

# Leadership In Action: Strategies to promote Public Leadership of People Living with HIV

Session 6799  
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# Meet the Team

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## **Antigone Dempsey**

Director, Division of Policy  
and Data

## **Jesse Milan, Jr**

Interim President & CEO,  
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## **Amelia Khalil**

Public Health Analyst,  
Division of Metropolitan  
HIV/AIDS Programs

## **Candace Webb**

Branch Chief, Division of  
State HIV/AIDS Programs,  
Western Services

# **HIV/AIDS Bureau Vision and Mission**

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## **Vision**

**Optimal HIV/AIDS care and treatment for all.**

## **Mission**

**Provide leadership and resources to assure access to and retention in high quality, integrated care, and treatment services for vulnerable people living with HIV/AIDS and their families.**



# HIV/AIDS Bureau Priorities

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- **NHAS 2020/PEPFAR 3.0** - Maximize HRSA HAB expertise and resources to operationalize NHAS 2020 and PEPFAR 3.0
- **Leadership** - Enhance and lead national and international HIV care and treatment through evidence-informed innovations, policy development, health workforce development, and program implementation
- **Partnerships** - Enhance and develop strategic domestic and international partnerships internally and externally
- **Integration** - Integrate HIV prevention, care, and treatment in an evolving healthcare environment
- **Data Utilization** - Use data from program reporting systems, surveillance, modeling, and other programs, as well as results from evaluation and special projects efforts to target, prioritize, and improve policies, programs, and service delivery
- **Operations** - Strengthen HAB administrative and programmatic processes through Bureau-wide knowledge management, innovation, and collaboration

# The Ryan White HIV/AIDS Program

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- **The Ryan White HIV/AIDS Program (RWHAP) provides a comprehensive system of care through HIV specialty care, primary care, and support services for low-income people living with HIV (PLWH)**
  - RWHAP works with cities, states and local community-based organizations to reach over 500,000 people living with HIV
  - RWHAP funds technical assistance, clinical training, and the development of innovative models of care
- **The RWHAP is funded at \$2.32 billion in fiscal year 2016**

# Moving Forward Framework

**RYAN WHITE**  
**HIV/AIDS PROGRAM**  
**MOVING FORWARD**  
**FRAMEWORK**



# PLWH Public Leadership & Health Outcomes

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- Ensuring that people living with HIV (PLWH) are engaged in public leadership will help achieve the primary goals of the National HIV/AIDS Strategy and maximize health outcomes of PLWH as they move through the HIV care continuum towards viral suppression.
- It is a HIV/AIDS Bureau (HAB) 2016 priority to enhance national and international PLWH leadership.
- How best to enhance leadership was the focus of an expert panel consultation.

# RWHAP Outcome Data

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**Substantial progress has been made, but HIV outcomes data for RWHAP clients highlight areas requiring more attention including:**

- **Viral Suppression- Increased from 69.5% to 81.4%**
  - Unstable Housing, 15-34 year olds, Transgender are 5 % to 17% below average
- **PLWH public leadership can help improve HIV outcomes**



# Developing Leadership Among PLWH

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- **People of Color Living with HIV Leadership and Training**
  - Secretary's Minority AIDS Initiative Fund (SMAIF) project
  - PLWH leadership and planning training
  - Develop tools to enable PLWH to participate on planning bodies, care teams, organizations, boards of directors, etc.
- **People Living with HIV Public Leadership Consultation**
  - Identify existing strategies that promote public leadership of PLWH
  - Address barriers and gaps in public leadership development of PLWH
  - Explore strategies to close these gaps

# PLWH Public Leadership Consultation

- Held May 18<sup>th</sup>, 2016
- Convened 15 expert panelists with diverse backgrounds, experiences, and expertise, most of whom are PLWH and all of whom are public leaders



JACQUELINE COLEMAN  
Director of Leadership Pipeline



# PLWH Public Leadership Consultation

## Participants

RICHARD ALESHIRE, MSW, ACSW  
HIV Client Services Program Manager  
Washington State Dept. of Health

PETER W. BYRD  
Peer Educator/Advocate

Jerry Bedford Jr.  
President, Board of Directors  
Cincinnati Health Network

CECILIA CHUNG  
Senior Strategist  
Transgender Law Center

GINA M. BROWN, MSW  
Planning Council Training Coordinator  
New Orleans EMA Planning Council

JACQUELINE COLEMAN, M.ED  
Director, Leadership Pipeline  
National Minority AIDS Council

# PLWH Public Leadership Consultation

## Participants

RUBY CORADO  
CEO, Casa Ruby

GRISSEL GRANADOS, MSW  
Project Coordinator  
Children's Hospital Los Angeles

LARRY V. DAY  
Manager, Peer Support Services  
JRI Health

JAMAL HAILEY  
Director of Programs  
STAR TRACK Adolescent HIV Program,  
University of Maryland's Pediatric AIDS Program,  
Co-Chair, Black Treatment Advocates  
Network for Baltimore

GRAHAM HARRIMAN, MA  
Director, Care and Treatment  
NYC Department of Mental Health  
and Hygiene

