

**“White Paper” on Parity, Inclusion,
and Representation (PIR)**

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I. Introduction

A. Purpose

A workgroup of the PWA/PWHIV Advisory Committee to the New York City and New York State HIV Prevention Planning Groups (PPG) met with national technical assistance providers and consultants to develop a “White Paper” on operationalizing parity, inclusion, and representation in the HIV prevention community planning process.

In addition to key City and State PPG materials, the workgroup used the following materials as references during the process:

1. Academy for Educational Development’s (AED) *Core Objective Review* for 1995 and 1996;
2. AED/CDC *Self-Assessment Tool* PIR section;
3. Centers for Disease Control and Prevention (CDC) *External Review* documents;
4. CDC’s In-depth Review Report on Inclusion and Representation;
5. CDC’s *Supplemental Guidance*;
6. PIR-related pieces from the National Association of People with AIDS (NAPWA) manual, *Positive Input*; and
7. PIR-related articles from the National Alliance of State and Territorial AIDS Directors (NASTAD) Bulletin.

B. Participants

The following are the various individuals who have participated, throughout the process, to develop this White Paper:

Committee Members: Jairo Pedraza, Michael Reynolds, Kim Nichols, Michelle Lopez, Brad Schock, Ernesto DeJesus, Albert LaCourt, Trent Royster, Bill Drumright, Marion Robinson, Reginald Robinson, and Dudley White, John Anthony Eddie, Ilene Chung, Don Bruner, Ernesto DeJesus, Darryl Ingram, Myron Gold, Pricilla Hardy, M. Saidia McGlaughlin, Alice Oviedo, Juan Rodriguez, Orlando Roman, W. Trent Royster, J. Edward Shaw, Fernando Soltero

PPG Staff: Bill Karchner (NYS), Pete Pappas (NYC), Dan Tietz (NYS), Wendy Shotsky (NYS), Darryl Wong (NYC)

TA Providers: Frank Beadle de Palomo (AED), Phillippa Lawson (consultant), Pablo Magaz (consultant), and Mike Shriver (NAPWA)

C. Purpose of the PWA/PWHIV Advisory Committee (source: Committee Brochure)

The purpose of the PWA/PWHIV Advisory Committee of the New York City and New York State HIV Prevention Planning Group is to facilitate - in a meaningful way - the participation of persons living with HIV and AIDS in the prevention planning process, and to serve as an advisory body to ensure such ongoing participation in the planning process [source: the 1998 NYC Comprehensive HIV Prevention Plan and the 1998 NYC HIV Prevention Plan].

In compliance with the CDC *Supplemental Guidance* that “*persons living with HIV infection should play a key role in identifying prevention needs...*” **the PPG recognizes the perspective, and voice of experiences of the PWA/PWHIV community and their unique and critical role to the success of the HIV prevention planning process in order to “...increase access to early medical intervention, to delay the onset of symptoms, and to prevent and treat complications of HIV infection.”**

In realizing this goal, **the PWA/PWHIV Advisory Committee supports the PPG membership process in actively seeking solicitations to include in all phases and activities and ranks**, members of the diverse PWA/PWHIV community from across the broad spectrum of the New York State population (source: the New York State HIV Prevention Planning Group By-Laws).

D. Advisory Committee Membership

The PWA/PWHIV Advisory Committee is comprised of:

- New York City PPG Members,
- New York State PPG Members, and
- Community Advisors/Associate Members (non-PPG members, who are active participants from the community),

Staff of the NYSDOH-AIDS Institute and NYCDOH act as staff liaisons to the Advisory Committee.

Committee membership is voluntary and supported by the PPG process.

II. Definitions of Parity, Inclusion, and Representation

After substantive discussion, it was decided that the following definitions of Parity, Inclusion and Representation were accurate:

- ◆*Inclusion:* Assuring that the views, perspectives and needs of populations infected, affected and at risk are represented and involved in a meaningful manner in the community planning process.
- ◆*Representation:* Representation is the assurance that those who are representing a

specific community or population truly reflect that community's or population's values, norms or behaviors. This is the assurance that those representatives who are included in the process are truly able represent their community or population and have mechanisms to provide information. At the same time, these representatives should be able to participate as group members in objectively weighing the priority needs of the jurisdiction. .

- ◆*Parity*: Ensuring that all members of the HIV Prevention Community Planning Group have the skills, knowledge and equal opportunity for input and participation, as well as equal voice in voting and other decision-making activities.

