

2008 Ryan White Grantee Meeting

The NYC/NYS People Living With AIDS/HIV Leadership Training Institute

A Peer-Centered Leadership Development Program for People Living with HIV/AIDS (PLWHA)



New York State
Department of Health, AIDS Institute
(Part B funder)



a program of Cicatelli Associates Inc.



New York City
Department of Health and Mental Hygiene
(Part A funder)



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Workshop Learning Objectives

- Identify benefits of and strategies for leveraging Part A and Part B funds to establish a unified program
- Identify important elements of a successful state-wide PWHA-driven leadership development initiative focused on health care education, empowerment and the Ryan White planning process
- Share best practices in creating leadership development programs for PWHA

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Consumer Involvement as a Cornerstone of the Ryan White (RW) CARE Act

Kiyoshi Kuromiya, founder of Critical Path and former member of the Philadelphia planning council:

"For the first time in history, a community of patients and their advocates have been given a voice in the Federal processes that determine what services are appropriate and needed. It is vital for us all that persons with HIV/AIDS get involved locally and nationally in this process, otherwise our seats at the table will disappear from lack of participation."

from Consumer Digest – Making a Difference!, HHS/HRSA, p. 13

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HRSA HIV/AIDS Bureau Positive Partners: Consumer Involvement in HIV Care

"The benefits of PLWH involvement in their own care, in the care of others, and in meeting the challenges of planning and service delivery are undisputed."

- Retrieved [on line] 7/08 from <http://hab.hrsa.gov/publications/September2002.htm>

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HRSA Part A

- Planning Council membership must reflect the local epidemic.
- At least 33 percent of the members must be PLWHA who are consumers of CARE Act services.

- Retrieved [on line] 7/08 from <http://hab.hrsa.gov/treatmentandmodernization/partapg.htm>

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HRSA Part B

- States are not required to convene Ryan White Part B consortia.
- NY has made a commitment to provide funding for Ryan White Part B HIV Care Networks to promote a coordinated community response that results in improved access to care and supportive services for those infected with HIV/AIDS.
- Consumer involvement in the Networks is vital; lead agencies are expected to promote PLWHA participation at all levels and must strive for at least 25% active consumer participation within the Network and its subcommittees.

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HRSA Part C

- Identify and engage key stakeholders, including PLWHA, in the planning process.
- Implement and manage consumer involvement to plan for the establishment and improvement of services.

Retrieved [on line] 7/08 from <http://hab.hrsa.gov/treatmentandmodernization/partcpg.htm>

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HRSA Part D

- Involve consumers in your programs; and
- Educate clients about research opportunities, benefits of participation, and how to enroll in research.

Retrieved [on line] 7/08 from <http://hab.hrsa.gov/treatmentandmodernization/partd.htm>

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NY State DOH AIDS Institute HIV primary care funded provider standards for consumer involvement

A written plan for consumer involvement describes structures that are in place to ensure active participation of People Living with HIV/AIDS (PLWHA) in the continuous development and improvement of HIV/AIDS programs.

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Steps for consumers to have a meaningful impact within Planning Bodies

1. Identify and recruit consumer members.
2. Ensure a reflective and accountable consumer membership.
3. Determine consumer roles and responsibilities.
4. Retain consumer members.
5. Provide appropriate and ongoing training and support.

- Retrieved [on line] 7/08 from <http://hab.hrsa.gov/publications/September2002.htm>

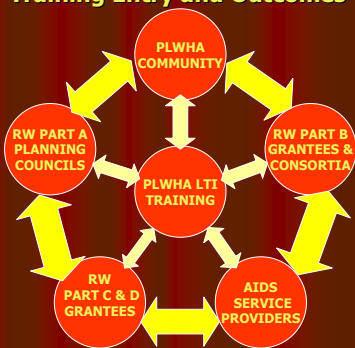
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1997 – 2007: The Original LTI

- Conceived, developed and implemented by and for PLWHA in 1997 to "pass the baton" to a new generation of leaders
- Endorsement, support and collaboration by RW Part A and Part B Grantees (both NYSDOH AIDS Institute and NYCDOHMH fund the initiative)
- Focus: to prepare PLWHA for participation in community planning bodies, and for advocacy around HIV/AIDS public policies and services

