

# Avenues of Formal Advocacy



## OBJECTIVES

**At the end of this unit, participants will be able to:**

- Explain what advocacy is and why it is needed
- Understand how advocates can use their voice
- Name five different types of advocacy groups for people with HIV
- Identify what advocacy opportunities exist and are missing in their community



## INSTRUCTIONS

1. Before the session begins, prepare flip chart sheets for the small group activity. Write the following questions on a sheet, one for each group (3–5 groups).
  - a. What qualities are needed to be an effective advocate?
  - b. What activities/actions are included in advocacy?
2. Review slides on advocacy (slides 2–4) and engage participants in a discussion.
3. Facilitate brainstorm activity (slide 5).
4. Review History of Involvement of people with HIV (slide 6), and their successes in improving their lives and communities.
5. Review slides on GIPA, Greater Involvement of People with HIV/AIDS, and MIPA (slides 7–8), and Meaningful Involvement of People with HIV/AIDS. Discuss GIPA principles (see materials section to access entire documents).
6. Discuss areas where advocates can get involved at the local, state, and national levels (slide 9). Provide examples of advocacy organizations and ask participants if they can name other organizations in their own communities.
7. Review slide on selecting methods of involvement (slide 10).
8. Review slides on Ryan White (slides 11–14). Utilize the resource to learn more.
9. Review the HIV care continuum slide (slide 15).

*(continued)*



## Related C3 Roles

Providing culturally appropriate health education and information; advocating for individuals and communities; building individual and community capacity; cultural mediation among individuals, communities, and health and social service systems

## Related C3 Skills

Interpersonal and relationship-building skills, capacity-building skills, communication skills, advocacy skills, education and facilitation skills



## Method(s) of Instruction

Lecture, brainstorm, group activity



## Estimated time

60 minutes



## Key Concepts

Advocacy, GIPA, MIPA, The Denver Principles, Ryan White Program



## Materials

- Computer with internet access and projector
- PowerPoint slides
- Flip chart sheets
- Markers
- Placards (see handouts)

## Handouts

- Placards (Print and laminate the following cards at 10x15 or preferred size, with the group name on one side and the definition on the other):
  1. Quality Improvement Committee
  2. Intra-agency and Regional Quality Management Teams
  3. Consumer Advisory Board (CAB)
  4. Community Planning Groups
  5. Consortia

# Avenues of Formal Advocacy



## **INSTRUCTIONS** *(continued)*

10. Facilitate the avenues for advocacy activity (slide 16). Use the placards that are in the handouts for this activity.
11. Facilitate community advocacy opportunities activity (slide 17, 10 minutes):
12. Share Dr. Martin Luther King, Jr. quote (slide 18).
13. Wrap up. To close, summarize and thank everyone for their participation.



## **Resources**

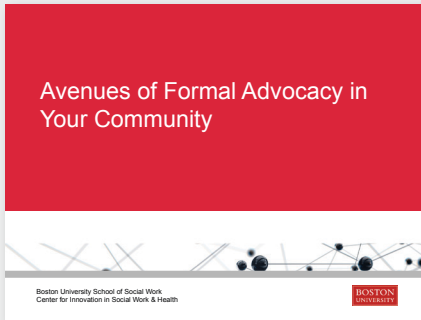
GIPA, MIPA and the Denver Principles: <http://vpwas.com/gipa-mipa-and-the-denver-principles/>

UNAIDS policy brief: The Greater Involvement of People Living with HIV (GIPA): <http://vpwas.com/wp-content/uploads/2014/10/d96596c4b961f1929dc8687ace6c44e6.pdf>

About Ryan White Programs Parts A–F: <https://hab.hrsa.gov/about-ryan-white-hivaids-program/about-ryan-white-hivaids-program>

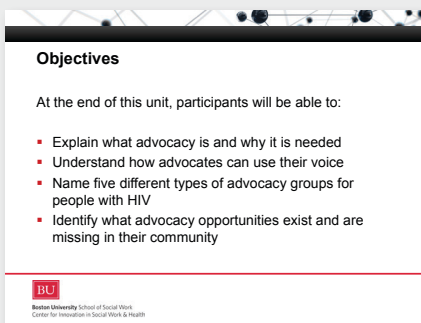
# Avenues of Formal Advocacy

## SLIDE 1



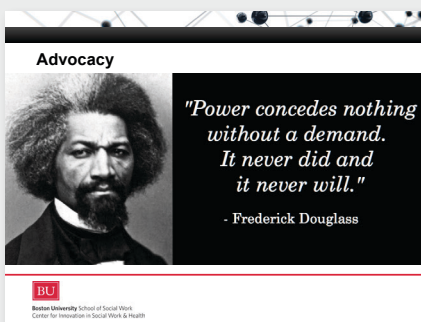
## SLIDE 2

Review the objectives.



