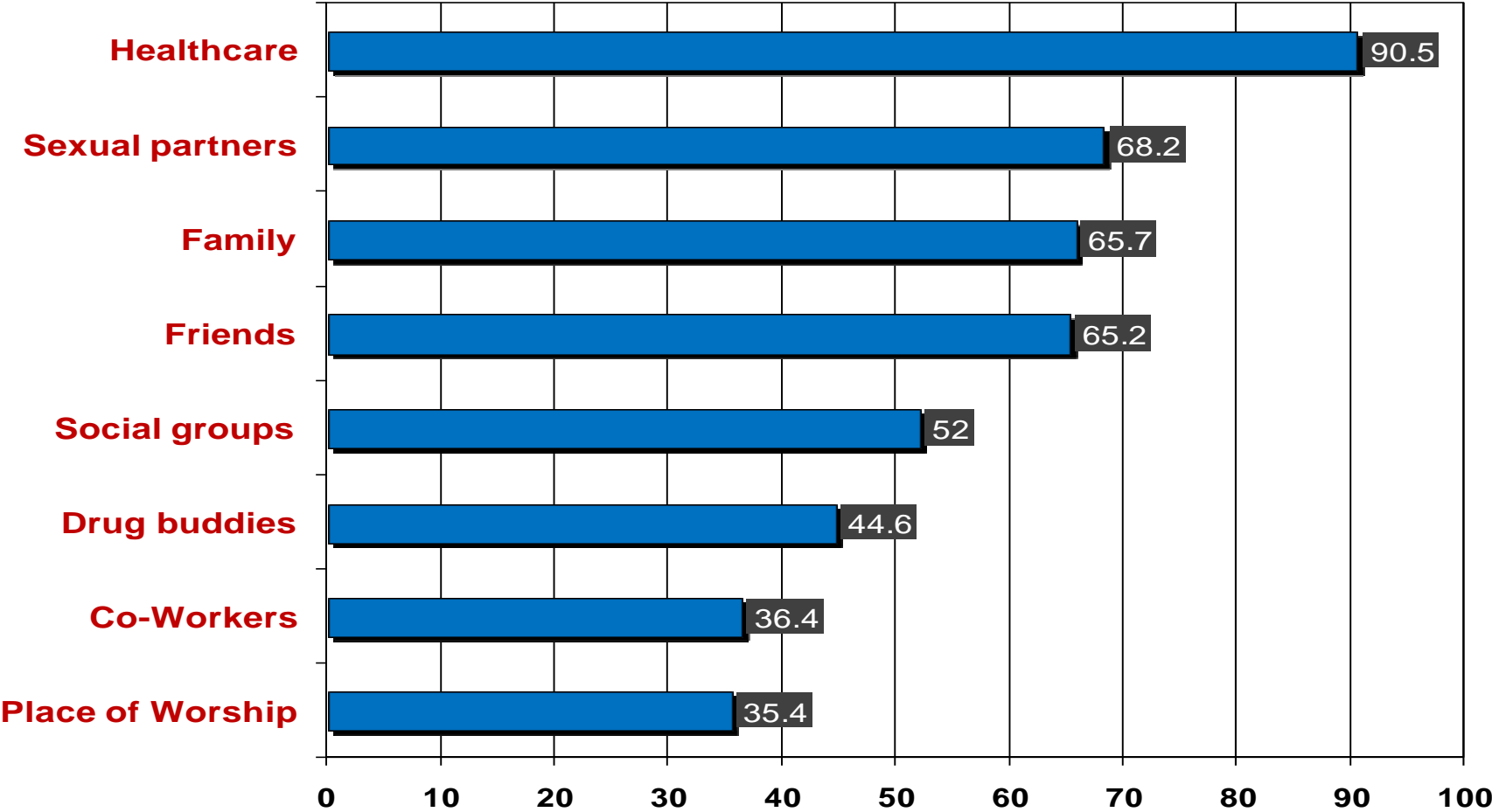
Treatment facility	%
– Private physician	21.9
– Public clinic / hospital	58.7
– VA Hospital	4.9
– AIDS Service Organizations	17.0

83% of ROAH Participants Rely on Medicaid

ROAH: Living Arrangement



ROAH: Stigma and Disclosure of HIV Status (%)



ROAH: Substance Use Including Tobacco Use

Current :

57 %

History:

84 %

ROAH: Substance Use Recovery

<u>Recovery Status</u>	<u>%</u>
• Ever enrolled in 12-step	62
• Currently in recovery	54
• No substance use in past 3 months	48
• In recovery for more than 1 year	44

