

Palm Beach County HIV CARE Council



MEMBERSHIP MANUAL

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*The Palm Beach County
CARE Council
hereby dedicates this
Membership Manual
to all whom have served
those with
HIV/AIDS.*

Mission Statement of the Palm Beach County HIV CARE Council

Establish a collaborative and balanced body of HIV infected and affected individuals, service providers, and community leaders and interested individuals whose responsibilities shall be to plan, develop, monitor, evaluate, and advocate for a medical and support service system for individuals and families affected by HIV Spectrum Disease.

THE PALM BEACH COUNTY HIV CARE COUNCIL

The Palm Beach County HIV Services Planning Council was created through an ordinance of the Board of County Commissioners in November, 1993. In August of 1997, the Planning Council and the Palm Beach County AIDS Consortium officially merged and became the Palm Beach County HIV Comprehensive AIDS Resources Emergency (CARE) Council. On August 19, 1997, the Bylaws for this new organization were approved by the Board of County Commissioners. The present CARE Council is made up of a maximum of 45 members who represent legislatively mandated membership categories; including individuals both infected and affected by HIV/AIDS, and reflects the diverse population of Palm Beach County.

DUTIES OF THE COUNCIL:

- To annually update HIV/AIDS service needs in Palm Beach County by conducting a needs assessment.
- To develop and maintain Comprehensive HIV/AIDS Service Plan
- To prioritize and allocate Ryan White Title I and Title II funds within Palm Beach County
- Assure community participation in needs assessment and priority setting
- To prioritize and allocate Housing Opportunities for People with AIDS (HOPWA) funds within Palm Beach County
- To prioritize and allocate Florida State General Revenue Patient Care and AIDS Network funds within Palm Beach County
- To assess the efficiency of administrative mechanisms in rapidly allocating funds to the areas of greatest need
- To work with community members and other planning bodies to ensure a coordinated system of care
- To maintain diversity and inclusion reflective of the epidemic in Palm Beach County in the Council membership
- Assure services to women, infants, children and youth with the HIV disease
- Work with other CARE Act representatives to develop the Statewide Coordinated Statement of Need (SCSN)

LEGISLATIVE REQUIREMENTS OF PLANNING COUNCIL

Planning Council Operations

Open meetings
Meeting minutes
Establish operating procedures to make planning tasks function smoothly
Meeting attendance records

Planning Council Membership Requirements

At least 33% of the members must be PLWH/As.

Planning Council Membership Categories:

- ▶ Health Care Providers including Federally qualified health centers
- ▶ Community-Based Organizations serving affected populations
- ▶ Social Service Providers
- ▶ Mental Health Providers
- ▶ Substance abuse providers
- ▶ Local Public Health Agencies
- ▶ Hospital or Health Care Planning Agencies
- ▶ Affected Communities including PLWH/As and historically underserved groups
- ▶ Hospital Planning Agencies or other Health Care Planning Agencies
- ▶ Non-elected Community Leaders
- ▶ State government, including the State Medicaid Agency and State Part B Program
- ▶ Part C Grantees (does not exist at this time in Palm Beach County)
- ▶ Part D Programs, or organizations with a history of serving children, youth and families with HIV/AIDS.
- ▶ Other Federal HIV Programs, including HIV Prevention Programs
- ▶ Representative of/or formerly incarcerated PLWHAs
- ▶ Federally Recognized Indian Tribe
- ▶ Co-infection with Hepatitis B or C from an underserved population

Planning Council Nomination Process

The planning council nominations process must be open, with criteria for membership delineated and publicized. Nominations criteria must include a conflict of interest standard.

Conflict of Interest

Planning councils are strictly prohibited from involvement in the selection of particular entities to receive Title I funding. If individual members of planning councils have a financial interest in, are a member of, or are employed by an organization seeking funds, they cannot participate (directly or in an advisory capacity) in the process of selecting entities seeking such funds.

Grievance Procedures

Planning councils and grantees must develop procedures for addressing grievances with respect to funding. Health Resources and Services Administration (HRSA) has developed model grievance procedures describing the elements that must be addressed in the local procedures, and must review and approve grievance procedures developed by grantees and planning councils.

Severe Need

The legislation defines severe need for Eligible Metropolitan Areas (EMAs) applying for supplemental grant funds. Priority consideration is to be given to EMAs based on such factors as sexually transmitted diseases (STDs), substance abuse, tuberculosis, severe mental illness, new or growing populations of PLWH/As, and homelessness, to the extent that such national incidence data is available.

Training

Members must develop/maintain 9 competencies determined by HRSA, which include the following:

- Know Ryan White HIV/AIDS Treatment Modernization Act
- Understanding roles and responsibilities
- Be comfortable with meeting procedures
- Understand conflict of interest
- Be sensitive to views of others
- Understand budgets
- Be sensitive to needs of underserved communities
- Understand technical issues, such as use of data in decision-making
- Understand treatment requirements and guidelines and their impact on cost of care.

Attendance records must be maintained. Each new member is given a membership manual.

Mentor Program

Each new member of the CARE Council is assigned a mentor. The role of the mentor is to help the new member of the CARE Council feel welcome, become comfortable with the CARE Council process and to update them on the latest CARE Council issues.

The Mentor Program is unstructured. The mentor and the person newly appointed to the CARE Council meet on an as needed basis. Their relationship should last about 3 months, perhaps longer if necessary.

Each month there are two (2) Mentor Sessions scheduled for two (2) hours each. The purpose of the scheduled sessions is so that CARE Council members may remain compliant with the Sunshine Amendment. In Florida, public officials (including CARE Council members) must abide by the Sunshine Amendment, and therefore can not meet privately to discuss CARE Council matters. The Mentor Sessions are where CARE Council members can meet and discuss CARE Council issues. Each session is publicly noticed, recorded and persons from the public are welcome to observe.

CARE COUNCIL COMMITTEES

Purpose of Committees:

Committees are appointed or elected for specific purposes. They should have defined assignments to complete within a specified time period.

Committees work in various ways: as a full body, in smaller groups or sub-committees, or through individuals. During committee meetings, the members work and plan collectively. Specific tasks, however, may be assigned to individuals or teams, during or between meetings.