III. Making PIR Operational

In order to operationalize PIR, the PWA/PWHIV Advisory Committee recommended that both the New York State and New York City PPGs adopt the following Values and Goals:

A. Values - PWA/PWHIV Advisory Committee Values

In focusing on the values of PIR, the following statements are identified as “key” to exploring the values the Committee shares:

- Inclusion and representation only have meaning through parity
- Equal opportunity and equal access must be tangible
- Parity encourages retention
- Education is a key component of parity
- Parity enables participation
- Parity facilitates objectivity, empowerment and illustrates respect
- Parity requires flexibility and creativity

After exploration, the PWA/PWHIV Advisory Committee distilled its core, shared values to the following concepts necessary for operationalizing PIR for all communities:

- Action
- Active involvement
- Clear and agreed-upon process
- Camaraderie
- Compassion
- Diversity
- Education (being informed)
- Honesty

- Leadership
- Objectivity
- Personal Responsibility
- Power (strength and wisdom)
- Product
- Solidarity
- Respect
- Visibility
- Voice

B. Goals for PIR

The PWA/PWHIV Advisory Committee examined its initial understanding of the goals of PIR, and has refined its view of the goals of PIR as follows:

- To create and maintain a table where there is “equity,” “powersharing,” and “partnership” among the CDC, health departments, and communities in HIV prevention.
- To involve broad-base community experience in developing the comprehensive HIV prevention plan.
- To develop and maintain broad-base community partnerships in the “process” and “outcome” of HIV prevention community planning.

C. Core Definition addition

In redefining its vision and goals for PIR, the PWA/PWHIV Advisory Committee added a definition for Retention which it views as the “fourth” unwritten component of PIR.

Retention: Supporting community planning group members through training, incentives, and other measures to encourage continued involvement and participation.

IV. The Importance of PIR: “Why is PIR Critical for the PWA/PWHIV Advisory Committee?”

HIV Prevention Community Planning is about creating a process that involves critical voices necessary to reducing the spread of HIV/AIDS. The PWA/PWHIV Advisory Committee operates as “micro process” embodying the goals of community planning.

A. What does an Advisory Committee Member Bring To, Take From, and Leave at the Table?

Members of the PWA/PWHIV Advisory Committee serve as a conscience to the full PPG, to get the full PPG out of the “privileged” mentality of organizational self-interest, and to remind the PPG of primary and secondary prevention goals in the community planning process.

1. Advisory Committee Members “**BRING TO**” the table:
 - ◆Burden of the disease
 - ◆Commitment
 - ◆Ego
 - ◆Emotion
 - ◆Expertise and skills
 - Professional
 - Community Advocacy
 - ◆Family Perspectives
 - ◆Frustration
 - ◆Grief
 - ◆Pain
 - ◆Passion
 - ◆Political Conflict
 - ◆Real-life experiences
 - ◆Respected community leadership
 - ◆Sacrifice
 - ◆Spiritual Commitment
 - ◆Support for each other
 - ◆Urgency
 - ◆Voices of those who are not or can not be present
 - ◆Volunteerism

2. Advisory Committee Members “**TAKE FROM**” the Table:
 - ◆Frustration
 - ◆Pride
 - ◆Message (voice) to the community
 - ◆Realization of goal
 - ◆Respect
 - ◆Satisfaction
 - ◆Self-realization

3. Advisory Committee Members “**LEAVE AT**” the Table:
 - ◆Better programs and products
 - ◆Better understanding of each other
 - ◆Clear focus and recommendations
 - ◆Focus on enhanced of quality of life
 - ◆Frustration

- ◆Health
- ◆History
- ◆Hope
- ◆Impact
- ◆Intangible feeling of realization
- ◆Legacy
- ◆Perspective/objective
- ◆Quality of life of other PWAs
- ◆Real awareness of personal limitations
- ◆Safe space for future PWAs
- ◆Sense of life
- ◆Sense of purpose
- ◆Silent voice of the majority
- ◆Struggle for a better life
- ◆T-cells
- ◆Trail-blazing

B. Barriers to Achieving PIR

The PWA/PWHIV Advisory Committee defines the following as major barriers to the full implementation of PIR in the community planning process:

