



# HIV/AIDS BUREAU DIVISION OF POLICY AND DATA CONSULTATION OVERVIEW

Executive Summary | November 2016

## PEOPLE LIVING WITH HIV PUBLIC LEADERSHIP CONSULTATION

### Introduction

Public leadership by people living with HIV (PLWH) is critical for advancing the vision and goals of the *National HIV/AIDS Strategy: Updated to 2020*. Substantial progress has been made in enhancing federal prevention, treatment, and care programs, with 81.4 percent of Ryan White HIV/AIDS Program (RWHAP) clients attaining viral suppression. However, disparities still exist among key RWHAP populations. More leadership is needed to improve health outcomes along the HIV care continuum and to help achieve our national goals. New and enhanced approaches must be identified to develop and support leadership roles by PLWH.

The Health Resources and Services Administration's HIV/AIDS Bureau convened a one-day expert consultation, representing a broad spectrum of leadership from across the RWHAP. The consultation goals were as follows:

- ▶ Better understand and identify gaps and barriers to public leadership for PLWH.
- ▶ Discuss promising strategies/models of public leadership for PLWH.
- ▶ Highlight key strategies and innovative tactics to identify potential opportunities and support PLWH who receive RWHAP-funded services as they serve in leadership positions.

Participants included 11 PLWH and four others, representing diverse leadership perspectives, experiences, and expertise in the RWHAP. Experts represented metropolitan, state, and community programs, as well as research, policy, advocacy, and health care service organizations. The facilitation team for the consultation included a senior technical expert who also is a public

Executive Summary of the meeting convened by the U.S. Department of Health and Human Services (HHS) Health Resources and Services Administration's HIV/AIDS Bureau (HAB), held on May 18, 2016.

PLWH leader and two consultants experienced with federal technical expert panels. The participants addressed four key questions related to the RWHAP: (1) What are the promising strategies to promote the public leadership of PLWH? (2) What are the gaps and barriers to PLWH public leadership? (3) How does public leadership of PLWH impact PLWH clinical outcomes/health status and quality of services? (4) How can HAB support the development of PLWH public leadership?

### Meeting Themes

The panel's discussions evolved around the following themes:

#### 1. Strengths and Qualities of PLWH Leadership:

Participants expressed the need for a clear definition of leadership and a set of guiding principles for PLWH in leadership positions. They proposed the following: "A leader is someone who leverages their power, agency, and responsibility on behalf of him- or herself to champion the cause of..." Each panelist named one PLWH leader they admire and identified qualities of leadership that person exemplifies. The participants' combined list of leadership qualities was powerful and inspiring.

## 2. BARRIERS TO PLWH PUBLIC LEADERSHIP

**DEVELOPMENT:** Panelists identified barriers spanning a broad spectrum, including the following:

- PLWH are not adequately acknowledged, tapped, or compensated for their wide range of expertise, whether they have earned it through educational credentials or life experiences.
- A lack of opportunity to grow into top leadership positions occupied by veteran PLWH leaders has hindered leadership development among youth living with HIV, and insufficient protocols exist to create productive and safe mentor/mentee relationships for up and coming PLWH leaders.

Participants noted that inadequate HIV services for transgendered people also are an ongoing barrier.

## 3. PROMISING STRATEGIES TO PROMOTE PLWH PUBLIC LEADERSHIP

**LEADERSHIP:** Panelists identified promising strategies, including the following:

- *Mentoring and peer programming:* Panelists emphasized the importance of having peers and mentors that “look like them” (e.g., diversity in socioeconomic status, sex, gender, race, gender identity, sexual orientation).
- *Creating opportunities for continuing education and training:* Panelists suggested programming and incorporating accessible opportunities for PLWH to advance their skills, expertise, and knowledge base is critical. Ideas included increasing opportunities for PLWH to attend and participate in international conferences; adding training tracks as part of national and international events, conferences, or other gatherings; and offering classes, training, and funding opportunities for professional certifications and degrees.
- *Including PLWH through participatory program development:* Panelists recommended including PLWH in program development, review, and selection processes as joint learning; capacity building; and stronger design, implementation, and results.

- *Hiring skilled PLWH for senior- and mid-level management positions:* Panelists advised advancing placement of PLWH leadership in senior- and mid-level management positions and in decision-making roles in government, nonprofit organizations and community-based agencies, and planning bodies and advisory groups.
- *Prioritizing, conducting, and publishing research:* Panelists emphasized the importance of PLWH leadership in developing and collaborating on defining research agendas, participating on teams conducting research, and publishing findings in medical and public health papers and journals.
- *Increasing and expanding opportunities for policy and program engagement:* Panelists targeted policy arenas focused on where decisions are being made, particularly for health care coverage (e.g., Medicaid).

## 4. PRIORITIZE IDEAS TO PROMOTE PLWH PUBLIC LEADERSHIP

**LEADERSHIP:** Panelists identified and prioritized the following ideas:

- *Increase accessibility to and robustness of workforce training, professional development, and employment opportunities:*
  - ▶ Integrate peer training, “train the trainers,” and mentoring into existing programs and events, and develop budgets and programmatic measurements for these activities. Hold national meetings and conference calls between agencies to develop integrated programming. Reach out to business executives (e.g., CEOs, CFOs), boards of directors, and other professionals for identifying future PLWH mentors.
  - ▶ Host in-person conferences with skills-building tracts and provide financial assistance to PLWH so they can participate. Initiate partnerships with the U.S. Departments of Education and Labor to help PLWH earn certifications and academic credentials.



- ▶ Improve recruitment strategies and support leadership development in HIV planning groups for specific, historically marginalized populations and underrepresented groups (e.g., women of color, transgender, youth, Asian-Pacific Islanders, Native Americans, American Samoans, PLWH, people receiving RWHAP services). Increase representation of these groups on planning councils and in other opportunities, and share information for how to navigate the planning councils.
- *Increase targeted and strategic engagement of consumers, experts, and potential partners:*
  - ▶ Engage consumers/clients as advisors for improving RWHAP services.
  - ▶ Expand the definition of “consumer” beyond RWHAP clients: including PLWH who do not require RWHAP services but offer expertise from private and public sectors.
  - ▶ Develop a continued consultation strategy for specific populations (e.g., transgender individuals, black women) and on specific topics (e.g., quality care, leadership).
  - ▶ Develop partnerships to integrate HIV and transgender-related care services.
  - ▶ Develop public-private partnerships to help finance longitudinal programming.

- *Fund evidence-based programs:*
  - ▶ Fund evidence-based programs that show successful results. Stop funding those that do not.
- *Expand outreach to and input from the PLWH community regarding public PLWH leadership:*
  - ▶ Use 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.

### Next Steps //

Information from the consultation can inform future work 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 the Special Projects of National Significance Program.