Types of Committees:

Standing Committees and **Program Support Committees** have permanent or ongoing functions.

The CARE Council's **Standing Committees** include:

- A. Executive Committee
- B. Planning Committee
- C. Priorities and Allocations Committee
- D. Membership Committee
- E. Support Services Committee
- F. Medical/Substance Abuse and Mental Health Services Committee
- G. Housing Services Committee
- H. Community Awareness Committee

The CARE Council's **Program Support Committees** include, but are not limited to:

- A. Management Information Systems (MIS) Committee
- B. Quality Assurance and Evaluation Committee

Ad hoc committees are formed when a specific need arises, and disbanded when the work is completed.

The CARE Council's **Ad hoc** Committee's include, but are not limited to:

- A. Bylaws Ad hoc Committee
- B. Elections Ad hoc Committee
- C. Grievance Ad hoc Committee

COMMITTEE RESPONSIBILITIES

Executive Committee:

The Executive Committee shall consist of the Chair, Vice Chair, Treasurer, Secretary, and Chair of each Standing Committee of the CARE Council. At least one person with HIV must be present to constitute a quorum for decisions.

The Executive Committee will meet on a regularly scheduled basis. It may also be convened by the Chair of the CARE Council and/or at the request of a Grantee or Lead Agency, to take action on time-sensitive issues relating to prioritization or allocation of funds which make it impractical to convene the CARE Council.

The duties and responsibilities of the Executive Committee shall include, but are not limited to, oversight of the grant application process, contracting processes implemented by Grantees or Lead Agencies on behalf of the CARE Council, and implementation of policy or actions established by the CARE Council. Emergency actions taken by the Executive Committee shall be subject to ratification of the CARE Council.

Priorities and Allocations Committee:

The Priorities and Allocations Committee, utilizing available data and information generated from Grantees and Administrative Agencies, and other CARE Council Committee's, through a group process, establishes a list of services appropriate and necessary to enhance the medical condition and improve the quality of life for persons living with HIV/AIDS in Palm Beach County. The Committee is also charged with establishing priorities for these services, and allocating available and/or potential funding to these services. The Priorities and Allocations Committee works closely with current funding streams to redirect under spent funds to those service categories most in need of additional dollars throughout the year.

Planning Committee:

The Planning Committee is charged with the overall development of major planning activities of the CARE Council. Included in these activities is development of a CARE Council Comprehensive Plan for HIV/AIDS Services for Palm Beach County Florida. In a collaborative nature, the Committee will work with all other planning/funding entities in Palm Beach County to ensure the plan encompasses all needed services and available resources. In addition, the Planning Committee is charged with the development of a Needs Assessment as outlined in HIV/AIDS Bureau (HAB) publications, the development of descriptions for all services purchased with Ryan White Title I, Title II, HOPWA, State of Florida AIDS Network and dedicated HIV/AIDS General Revenue dedicated funds.

The Planning Committee is also responsible for the development and implementation of evaluation tools and programs to ensure quality services are provided to persons

utilizing HIV/AIDS services in Palm Beach County.

Membership Committee:

Charged with identifying and recruiting members for the CARE Council and its Committees who are reflective of the HIV/AIDS epidemic in Palm Beach County. The committee is responsible for the following activities:

- Recruitment Plan;
- Recruiting New Members;
- Training New and Existing Members of the Council in Council responsibilities, policies and procedures the Council uses to address its responsibilities;
- Ensuring the Council membership list complies with necessary grant requirements;
- Monitoring membership attendance as required by *Policies and Procedures*.

Support Services Committee:

- Work with the Planning Committee on development of the Support Services module of the CARE Council's Comprehensive Plan;
- Work with the Planning Committee to develop service definitions relating to each of the supportive services for the RFP process;
- Responsible to develop unit cost information for each of the supportive services;
- Establish county-wide standards relating to the delivery of each of the support services;
- Work with the grantee, medical services, housing services, substance abuse/mental health committees and other funders on Quality Assurance standards and other program management issues relating to each of the support services.

Medical Services Committee:

- The Medical Services Committee is responsible for detailed planning and oversight of all services relating to the general health of persons living with HIV/AIDS who receive services funded through the collaborative funding sources of the CARE Council;
- This committee should remain up-to-date on the latest HIV/AIDS medical treatments and convey to the Planning Committee the need for inclusion of such services in the CARE Council's Comprehensive Plan;

- Responsible to develop unit cost information for each of the medical services;
- Establish county-wide standards relating to the delivery of each of the medical services;
- Work with the grantee, support services, housing services, substance abuse/mental health committees and other funders on Quality Assurance standards and other program management issues relating to each of the medical services.

Housing Services Committee:

- Responsible for development of the Housing Services module of the CARE Council's Comprehensive Plan;
- Responsible for development of service definitions relating to housing for the RFP process;
- Responsible to develop unit cost information for housing services;
- Work with the various local housing authorities to establish county-wide standards relating to the delivery of group housing services, and the provision of rental housing units or financial assistance related to housing or housing support services;
- Work with the grantee or other funding providers on Quality Assurance standards and other program management issues relating to housing for individuals and families utilizing AIDS housing funds or programs.

Community Awareness Committee:

- Outreach to HIV/AIDS service consumers;
- Act as an informal caucus to bring consumer issues to the Council, or council committees as appropriate. (This would be especially true if there was a general consumer concern regarding a specific service or service provider);
- Help identify ways to reach the PLWH/A communities served, including minority and other special populations;
- Provide an ongoing link with the community. Bring community issues to the Council, as well as information about available treatment, research, and care information to the community.

Substance Abuse/Mental Health Committee:

- The Substance Abuse/Mental Health Committee is responsible for detailed planning and oversight of all substance abuse and mental health services relating to persons living with HIV Spectrum Disease and who receive services funded through the

collaborative funding sources of the CARE Council.