- CDC *Supplemental Guidance* (purposeful ambiguity weakens the full inclusion and participation of PWA/PWHIVs)
- Diversity (no two PWA/PWHIVs share the same experience)
- Failure to address “bias” (bias is a conflict of interest, not seeing the “bigger picture,” focus is on “own” and “ownership.”)
- Failure to create a truly inclusive process (e.g., poorly accessible meeting sites and times; lack of understanding of the concepts/roles of community planning among PWAs)
- Health status (PWA/PWHIVs have varying needs and capacities directly related to their health)
- Inappropriate control (marginalizes/minimalizes, powersharing, excludes shareholders)
- Institutionalization of “privilege” (leads to paternalism; destroys inclusion, ignores or excludes the expertise of consumers; creates power imbalance)

- Lack of conflict of interest guidelines (the process almost unfairly defines participants as “providers” who often are conflicted in their roles; organizational self-interest creates barriers to representation, shared responsibility, inclusion in decision making, parity, effective resource allocation, priority setting, honesty, trust and effective prevention planning)
- Lack of financial resources (health status often limits income and thus, active participation at out-of-town meetings, etc.)
- Lack of grievance procedures
- Lack of historical and functional education on process for PWA/PWHIVs (who may be more familiar with Ryan white Councils/Consortia)
- Lack of standard definitions for “target populations” (government vs. community/people)
- Lack of or inappropriate mechanisms for outreach (e.g., lack of clearly defined goals for the various populations or systematic, ongoing outreach and recruitment efforts; competition among various bodies/groups for consumers)
- Lack of initial and ongoing orientation and training (not fully prepared to participate from the beginning)
- PWA/PWHIVs are often viewed/perceived as not equal or as ‘tokens’
- PWA/PWHIVs possess varying and diverse expertise (e.g., some have experience in behavioral science)
- Structure of PPG (State vs. Regional, lack of follow-thru at the State/City-level)

C. Possible Solutions

- Develop and institute mechanisms for health diversity, e.g., proxies, alternates, etc.
- Provide historical information, education, and materials dealing with PWA Committee and PPG to all members, and implement:
 1. Archives;
 2. Formal orientation for new members, and
 3. On-going orientation for existing members

- Recognition and sensitivity training of diverse experiences for PWA Committee and PPG

V. Action Steps/Observations for Operationalizing PIR as of 1997

A. Recommendations for the New York City and State PPGs

- 1.
2. Develop mechanisms to support active involvement in PPG meetings such as (a) sending agendas in advance, (b) following (and timing) agenda items, (c) examining other possible decision making processes (in addition to consensus), (d) leadership training for members, (e) review PPG by-laws to address membership, (f) enhanced communication mechanisms to ensure timeliness and access to all.
3. Provide ongoing training on the basic steps of HIV Prevention Community Planning (with focus on (a) *Supplemental Guidance*, (b) behavioral science).
4. Develop mechanisms to protect against self-interest (e.g., Conflict of Interest Form; Statement/definition including - Is it where you get services?, Board Members, Can't vote on an issue that you have an affiliation with or relationship to, Negative "catch 22" for consumers... "we have relationships with providers of services; "Financial gain" (what I do for a living)).
5. Develop mechanisms to breakdown "privilege" (e.g., cultural awareness training for providers, skills building for providers and consumers, recommend to PPG language for by-law on conflict of interest, enforce/amend by-laws to include PWAs across all committees).
6. Develop new modes for communication among PWA/PWHIVs statewide , (including regular recruitment forums, buddy mentoring, standard mailouts, and electronic communication media).
7. Mandate PWA/PWHIV Advisory Committee representation on Steering Committee/Executive Committee.
8. Continue and enhance brochure and other communications
9. Develop formal mechanisms for outreach to PWA/PWHIVs (material needs: information on the importance and linkages between prevention and care).