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Training Entry and Outcomes



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LTI Program Values

- *Support*
- *Empowerment*
- *Involvement*
- *Integrity*
- *Accountability*
- *Inclusion*
- *Mentorship*

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Original LTI Program Curricula

Training Module	Training Topics
Core (3 days)	History of PLWHA advocacy in New York State; effective leadership; and identity, diversity and disclosure.
Community Advisory Boards: What You Need to Know About Being a Member (2 days)	Provides basic information about the essential types and functions of AIDS-related Community Advisory Boards (CABs) and member roles.
Proposal Review (2 days)	Provides an overview of the components of a proposal for funding and focuses on the role of consumers in the review and scoring process.
Introduction to Community Organizing (2 days)	Introduces basic concepts and techniques used in devising and implementing a community-level effort for change.
Community Planning: Understanding the Process (2 days)	Provides an understanding of the purpose and structure of the Ryan White HIV/AIDS Treatment Modernization Act, HIV care and prevention community planning processes, and the opportunities for PLWHA participation.
Presentation Skills (2 days)	Introduces basic public speaking techniques with opportunities for individual practice for all participants.
Trainer Skills (3 days)	Provides basic facilitation skills for individuals who lead trainer workshops.
Working Effectively in Groups (2 days)	Promotes understanding of interpersonal dynamics in task-oriented groups and builds skills for effective participation.
Consumer Advisory Board Leadership Skills (2 days)	Provides information on topics such as officers' roles, developing meeting agendas, facilitating meetings, parliamentary procedures, and documenting public meetings.

PLWHA Leadership Training Institute Core Training Participant Demographics 8/1/97 – 3/31/07

TYPE OF TRAINING	Core (5 days)	%	Core (3 days)	%
# of Sessions	24		65	
# of Participants	385		1060	
GENDER				
Male	234	61%	542	51%
Female	138	36%	440	42%
Transgender (Male)			8	1%
Transgender (Female)			12	1%
Missing	13	3%	58	5%
GENDER TOTAL	385	100%	1060	100%

**PLWHA Leadership Training Institute
Core Training Participant Demographics
8/1/97 – 3/31/07**

RACE/ETHNICITY				
White, Non-Hispanic	97	25%	169	16%
Black, Non-Hispanic	171	44%	597	56%
Hispanic/Latino/Latina	70	18%	192	18%
Asian Pacific Islander	3	1%	6	1%
American Indian	8	2%	13	1%
Missing	36	10%	83	8%
RACE/ETHNICITY TOTAL	385	100%	1060	100%

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**PLWHA Leadership Training Institute
Core Training Participant Demographics
8/1/97 – 3/31/07**

EDUCATION				
Less than High School	55	14%	214	20%
High School Diploma/GED	119	31%	329	31%
1-2 years of College	111	29%	232	22%
3-4 years of College	37	10%	87	8%
Graduate School	21	5%	41	4%
Missing	42	11%	157	15%
EDUCATION TOTAL	385	100%	946	100%

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**PLWHA Leadership Training Institute
Core Training Participant Demographics
8/1/97 – 3/31/07**

AGE				
13-19			2	0%
20-24	8	2%	21	2%
25-49	137	36%	704	66%
50+ years	31	8%	200	19%
Missing	209	54%	133	13%
AGE TOTAL	385	100%	1060	100%

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**PLWHA Leadership Training Institute
Core Training Participant Demographics
8/1/97 – 3/31/07**

*SELF-IDENTIFICATION I			
Living with AIDS	195	51%	349 33%
Living with HIV	263	68%	722 66%
History of Substance Abuse	305	79%	440 42%
In a Drug Treatment Program	35	9%	142 13%
History of Incarceration	119	31%	173 16%
History of Homelessness	109	28%	159 15%
History in Sex Trade	29	8%	65 7%
Deaf or Hard of Hearing	8	2%	
Blind or Difficulty Seeing	8	2%	
SELF-IDENTIFICATION I TOTAL			