- This committee shall remain current with proven effective, innovative and empirically-based substance abuse and mental health treatments for individuals with HIV/AIDS and convey such interventions to the Planning Committee for inclusion in the CARE Council's Comprehensive Plan. Substance Abuse/Mental Health providers will participate in the process.
- Responsible to develop unit cost information for each of the supportive services;
- Review, update and recommend regulations and standards of care relating to residential and outpatient services for chemical dependency and mental health issues.
- Work with the grantee and the Quality Assurance and Evaluation Committee relating to issues of quality assurance and other program management issues relating to each service under the umbrella of substance abuse and mental health.

Quality Assurance and Evaluation Committee:

The Quality Assurance and Evaluation Committee (QAEC) is responsible for ensuring that HIV funded agencies participating in the Coordinated Services Network (CSN) comply with standards of care established by the Palm Beach County HIV CARE Council in the delivery of services to their clients with HIV/AIDS.

Committee responsibilities will include:

- Overseeing the Palm Beach County HIV CARE Council's Quality Assurance Program.
- Developing written Quality Assurance and Evaluation Plans.
- Establishing quality assurance and evaluation activities including cost effectiveness analyses, monitoring medical and support service standards of care outcome indicators (specific information that tracks a program's success) and client-level outcomes (benefits or changes for clients during or after receiving services).
- Assisting Ryan White Part A and B, HOPWA, State of Florida AIDS Network, and HIV/AIDS General Revenue Grantees in ensuring funded service providers are implementing their own continuous quality improvement activities that are consistent with the Palm Beach County HIV CARE Council's Standards of Care.
- Working collaboratively with other quality assurance and evaluation entities in Palm Beach County including persons living with HIV/AIDS.
- Any non-compliance found by the Quality Assurance Coordinator or Quality Assurance and Evaluation Committee must be reported to the funder.

Management Information Systems (MIS) Committee Responsibilities and Committee Membership:

The MIS Committee is responsible for ensuring that issues are addressed relating to the data collections network used by the EMA. The committee focuses on Data Collection/Reporting issues, and the effective operation of the MIS Network.

Membership of the committee shall consist of a representative of each of the Case Management Agencies participating in the network, a representative of each of the funding sources financing the network and other invited participants. Other agencies participating in the network may become members of the committee. Members of the CARE Council may become members of this committee following appropriate approved policies.

Committee responsibilities will include:

- Establishes system-wide operating policies and addresses issues relative to the network as a whole;
- Develops methodology for effective data system operation; and
- Reviews system needs and makes recommendations for enhancement or improvement to the CARE Council.

Each CARE Council member must belong to at least one of the Standing Committees.

**CARE COUNCIL COMMITTEE STAFF ASSIGNMENTS AND THEIR CONTACT
NUMBER**

CARE Council -

*Health Planner, Sonja Swanson 844-4220 ext 14
Secretary, Sarah Withrow 844-4220 ext 28*

Executive Committee -

*Health Planner, Sonja Swanson 844-4220 ext 14
Secretary, Sarah Withrow 844-4220 ext 28*

By-Laws Committee -

*Health Planner, Sonja Swanson 844-4220 ext 14
Secretary, Sarah Withrow 844-4220 ext 28*

Membership Committee -

*Membership Coordinator, Annette Murzike-Dunn 844-4220 ext 19
Secretary, Sarah Withrow 844-4220 ext 28*

Medical/Substance Abuse and Mental Health Committee -

*Quality Assurance Coordinator, Shoshana Ringer 355-4788
Secretary, Sarah Withrow 844-4220 ext 28*

Priorities and Allocations Committee -

*Health Planner, Sonja Swanson 844-4220 ext 14
Secretary, Sarah Withrow 844-4220 ext 28*

Planning Committee -

*Health Planner, Sonja Swanson 844-4220 ext. 14
Secretary, Sarah Withrow 844-4220 ext 28*

Community Awareness Committee -

*Membership Coordinator, Annette Murzike-Dunn 844-4220 ext 19
Secretary, Sarah Withrow 844-4220 ext 28*

Support Services Committee -

*Quality Assurance Coordinator, Shoshana Ringer 355-4788
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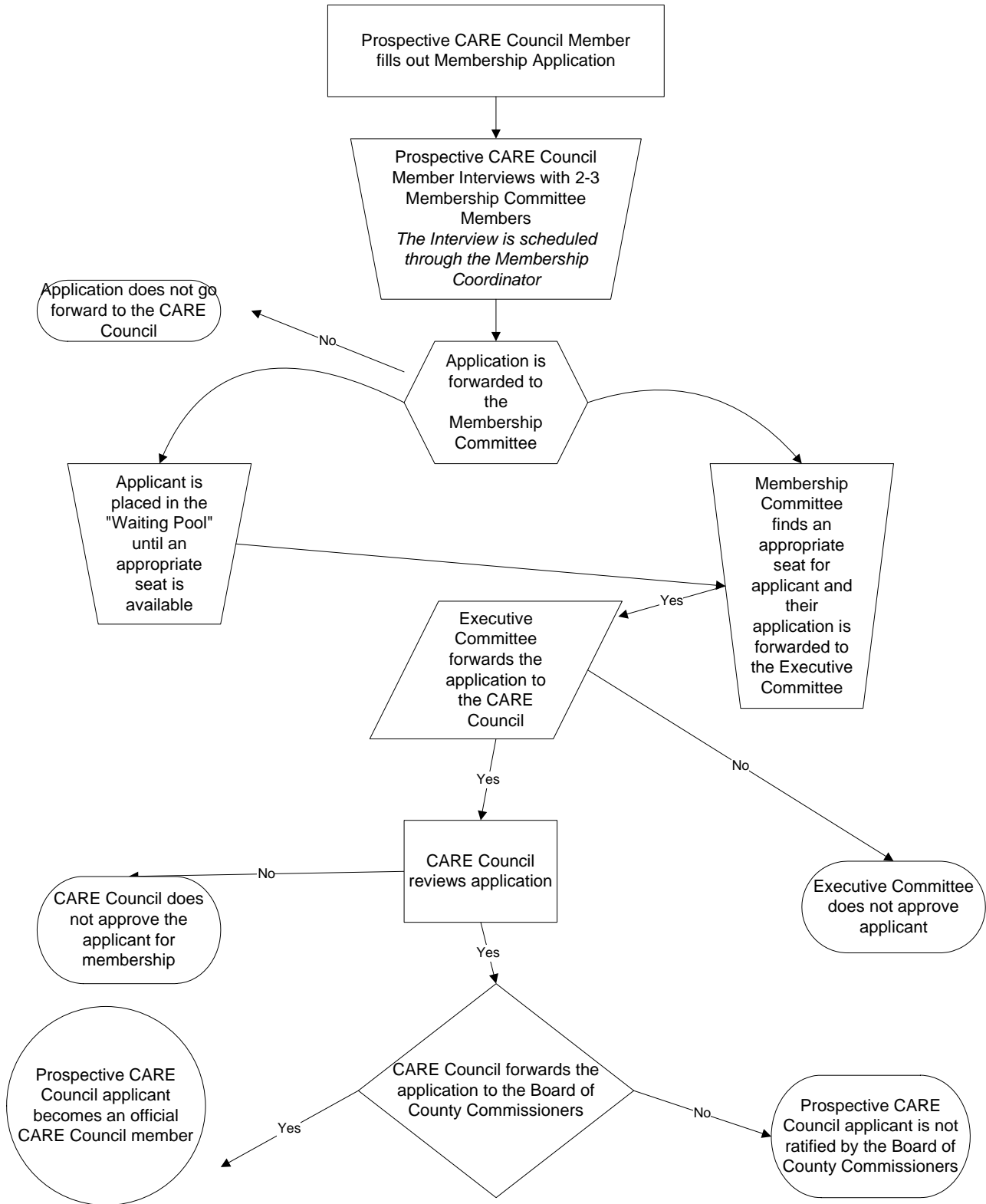
Quality Assurance Committee -