Depression in ROAH vs. Other Older Adults

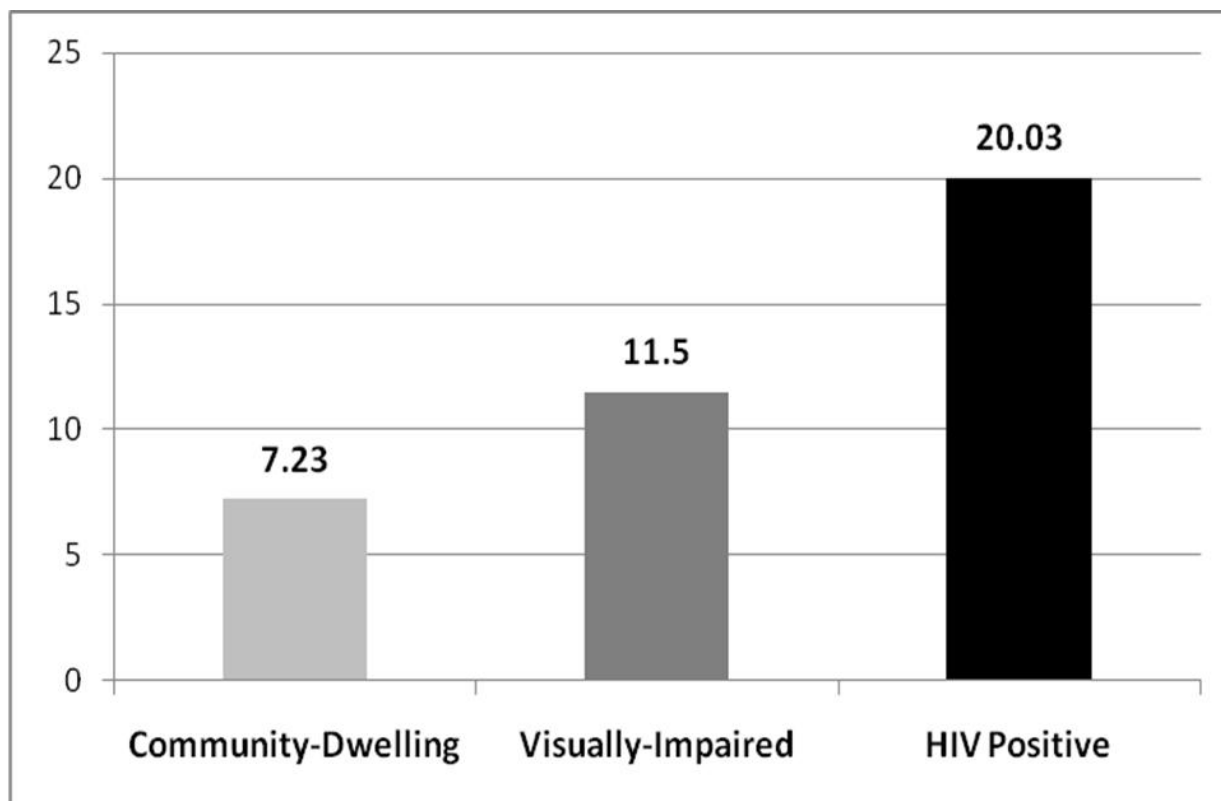


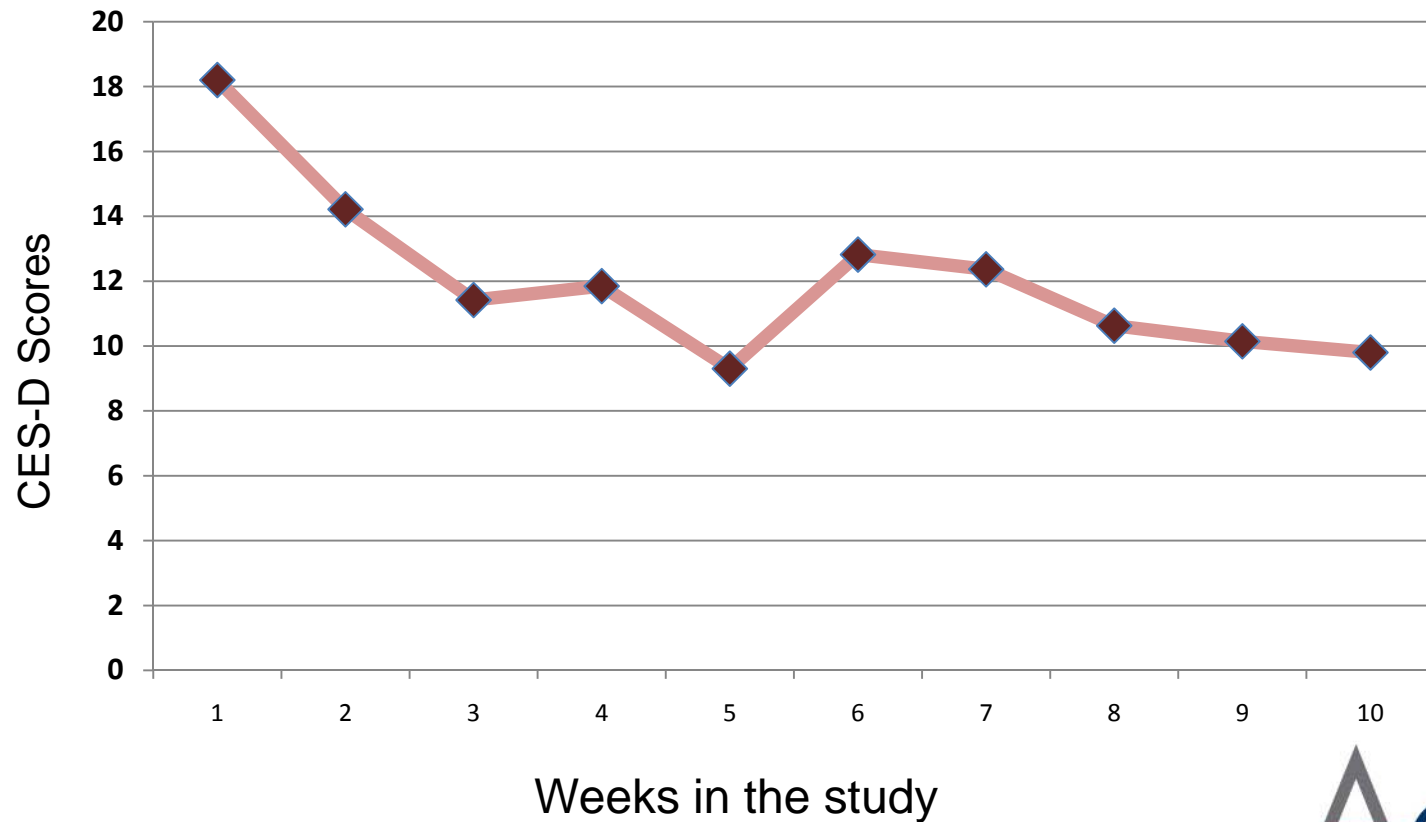
Figure 2 Comparison of Average CES-D Scores among Middle-age and Older Adults who are Community-dwelling, Visually-Impaired, or Living with HIV in ROAH. Data on Community-dwelling adults and visually impaired adults were obtained from Gump et al. (2005) and Horowitz et al. (2006), respectively.