## SLIDE 3

Why advocate, why speak out? Read Frederick Douglas quote.



## SLIDE 4

Review the slide.

Why is advocacy needed?

Frederick Douglass's quote says, in essence, if you don't ask, you get nothing. You need advocacy to promote or defend the cause of another.


Advocacy can sometimes get a bad reputation, but advocates work for things that matter to their communities. It does not necessarily involve confrontation or conflict. It does not have to be political. The goal is to make things better for everyone, not just one person. Change comes about by fixing broken systems.

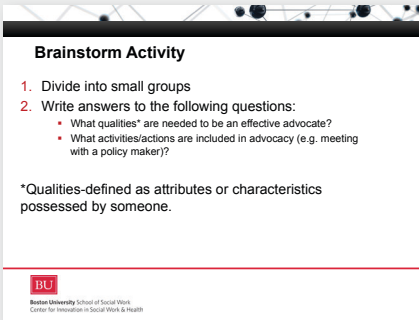
For example, a young woman with children found it difficult to get to the health department in her area because the bus stop was two blocks away from the health department. That was a problem for her individually but it also affected many people. However, she was the one person who asked about it, and the end result was that a bus stop and an awning were installed right in front of the health department, making access easier. She did not protest; she worked with members in the community, the health department, and other allies. She had meetings with the managers at the bus system who could make a difference.

Instructor can also provide their own example of advocacy and resulting change from their work or community.

**Advocacy**

- **What is advocacy?**
  - Is an activity by an individual or group which aims to influence decisions within political, economic and social systems and institutions that lead to a selected goal.
- **Why is advocacy needed?**
  - To plead, promote or defend the cause of another, specifically on a board, panel, hearing etc.
- **Advocates work for things that matter to their communities. It does not necessarily involve confrontation or conflict.**

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**Brainstorm Activity**

1. Divide into small groups
2. Write answers to the following questions:
  - What qualities\* are needed to be an effective advocate?
  - What activities/actions are included in advocacy (e.g. meeting with a policy maker)?

\*Qualities-defined as attributes or characteristics possessed by someone.

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## SLIDE 5

Activity: 10 minutes

Say, "Now we're going to do a brainstorm activity about being an effective advocate. Similar to being an effective CHW, there are also qualities that make one an effective advocate. What are they?"

Divide participants into small groups and distribute flip chart sheets with questions.

Have each group choose a recorder to write group responses, and a reporter to share responses with the larger group. Allow five minutes to record responses to the prompts.

Allow five minutes for groups share their responses about:

- Qualities needed to be an effective advocate and
- Activities/actions are included in advocacy.

### Examples of qualities

- Compassionate
- Helpful
- Patient
- Professional

### Examples of activities/actions

- AIDS walk
- Leadership and/or support group network sharing
- Public speaking
- Contacting public officials via
  - Phone calls
  - Texting
  - Writing letters
  - Public speaking
- Meeting with policymakers, community leaders, or others in leadership positions
- Speaking to the media
- Filing an amicus brief

You can advocate from the privacy of your own home for people with HIV and others by calling to remind them of meetings, texting. In advocacy there is a place for all of us.

## SLIDE 6

All people with HIV and their allies benefit from the work of advocates.

Here are some of the ways individuals have been involved in local, regional, or national community decision-making:

### The Denver Principles

- A document written by people with HIV
- It made a strong statement of identity in relationship to the world and the healthcare system. Condemns the use of the word victim, and provides recommendations and rights for people with HIV.
- This document is still considered landmark and is referenced frequently as an example of empowerment, and demonstrates the community's ability to understand themselves in relationship to the world—a powerful voice when people speak together. The fingerprint represents the authorship of people with HIV.

