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 of AIDS and to reduce new infections.
USA AIDS Cases Over Age 50 - CDC

- 1994: 10,000
- 2005: 120,000

HAART
Median Life Years at Age 20 with HIV and in Care

<table>
<thead>
<tr>
<th>Period</th>
<th>Median Life Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>'85-87</td>
<td>2</td>
</tr>
<tr>
<td>'90 to '92</td>
<td>4</td>
</tr>
<tr>
<td>'95 to '97</td>
<td>24.3</td>
</tr>
<tr>
<td>'00 to '02</td>
<td>27.1</td>
</tr>
<tr>
<td>'03 to '05</td>
<td>33.2</td>
</tr>
</tbody>
</table>
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
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
WHO

Are These Older Adults Living with HIV?
RESEARCH on OLDER ADULTS with HIV

Stephen E. Karpiak, PhD
Mark Brennan, PhD
Principal Investigators
ACRIA Center on HIV and Aging

Nearly 1,000 NYC Adults Over Age 50
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

- Female: 31%
- Male: 69%
- Latino: 32%
- Black: 44%
- White: 21%
- API / Am. Indian: 3%
ROAH: Age Distribution

Mean Age = 55.3 / Age range 50-78
ROAH: Sexual Self-Identification

- Heterosexual: 67%
- Bisexual: 9%
- Homosexual: 24%
## ROAH:HIV Treatment and Care

<table>
<thead>
<tr>
<th>Treatment facility</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private physician</td>
<td>21.9</td>
</tr>
<tr>
<td>Public clinic / hospital</td>
<td>58.7</td>
</tr>
<tr>
<td>VA Hospital</td>
<td>4.9</td>
</tr>
<tr>
<td>AIDS Service Organizations</td>
<td>17.0</td>
</tr>
</tbody>
</table>

83% of ROAH Participants Rely on Medicaid
ROAH: Living Arrangement

- Alone: 70%
- With Partner or Spouse: 14%
- With Others: 16%
ROAH: Stigma and Disclosure of HIV Status (%)
ROAH: Substance Use
Including Tobacco Use

Current: 57 %

History: 84 %
ROAH: Substance Use Recovery

<table>
<thead>
<tr>
<th>Recovery Status</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ever enrolled in 12-step</td>
<td>62</td>
</tr>
<tr>
<td>Currently in recovery</td>
<td>54</td>
</tr>
<tr>
<td>No substance use in past 3 months</td>
<td>48</td>
</tr>
<tr>
<td>In recovery for more than 1 year</td>
<td>44</td>
</tr>
</tbody>
</table>
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

Weeks in the study

CES-D Scores

Administration on Aging
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

- Elderly 70+: 1.1
- ROAH: 3.3
>50% of Deaths Attributed to Non-AIDS Events

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

Administration on Aging
Social networks are a significant health and services resource

Caregiving = $400 Billion Annually

CAREGIVERS are derived from SOCIAL NETWORKS
Please refer to the image description found on page 65 for an accessible version of this graph.
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

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

Percent reporting sex in last 12 months

<table>
<thead>
<tr>
<th>Age</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>57-64</td>
<td>83.7</td>
<td>61.6</td>
</tr>
<tr>
<td>65-74</td>
<td>67.0</td>
<td>39.5</td>
</tr>
<tr>
<td>75-85</td>
<td>38.5</td>
<td>16.7</td>
</tr>
</tbody>
</table>

Please refer to the image description found on page 66 for an accessible version of this graph.
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

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
• 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

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

Pedro
My name is Pedro, but my friends call me "Petey." 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.

Brenda
My name is Brenda. I'm a 79-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

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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
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?
Contact Information

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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


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