**Over 2/3 of the ROAH participants
had moderate to severe depression**

**Depression decreases adherence to ALL
medication including HIV meds**

**Although enrolled in medical care their
depression remains poorly managed**

A Simple Phone Call ACRIA Study Using the MacArthur Model for Depression

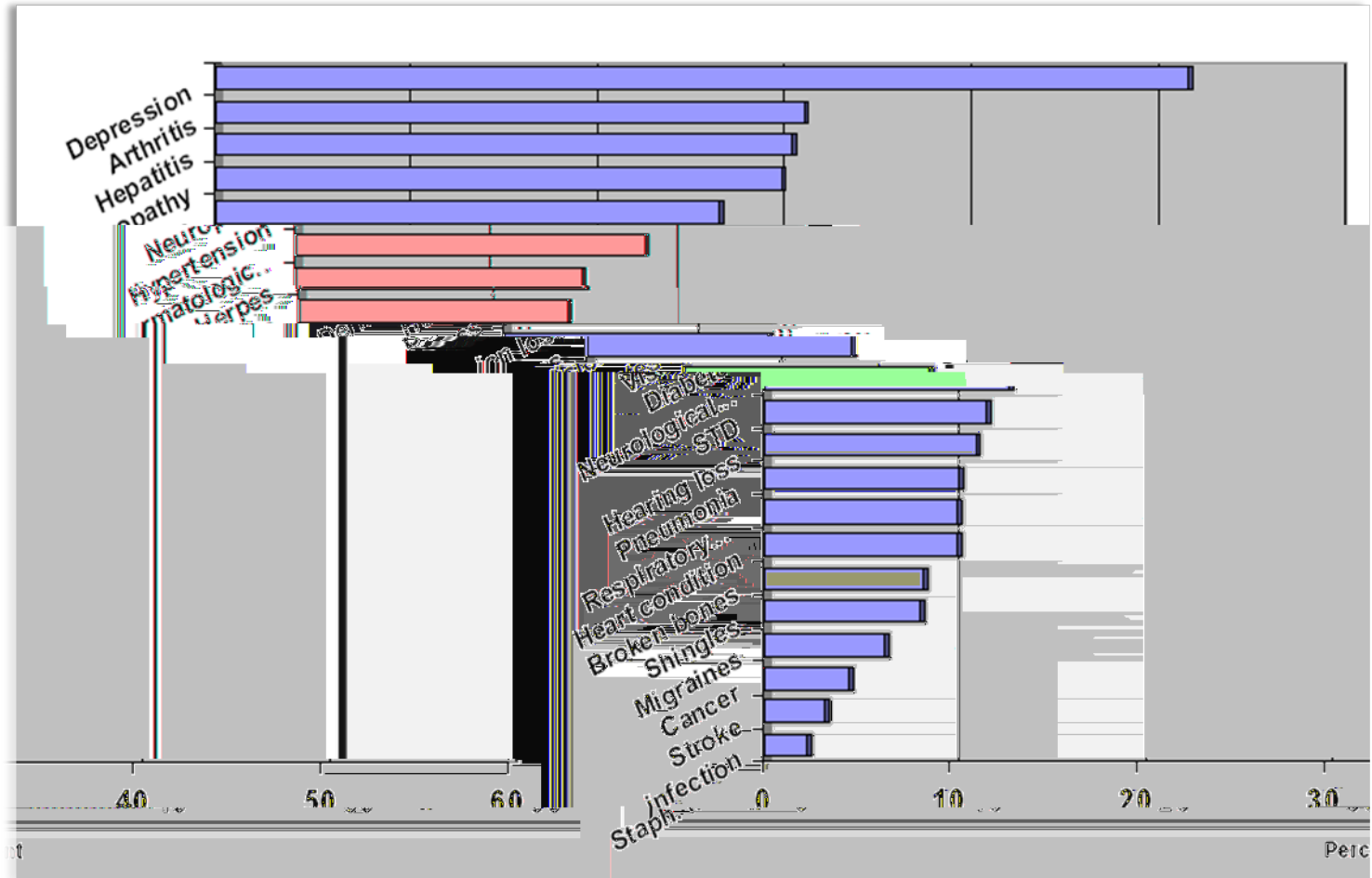


The Complications of Success

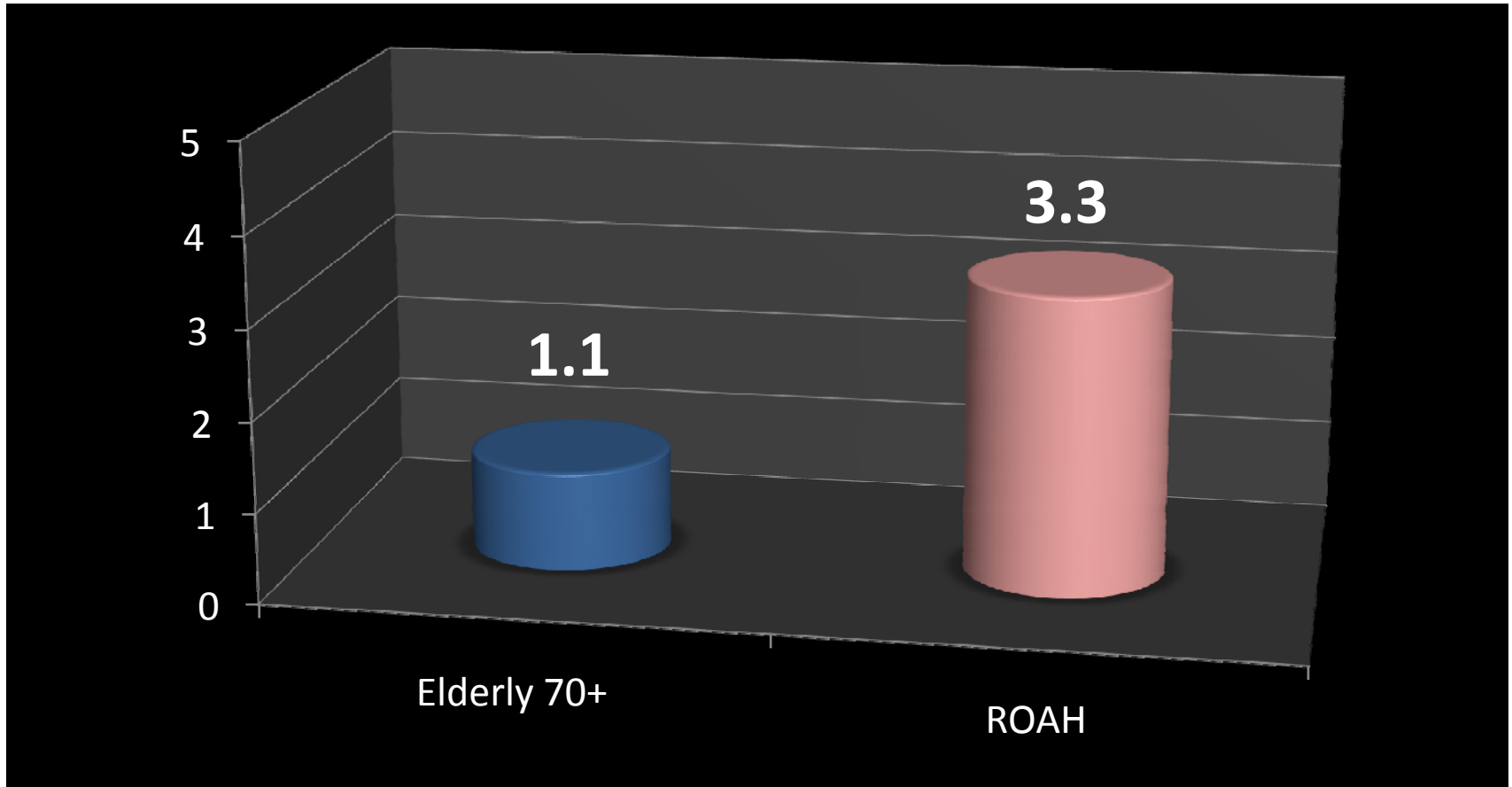
Older adults with HIV
are developing at an early age
illnesses that are more typically associated with
later senior years.

These include Cancers – Cardiovascular Disease - Osteoporosis
Liver and Kidney Disease – Diabetes