### Ryan White

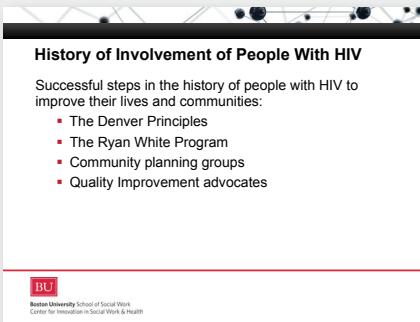
- Once the country heard the voice of people with HIV, funding slowly trickled in and finally reached the point of needing governmental management to address the HIV/AIDS crisis. This happened through the Ryan White legislation, enacted in 1990.
- Ryan White is represented by the blueprint because it is a system of care that was built in partnership with allies: legislative leaders, government workers, and communities. It was a piece of legislation that contained within it the ability to grow and change and give control to people with HIV .

### Community planning members

Empowerment and legislation—community planning groups were built: planning councils, consortia, and consumer advisory boards. A system of care and prevention was built.

### Quality Improvement

Involvement is needed and impactful in this area. People with HIV want to and need to be at the table before decisions are made to improve care. There is an opportunity to make systems the best they can be—this requires knowledge, passion, experience, and skills, and partnerships with doctors, nurses, data managers, case managers, etc.



## SLIDE 7

GIPA (Greater Involvement of People with HIV/AIDS) began in 1994 and evolved over time into MIPA, Meaningful Involvement of People with HIV.

GIPA is not a project or program, GIPA is a principle that aims to realize the rights and responsibilities of people with HIV, including their right to self-determination and participation in decision-making processes that affect their lives. GIPA also aims to enhance the quality and effectiveness of the AIDS response.

GIPA is an initiative to strengthen the capacity of people with HIV/AIDS, their networks, and community-based organizations to participate fully in regional, national, and global levels, stimulating the creation of supportive political, legal, and social environments.

GIPA stands for two important things:

1. To recognize the important contributions people with HIV can make in the response to the epidemic, and
2. To create space within society for our involvement and active participation in all aspects of that response.

The GIPA principles were formalized at the 1994 Paris AIDS Summit when 42 countries agreed to “support a greater involvement of people with HIV at all...levels... and to...stimulate the creation of supportive political, legal and social environments.”

## SLIDE 8

GIPA principles emphasize involvement and empowerment for people with HIV in all areas, including:

- Policy-making process—participating in the development and monitoring of HIV-related policies at all levels.
- Program development and implementation—providing knowledge and skills through participating in the choice, design, implementation, monitoring, and evaluation of prevention, treatment, care, and support programs and research.
- Leadership and support, group networking and sharing—people with HIV take leadership roles in HIV support groups or networks, seek external resources, encourage participation of new members, or simply participate by sharing their experiences with others.
- Advocacy—people with HIV advocate for law reform, inclusion in the research agenda, and access to services, including treatment, care, and support; and for resource mobilization for networks of people with HIV and for the broader response.
- Campaigns and public speaking—people with HIV are spokespersons in campaigns or speakers at public events.
- Personal decisions—people with HIV are actively involved in their own health and welfare. They take an active role in decisions about treatment, self-education, therapies, opportunistic infections, adherence, and positive prevention.
- Treatment roll-out through educating others on treatment options, side effects, and adherence. People with HIV are involved as home-based and community health care workers.

**GIPA/MIPA**

- GIPA stands for the “Greater Involvement of People with HIV” – It previously stood for AIDS (language now uses HIV).
- Values self-determination, the belief that individuals and communities should have the right to participate in the decision making process.

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**GIPA Principles: People With HIV Involvement**

- Policy-making process
- Program development and implementation
- Leadership and support, group networking and sharing
- Advocacy
- Campaigns and public speaking
- Personal decisions
- Treatment roll-out and preparedness

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## SLIDE 9

Review the slide.

Partnerships: Forming and evaluating partnerships is crucial to advocacy/involvement goals.

Allies: We need allies/collaborators/supporters

Whether it's picking up the phone, sending an email, meeting with your legislators, or hitting the streets, there is a place for you in advocacy.

Examples of advocacy organizations:

U.S. Positive Women's Network is primarily an advocacy organization that focuses on a nationwide community of women with HIV. Their mission is to involve women with HIV, in all their diversity, including gender identity and sexual expression, in all levels of policy and decision-making. PWN-USA inspires, informs, and mobilizes women with HIV to advocate for changes that improve their lives and uphold their rights.

Ask participants if they can name other organizations in their own communities.

## SLIDE 10

Review the slide.