10. Involve PAW/PWHIVs in discussions and TA on infrastructure, structures, operations, maintenance of process.
11. Include PWA/PWHIV Advisory Committee members in needs assessment processes (use our voices).
12. Support and activate regional/local bilateral information exchange (with a special focus on financial support to PWA/PWHIVs and gaps in geographic representation; information to local constituencies and from constituencies; increased visibility at the community level; and conference calls).
13. Quarterly reports are provided in advance to PWA Committee members for input.
14. Develop and maintain mentorship for members and alternates.
15. Institute incentives to recruit and retain PWA/PWHIV members (such as public statements, i.e., flyers, newspapers; always having interpreters and wheelchair accessibility; public notice of Open Nominations; all materials need to be translated - language specific - TTY accessible, and designed to be people oriented; time and hour sensitivity of meetings; need to examine and discuss other forms of support).
16. Develop leadership training for “new” and all PAW/PWHIVs (including orientation to PPG; outreach - enhance, target, and refine outreach strategies; and collaborating with other bodies).
17. Create a process to review and hold the NYC PPG accountable for a line-item budget for the PWA Committee.
18. Create a joint task force to address uniform financial and personnel commitments and resources, including key players.
19. Develop an objective priority setting process that uses all available quantitative and qualitative data (epidemiologic, anecdotal, etc.) And community input.
20. Develop a standard set of support criteria for members, including, but not limited to: (a) interpreters, (b) translators, (c) child care, (d) bottled water, (e) literacy level (including grade level), and ASL) awareness, (f) skills building opportunities, (g) large print (over 20 point), Braille and audio tape.

21. Develop mechanisms for State and City PPG to cooperate (pool resources/\$) for comprehensive support such as: (a) transportation, (b) compliance with the Americans with Disabilities Act, (c) facilitation mechanism (non-offensive), (d) nutritional considerations, (e) meeting hours, (f) mentoring, (g) training, (h) skill sets, (i) co-chair and committee chair orientation.
22. Develop mechanisms for recruitment and outreach (non-censored) in the most appropriate manner for all populations (including resources for translations, changing meeting times, incentives for retention, determination of attendance/responsibility).
23. Develop survey techniques, include questions to capture information on Deaf Community, Latinos, etc. (including access DSS data, special/over sampling surveys, don't use, ban the phrase: "hard to reach.")
24. Revisit the nominations process (i.e., "evaluation" criteria, and continue to have a PWA Committee- recommended slate.
25. Develop an archive system to store all relevant PPG documents with special attention to HIV confidentiality.

B. Possible Recommendations for TA-Related to PIR for the New York City and NYS PPGs (as of 1997)

The workgroup designated these activities in terms of their urgency for completion: Primary (urgent), Secondary (not as urgent).

1. [Primary] To create a value statement dealing with: beyond HIV/AIDS, *who* is the individual (what does a Committee member bring to, take from, and leave at the table?).

✓Done as part of this document.
2. [Primary] To create language about ensuring that representation is a shared responsibility between PWAs and non-PWAs, and must be broad across committees (also, issues regarding stipends/reimbursement and need for alternate/proxy).
3. [Primary] To create an outline for guidelines ("template") of/for PIR.

✓Done as part of this document.

4. [Primary] Re-examine, re-define, or expand definition of parity to make it operational.

✓Done as part of this document.
5. [Primary] Identify specific strategies and methods that address the WHO, WHERE, and HOW to achieve parity.

✓Partially completed as part of this document.
6. [Primary] Draft a statement that provides a rationale and states the value of achieving parity.

✓Done as part of this document.
7. [Primary] To achieve geographic diversity among PWA representatives to the PWA Committee.
8. [Primary] To educate PWAs in New York about the PPG and ways that they can become involved in the community planning process.
9. [Primary] To create a PWA infrastructure that will guarantee financial and personal support; the capacity and skills development; the meeting formats; the goal and task orientation; and articulated process by which PWA participation in the PPG processes is maximized.
10. [Secondary] To create a definition of: (a) Community Advisor/Associate Member, (b) PPG Member, (c) Staff Liaison, and (d) Committee Co-Chairs.
11. [Secondary] To develop a Job Description for Committee Members (all of the above), including: (a) listing roles and responsibilities, (b) accountability, (c) attendance requirements, (d) proxies/alternates, and (e) signature of understanding.
12. [Secondary] To create a Conflict of Interest form
13. [Secondary] To recommend to Full PWA Committee to develop amendments/modify PPG by-laws.
14. [Secondary] To develop an evaluation tool for PWA Committee meetings.
15. [Secondary] To define standards and processes of Orientation (i.e., new members, re-orientation, etc., that includes at least the following: history

of HIV Prevention Community Planning: what is HIV Prevention Community Planning?, and principles of Principles, Inclusion, Representation, and Retention).

16. [Secondary] To recommend structure and standards for PWA Committee group process.
17. [Secondary] To define recommendations for Community Advisors' participation in the PWA Leadership Training Institute (LTI).
18. [Secondary] To create standards and guidelines for Buddy Process (i.e., mentor process).

