The Power of Positive Voices

Today's Webinar Will Explore:

• Background on positive organizing and meaningful involvement of people living with HIV;
• The power of positive voices to change the course of the epidemic, unique impact;
• Lessons learned from current day efforts; and
• Moving forward – concepts and funding opportunity.
What is Meaningful Involvement?

At its most basic, it means two important things:

• Recognizing the important contribution people infected or affected by HIV/AIDS can make in the response to HIV; and

• Creating space within society for the involvement and active participation of people living with HIV in all aspects of that response.

UNAIDS (1999)
The Denver Principles

Statement from the Advisory Committee of People with AIDS (1983)

We condemn attempts to label us as “victims,” a term which implies defeat, and we are only occasionally “patients,” a term which implies passivity, helplessness, and dependence upon the care of others. We are “People with AIDS.”

Photo credit Peter Staley 1983
When we didn’t have much, we still had our voices.
And continues to today…

IAC 2012 Photo by Kevin Lamarque/Reuters
Why Positive Involvement Matters

• Ensure programs meet the needs - no one knows our needs better than us;
• Meaningful engagement can translate to empowerment – impactful for the individual engaged and the system;
• Brings the urgency and realness to the work;
• Nothing better shows the opportunity of living well with HIV than someone actually doing it;
• Leverages power of community in fighting discrimination, stigma and isolation – “There is no liberation without community” – Audre Lorde
How can PLHIV be involved?

• Personal-active role in self determination / ensure personal health & wellness;

• Campaigns and public speaking - spokespersons / fighting stigma creating awareness;

• Advocacy- for law reform, research agendas and access to services / develop and monitor policy at all levels;

• Leadership and support, group networking and sharing;

• Program Development and Implementation – from trustee to staff and volunteer to peer

Modified from UN policy brief Greater Involvement of People with AIDS 2007
“Once social change begins, it cannot be reversed. You cannot un-educate the person who has learned to read. You cannot humiliate the person who feels pride. You cannot oppress the people who are not afraid anymore.”

- Cesar Chavez
Legacy’s History

- **1978** The Clinic founded to provide screening, diagnosis, treatment and prevention of STD primarily for gay men.

- **1982** As the AIDS crisis was emerging, Montrose Clinic initiated PACE (Program for AIDS Counseling and Evaluation), marking the first effort of this kind in Houston.

- **1985** Montrose Clinic became HIV testing site—the first community-based organization in the state and second in the nation. Staff and volunteers developed a comprehensive program to provide anonymous and confidential testing.

- **2007** Legacy Community Health Services was granted full status as a Federally Qualified Health Center, offering primary care services to Houston's uninsured and underinsured.
Timeline

- AIDS United Training / AIDS Watch – April 2014
- Revised POP+ Scope - June 2014
- Held Focus Group w/long term HIV+ advocates – June 10, 2014
- Marketing/Outreach – May-August, 2014
- Developed Program – July-August, 2014
- POP+ Training Sessions – Sept. 30-Nov. 4, 2014
MIPA Community-wide Training
Purpose

- Build leadership in the HIV community through advocacy trainings for PLHIV that will
- Expand civic engagement through meaningful involvement in public policy and community organizations
- Create a network of social support
- Reduce stigma
- Ensure access to care
Program Description

Six week advocacy training program designed by and for PLHIV building on the principles of the Denver Principles, GIPA and MIPA that teaches how to:

- Become leaders in the HIV/AIDS community
- Advocate for issues affecting people living with HIV/AIDS
- Get educated about issues that impact people living with HIV/AIDS
- Get empowered to use their voice to make a difference and have meaningful involvement with HIV/AIDS organizations
Six Week Program

- POP+ Overview/Denver Principles/GIPA
- HIV 101 – The Basics
- Advocacy Panel – Mentors
- Affordable Care Act/ Mental Health
- Community Organizing
- Effective Leadership
- Using Your Story as an Effective Advocacy Tool
- Movie: “How to Survive A Plague”
- Utilized long-term HIV+ advocates as mentors and program trainers
Requirements

