

# **Red Ribbon Silver Threads** Healthy Aging in the Era of HIV/AIDS

Forum Proceedings



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## Table of Contents

|   | <u>Page</u> |
|---|-------------|
| <b><i>I. Introduction</i></b> .....   | 3           |
| <b><i>II. Summary of Forum Recommendations</i></b> .....                    | 4           |
| <b><i>III. Plenary Sessions</i></b> .....                                   | 9           |
| A Public Health Blueprint for Healthy Aging.....                            | 9           |
| - Dr. Linda Fried   |             |
| HIV Clinical Issues in Older Adults and Research from the Front Lines.....  | 10          |
| - Dr. Amy Justice   |             |
| - Dr. Stephen Karpiak   |             |
| - Dr. Judith Aberg  |             |
| Data Overview and Current Planning and Programs: Federal, State, Local..... | 12          |
| - Dr. Deborah Parham Hopson   |             |
| - Dr. Monica Sweeney  |             |
| - Dr. Alvaro Carrascal  |             |
| <b><i>IV. Workshops</i></b>   |             |
| 1. HIV Disease and Co-morbidities in Older Adults.....                      | 14          |
| 2. Healthy Aging with HIV: Clinical and Individual Perspectives.....        | 18          |
| 3. Designing a Model of HIV Care and Service for Older Adults.....          | 24          |
| 4. Factors that Increase or Decrease HIV Risk.....                          | 30          |
| 5. Sexuality and Sexual Health in an Aging Population.....                  | 34          |
| 6. Funding Programs/Paying the Bills.....                                   | 41          |
| 7. Educating the Workforce, the Community, and the Individual.....          | 46          |
| <b><i>V. Access to Additional Forum Materials</i></b> .....                 | 50          |

# **Red Ribbon, Silver Threads: Healthy Aging in the Era of HIV/AIDS**

## ***I. Introduction***

The increasing number of older adults living with HIV and the often unrecognized threat of HIV infection in people over 50 prompted the AIDS Institute (the Institute) of the New York State Department of Health to sponsor a forum on December 7, 2009, titled “Red Ribbon, Silver Threads: Healthy Aging in the Era of HIV/AIDS.”

Substantial numbers of people aging with HIV was not an issue that clinicians and researchers expected to face even 10 years ago. However, thanks in large part to the success of HIV treatment, in 2007 more than a third of people with HIV in New York State were over 50 and nearly 75% were over 40, reported Humberto Cruz, Director of the AIDS Institute, in opening remarks at the forum.

Medications have dramatically lengthened and improved the quality of life for people with HIV, but life spans are still not normal, and people struggling with long term HIV infection face the many other chronic diseases that challenge all older adults. The possibility of new HIV infection is also a threat to sexually active but uninformed or misinformed seniors, who are often diagnosed with HIV infection late in the course of the disease. Lack of knowledge or the stigma still associated with HIV keeps many people from learning their status or seeking treatment.

The forum was intended to highlight these issues and bring experts from the fields of HIV/AIDS, chronic disease, and geriatrics together with consumers, caregivers, and community members to recommend steps to improve HIV prevention and care for older adults.

More than 170 forum participants, including clinicians, researchers, program directors, government officials, policy planners, and interested older adults were invited to the City University of New York Graduate Center to make specific program, policy, and funding recommendations to the Institute. They attended plenary sessions and workshops designed to allow in depth discussions among a cross section of people on issues related to clinical care, prevention, financing, and public and professional education and training and to help formulate an effective model of care for older adults with HIV.

This report presents the program, policy, and funding recommendations from the forum. It is provided as a resource for policy makers, funders, public and private organizations, and individuals who are interested in issues related to HIV/AIDS and aging.

## ***II. Summary of Forum Recommendations***

A particular focus of the forum, reflected in its title, was *healthy* aging; that is, the intent to extend not only the length of life, but its quality. Healthy aging for people with and without HIV infection means preventing or delaying conditions that can become chronic and disabling, thus compressing any illness or disability into a shorter period at the end of life, a goal of obvious individual and societal value. Healthy aging requires personal commitment to good health habits and, for older people with HIV, it requires that clinicians understand the ways that HIV can accelerate the process of aging and aging can change the course of HIV disease.