Quality Assurance Coordinator, Shoshana Ringer 355-4788

MIS Committee -

Sheron Hoo-Hing 355-4700

Prospective CARE Council Member Application Process



RYAN WHITE HIV/AIDS TREATMENT MODERNIZATION ACT

Ryan White HIV/AIDS Treatment Modernization Act was named after an Indiana teenager who was diagnosed with AIDS in the mid-1980s, when there was widespread ignorance about HIV/AIDS. Through active public education, Ryan White put a human face on a disease that had been cloaked in secrecy and fear. Ryan died in 1990 at the age of 18, four months before the Ryan White HIV/AIDS Treatment Modernization Act was passed.

The Ryan White Comprehensive AIDS Resources Emergency Act (i.e. Ryan White CARE Act/CARE Act) is a Federal law that was first passed by Congress in 1990. The law was re-authorized again in 1996 and 2001 with new requirements. In 2006 the Act was changed again to the Ryan White HIV/AIDS Treatment Modernization Act. This Ryan White HIV/AIDS Treatment Modernization Act is intended to help communities and States increase the availability of primary health care and support services, in order to reduce utilization of more costly inpatient care, increase access to care for underserved populations and improve the quality of life of those affected by the epidemic.

The Health Resources and Services Administration (HRSA) has lead responsibility for the implementation of the Ryan White HIV/AIDS Treatment Modernization Act. Within HRSA's Bureau of Health Resources Development, the Division of HIV Services (DHS) administers Parts A and B of the Ryan White HIV/AIDS Treatment Modernization Act, and has the additional responsibility of developing and disseminating technical assistance materials to state and local grantees. The Bureau of Primary Health Care is responsible for Part C; the Maternal and Child Health Bureau is responsible for Part D; and the Bureau of Health Professions is responsible for AIDS Education and Training Center (AETC)'s and the Dental Reimbursement Program under Part F.

RYAN WHITE HIV/AIDS TREATMENT MODERNIZATION ACT **PURPOSE**

- To revise and extent the program for providing life-saving care for those with HIV/AIDS.
- Address the unmet care and treatment needs of persons living with HIV/AIDS by funding primary health care and support services that enhance access to and retention in care.

RYAN WHITE HIV/AIDS TREATMENT MODERNIZATION ACT **STRUCTURE**

Responsibility for administering the Ryan White HIV/AIDS Treatment Modernization Act falls upon the Health Resources and Services Administration (HRSA), which is part of the Public Health Service, within the U.S. Department of Health and Human Services.

Part A: Subpart I:
Eligible Metropolitan Areas (EMAs) with the largest number of reported cases of AIDS to meet the emergency service needs of people living with the HIV disease.
Subpart II:
Transitional Grant Areas (TGAs)

Part B: Base:
Is received by all 50 States (and Puerto Rico, some territories, and District of Columbia -D.C.) to improve the quality, availability and organization of health care and support

services for individuals living with HIV disease and their families.

ADAP and ADAP Supplemental:

AIDS Drug Assistance Program

Emerging Community (EC) Supplemental Grant:

New Supplemental Grant Program:

- Part C: Public and nonprofit entities, such as Community and Migrant Health Centers, to support capacity building, early intervention services for people living with HIV disease, including HIV counseling and testing, primary care, and referrals to health and support services.
- Part D: Clinical research on therapies for children with HIV disease and pregnant women with HIV, and health care to children and their families.
- Part E: Emergency Response Employees: Provisions to address public health emergencies.
- Part F: AIDS Education and Training Centers (AETCs), Special Projects of National Significance (SPNS), Dental Reimbursement, and Minority AIDS Initiative (MAI).

PART A

Part A is administered by the Division of HIV Services (DHS) within Health Resources and Services Administration (HRSA).

Part A funds go to areas that have been hit hardest by the HIV epidemic. These areas are called eligible metropolitan areas (EMAs) and are usually cities or counties. In order to be eligible, the EMA must have a population of at least 50,000 to qualify as a new EMA. Subpart 1, EMAs, must have cumulative total of more than 2,000 AIDS cases during the most recent 5 year period. Subpart II, TGAs, must have cumulative total of 1,000-1,999 AIDS cases during most recent 5 year period.

GRANTEE:

The grant goes to the chief elected official (CEO) of the major city or county in the EMA. The CEO may be the mayor, county executive, chair of the board of supervisors, or judge. Part A funds may be used for HIV outpatient health and support services, case management and comprehensive treatment services.

Part A funds cannot replace existing local/state funds or be used to pay for services which can be covered by other sources such as Medicaid, Medicare, state/local programs, or private health insurance plans.