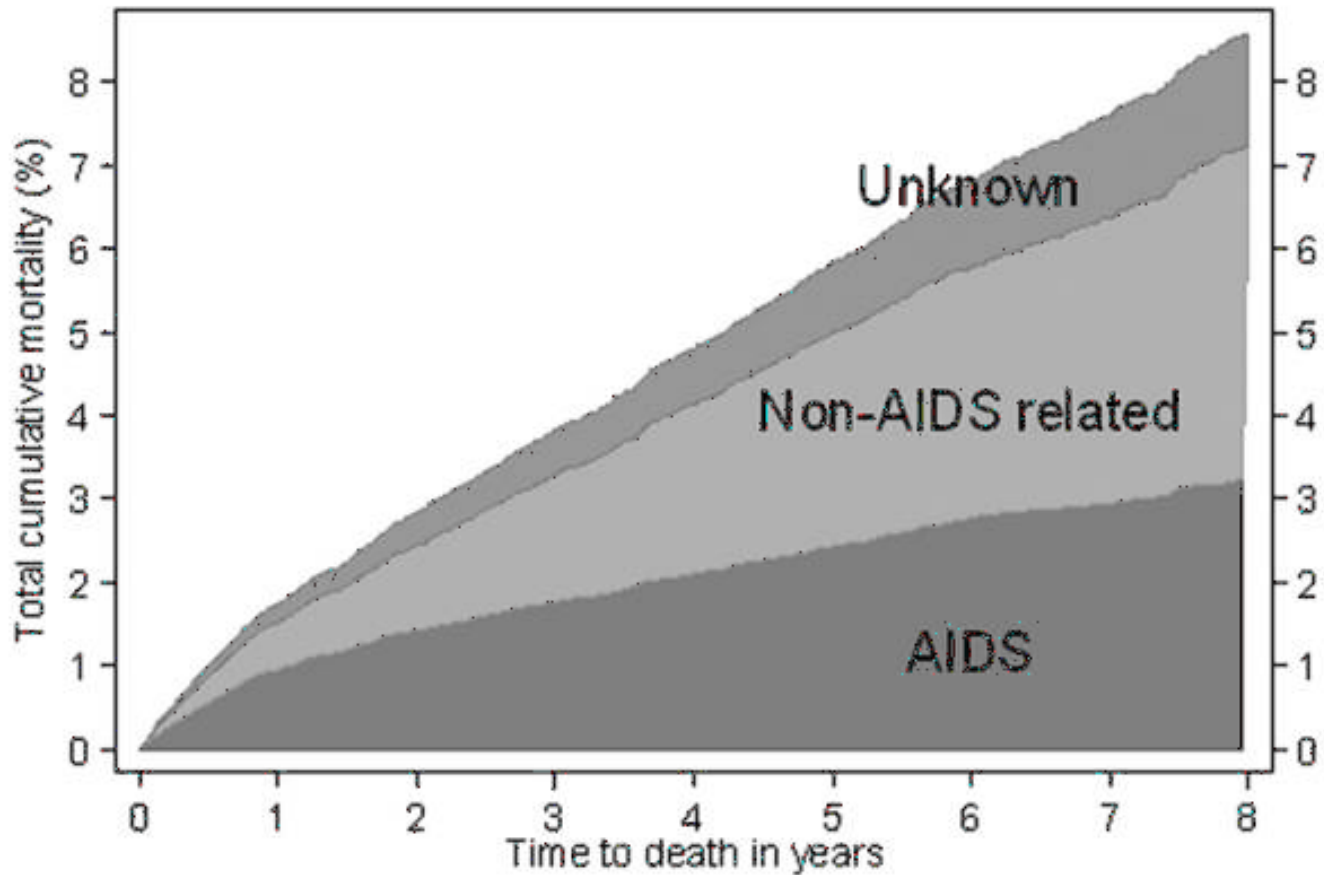
ROAH: Comorbid Health Problems



Average Number of Comorbidities



>50% of Deaths Attributed to Non-AIDS Events



Cumulative Mortality by COD Among Those initiating HAART(1996-2006) ART-CC, CID 2010: 1387-1396

AAHIVM: Guides for the Management of Older Adults with HIV

**Expert Panel of 14
Leaders in HIV
Treatment Research
and Geriatric Care**

American
Academy of
HIV Medicine

American
Geriatrics
Society

ACRIA Center
on HIV and
Aging

HIV

**Cancers – Cardiovascular Disease
Osteoporosis – Liver and Kidney
Disease – Diabetes**

**Multimorbidity
Care
Management**

**Mental
Health**

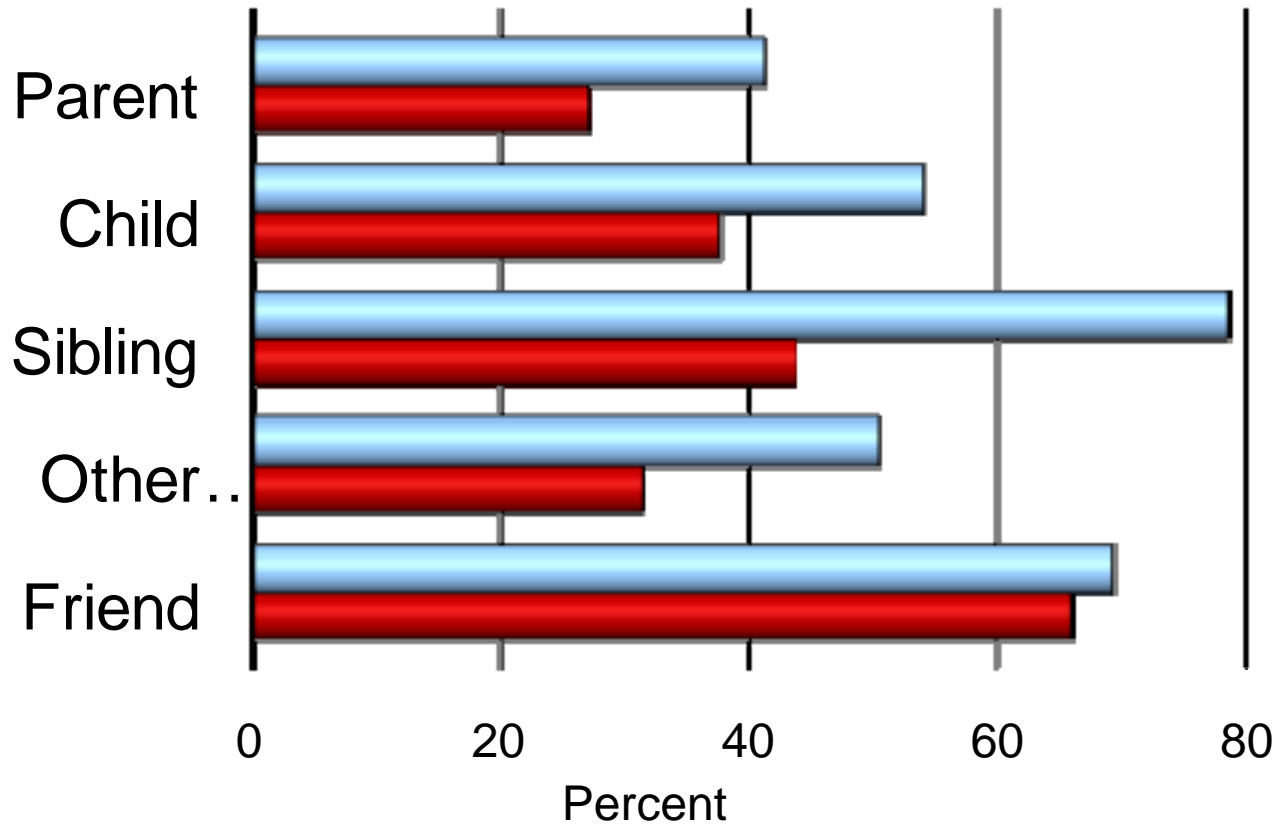
**Social
Isolation**

Social networks are a significant health and services resource

Caregiving = \$400 Billion Annually

CAREGIVERS
are derived from
SOCIAL NETWORKS

ROAH: Social Network Composition



Please refer to the [image description](#) found on page 65 for an accessible version of this graph.