VI. Notes on PWA/PWHIV Advisory Committee Mission-Related Issues

The PWA/PWHIV Advisory Committee is a unique structure with a special mission. After agreeing upon definitions of PIR, the workgroup focused on the Advisory Committee's mission-related issues.

A. How Would You Classify the Advisory Committee?

- ◆ Responds to and addresses issues regarding PWA/PWHIVs
- ◆ Supports multiple committees - via Committee members' involvement
- ◆ Works against having self-interest
- ◆ Focuses on both Primary and Secondary Prevention
- ◆ Supports diversity at all levels
- ◆ Involves PWA/PWHIVs in ALL levels of discussion - not "tokens"

B. What Does the Advisory Committee Do?

- ◆ Provides direct input to two planning bodies - the New York State and New York City PPGs
- ◆ Responds to PPGs (according to their different timeframes)
- ◆ Provides leadership in addressing Secondary Prevention
- ◆ Provides leadership in action (e.g., forming the Advisory Committee)
- ◆ Role-models PIR (e.g., the development of this "White Paper")

GLOSSARY OF PREVENTION PLANNING TERMS

Compiled by Rob McMurrough

*Add--dental dams
female condoms*

Talk to the CDC

Accountability: A framework that has been created to determine how a group and its members will be responsive and responsible to itself and the community as it carries out its mission.

Advocacy: Representation of the needs of a particular community. This can involve education of health and social service providers, local policy makers, elected officials and the media.

AIDS: Acquired Immunodeficiency Syndrome; clinical definition of illnesses caused by HIV: A CD4 count less than or equal to 200, or one or more diagnosed opportunistic infections.

Antibodies: Proteins made in the blood that identify foreign particles and stimulate an immune response.

ASO: AIDS service organization, which may provide a variety of services for the community, including, but not exclusive to: support, health services, prevention, housing, advocacy, intervention, information and referral, etc.

At-Risk Communities: Specific groups of people in a defined area who have a greater chance of becoming HIV-infected due to behaviors or actions common to the group (i.e., injection drug users, men who have sex with men).

Attitude: A state of mind or feeling with regard to a particular subject.

Behavioral Risk Factor Surveillance System (BRFSF): A telephone survey conducted by nearly all states that provides information about a variety of health risk behaviors, from smoking and alcohol use to seat belt use and knowledge of HIV transmission.

Behavioral Science: A science, such as psychology or sociology, that seeks to survey and predict responses (behaviors and actions) of individuals or groups of people to a given situation, i.e., why people do what they do.

By-Laws: Standing rules written by a group to govern their internal function; addresses issues of voting, quorums, attendance, etc.

Capacity Development: Building the abilities and knowledge of individuals or groups so that they may fully participate in a process or organization.

Casual Contact: Normal day-to-day contact (such as shaking hands) among people at home, school, work or in the community.

CBO: Community-based organization, a structured group offering services to specific groups of people in a defined area. These groups may include minority groups, housing for the homeless, AIDS service organizations, etc.

CDC: The Centers for Disease Control and Prevention; this is the federal agency responsible for tracking diseases that endanger public health, such as HIV and tuberculosis.

Co-Chair(s): Person(s) assigned by the grantee and elected from community members to a particular planning group; they are responsible for organizing, convening, and leading the HIV Community Prevention Planning groups.

Coalesce: To grow together to form one whole unit.

Coalition: An alliance of community groups, organizations or individuals to meet a goal or purpose.

Collaboration: A group of people or organizations working together to solve a problem in a process where individual views are shared and discussed and may be changed as the group progresses toward its goal.

Community: A group of people or organizations working together to solve a problem in a process where individual views are shared and discussed and may be changed as the group progresses toward its goals.

Community Prevention Planning: An ongoing process in which state and local health departments share responsibility for developing a prevention plan with other governmental and nongovernmental agencies and representatives of the community.

Comprehensive HIV Community Prevention Plan: the result of the Community HIV Prevention Planning process, this is a plan that has taken into account many different points of view and perspectives in order to provide the most effective prevention efforts within a specific area.

Compromise: A “give and take” process where all points of view are considered and weighed in order to reach a common plan or goal.

Condom: A latex tube used to cover the penis during sexual intercourse to prevent pregnancy or sexually transmitted diseases (STDs).

Condom Availability: A term referring to efforts to make free or inexpensive condoms easily available in places such as schools, community clinics, etc.