PART A IMPLEMENTATION OVERVIEW

CHIEF ELECTED OFFICIAL (CEO)	CEO/GRANTEE	PLANNING COUNCIL
Designates planning council	Administers funds in accordance with planning council priorities	Develops comprehensive plan consistent with state and local plans
Must distribute funds in accordance with planning council priorities	Selects providers and contractors	Establishes priorities and allocates funds across service categories
	Prepares grant applications to HRSA and reports	
	Monitors contract activities; provides reports to planning council	Assesses the efficiency of the administrative mechanism for the allocation of funds
	Works with the planning council to: <ul style="list-style-type: none"> Set process and dates for allocation of funds Support planning council work Conduct comprehensive needs assessment Establish grievance procedures 	Assesses, at its discretion, the effectiveness of services offered in meeting identified needs
		Participates in the development of the Statewide Coordinated Statement of Need (SCSN)

PART A IMPLEMENTATION

Funding:

- Formula funds provide direct financial assistance to EMAs most severely affected by the HIV epidemic and depends on the numbers of persons infected with HIV.
- Supplemental funds provide direct financial assistance to EMAs that demonstrate severe need for funding in addition to their formula-based awards.

Use of funds:

- Cannot replace existing municipal or State funds
- Priority for women, infants, and children- services in proportion to their percentage within the EMAs total AIDS population
- Private for-profit entities, if they are the only providers of high quality HIV care in the area
- Aggregate administrative costs across entities capped at 10%
- Grantee administrative costs capped at 5%
- No funds for construction, land purchase, or cash payments to intended recipients of services
- Payor of last resort

Eligible providers and services:

- Public or nonprofit entities
- Private for-profit entities, if they are the only providers of high quality HIV care in the area
- Substance abuse and mental health treatment programs are also specifically cited as eligible for funding include:
 - ▶ Outpatient and ambulatory health and support services
 - ▶ Inpatient case management services that expedite discharge

PALM BEACH COUNTY HIV CARE COUNCIL
Part A - RYAN WHITE CARE ACT GRANT
MARCH 1, 2008 - FEBRUARY 28, 2009

SERVICE CATEGORY DEFINITIONS

CORE MEDICAL SERVICES

1. Medical Care

a Ambulatory/Outpatient Primary Care

Provision of professional diagnostic and therapeutic services rendered by a physician, physician's assistant, registered nurse, or nurse practitioner in an outpatient setting. Settings include clinics, medical offices, and mobile vans where clients generally do not stay overnight. Emergency room services are not outpatient settings. Services includes diagnostic testing, early intervention and risk assessment, preventive care and screening, practitioner examination, medical history taking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, education and counseling on health issues, well-baby care, continuing care and management of chronic conditions, and referral to and provision of specialty care (includes all medical subspecialties). *Primary medical care* for the treatment of HIV infection includes the provision of care that is consistent with the Public Health Service's guidelines. Such care must include access to antiretroviral and other drug therapies, including prophylaxis and treatment of opportunistic infections and combination antiretroviral therapies. NOTE: Early Intervention Services provided by Ryan White Part C and Part D Programs should be included here under *Outpatient/ Ambulatory medical care*.

b Laboratory Diagnostic Testing

HIV viral load testing, CD4/CD8, CBC with diff., blood chemistry profile, & other FDA approved routine tests for the treatment of patients with HIV disease. In addition, routine tests pertinent to the prevention of opportunistic infections (VDRL, tuberculin skin-tests, AFB, pap smear, toxoplasmosa, hepatitis B, & CMV serologies) & all other laboratory tests as clinically indicated (e.g. HCV serology) that are generally accepted to be medically necessary for the treatment of HIV disease & its complications and have an established Florida Medicaid reimbursement rate.

c Drug Reimbursement Program

Local Supplemental Drug Program

Provision of injectable and non-injectable prescription drugs, at or below Public Health Service (PHS) price, and/or related supplies prescribed or ordered by a physician to prolong life, improve health, or prevent deterioration of health for HIV+ persons who do not have prescription drug coverage and who are not eligible for Medicaid, Health Care District, or other public sector funding, nor have any other means to pay. This service area also includes assistance for the acquisition of non-Medicaid reimbursable drugs.

ADAP Supplemental Drug Program

Program to expand Florida AIDS Drug Assistance Program (ADAP) locally by paying for FDA approved medications on the State of Florida ADAP formulary when the Florida ADAP is unable to pay for such medications for patients enrolled in the Florida ADAP program & patients are ineligible for other local health care programs which pay for these medications. Medications purchased under this program must be purchased at Public Health Services prices or less.

Nutritional Supplements

Provision of nutritional supplement prescribed as a treatment for diagnosed wasting syndrome. Counseling linked to Primary Medical Care, Nurse Care Management or Human Services Management.

Pediatric AZT

d Specialty Outpatient Health Care

Short term treatment of specialty medical conditions and associated diagnostic procedures for HIV positive patients based upon referral from a primary care provider, physician, physician assistant, registered nurse. Specialties may include, but are not limited to, outpatient rehabilitation, dermatology, oncology, obstetrics and gynecology, urology, podiatry, pediatrics, rheumatology, physical therapy, speech therapy, occupational therapy, developmental assessment, and psychiatry.

e Oral Health

Diagnostic, preventive, and therapeutic services provided by general dental practitioners, dental specialists, dental hygienists and auxiliaries, and other trained primary care providers.

f Early intervention services (EIS)

Includes counseling individuals with respect to HIV/AIDS; testing (including tests to confirm the presence of the disease, tests to diagnose to extent of immune deficiency, tests to provide information on appropriate therapeutic measures); referrals; other clinical and diagnostic services regarding HIV/AIDS; periodic medical evaluations for individuals with HIV/AIDS; and providing therapeutic measures.

g Nurse Care Coordination

A range of client-centered services provided by a registered nurse and coordinated with the client's primary outpatient healthcare provider, providing the Ryan White patient's main link with ongoing medical services.

h Health Insurance Premium & Cost Sharing Assistance

Provision of financial assistance for eligible individuals living with HIV to maintain a continuity of health insurance or to receive medical benefits under a health insurance program. This includes premium payments, risk pools, co-payments, and deductibles.