*multiple selections possible

**PLWHA Leadership Training Institute
Core Training Participant Demographics
8/1/97 – 3/31/07**

*SELF-IDENTIFICATION II			
Gay or Bisexual Man	104	27%	42 4%
Heterosexual Man	97	25%	42 4%
Heterosexual Woman	95	25%	63 6%
Man Who Has Sex with Men	59	15%	
Lesbian or Bisexual Women	22	6%	4 0%
Woman Who Has Sex with Women	20	5%	
Heterosexual			457 43%
Bisexual			68 6%
Gay or Lesbian			210 20%
Missing			174 16%
SELF IDENTIFICATION II			n/a

**PLWHA Leadership Training Institute
Core Training Graduates by Region
8/1/97 – 3/31/07**

Region				
Central	14	4%	90	8%
Lona Island	23	6%	68	7%
Lower Hudson	12	3%	61	6%
Mid-Hudson	14	4%	55	5%
New York City	154	40%	456	43%
Northeast	58	14%	90	8%
Rochester	54	14%	104	10%
Southern Tier/Tri-County		0%	14	1%
Western	14	4%	81	8%
Missing	42	11%	41	4%
Region Total	385	100%	1060	100%

**PLWHA Leadership Training Institute
Core Program Evaluation Results
8/1/97 – 3/31/07**

- Over 98% (N=1,332) reported that the LTI Core training was very good at teaching leadership skills.
- 99% reported that they were glad they participated in the LTI Core training and would recommend it to a friend.
- 61% of those completing the LTI Core training participated in a six-month follow-up telephone interview.

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**PLWHA Leadership Training Institute
Core Program Evaluation Results
8/1/97 – 3/31/07**

- 70% reported that they increased their involvement in an HIV/AIDS group or organization.
- 47% reported that they participated in community advocacy activities which they had not tried before.
- 88% reported disclosing their HIV status to people outside of their immediate family and close friends.

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**PLWHA Leadership Training Institute
Core Program Evaluation Results
8/1/97 – 3/31/07**

- 52% became members, leaders or volunteers on local, statewide, national and international HIV/AIDS planning and advisory bodies (e.g., Ryan White Title I Planning Councils, Ryan White Title II Consortia, HIV Prevention Community Planning Groups, ASO advisory boards, and boards of directors of not-for-profit organizations).

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HIV Planning Council Training Series (NYC Only)

1. Community Planning (2 days)

- Designed to help participants understand the purpose and structure of the Ryan White Treatment and Modernization Act and the HIV Prevention Community Planning process
- Emphasis on opportunities for participation and leadership in Ryan White and HIV Prevention Community Planning bodies

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HIV Planning Council Training Series (NYC Only)

2. Working Effectively in Groups (3 Days)

- Designed to promote understanding of interpersonal dynamics in task-oriented groups (committees, advisory boards, etc.), and to build skills for effective participation.
- Emphasis on beneficial group roles, managing conflict, and dealing with "difficult" behaviors in a group setting.

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HIV Planning Council Training Series (NYC Only)

3. Understanding Data (2 days)

- Participants learn how to decipher NYC HIV Planning Council data and use it to participate in and influence important decisions about programs and funding.

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HIV Planning Council Training Series (NYC Only)

4. Priority Setting and Resource Allocation (2 Days)

- Participants discover how program priorities and funding levels are determined so they can better advocate for their communities' needs.

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HIV Planning Council Training Series (NYC Only)

- 14 programs offered between July 2007 – June 2008
- 136 total participants (unduplicated count = 68)

Age:

72% 25-49
25% 50+
3% 20-24

Race/ethnicity:

1% American Indian
3% Asian/Pacific Islander
53% Black, Non-Hispanic
25% Latina/Latino
15% White/Non-Hispanic
3% Other (unspecified)

Sex/gender identity:

37% female
63% male

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Pilot - Ryan White Part B LTI Training

(Based on policy changes within the RW Treatment Modernization Act)
April 1, 2007 – March 31, 2008

"Self-Management: Becoming Your Own Health Care Advocate" (3 Days)