Ask:

- How would you determine which area to become involved in/advocate for?
- What kind of leader do you want to be?
- What issues would you work on?
- What methods are you most comfortable with?

Emphasize that methods should focus on the problem and partners, not them.

Using these steps and your knowledge of your community, you can select the method that is more likely to achieve your desired goal.

**Getting Involved**

**Local**

- Quality Improvement Committees
- Community Advisory Boards (CABS)
- Community Planning Group
- Ryan White Planning Council

**State & National**

- Consortia
- Quality Management Team

**Examples of Advocacy Organizations**

- AIDS Watch: [www.aidswatch.org](http://www.aidswatch.org)
- U.S. Positive Women's Network (PWN): [www.pwn-usa.org](http://www.pwn-usa.org)
- Seroproject: [www.seroproject.com](http://www.seroproject.com)
- Real Voices - Real Choices: [www.missourimhf.org](http://www.missourimhf.org)
- Empower Missouri: [www.empowermissouri.org](http://www.empowermissouri.org)

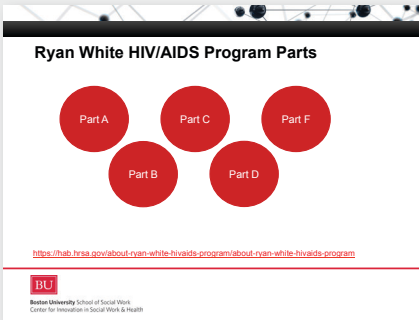
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**Selecting Methods of Involvement**

1. Identify and define the problem.
2. Identify stakeholders and potential partners
3. Examine individual and community relationships with the identified partners/stakeholders
4. Determine response based on these relationships
5. Identify next steps

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## SLIDE 11

The Ryan White program has multiple funding streams—meaning they spend money in different ways. Each of these parts funds different kinds of programs to deliver different services. Each RW part addresses a different part of the epidemic.

**Part A** – Grants funding for medical and support services to Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs). EMAs and TGAs are population centers that are the most severely affected by the HIV/AIDS epidemic. Funding is given to office of a city/chief/mayor. TGA must have reported at least 1,000 new diagnosis in the previous 5 years.

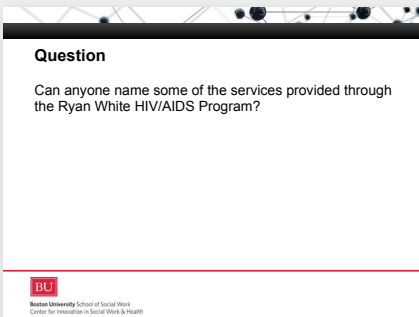
**Part B** – Grants funding to states and territories to improve the quality, availability, and organization of HIV health care and support services. A portion of funds in each state is designated for AIDS Drug Assistance Program (ADAP).

**Part C** – Grants funding to local, community-based organizations to support outpatient HIV early intervention services and ambulatory care.

**Part D** – Grants funding to support family centered, comprehensive care for women, infants, children, and youth with HIV.

**Part F** – Grant funding that supports several research, technical assistance, and access to care programs. There are four programs—AIDS Education Training Sites (AETCs), Special Projects of National Significance (SPNS), Minority AIDS Initiatives (MAI), and Dental Reimbursement programs.

All of the parts together represent a system of care that has shown better outcomes than Medicare, Medicaid, and even private insurance. The parts create a safety net for people with HIV when working in concert, and when informed by community experience (the needs of different communities).



## SLIDE 12

Review the slide.

Core Medical Services	Support Services
Outpatient and ambulatory health services	Non-medical case management
AIDS Drug Assistance Program treatments	Child care services
Oral health care	Emergency financial assistance
Early Intervention Services	Food/home delivered meals
AIDS pharmaceutical assistance	Other professional services
Health insurance premium and cost sharing assistance for low-income individuals	Linguistic services
Home health care	Medical transportation
Home and community-based health services	Outreach services
Mental health and substance use services	Psychosocial support services
	Referral for healthcare rehabilitation services respite care
	Substance use services (residential)

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## SLIDE 13

Ryan White planning bodies are charged with making informed decisions about what services are offered and how much money can be spent in each category. Clinics and other community-based organizations apply at federal, state and regional levels for Ryan White program funds. These funds are awarded based on how well the applicant demonstrates their ability to meet identified priorities.

Review slide, listing Ryan White services provided.