i Home Health Care

Includes the provision of services in the home by licensed health care workers such as nurses and the administration of intravenous and aerosolized treatment, parenteral feeding, diagnostic testing, and other medical therapies. Also includes skilled health services furnished to the individual in the individual's home based on a written plan of care established by a case management team that includes appropriate health care professionals. Services include durable medical equipment; home health aide services and personal care services in the home; day treatment or other partial hospitalization services; home intravenous and aerosolized drug therapy (including prescription drugs administered as part of such therapy); routine diagnostics testing administered in the home; and appropriate mental health, developmental, and rehabilitation services. Inpatient hospitals services, nursing home and other long term care facilities are NOT included.

j Hospice Services

Includes room, board, nursing care, counseling, physician services, and palliative therapeutics provided to clients in the terminal stages of illness in a residential setting, including a non-acute-care section of a hospital that has been designated and staffed to provide hospice services for terminal clients.

k Mental Health Services

Psychological and psychiatric treatment and counseling services offered to individuals with a diagnosed mental illness, conducted in a group or individual setting, and provided by a mental health professional licensed or authorized within the State to render such services. This typically includes psychiatrists, psychologists, and licensed clinical social workers.

l Medical nutrition therapy

Provided by a licensed registered dietitian outside of a primary care visit and includes the provision of nutritional supplements. Medical nutrition therapy provided by someone other than a licensed/registered dietitian should be recorded under psychosocial support services.

m Medical Case management services (including treatment adherence)

A range of client-centered services that link clients with health care, psychosocial, and other services. The coordination and follow-up of medical treatments is a component of medical case management. These services ensure timely and coordinated access to medically appropriate levels of health and support services and continuity of care, through ongoing assessment of the client's and other key family members' needs and personal support systems. Medical case management includes the provision of treatment adherence counseling to ensure readiness for, and adherence to, complex HIV/AIDS treatments. Key activities include (1) initial assessment of service needs; (2) development of a comprehensive, individualized service plan; (3) coordination of services required to implement the plan; (4) client monitoring to assess the efficacy of the plan; and (5) periodic re-evaluation and adaptation of the plan as necessary over the life of the client. It includes client-specific advocacy and/or review of utilization of services. This includes all types of

case management including face-to-face, phone contact, and any other forms of communication.

n Substance Abuse Services-Outpatient

Provision of medical or other treatment and/or counseling to address substance abuse problems (i.e., alcohol and/or legal and illegal drugs) in an outpatient setting, rendered by a physician or under the supervision of a physician, or by other qualified personnel.

SUPPORT SERVICES

2. Case Management (non-Medical)

Includes the provision of advice and assistance in obtaining medical, social, community, legal, financial, and other needed services. Non-medical case management does not involve coordination and follow-up of medical treatments, as medical case management does.

3. Referral for Health Care/Supportive Services

The act of directing a client to a service in person or through telephone, written, or other type of communication. Referrals may be made within the non-medical case management system by professional case managers, informally through support staff, or as part of an outreach program.

4. Housing Services

Provision of short-term assistance to support emergency, temporary or transitional housing to enable an individual or family to gain or maintain medical care. Housing-related referral services include assessment, search, placement, advocacy, and the fees associated with them. Eligible housing can include both housing that does not provide direct medical or supportive services and housing that provides some type of medical or supportive services such as residential mental health services, foster care, or assisted living residential services.

5. Substance Abuse Services- residential

Provision of treatment to address substance abuse problems (including alcohol and/or legal and illegal drugs) in a residential health service setting (short-term).

6. Food Bank/Home Delivered Meals

Food bank/home-delivered meals include the provision of actual food or meals. It does not include finances to purchase food or meals. The provision of essential household supplies such as hygiene items and household cleaning supplies should be included in this item. Includes vouchers to purchase food.

7. Emergency Financial Assistance

Provision of short-term payments to agencies or establishment of voucher programs to assist with emergency expenses related to essential utilities, housing, food (including groceries, food vouchers, and food stamps), and medication when other resources are not available.

NOTE: Part A and Part B programs must be allocated, tracked and report these funds under specific service categories as described under 2.6 in DSS Program Policy Guidance No. 2 (formally Policy No. 97-02).

8. Medical Transportation Services

Includes conveyance services provided, directly or through voucher, to a client so that he or she may access health care services.

9. Treatment Adherence Counseling

Provision of counseling or special programs to ensure readiness for, and adherence to, complex HIV/AIDS treatments by non-medical personnel outside of the medical case management and clinical setting.

10. Outreach Services

Programs that have as their principal purpose identification of people with unknown HIV disease or those who know their status so that they may become aware of, and may be enrolled in care and treatment services (i.e., case finding), not HIV counseling and testing nor HIV prevention education. These services may target high-risk communities or individuals. Outreach programs must be planned and delivered in coordination with local HIV prevention outreach programs to avoid duplication of effort; be targeted to populations known through local epidemiologic data to be at disproportionate risk for HIV infection; be conducted at times and in places where there is a high probability that individuals with HIV infection will be reached; and be designed with quantified program reporting that will accommodate local effectiveness evaluation.

11. Legal Services

Provision of services to individuals with respect to powers of attorney, do-not-resuscitate orders and interventions necessary to ensure access to eligible benefits, including discrimination or breach of confidentiality litigation as it relates to services eligible for funding under the Ryan White Program. It does not include any legal services that arrange for guardianship or adoption of children after the death of their normal caregiver.

12. Health Education/Risk Reduction

Provision of services that educate clients with HIV about HIV transmission and how to reduce the risk of HIV transmission. It includes the provision of information; including information dissemination about medical and psychosocial support services and counseling to help clients with HIV improve their health status.

13. Psychosocial Support Services

Provision of support and counseling activities, child abuse and neglect counseling, HIV support groups, pastoral care, caregiver support, and bereavement counseling. Includes nutrition counseling provided by a non-registered dietitian but excludes the provision of nutritional supplements.