1. Pre-training assessment of health, health care utilization, and knowledge of HIV care
2. Post-training assessment of knowledge gain
3. Individual health care action plan
4. Follow-up assessments at three and six months
5. Peer mentors work with training graduates for six months following training through:
 - regular telephone conversations
 - in-person meetings
 - documentation of health care utilization and outcomes

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Pilot
"Self-Management" training curriculum

Day 1

1. Introduction to the PWA self-empowerment movement
2. Characteristics of "good health care"
3. Techniques for working effectively with health care providers
4. Ways to make the most of health care visits

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Pilot
"Self-Management" training curriculum

Day 2:

1. HIV Basics (HIV vs. AIDS; viral load; T-cells)
2. Understanding Labs [CBC, chem. screen, lipid panel, sugar levels, CD4 count and percentage, viral load, resistance testing]
3. NYS Standards of HIV Care (for frequency of various tests and vaccines)

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Pilot
"Self-Management" training curriculum:

Day 2: (continued)

4. Understanding Medications (concepts of anti-retrovirals, ARV classes and combination therapy; U.S. guidelines for starting ARV therapy; adherence; resistance)
5. Mental Health (general issues, specific concerns for PWHA, types of treatment, other supports, choosing a provider)
6. Opportunistic infections (definition, relation to CD4 levels, types of OI's, prophylaxis & treatment) and staying healthy (diet, rest, exercise, etc.)

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Pilot
"Self-Management" training curriculum:

Day 3:

1. Individual health care goal setting and creation of individual action plans
2. The mentor relationship: purpose and process
3. Matching mentors & mentees
4. Mentor-mentee meetings (small group and individual)

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Pilot
"Self-Management" Training
Participant Characteristics

<p>Age:</p> <p>62% 25-49 36% 50+ 2% 20-24</p> <p>Sex/gender identity:</p> <p>52% female 47% male 2% transgender/male</p>	<p>Race/ethnicity*:</p> <p>6% American Indian 3% Asian/Pacific Islander 26% Black, Non-Hispanic 6% African 30% African American 2% Caribbean 20% Latina/Latino 20% White/Non-Hispanic</p> <p style="font-size: x-small;">* multiple selections possible</p>
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Pilot
"Self-Management" Training
Participant Characteristics

<p>Formal education:</p> <p>28% Less than high school 26% High School/GED 28% College – 2 Years 9% College – 4 Years 6% Graduate School 3% Other</p>	<p>Health care payer:</p> <p>6% Private health insurance 27% Medicare 83% Medicaid 9% ADAP (medications) 6% ADAP + (primary care) 0% Self-pay</p>
<p>Sexual orientation:</p> <p>69% Straight, heterosexual 15% Lesbian, gay, homosexual 15% Bisexual</p>	

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**Pilot
"Self-Management" Training
Evaluation**

Pre- vs. Post-training
25-question HIV knowledge assessment (N=66)

- average score increased from 63% to 70% correct
- 68% (45) scores increased (average = 14%)
- 20% (13) = no change

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**Pilot
"Self-Management" Training
Evaluation**

Participant comments on completing the training:

- I learned the importance of adherence.
- Learned how important patient-doctor relationship is
- Taught me how to be an advocate with my healthcare.
- I learned so much about medications in this training.
- This training has helped me to think in a positive way about my HIV identity
- I learned that my labs are important to my HIV care.
- I am ready to start meds as a result of this training.
- As a result of this training, I am going to ask my doctor for a pap smear.
- I am motivated to share this information with others.
- I feel more confident making decisions and communicating better.