Condom Distribution: Prevention program that distributes condoms to people at high-risk for HIV infection in places where they live, work, etc.

Conflict: A disagreement among two or more parties.

Conflict of Interest: A conflict between one's obligation to the public good and one's self-interest; for example, if the board of a community-based organization is deciding whether to receive services from Company A and one of the board members also owns stock in Company A, that person would have a conflict of interest.

Continuity: Having the same or a similar situation, person or group over a period of time.

Cost Effective: Economical and beneficial in terms of the goods or services received for the money spent.

Data: Information that is used for a particular purpose.

Defined Populations: People grouped together by gender, ethnicity, age, or other social factors.

Dispute: A conflict in which the parties involved have brought an internal disagreement into the public arena.

Diverse/Diversity: Made up of all kinds; having a variety of people, perspectives, etc., in one organization, process, etc.

Efficacy: Power or capacity to produce a desired effect. If a prevention program has *efficacy*, it has been successful in achieving what it was intended to do.

Empowerment: A process in which a person develops knowledge, abilities and skills that allow him or her to have greater control over life challenges.

Epidemic: A disease that has spread rapidly among a large number of people within a short period of time.

Epidemiology: The study of epidemics and epidemic diseases such as HIV and tuberculosis; in prevention planning, this epidemiologic information shows us which populations, age groups, ethnic groups, etc., are affected by HIV in a defined area.

Ethnicity: A group of people who share the same place of origin, language, race, behaviors, or beliefs.

Etiquette: Different groups have certain norms for acceptable and unacceptable behavior that are important when conflict arises.

Evaluation Goal: A broad statement about the purpose of the evaluation; what will be gained by conducting an evaluation of the community planning process.

Evidence-Based: In prevention planning, based on evidence that is collected from scientific data, such as reporting of AIDS cases to health departments and needs assessments conducted in a scientific manner.

Fiscal Year (FY): A twelve-month period set up for accounting purposes; for example, the federal government's fiscal year runs from October 1 to September 30 of the following year.

Focus Group: An open-minded discussion and interview process to determine attitudes and opinions and to test new ideas among a small number of people who share common knowledge of the subject being discussed.

Forum: A meeting or other outlet that provides an opportunity to share ideas and concerns on a particular topic in order to resolve disputes.

Funded Sites: In prevention planning, all state health departments, the District of Columbia, US Territories and six local health departments (New York City, Philadelphia, Chicago, Houston, San Francisco and Los Angeles) that receive federal funding for prevention efforts from the Centers for Disease Control and Prevention (CDC).

Gender: A person's sex, i.e., male or female.

Grant: The money received from an outside group for a specific program or purpose. Applying for a grant is a competitive process that involves detailed explanations of why there is a need for the money and how it will be spent.

Grantee: The person or group receiving funds from an outside source. Term referring to state and local health departments that have received money from the CDC for prevention planning in their areas. See FUNDED SUES.

Grassroots: Social groups at a local level rather than at the center of a major political activity or area; referring to locally-based community members being the actively involved in program activities.

Guidance: The CDC document which gives additional information and rules for receiving funds for HIV prevention programs and introduces the new HIV Prevention Community Planning rules and ideas for the next fiscal year; the guidance that provides additional information for the CDC program announcement #300.

Guidelines: Rules and structures for creating a program.

Harm Reduction: Behavior changes that reduce the chance of hurting one's self or another person; making changes in action to improve health and well-being. See SECONDARY PREVENTION.

High Risk Behavior: Actions or choices that may allow HIV to pass from one person to another, especially through such activities as sexual intercourse and injecting drug use.

HIV (Human Immunodeficiency Virus): The virus that damages the immune system and causes AIDS.

HIV Prevention Community Planning: A new program started by the CDC in which people from at-risk communities and those who are HIV-infected meet with scientists and other professionals in order to decide on the most effective HIV prevention programs and methods for stopping the spread of HIV in their area.

HIV-Related Mortality Data: Statistics that measure the level of HIV infection among selected populations that have been targeted for surveys.

HRSA/Health Resources Service Administration: A federal agency under the health and Human Services department and part of the Public Health Service; HRSA is responsible for overseeing the Ryan White CARE Act.

IDU/IVDU: Injecting drug user; intravenous drug user; term used to refer to people who inject drugs directly into their bloodstream by using a needle and syringe.