Recommendations to serve these objectives addressed topics in several broad categories:

### **Education targeted to individuals:**

- healthy behavior and healthy aging
- risk of HIV infection for older adults
- importance of HIV and STI testing
- symptoms of acute HIV infection

### **Education and planning targeted to communities:**

- implications of HIV and aging for individuals and communities
- social networks, support, and infrastructure for aging adults
- ageism and the stigma of HIV

### **Clinical care:**

- HIV prevention, including discussion of sexual behavior and sexual health care
- routine HIV testing for all sexually active adults
- screening for and treatment of diseases of aging that may have earlier onset in people with HIV
- assessment of the total burden of HIV and co-occurring diseases and their impact on functional status
- coordination of care encompassing primary, specialty, and support services

### **Workforce planning and training:**

- appropriate care for older adults regardless of setting or type of provider
- adequate number of providers skilled in chronic disease management, geriatrics and HIV care
- cross training, interdisciplinary collaboration, and team management

### **Policy and funding:**

- models of care integrating the management of chronic disease, geriatrics and HIV services
- reduction of health disparities
- improved access to care for seniors
- active participation of older adults in the design and implementation of services

- provider reimbursement for assessment, counseling, and care coordination

**Research:**

- interaction of HIV disease and the aging process
  - HIV incidence and transmission among seniors
  - evaluation of clinical outcomes
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The body of the report offers presentation summaries and details specific recommendations and discussion points from each workshop, which readers are urged to review. However, since many proposals overlap, the primary issues are summarized below.

## **Forum Recommendations:**

### **Education Targeted to Individuals**

- I. Develop and implement a multi-faceted public education campaign about sexual health and HIV prevention and treatment specifically for older adults.*

HIV prevention messages should be designed for seniors with varied backgrounds and needs. Prevention programs should use a range of strategies (including social media) and settings (traditional places seniors gather and non-traditional places they may be reached).

### **Education and Planning Targeted to Communities**

- II. Design community education strategies to increase public understanding of healthy aging, HIV risk factors, and HIV and STI testing and treatment, and to decrease stigma surrounding both HIV and aging.*
- III. Establish a senior Consumer Advisory Board (CAB) and engage older adult peers in community education and in designing and improving services.*

Education should address the many HIV and STI risk factors for older adults, including lack of access to health care, HIV information, and testing; inadequate support services; social isolation; cultural, community, and provider assumptions that seniors are sexually inactive; and issues such as poverty, immigration status, mental health, and drug use, which can affect sexual behavior and health care outcomes.

Communities should undertake activities and infrastructure improvements to address these issues and to encourage healthy aging in a variety of ways, including utilizing the skills and experience of older adults with and without HIV and recognizing the vital roles they can play.

## Clinical Care

- IV. Amend HIV Clinical Guidelines to focus recommendations specifically on assessment and treatment of aging patients, particularly co-morbidities and the impact of an individual's total disease burden, and revisit the HIV primary care medical model to highlight issues of aging.***
- V. Discuss sexual behavior and injection drug use with older adults and make HIV and STI testing a routine part of health care for sexually active people of any age.***
- VI. Devise strategies to improve communication with older adults, especially those with hearing, vision, health literacy, dementia, or other problems, in order to facilitate patient disclosure of symptoms and encourage earlier identification and treatment of HIV infection and co-morbidities.***

Physicians should be aware of the possibility of rapid aging in PLWHAs and variation in the presentation of diseases of the aging, which may require earlier treatment than current age defined protocols.

Standard care for older adults should include screening for frailty; determination of functional status; discussions about sexuality and HIV/STIs; screening for physical abuse, substance abuse, and mental health; assessment of socioeconomic issues such as isolation and poverty (that may lead to depression, poor nutrition, and other problems), and attention to generational barriers to care, polypharmacy, and health care coordination. New tools should be developed and used to assess total disease burden and impact.

Physiological diversity increases with age. Providers should understand that there is no one senior population, but rather differences in health and service needs among various older age groups and among individuals at any given age. Further, behaviors and beliefs vary with sexual orientation, marital status, socioeconomic status, and culture.