- Must be HIV+
- Required Reading - The Four Agreements
- Complete an advocacy project – or agree to attend Texas Advocacy Day
- Participate in 2 non-HIV community projects
- Only one absence allowed
- Meet with mentors at least twice
- Provided gift card to trainers as way to operationalize GIPA principles
- Mileage Reimbursement to participants
Graduation
Measures of Success

- Outreached to estimated 350 persons using Facebook, Newspaper, radio, and via Legacy’s website
- Conducted 6 training sessions
- 15 PLHIV completed program
- Performed 2 non-HIV community projects (Food Bank & Toy Drive)
- Conducted one community-wide training on MIPA facilitated by US PLHIV Caucus
Accomplishments

- Created POP+ Secret Facebook Page
- Participated in Legacy’s WAD Ceremony: Mentors designed logo used on POP+ T-shirts
- Prepared WAD Proclamation issued by COH
- Participant elected Vice President of RWPC
- Two participants appointed to RWPC
- Participated in Texas Advocacy Day (Feb. 2015)
- One participant attended AIDSWatch 2015 (1st time)
T-shirts
Current activities

- Second POP class scheduled to begin Sept. 29\textsuperscript{th} – Nov. 3\textsuperscript{rd}, 2015
- Continue to use POP+ as vehicle to build Houston HIV advocacy community
  - Recently worked to oppose Texas Senate Bill 779
- Continue assisting POP+ participants w/individual advocacy efforts
- Continue collaborations with other organizations
MIPA / GIPA / Positive Organizing

• You’ve heard about the basics, and it sounds great but...

• **HOW** do you do it?
Where are PLHIV now in your area?

- Target Audiences
- Contributors
- Speakers
- Implementers / Staff
- Experts
- Decision Makers
Engagement

Degrees of Involvement

• How active are PLHIV in the process?
• How does this process renew/mentor?

Internal/External

• Did PLHIV bring it up?
• Was it foisted on PLHIV community from another source (service agency, research team, etc.)?
If you don’t know...

Consult / Assess

- Involve diverse constituents
- Can do focus groups, interviews, surveys,
- Include literature review – government, academic, organizational
- Critically reflect on findings!
Some other ideas...

- Advocacy
- Media campaign
- Social groups (with a purpose!) to fight isolation
- Community work that is public about HIV-status
- Meetings & quality improvement plans with key stakeholders
What about stigma?

- Stigma is pervasive and exists at the personal, community and institutional levels.
- To be effective, stigma initiatives must address 1 of those levels locally.
- What could that look like?
One Example: The Stigma Index

- The Stigma Index is an international effort coordinated by Global Network of People Living with HIV (GNP+) to measure HIV stigma.

- The Stigma Index data is collected and analyzed by PLHIV, with PLHIV, and for PLHIV.

- Stigma Index findings are used to drive policy and benefits from media attention.
Additional concrete suggestions for greater involvement

• Review employment practices – are they inviting (recruitment, job descriptions, etc)

• Ensure opportunities for being “Out” – inviting positive recognition

What are other barriers to greater involvement that should be addressed, or suggestions for making it so?
GOAL: Increase grass-roots mobilization and engagement of PLHIV within HIV-service organizations, community networks and policy bodies to combat HIV-related stigma, to improve HIV-related policy and ensure the most effective response to the epidemic.

- Ten (10) Grants @ average of $15,000
- Must have PLHIV engaged, or posited, to play leadership roles
- Engage at least 50 PLHIV overall
- Six to 10 month project
- Preference for projects that change systems
Timeline:

July 1, 2015: Request for Proposals Released (insert web-link)
July 20, 2015: Application assistance conference call
Aug 14, 2015: Complete Applications due
October 4, 2015: Awarded applications notified
Oct 15, 2015: Grant period begins
Feb 27, 2016: One day grantee meeting in advance of AIDSWatch 2016

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