Immune System: The body's defense system against disease and infection.

Inclusion: An appearance that all affected communities are represented in the community planning process.

Intercourse: Intimate sexual contact between the penis and vagina or anus, or the mouth and sex organs.

Intervention: An activity whose objective is to change or avert high-risk behavior that may result in HIV infection.

Invitee: A person who is formally asked to participate in a process or event.

Jargon: Language that is coherent and meaningful only to a group of persons who are engaged in a shared activity; slang.

Jurisdiction: An area or region that is within the responsibilities of a particular government

agency; in prevention planning, this term usually refers to an area whose HIV prevention activities are monitored and managed by a state or local health department (i.e., Jonestown is within the jurisdiction of the Jones County Health Department.”)

KABBS: Knowledge, Attitude, Behavior and Belief Surveys; these are tools that are used to examine how people change their attitudes about HIV infection and relate it to their lives.

Language: Verbal or written communication among different cultural groups using particular words and figures of speech.

Leadership: The ability or skills needed to conduct, influence or guide community groups and individuals in any effort, or the process of developing these abilities and skills.

Letter of Concurrence: A part of a grantee’s application to the CDC. This letter states that the planning group agrees with the prevention programs outlined in the grant application. This letter will explain how the planning group created their HIV prevention plan.

Letter of Justification: A part of a grantee’s application to the CDC. If the planning group does not agree with the prevention plan in the health department grant application, the health department must explain why they want a different plan in a letter of justification.

Letter of Non-Concurrence: Apart of a grantee’s application to the CDC. If a planning group does not agree with the health department’s prevention plan in the grant application, the group must include a letter explaining why members disagree with the plan.

Lubricant: A substance put on condoms to make them slippery during sexual intercourse; lubricants are important because they prevent friction and tearing of vaginal and anal muscles and reduce any bleeding that may increase the risk of HIV transmission. They also prevent condoms from breaking and should be water-based because oil-based lubricants can destroy condoms.

Mandate: A directive, or comment which can be used to refer to a call for change as authorized by a government agency.

Measurable Objective: An intended goal that can be proved or evaluated.

Mechanism: A process, physical or mental, by which something is done or comes into being.

Monogamy: The practice of being married to one person, or being in an intimate relationship with a single individual.

Names Reporting: A law in effect in some areas which requires health departments to use a person’s name when reporting their HIV status or disease condition to the CDC and other agencies.

Needle Exchange: A prevention program in which injection drug users can get clean needles by turning in their used needles. Such program may include education in HIV risk reduction and rehabilitation opportunities.

Needs Assessment: The process of obtaining and analyzing findings about community needs. Needs assessments may use several methods of information and data collection to determine the type and extent of unmet needs in a particular population or community. For example, a needs assessment may use personal interviews or questionnaires with a diverse group of community members in order to find out what they know about protecting themselves from HIV infection.

Networking: Establishing links among agencies and individuals that may not have existed previously; also strengthening links that are used infrequently. Working relationships can be established to share information and resources on HIV prevention and other areas.

NGO/Non-Governmental Organization: A private group that is not associated with federal, state, or local agencies, yet often has programs or services that are similar to those offered by government agencies.

NIH/National Institute of Health: A division of the federal Health and Human Services agency which conducts medical research and offers the AIDS Clinical Trials program.

OAR/Office of AIDS Research: A division of the National Institutes of Health (NIH) which is dedicated to studies of HIV and its related diseases.

Objective: Not affected by personal feelings or prejudice when making an analysis of a situation of thing.

Opportunistic Infection: An infection or disease that occurs due to the inability of the immune system to fight off bacteria, viruses and microbes.

Outcome Evaluation: Evidence of whether a prevention intervention has resulted in the intended short-term effects.

Pandemic: An epidemic that occurs in a large area or globally, as with HIV and AIDS. See EPIDEMIC.

Parity: A situation in which all members have equal voice, vote and input in a decision making process.

Participatory Planning: The process of identifying needs and making decisions through the broad-based involvement of a wide range of viewpoints, wherein differences in background perspective and experience are essential and valued.

Partner Notification: Law requiring, or program encouraging, people who test positive for HIV

to give the health department the names of people with whom they have engaged in high risk activities (sexual, needle sharing) so that the health department can notify these individuals that they may have been exposed to HIV.

PHS/Public Health Service: This federal agency addresses all issues of public health in the United States (the CDC is part of the Public Health Service).