Some states add additional funds to their Ryan White funding to offer more services. Because of this, and the mandates around local control, Ryan White programs aim to reflect the communities they serve.

As part of this aim, the involvement of people with HIV has been and continues to be a priority at all levels of the program. You can find people with HIV who work for the HIV/AIDS Bureau at the federal government, in local and state governments, in county health departments, and in thousands of clinics and hospitals across the country.

Another part of the structure for some states/territories is prevention dollars being funded through the CDC. Many HIV planning groups or councils have integrated their Ryan White Part A/B for care and treatment with prevention dollars through the CDC.

Five-year integrated community plans are created. An epidemiological profile, often called "Epi profile," gives a snapshot of the community, which helps in the design and implementation of research projects and new services.

**Ryan White HIV/AIDS Planning Councils**

- The Ryan White HIV/AIDS Program (RWHAP) is the largest federal program focused specifically on providing HIV care and treatment services to people with HIV.
- The RWHAP was first created in 1990 with the passage of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.
- Since its inception, the Ryan White legislation has been reviewed and updated or reauthorized in 1996, 2000, 2006, and 2009.

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## SLIDE 14

Review the slide.

One of the primary structures that people with HIV are involved in are Planning Councils. Planning Councils that are not just advisory, but are decision-making bodies. Planning Councils have enormous control over what services are funded and how those services are delivered.

The legislation mandates that 33% of the Planning Council must be people with HIV. Other members will include representatives from providers and stakeholders from throughout the region.

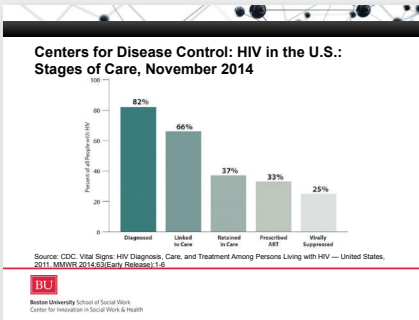
These planning bodies are tasked with regularly assessing the needs of the jurisdiction/state, prioritizing those needs into services, and then determining how much money to allocate to each service category.

Individuals have to apply to be members of Planning Councils and adhere to each council's by-laws and requirements.

Planning bodies use a parliamentary procedure to make decisions.

There are guides online and trainings to help better understand how parliamentary procedure works.

# Avenues of Formal Advocacy



## SLIDE 15

Reintroduce the HIV care continuum as a way to evaluate HIV care and treatment system outcomes.

Ask participants if they can name some services to help improve outcomes at any stage of the continuum (for example, free HIV screening support results in increased diagnosis). Take a few examples, then move to the next activity.

### Avenues for Advocacy

- Quality Improvement Committees
- Inter-Agency Quality Management Team
- Community Advisory Boards (CABS)
- Community Planning Group
- Consortia

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## SLIDE 16

Activity: 15 minutes

Divide participants into five groups and distribute placards.

Ask volunteers to read the name of the type of advocacy group and then read the definition.

Ask, “Has anyone participated in one of these groups?”

Allow 3 minutes per type of group.

### Community Advocacy Opportunities

What's in my Community?

1. Divide into the small groups.
2. Work together to identify:
  - What opportunities already exist in your community or region to advocate for people with HIV? (e.g. CAB, consortium, coalitions, etc.)
  - What is missing that you would like to incorporate into your community or region?
  - What needs to happen in order to create these advocacy opportunities? (e.g. starting a CAB or Community Planning Group)?
  - What role can you play in making this happen?

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## SLIDE 17

Community advocacy opportunities activity (10 minutes)

Divide participants into small groups.

Work together to answer questions on the slide.

At the end of the activity, ask participants to give the name of an advocacy group in their area that has not been discussed. Ask who is involved in advocacy, and if anyone plans to become involved.

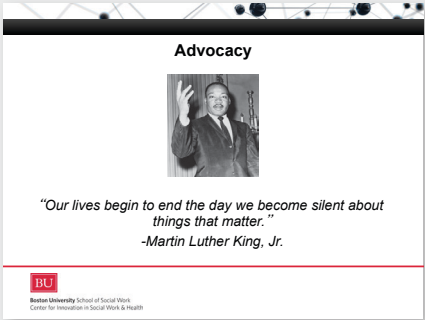
There are many other types of involvement:

- Research advisory boards
- Technical expert panels
- Statewide advisory boards
- Completing satisfaction surveys
- Participating in focus groups
- Many more

## SLIDE 18

Ask for a volunteer to read the quote.