Living Functional

ACRIA's Research Demonstrates that Older Adults with HIV have Fragile Social Networks

Lead to greater reliance on formal support services



Increase levels of isolation, loneliness and depression that contribute to diminished health outcomes



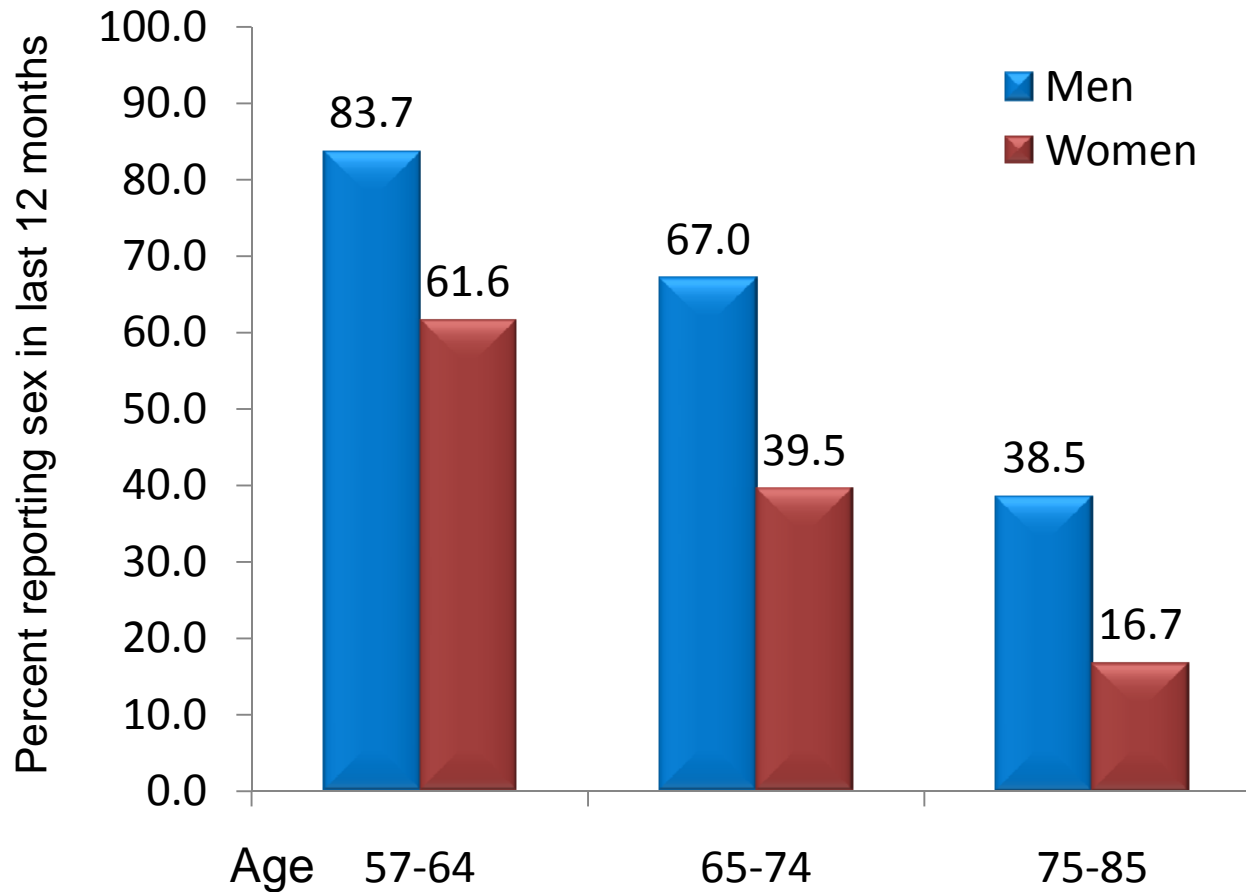
Increase the likelihood they will enter and remain longer in long-term care facilities

There is NO

**Great sex
After 50!**

And other outlandish lies about getting older

Sex is Not Only for the Young



Please refer to the [image description](#) found on page 66 for an accessible version of this graph.

Lindau et al. *NEJM* 2007 357(8):762-774

In 2009

**1 of every 6
New
HIV Diagnoses
in the U.S.
Was in People Age 50
and Older**

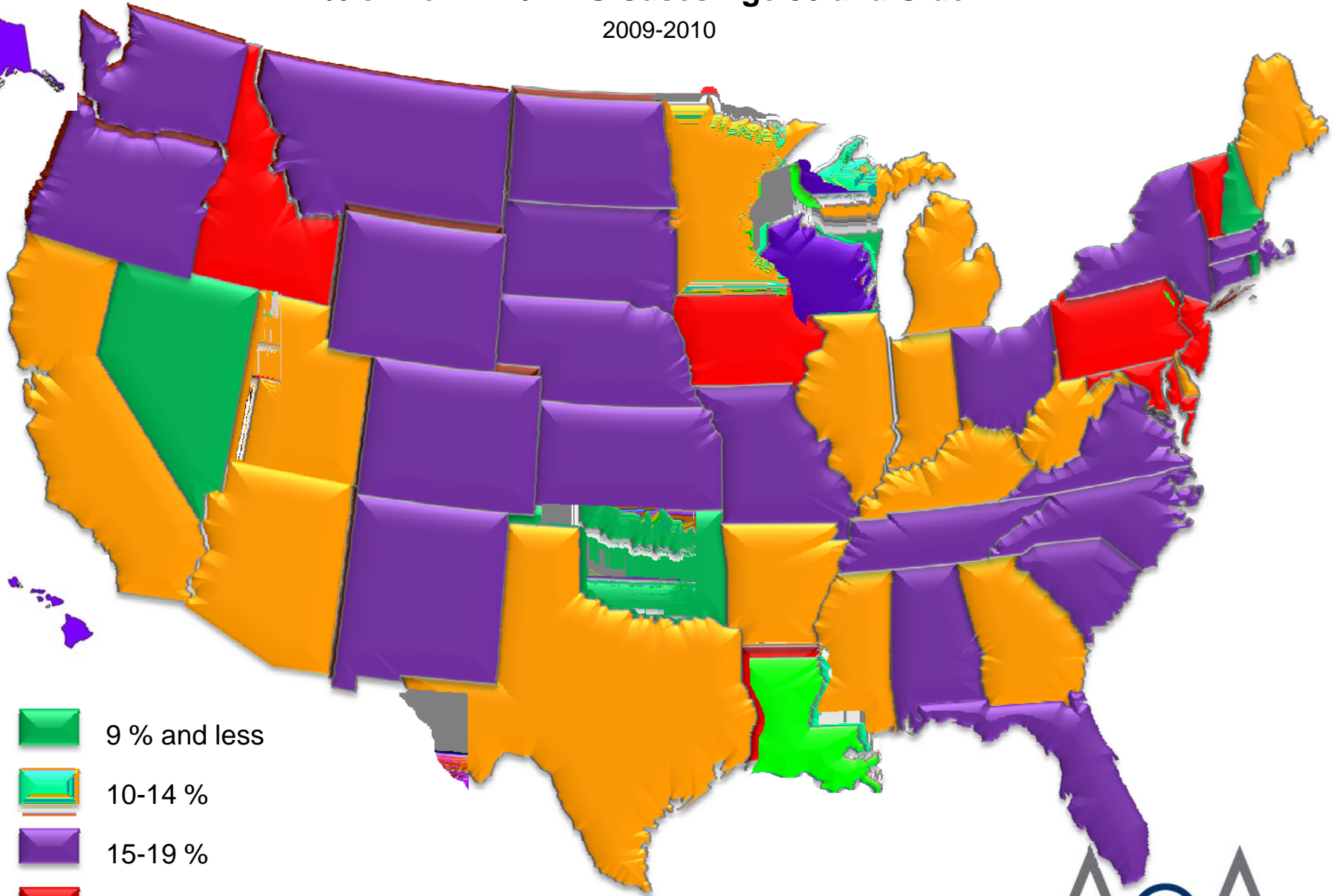
Why are older adults getting HIV ?