PIR: Parity, inclusion and representation.

Planning Process: Steps taken and methods used to gather information, interpret it and produce a plan for rational decision making.

Prevention Program: A group of interventions designed for reduction of disease among individuals whose behavior, environment, or genetic history places them at high risk for exposure.

Prevention Services: Interventions, programs and structures designed to change behaviors that lead to HIV infection. Examples include condom distribution, needle exchange programs, mentoring and counseling programs, and outreach education efforts among high schools or groups at high risk for HIV infection.

Primary Prevention: Interventions and education which is intended to help people stop behaviors that may lead to their becoming infected with HIV; may include condom education, counseling that reduces the number of sex partners, HIV antibody testing/counseling, or needle exchange programs and drug abuse counseling.

Prioritize: A process of deciding which program or items are most important, with a given set of criteria. In prevention planning, this refers to helping the greatest number of people in need who are at the greatest risk of HIV infection, with the most effective programs available.

Process: the method used in undertaking a project; different groups think about and act upon projects and tasks differently and may use diverse decision-making styles, timeframes and methods.

Process Evaluation: Documentation that a particular prevention intervention has been carried out.

Process Objectives: Specific activities involved in the implementation of a program in order to produce the desired results.

Program Announcement #300: The CDC mandate in which the agency awards grants to state and local health departments to fund HIV prevention programs.

Program Goal: A broad statement about the ultimate purpose of a program.

PWA/PLWA: Person with AIDS; person living with AIDS.

PWAC: People with AIDS Coalition.

Quantifiable: Referring to the ability to measure; if an action or program has an outcome that can be measured in terms of numbers or statistics, it is quantifiable.

Representation: Assurance that members of a planning group who represent a portion of the affected community actually share that community's values, norms, and behaviors.

Resolution: A course of action decided or determined upon.

Ryan White CARE Act: The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was passed by Congress in 1990; it provided us with the first federal funding levels for HIV/AIDS care.

Safer Sex: Sexual activity that is intended to reduce the risk of transmission of HIV.

Secondary Data: Existing data, or information, that is gathered and used in a project.

Secondary Prevention: Prevention programs that serve the needs of people infected with HIV, informing them about how they can protect their health and prevent the further spread of the virus.

Segmented Responsibilities: Roles and activities organized along lines of broad task areas.

Sero-Incidence: A statistical term that refers to the number or rate of new HIV or AIDS cases in a particular period of time (one year, five years, etc.).

Sero-Prevalence: A statistical term referring to the long-term rate or percentage of people infected with HIV or diagnosed with AIDS in a defined population.

Sexually-Transmitted Disease/STD: A disease that is spread through intimate sexual contact, such as HIV, herpes, syphilis, gonorrhea.

Shared Responsibilities: Joint oversight of staff and committee activities and shared responsibility for coordination of the planning effort; this can include facilitation of meetings in which the role of meeting chair rotates for each meeting.

Social Science: The study of individuals and groups, their behaviors and actions in relationship to society.

Stakeholders: Those individuals/groups who have a major interest and involvement in a process; participants in the community planning process.

Standard Setting: The process of developing guidelines and evaluation tools for prevention messages and methods, including model or instructional intervention, educational materials and training for prevention workers.

Subjunctive: Basing one's analysis of a situation or thing on one's personal feelings or attitudes.

Surveillance Data: Statistics representing people with HIV or AIDS in a given area that are reported to the CDC from public health officials who collect them from testing sites, treatment facilities and other groups, and analyze them to produce a full picture of trends in the epidemic in the states and throughout the nation.

Symptom: A change in the way a person feels that may mean a change in health.

Syndrome: A group of signs or symptoms that indicate a specific disease.

Target Populations: Groups of people who are the focus of HIV prevention efforts due to high rates of HIV infection among those groups; they are defined by using CDC AIDS surveillance data broken down by ethnicity, gender, sexual orientation, and other factors.

Technical Assistance: Training and skills development which allows people and groups to do their jobs better; this includes education and knowledge development in areas that range from leadership and communications to creating an effective needs assessment tool and understanding statistical data.

Valuing the Process: Developing a sense of group ownership and belief in the community planning process, and recognizing the importance of broadening its impact.

Youth Risk Behavior Surveillance System (YRBSS): National, state, and local school-based surveys of adolescents addressing health issues that include drug use and sexual behavior.