Ask participants to share their reflection of these words.



# QUALITY IMPROVEMENT COMMITTEE

## QUALITY IMPROVEMENT COMMITTEE DEFINITION

What is Quality Improvement (QI)? In health care, the purpose of quality improvement is to improve and measure:

- the patient experience;
- health outcomes;
- employee satisfaction; and
- costs.

QI committees are usually multidisciplinary—they involve employees from various role groups and parts of the clinic and/or program—medical providers, CHWs, case managers, pharmacists, administrators, nurses, etc. Effective QI committees involve the patient, employee, and funder perspectives.

The QI committee works together to come up with better practices that will address a specific problem or weakness. An effective committee uses data to identify areas needing improvement and focuses on:

- systems and processes;
- patient needs and impacts;
- teamwork; and
- measuring the improvement and desired outcomes.

Usually committees make small improvements that contribute to greater successes over time.

QI efforts can lead to measurable improvements in health care services and the health status of targeted patient groups.

**INTERAGENCY  
AND REGIONAL  
QUALITY  
MANAGEMENT  
TEAMS**

## **QUALITY MANAGEMENT TEAM DEFINITION**

- A quality management team builds capacity and capability for quality improvement.
- The team involves quality managers, program leaders and other key staff. It may link quality improvement to state, federal (including Ryan White) or an organization's overall quality program goals.
- Responsibilities may include strategic planning, providing guidance, facilitating change, allocating resources and establishing a common culture.

Ryan White recipients are required to have clinical quality management programs which must collect performance data and conduct improvement projects on at least one item annually (most teams conduct more). Traditionally these teams have been built with clinic or provider staff members but recently the National Quality Center developed a comprehensive training program for quality advocates (patients) which has helped people with HIV seek and obtain seats at quality management tables, allowing the community to have greater input into efforts to improve services.



# Consumer Advisory Board (CAB)

## CONSUMER ADVISORY BOARD DEFINITION

A CAB is an advisory committee of consumers that meet with the clinic leadership team on a regular basis. CAB members:

- Provide valuable feedback on services and systems;
- Give advice and input into program planning and quality improvement;
- Provide recommendations and bring new issues to the attention of the health center or clinic leadership;
- Initiate and assist with client engagement activities; and
- Identify gaps, needed service improvements and address other tasks as necessary.

CABs generally have by-laws and membership applications. Ryan White Parts C and D grantees are required to have CABs.

# Community Planning Groups

## COMMUNITY PLANNING GROUPS DEFINITION

- A core goal of community organizing is to represent the **community** (people with HIV) and **influence** key decision-makers on a range of issues over time.
- Community Planning Groups can be ad hoc (one time only) or ongoing. They address a range of issues such as housing, public safety, disease prevention, crime, transportation, etc.
- Ideally, you are at the table with planning groups early—*before* important decisions are made. You have a lot to contribute: your experiences (personal and clients), HIV specific data, Ryan White connections, etc.
- Community organizers work with and develop new local **leaders**, facilitating coalitions and assisting in the development of campaigns.
- Participating in local planning groups can:
  - Promote community awareness about HIV, including trends and programs
  - Increase the likelihood that the needs of people with HIV are better met
  - Strengthen community partnerships and alliances

**CONSORTIA**

## **CONSORTIA DEFINITION**

- You may have a consortium of agencies and PLWH that are addressing HIV in your community.
- A consortium is a network of people and agencies dedicated to improving the health and well-being of individuals and communities impacted by HIV/AIDS.
- Members reflect the diversity of the communities served and include representatives from agencies that provide HIV/AIDS prevention and care services.
- A consortium is responsible for developing recommendations about programs and services, areas of greatest need, and the best methods to meet those needs.
- A consortium can be very influential in shaping policies and funding decisions.

# Acknowledgements

This curricula draws from and is adapted from other training curricula for peer educators and community health workers, such as the Building Blocks to Peer Success (<https://ciswh.org/resources/HIV-peer-training-toolkit>) and the Community Capacitation Center, Multnomah County Health Department (<https://multco.us/health/community-health/community-capacitation-center>)

## Team

Serena Rajabiun

Simone Phillips

Alicia Downes

Maurice Evans

LaTrischa Miles

Jodi Davich

Beth Poteet

Rosalia Guerrero

Precious Jackson

Maria Campos Rojo

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