14. Rehabilitation Services

Provided by a licensed or authorized professional in accordance with an individualized plan of care intended to improve or maintain a client's quality of life and optimal capacity for self-care. Services include physical and occupational therapy, speech pathology, and low-vision training.

15. Linguistics Services

Provision of interpretation and translation services.

16. Child Care Services

Provision of care for the children of clients who are HIV-positive while the clients attend medical or other appointments or Ryan White Program-related meetings, groups, or training.

NOTE: This does not include child care while a client is at work.

17. Respite Care

Provision of community or home-based, non-medical assistance designed to relieve the primary caregiver responsible for providing day-to-day care of a client with HIV/AIDS.

PART B: FUNDING TO STATES, District of Columbia (D.C.), PUERTO RICO AND ELIGIBLE U.S. TERRITORIES

Part B Base and ADAP grants are awarded on a formula basis to States, the District of Columbia, Puerto Rico, and eligible U.S. territories to provide health care and support services for people living with HIV disease. Grants are awarded to the State agency designated by the governor to administer Part B, usually the health department.

Eligible Services:

Part B Base funds may be used to support the same service categories as Part A. Part A should be used as a supplemental means.

PART C

Part C supports comprehensive primary health care and other services for individuals who have been diagnosed with HIV disease.

Part C Services include:

- Risk-reduction counseling, partner involvement in risk reduction, education to prevent transmission, antibody testing, medical evaluation, and clinical care;
- Antiretroviral therapies, protection against opportunistic infections, ongoing medical, oral health, nutritional, psychosocial, and other care for HIV infected clients;
- Case management to assure access to services, and continuity of care for HIV infected clients; and
- Addressing “co-epidemics” that occur frequently in association with HIV infection, including tuberculosis and substance abuse.

PART D

The Part D program is located in the Comprehensive Family Services Branch of the HIV/AIDS Bureau's Division of Community Based Programs. Title IV focuses on providing comprehensive, community-based, and family centered services to children, youth, and women living with HIV and their families. The program services include primary and specialty medical care, psychosocial services, and logistical support, as well as outreach and prevention to provide a continuum of care for at-risk populations.

PART F

Aids Education and Training Centers (AETC) Program

The AIDS Education and Training Centers (AETC) Program currently supports a network of 14 regional centers (and over 70 associated sites) that conduct targeted, multidisciplinary education and training programs for health care providers treating persons with HIV/AIDS. The AETCs, which serve all 50 States, the Virgin Islands, Puerto Rico and the six United States Pacific Jurisdictions, increase the number of health care providers who are effectively educated and motivated to counsel, diagnose, treat, and medically manage individuals with HIV infection and to help prevent high risk behaviors that lead

to HIV transmission.

Minority HIV/AIDS Initiative

Minority HIV/AIDS Initiative funds target programs to enhance effective HIV/AIDS efforts that directly benefit racial and ethnic minority communities in three broad funding categories: technical assistance and infrastructure support, increasing access to prevention and care, and building stronger community linkages to address the HIV prevention and health care needs of specific populations.

HIV/AIDS Dental Reimbursement Program

The HIV/AIDS Dental Reimbursement Program reimburses dental schools and post-doctoral dental education programs for un-reimbursed cost incurred in providing oral health care to patients with HIV infection. Eligible applicants must have documentation of un-reimbursed costs of oral health care for HIV positive persons, and must be accredited by the Commission on Dental Accreditation.

Special Projects of National Significance (SPNS)

Special Projects of National Significance (SPNS) projects are funded by HIV/AIDS Bureau (HAB) and Health Resources and Services Administration (HRSA) to establish innovative demonstration, research and evaluation projects that respond to the challenge of HIV/AIDS service provision to underserved and vulnerable populations.

HOUSING OPPORTUNITIES FOR PERSONS WITH AIDS (HOPWA)

OVERVIEW AND BACKGROUND

The HOPWA program was authorized by the AIDS Housing Opportunities Act (AHOA) and amended by the Housing and Community Development Act of 1992 (Pub. L 102-550, approved October 28, 1992). The program is designed to provide States and localities with resources and incentives to devise long-term comprehensive strategies for meeting the housing needs of persons and their families with Acquired Immunodeficiency Syndrome (AIDS) and related diseases. The program authorizes formula grants to localities for housing assistance and services. The City of West Palm Beach, as the largest Eligible Metropolitan Statistical Area (EMSA) in Palm Beach County, is the recipient of the HOPWA formula grant funds. The City of West Palm Beach is responsible for serving eligible persons who live anywhere within the EMSA.

HOPWA AND COLLABORATION WITH THE PALM BEACH COUNTY HIV CARE COUNCIL

As the jurisdictional entity responsible for the HOPWA program on a countywide basis, the City of West Palm Beach collaborates with the PBC HIV CARE Council in an effort to better serve the HIV/AIDS community. By Resolution Number 137-01, the City of West Palm Beach approved the Palm Beach County HIV CARE Council to make funding recommendations to the City Commission. This relationship provides the necessary information to the recommending body to assure that the needs of individuals with HIV/AIDS are a part of the funding process.

HOUSING CATEGORY DESCRIPTIONS

Tenant-Based Independent Housing:

The Tenant-Based Independent Housing Assistance (TBIHA) program serves persons who require assistance with rental payments for an extended period of time. This program is intended to provide housing that enables low and very low income people with HIV/AIDS to live independently. TBIHA refers to a residential setting such as a house, an apartment, congregate apartment clusters or shared group housing. TBIHA refers to the concept of "independent living" where a resident can maintain activities of daily living (dressing, bathing, eating) without assistance. The goal is to provide eligible households with financial assistance. The goal is to provide eligible households with financial assistance for affordable housing. The maximum amount of monthly assistance under this program is the U.S. Housing and Urban Development (HUD) published fair market rents (FMR) for unit size in Palm Beach County less the amount of the participant's required share of the rent payment, usually thirty percent (30%) of the individual or family's adjusted monthly income. The assistance is ongoing, subject to continued eligibility, and the availability of HOPWA funds. The City will accept proposals of TBIHA directed at persons who required assistance with rental payments for an extended period of time and greater assistance in locating and maintaining housing. In addition, persons receiving assistance through this program must be engaged in participation with Workforce Development agencies and other organizations that promote self sufficiency through job training and educational opportunities (Agencies must provide grantee with guidelines and criteria that determine applicability for client involvement). *Review Code of Federal Regulations, Housing and Urban Development, 24 HOPWA Regulations, Part 574, Subpart E, Section 574.320, Additional Standards for Rental Assistance*