LINDA SCRUGGS , MHS  
Director,  
Ribbon Consulting Group

# PLWH Public Leadership Consultation

## Participants

VENTON JONES, JR., MSHCAD  
Program Manager  
LGBT Health and Wellness Initiatives  
National Black Justice Coalition

SOPHY S. WONG, MD  
Medical Director, Bay Area/North Coast AIDS Education  
and Training Center  
Medical Director, HIV ACCESS Clinical Advisor HIV and  
Hepatitis Screening Project  
Internist and HIV specialist, Asian Health Services  
Assistance Clinical Professor of Medicine UCSF

TERRANCE MOORE  
Deputy Executive Director  
National Alliance of State and  
Territorial AIDS Directors

# PLWH Public Leadership Consultation

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## Facilitation team:

**Jesse Milan Jr., JD, a Senior Subject Matter Expert and recognized public PLWH leader.**



**Abby Dilley, RESOLVE, experienced facilitator for federal technical expert panels.**



# HRSA PLWH Public Leadership Consultation – Purpose

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**To better understand and identify existing strategies/models that promote the public leadership of PLWH, and to more fully engage PLWH in public leadership.**

# HRSA PLWH Public Leadership Consultation – Goals

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- Better understand and identify gaps and barriers to public leadership of PLWH.
- Discuss promising strategies/models of public leadership of PLWH.
- Highlight key strategies and innovative tactics to better involve public leadership of PLWH, serving the needs of PLWH and receiving RWHAP-funded services.



# Defining Leadership

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***A leader is someone who leverages their power, agency, and responsibility on behalf of him or herself to champion the cause of...***

**Source: Summary statement from the May 18 PLWH Public Leadership Consultation panel deliberations**

# Leadership is...

a mentor visionary, passionate, and energetic  
goes the extra mile **thirsty for knowledge** an activist  
**strong** a convener and bridges divides unapologetic  
dedicated to a lifetime of service willing to put in late nights  
**committed to social justice** willing to grind it out  
willing to say, "If not me, than who?" as their mantra for action

dedicated to working with youth and marginalized populations  
**groundbreaking** says the unpopular, and what must be said **optimistic**  
persistent in their fight to survive **hopeful** a teacher and mentor  
brave and fearless compassionate and accepting an advocate  
**a beautiful soul** has a sense of humor **encouraging**  
open about their HIV status **a master at their craft**  
tireless **a transformative thinker** willing to partner  
bright and balanced a role model not afraid to speak up

# HRSA PLWH Public Leadership Consultation – Key Questions

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- What are the promising strategies to promote the public leadership of PLWH?
- What are the gaps and barriers to PLWH public leadership?
- How does public leadership of PLWH impact PLWH clinical outcomes/health status and quality of services?
- How can HAB support the development of PLWH public leadership?

# Key Themes from Consultation

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- **PLWH public leadership – definitions and qualities**
- **Gaps and barriers**
- **Promising strategies**
- **Prioritized ideas to consider**

# Gaps and Barriers

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- **PLWH have wide ranging expertise through education and/or life experience often not acknowledged, tapped or leveraged**
- **Ongoing obstacles of discrimination, stigmatization, bias, power and privilege differentials, inattention to social justice and human rights**
- **Youth leadership hindered by lack of opportunity in top positions and strong protocols for safe and productive mentorships**
- **Inadequate services for transgender population**

# Promising Strategies

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- **Mentoring and peer programming**
- **Creating opportunities for continuing education and training**
- **Participatory program development**
- **Placement in senior and mid-level management positions**
- **Prioritizing, conducting, and publishing research**
- **Increasing and expanding policy and advocacy activity**

# Reflections

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**For any participants of the  
consultation in the audience**

Please share your  
experiences and  
reflections from the  
consultation

# Prioritized Ideas from Experts

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- Expanding definition of “consumer” to include PLWH who may not need RWHAP services, but have important experience and expertise to contribute
- Integrating peer training, “train the trainers,” and mentoring into existing programs and events.
- Hosting in-person conferences with skill-building tracts, along with financial assistance.
- Developing public-private partnerships to assist in financial longitudinal programming.
- Funding evidence-based, successful programs.



# Prioritized Ideas from Experts

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Improving recruitment strategies and supporting leadership development in *historically-marginalized* populations and *under-represented groups*

- Women of color
- Transgender
- Youth
- Native American
- Asian-Pacific Islander
- PLWH

# Prioritized Ideas from Experts

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- Engaging consumers and clients as advisors for improving Ryan White services
- Using input from this consultation to develop and distribute a public leadership survey to a larger cross-section of PLWH to gather more input and validate information from this meeting.
- Developing partnerships to integrate HIV and transgender-related care services

## **Next Steps**

### **HRSA PLWH Public Leadership Consultation**

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**Information from the consultation will help inform future work in the HIV/AIDS Bureau in the following areas:**

- **Identify technical assistance topic areas that can support PLWH leadership development and ideas on possible partnerships between HAB, federal partners, and stakeholders.**
- **Share ideas on future focus areas for HAB special studies, technical assistance cooperative agreements, or Special Projects of National Significance (SPNS).**

# Questions, Feedback and Ideas

HRSA PLWH Public Leadership

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**Share observations, questions for panelists, and your additional ideas about Public Leadership for PLWH !**

# Contact Information

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