Lack of awareness of HIV risk factors

- Many older people may be newly single due a death or divorce
- Belief that HIV only affects younger people
- **Unprotected sexual activity**
 - Menopause = No risk for pregnancy = No condom
 - Unaware of safer sexual activities
- **Lack of HIV prevention and interventions tailored for older adults**
- **Seniors not considered at risk: don't ask, don't tell**

% of New HIV/AIDS Cases Age 50 and Older

2009-2010



- 9 % and less
- 10-14 %
- 15-19 %
- 20 % and more

Please refer to the [image description](#) found on page 67 for an accessible version of this map.

ROAH: *First* Data on Risk Behavior in Older Adults

- Substance use impact - Significant
- Viagra and other ED Drugs' Impact - None
- Of those older adults with HIV who are sexually active 16% engaged in high risk sexual behavior in the last 3 months

The New York Council Funded HIV and Older Adults Initiative

2007-2011



The New York Council Funded HIV and Older Adults Initiative

2007-2011

- Partner with agencies serving older adults creating a network with local HIV service providers
- Create awareness about HIV and older adults through materials development and social messaging
- HIV prevention intervention: (Community Promise)
- Change knowledge, attitudes and beliefs
- HIV testing and access to care
 - 1,500 older adults have been tested
 - 20,000 condoms distributed
 - 300 older adults have been brought into care services

Sample of ACRIA's Older Adults Materials



**Conózcalo. Combátalo.
Derrótelo.**

**Detenga el
SIDA.**



Funded in whole by the New York City
Department of Health and Mental Hygiene



Pedro

My name is Pedro, but my friends call me Pete. I was born and raised in the South Bronx by very religious parents. They thought all homosexuals were going to hell, so I never told them I was gay.

Felipe

My name is Felipe, but people call me "Negrito." I'm 59 years old and was born in Venezuela. I managed to get across the U.S. border with help from friends. I was

Las personas mayores también pueden tener VIH....

En la Ciudad de Nueva York, dos de cada tres personas VIH positivas tienen 40 ó más años de edad, y una de cada tres tiene más de 50.

Su Comunidad Necesita de su Sabiduría

Para Detener el SIDA

Brenda

My name is Brenda. I'm a 59-year-old grandmother living in Harlem. Some years ago, I met a man who I thought was wonderful. We were both doing drugs – in fact that's how we met.



Program Accomplishments

In New York City and State

- Over 8,000 HIV and aging service provider staff and peers have attended trainings
- Over 600 days of training on 25 different modules
- All 51 City Council Districts

Nationally

- 75 organizations receive ongoing CBA/TA
- Support from the MAC AIDS Fund



In June 2011

ACRIA launched the first-ever wide spread social messaging campaign on HIV specifically targeting older adults





Thank You

Stephen Karpiak, PhD

Skarpiak@acria.org

AIDS Community Research Initiative of America

**Training, Technical Assistance, Capacity Building,
Materials and Consulting**

Contact: Luis Scaccabarrozzi

LScaccabarrozzi@acria.org

ACRIA Center on HIV and Aging

<http://www.acria.org>





Jane Pecinovsky Fowler

Founder/Director of HIV Wisdom for Older Women,
an outreach program at Family Health Care Services in
Kansas City, KS, and

HIV Activist and Prevention Speaker/Educator
North Kansas City, MO

Second Opinion

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Discover *first hand* how doctors navigate their way through *tough* medical decisions in a way you've *never* seen before.



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HIV In Middle Age

Topics: [Aging](#), [Sexual Health](#)

Transcript: [HIV in Middle Age \(transcript\)](#)

While sexually transmitted diseases were once thought of as a problem in the young population, diseases such as HIV are rising at alarming rates in the middle age and elderly. Second Opinion addresses the social, medical, physical and cultural factors that are contributing to this trend.

Older women are often overlooked in HIV prevention because it is incorrectly assumed that they no longer engage in sexual relations—though many, of course, do. But most don't realize that this activity can put them at risk of becoming infected with a sexually transmitted disease (STD).