## Professional Education/Workforce Planning and Training

- VII. Expand professional education and workforce training about HIV and aging at all levels to assure adequate and culturally competent HIV and chronic disease management and staffing, encourage clinicians and health care teams to discuss sexuality and provide sexual health care to older adults, and improve coordination of care.***

Education should cross-train providers, including HIV, primary care, and geriatrics MDs, Pas, NPs, and case managers, as well as specialists in mental health, substance use, and specific populations (LGBT, women, immigrants).

Agencies should support collaborations with educational institutions to address workforce development and ensure that providers are able to meet the needs of aging PLWHAs.

## Policy and Funding

- VIII. Engage existing government-sponsored task forces of agency planners, providers, consumers, and workplace organizations to review emerging models of geriatric and HIV care. Approaches to outreach, training, and care coordination should also be examined to reflect new models appropriate to various aging populations.*
- IX. Encourage the development of best practices, networks, and collaborations for co-located, integrated, accessible HIV and aging services.*
- X. Review existing models of care for geriatric and chronically ill populations to determine how they may be modified and enhanced for use by aging PLWHAs. In addition, review current HIV program models, including COBRA comprehensive case management, AIDS nursing homes, and AIDS adult day care to meet the health care, social support, and other needs of the aging HIV/AIDS population.*
- XI. Develop an expanded continuum of supportive and residential care options, such as supportive housing, social day care, naturally occurring retirement communities, and assisted living for persons aging with HIV.*

Program models should incorporate prevention and treatment for co-occurring conditions, and comprehensive systems of care for PLWHAs should address multiple medical needs. Prevention programs should raise HIV and STI awareness and encourage testing among older people. Innovative strategies should be engaged to reduce the main risk factors for chronic diseases among PLWHAs (smoking, lack of physical activity, and poor diet).

Intra- and interagency collaboration among New York State agencies, including the AIDS Institute, the Department of Aging, Office of Mental Health, Office of Alcoholism and Substance Abuse Services, Office of Temporary and Disability Assistance, and other units within the Department of Health should focus upon developing effective program models for aging adults.

Care and services should be established in communities where older and retired adults are located. Home and community based care for aging in place with HIV should be provided in residential settings, such as supportive housing and assisted living programs.

Care should be further facilitated by improving supportive services for seniors, such as transportation, mental health and substance abuse treatment, and case management.

Interoperable electronic health record systems should permit patient access to personal health records and provider sharing of health information consistent with confidentiality law.

## Research

***XII. Encourage research on the interaction of HIV disease and the aging process. Collect and analyze data on HIV risk factors and HIV incidence and transmission among seniors. Evaluate clinical outcomes, using research findings to inform programs and services.***

Multi-disciplinary collaboration, meaningful community partnerships, and continuous quality improvement of programs and planning based on research data could substantially and quickly improve understanding of HIV and aging issues and interventions for older adults.

## Emerging Federal and State Law

Passage of the Federal Patient Protection and Affordable Care Act (PPACA), New York State's multiyear health care restructuring now underway, and the newly expanded HIV testing law will influence the HIV and aging recommendations outlined in this report. The AIDS Institute is currently analyzing the impact of federal health care reform on the delivery of health care and supportive services to persons with HIV. Efforts are underway to ensure HIV inclusion in new federal funding streams for prevention, wellness, health disparities, and work force investments. Federal health care reform includes opportunities for support of new models of care coordination, primary care, and community based long term care services using Medicaid, Medicare, and private insurance. The AIDS Institute will participate in health care reform implementation teams within the Department and through interagency work groups. During this multi-year transition, clear communication channels will be established among stakeholders, including government agencies, health providers, community organizations, and PLWHAs. Multiple new health insurance options will bring a renewed focus on health education, case management, and benefit coordination.

Implementation of the NY State expanded HIV testing law is a priority for the AIDS Institute. The law requires that an HIV test be offered to every individual between the ages of 13 and 64 years of age (and younger or older if there is evidence of HIV related risk activity) in most health care sites. This requirement will have a direct impact on older adults, who have historically received inadequate assessment for HIV risk factors and had limited access to testing.

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Additional Forum materials: This document offers summaries of slides and oral presentations submitted by forum speakers. Text included here should not be construed as a transcript of the live presentation.

The slide presentations of plenary and workshop panel speakers, the forum agenda, a webcast of the morning plenaries, a resource list of websites and articles, the full text of some publications, and other materials and links are available online at:

**<http://www.health.state.ny.us/diseases/aids/conference/index.htm>**

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