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**Pilot
"Peer Mentor" training includes:**

- understanding standards of HIV healthcare
- roles and responsibilities of mentors
- establishing and maintaining appropriate boundaries
- confidentiality rules and procedures
- making "referrals"
- requesting documentation from mentees, follow-up and reporting

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**Pilot
"Peer Mentor" Training
Mentor Characteristics**

<p>Age: 46% 25-49 54% 50+</p>	<p>Race/ethnicity*: 8% American Indian 0% Asian/Pacific Islander 31% Black, Non-Hispanic 13% African 50% African American 25% Caribbean 23% Latina/Latino 35% White/Non-Hispanic</p> <p><small>* multiple selections possible</small></p>
<p>Sex/gender identity: 38% female 58% male 4% "other" (unspecified)</p>	

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**Pilot
"Peer Mentor" Training
Mentor Characteristics**

<p>Formal education: 8% Less than high school 23% High School/GED 35% College – 2 Years 19% College – 4 Years 4% Graduate School 12% Other</p>	<p>Health care payer: 42% Private health insurance 42% Medicare 42% Medicaid 39% ADAP (medications) 19% ADAP + (primary care) 12% Self-pay</p>
	<p>Sexual orientation: 42% Straight, heterosexual 58% Lesbian, gay, homosexual</p>

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**Pilot
"Self-Management" Training
Evaluation**

Baseline to 6-month surveys assess multiple domains:

- Housing
- Social connectedness
- Doctor-Patient relationship
- Community involvement
- Spirituality
- Current health indicators (cd4 count, viral load)
- ARV therapy
- Stigma & discrimination
- Health care utilization
- Behavioral health care
- Support services
- Self-care behaviors/activities

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Pilot "Self-Management" Training Evaluation

- 32 6-month follow-up surveys completed as of 8/1/08; remainder to be completed in August-September 2008
- Feedback to date strongly favorable from participants and mentors alike
- Sample responses describe a number of positive changes observed at 6 months.
- In all 3 sample profiles that follow (slides 44-46), respondents "strongly agreed]" with the statement, "I believe my mentor's support helped to motivate me to act to improve my HIV health care."

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Pilot "Self-Management" Training Evaluation

*Profile #1:
Latino heterosexual male, 25-49, High school/GED, Medicaid*

- "What was the CD4 cell count in your most recent test?"
Δ from "193" to "313"
- "What was your most recent viral load?"
Δ from "400" to "Under 100"
- "Did you see any professional for the primary purpose of getting help for a psychological or emotional issue?"
Δ from "No" to "Yes"
- "I manage to eat a healthy, balanced diet most of the time."
Δ from "Neutral" to "Strongly agree"

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Pilot "Self-Management" Training Evaluation

*Profile #2:
American Indian male, 25-49, less than high school, Medicaid*

- "On average, during the last 30 days I took..."
Δ from "Most of my pills" to "All of my pills every day"
- "How often do you smoke cigarettes?"
Δ from "Every day" to "Some days"
- "I feel that I am part of a community"
Δ from "Neutral" to "Strongly agree"
- "In a crisis, I would have the support I need from family and/or friends"
Δ from "Neutral" to "Strongly agree"

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**Pilot
"Self-Management" Training
Evaluation**

*Profile #3:
African American heterosexual male, 25-49, college/2 yrs, Medicaid*

- "On average, during the last 30 days I took..."
△ from "About 1/2 my pills" to "All of my pills every day"
- "When was the last time you missed at least one dose of your HIV medications?"
△ from "Within the past week" to "Between 1 and 3 months ago"
- "Did you participate in a support group or self-help group?"
△ from "No" to "Yes"

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**Pilot
"Self-Management" Training
Lessons Learned To Date**

- Numbers attended (N=66) were significantly lower than numbers confirmed (N=100).
- Lack of overnight accommodations impacts enrollment.
- Length of training may be challenging for participants due to practical or psycho-social reasons.
- Six months working with a mentor may play a role in discouraging attendance.
- Other opportunities for training and peer support programs to improve PLWHA health outcomes "compete" with LTI.
- Outreach and recruitment is a challenge.
- Mentor's time commitment is considerable in some cases.

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**Will consumer involvement remain a
cornerstone of the
RW Treatment Modernization Act ?**

Kiyoshi Kuromiya:
"Our ranks are now very much depleted by death and burnout, and we need to stress the importance of participation by a new generation, even more diverse than the last, of patient activists and advocates. This life and death struggle is only empowering if you are part of it."

from Consumer Digest – Making a Difference!, HHS/HRSA, p. 13

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