- Nearly 10 percent (9.5) of AIDS cases in the U.S. female population are said to be in women older than age 50; and, numbers of cases are expected to increase, as women of all ages survive longer due to improved drug therapy and other treatment advances.
- In the last decade, AIDS cases in women over 50 were reported to have tripled, while heterosexual transmission rates in this age group may have increased as much as 106 percent. But, because not all U.S. states report HIV infections, it is impossible to know how many older American women are HIV-infected, but not diagnosed with AIDS.



Panelists

[Louis J. Papa, MD](#)

[Jane Pecinovsky Fowler](#)

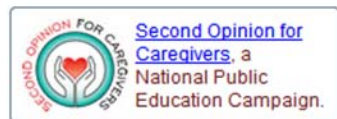
[Jennifer L. Hillman, Ph.D.](#)

[Amy C. Justice, MD, PhD](#)

[Amneris E. Luque, MD](#)

Sections on this page

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- [Search MedlinePlus](#)
- [Resources](#)



www.secondopinion-tv.org/episode/hiv-middle-age



Doreen Bermudez
Training Coordinator
National Resource Center on
LGBT Aging

HIV & Older Adults
Implementing in Community Service Providers
Settings

Community Approach on HIV & Older Adults

- Assessment(s) on where older adults are in the community
- Gaining access to Service Providers/Settings
- Creating an aging network curricula appropriate for service providers
- Creating a realistic structure promoting inclusion of HIV “conversations”
- Creating & Implementing follow up system

Community Approach on HIV & Older Adults

- Inclusion of HIV testing (associations with stigma-pre and post counseling)
- Addressing the LGBT(gay, lesbian, bisexual & transgender) community.
- Non-traditional settings
- Adjusting/flexibility of content/time

Sexuality, Older Adults & Service Providers

- Making assumptions
- Limiting language to define relationships
- How older adults are alienated and marginalized

Sexuality, Older Adults & Service Providers

- Understanding minority stress
- Cultural competency
- Language
- Consistency

Sexuality, Older Adults & Service Providers

- Risk factors for older adults
- Having a vision
- Creating a plan
- Implementation
- Capturing data/evaluation

Area Agencies on Aging Educating Seniors on HIV



Courtney Williams

Community Planner

District of Columbia Office on Aging

441 4th Street, NW, Suite 900 South

Washington, DC 20001

Phone: (202) 724-5622

Website: <http://www.dcoa.dc.gov>



Resources

US Administration on Aging

www.aoa.gov/AoARoot/AoA_Programs/Special_Projects/HIV_AIDS

AIDS Community Research Initiative of America

www.acria.org

HIV Wisdom for Older Women

www.hivwisdom.org

National Resource Center for LGBT Aging

www.lgbtagingcenter.org

District of Columbia Office on Aging

www.dcoa.dc.gov

Questions?

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Jane P. Fowler jane@hivwisdom.org
Director
HIV Wisdom for Older Women



Doreen Bermudez DBermudez@sageusa.org
Training Coordinator
National LGBT Resource Center



Courtney Williams Courtney.Williams@dc.gov
Community Planner
District of Columbia Office on Aging



Questions/Comments/Stories/ Suggestions for Future HIV and Aging Webinar Topics?

Send them to:

Danielle.Nelson@aoa.hhs.gov

Image Description of % of People with HIV Age 50 and Older 2009-2010 Map

A map of the United States showing the % of people with HIV age 50 and older in 2009-2010 (image of map found on [page 14](#)):

40% or More: Connecticut, Idaho, Iowa, Louisiana, Maryland, Massachusetts, New Jersey, New York, Pennsylvania, Texas, and Vermont

30 to 39%: Alaska, California, Florida, Hawaii, Kansas, Missouri, Nebraska, New Hampshire, New Mexico, North Carolina, Ohio, Oregon, Rhode Island, South Carolina, South Dakota, Tennessee, Virginia, and Washington

20 to 29%: Arizona, Arkansas, Colorado, Delaware, Georgia, Illinois, Indiana, Kentucky, Maine, Michigan, Minnesota, North Dakota, Utah, West Virginia, and Wyoming

19 % and Under: Alabama, Mississippi, Montana, Nevada, Oklahoma, and Wisconsin

Image Description of ROAH: Social Network Composition Graph

Parent Living: Slightly above 40%
Parent Functional: Below 30%

Child Living: Above 50%
Child Functional: Below 40%

Sibling Living: Nearly 80%
Sibling Functional: Above 40%

Other.. Living: 50%
Other.. Functional: 30%

Friend Living: 70%
Friend Functional: Below 70%

Image of bar graph found on [page 37](#).

Image Description of Sex is Not Only for the Young Graph

Percent reporting sex in the last 12 months:

Age 57-64: Men 83.7% Women 61.6%

Age 65-74: Men 67% Women 39.5%

Age 75-85: Men 38.5% Women 16.7%

Lindau et al. *NEJM* 2007 357 (8): 762-774

Image of bar graph found on [page 40](#).

Image Description of % of New HIV/AIDS Cases Age 50 or Older 2009-2010 Map

A map of the United States showing the % of new HIV/AIDS cases age 50 or older (image of map found on [page 43](#)):

9% or less: Nevada, New Hampshire, Oklahoma, Rhode Island, and Wisconsin

10-14%: Arizona, Arkansas, California, Delaware, Georgia, Illinois, Indiana, Kentucky, Maine, Michigan, Minnesota, Mississippi, Texas, Utah, and West Virginia

15-19%: Alabama, Alaska, Colorado, Connecticut, Florida, Hawaii, Kansas, Massachusetts, Missouri, Montana, Nebraska, New Mexico, New York, North Carolina, North Dakota, Ohio, Oregon, South Carolina, South Dakota, Tennessee, Virginia, Washington, and Wyoming

20% or more: Idaho, Iowa, Louisiana, Maryland, New Jersey, Pennsylvania, and Vermont