Homelessness Prevention/Short-Term Housing Assistance

The Short-Term, Rent, Mortgage and Utility Assistance (STRMUA) program serves persons who require assistance with rental or mortgage payments for a transitional period, not to exceed twenty-one (21) weeks within a fifty-two (52) week period. In extraordinary circumstances, such as threatened eviction or foreclosure, short-term assistance may be applied to past due rent or mortgage payments not to exceed eight (8) weeks. The goal is to prevent eligible persons from becoming homeless as result of temporary financial pressures. The maximum amount of monthly assistance under this Program is the US Housing and Urban Development (HUD) published fair market rents (FMR) for unit size in Palm Beach County. The goal of providing utility assistance is to provide eligible households with assistance in paying utility bills. Eligible costs include fees for reconnecting, ongoing electricity, gas, sewer and water services. *Review Code of Federal Regulations, Housing and Urban Development, 24 HOPWA Regulations, Part 574, Subpart D, Section 574.330, Additional Standards for Short-Term Supported Housing.*

III. Provider-Based Supportive Housing

Provider-Based Supportive Housing (PBSH) program refers to housing in a residential setting in which a range of supportive services are provided on-site. Supportive housing programs are required when truly independent living is not appropriate because an individual needs assistance with the activities of daily living. This type of housing incorporates a broad array of supportive living arrangements such as small group homes, single room occupancy (SRO) residences, board and care homes. PBSH should require residents to participate in at least a minimum level of support services, such as weekly meetings, updating care plan and goals, etc. Supportive housing programs should provide or require participation in substance abuse counseling and treatment. To maximize the limited resources available to meet the housing needs of persons living with HIV/AIDS, HOPWA funds are not being directed at support services. Successful awardees are required to ensure that recipients served by their programs receive these services. *Review Code of Federal Regulations, Housing and Urban Development, 24 HOPWA Regulations, Part 574, Subpart E, Section 574.340, Additional Standards for Community Residences.*

IV. Nursing/Hospice Facility Services

The Nursing/Hospice Facilities Services (NHFS) program serves individuals that need 24-hour nursing and attendant care.

Nursing Facilities- Some patients with HIV/AIDS need the continuous availability of procedures including the administration of injections, infusions and application of dressings. Services may also include occupational and physical therapy, respiratory therapy, meals and nutritional counseling and therapeutic activities. To maximize the limited resources available to meet the housing need of persons living with HIV/AIDS, HOPWA funds are not being directed at support services. Successful awardees are required to ensure that recipients served by their programs receive these services.

Hospice Facilities- These types of housing services ease the pain and suffering of individuals during the end stage of AIDS. Services include skilled nursing, attendant care, treatment for pain control and symptom management, and dietary services. Nursing facilities are intended for individuals who need the continuous availability of nursing care and are too sick to remain at home, but do not require immediate access to the full range of medical services in an acute care hospital. Hospice facilities are intended for the terminally ill individual whose homes are no longer available or appropriate, or who are homeless and do not require any form of curative care. *Review Code of Federal Regulations, Housing and Urban Development, 24 HOPWA Regulations, Part 574, Subpart D, Section*

574.340, *Additional Standards for Community Residences.*

V. Transitional Housing

Transitional Housing (TH) programs provide short-term housing for individuals unable to move into permanent housing. The duration of this type of housing is for a period of up to one (1) year. These programs often target a specific sub-population, and residents can be required to participate in counseling programs to assist them in overcoming a specific problem, such as long term substance abuse recovery. All TH is intended to prepare formerly homeless individuals to move into supportive or permanent housing, either tenant-based independent such as a rental apartment or to provider-based supportive housing. TH can be provided at a single site, scattered sites, or through rental assistance in the communities. TH is often designed to serve special target populations. Special populations that may benefit from transitional housing include (1) individuals who are dually and triply diagnosed, (2) individuals leaving incarceration or with a criminal history, (3) individuals who need support to remain abstinent from drug use, and (4) families with children. *Review Code of Federal Regulations, Housing and Urban Development, 24 HOPWA Regulations, Part 574, Subpart D, Section 574. 340, Additional Standards for Community Residences.*

HIV Patient Care Network

Overview

HIV Patient Care Network funding is from Florida State revenue dollars. The funding is allocated by the Florida State Legislature. The State shows the dollars as matching funds in their application for the Ryan White Title II federal funds. The CARE Council is considered an advisory body in the allocation of Network funds. The other areas that receive Network funding include Dade County, Monroe County, East Central Florida (Orange, Osceola, Seminole and Brevard Counties), West Central Florida (Hillsborough, Polk, Pinellas and Pasco Counties), and Northeast Florida (Duval, St. Johns, Clay, Nassau, Baker, Volusia and Flagler counties).

HIV/AIDS Patient Care

Overview

HIV/AIDS Patient Care funds are from Florida State revenue dollars. These funds are allocated to Health Departments in 29 of the 67 counties. There is no advisory board requirement, but the Palm Beach County Health Department reports the use of these funds on a quarterly basis to the Palm Beach County HIV CARE Council.

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.

ACTG (AIDS Clinical Trials Group): A network of medical centers around the country in which federally-funded clinical trials are conducted to test the safety and efficacy of experimental treatments for AIDS and HIV infection. These studies are funded by the National Institute of Allergy and Infectious Diseases (NIAID).

Acute: Reaching a crisis quickly; very sharp or severe.

ADAP (AIDS Drug Assistance Program): A State-administered program authorized under Part B of the Ryan White Act that provides FDA-approved medications to low-income individuals with HIV disease who have limited or no coverage from private insurance or Medicaid.

Administrative Agent or Fiscal Agent: An organization, agent, or other entity (i.e., public health department or community based organization) which assists a grantee in carrying out administrative activities (e.g., disbursing program funds, developing reimbursement and accounting systems, developing Requests for Proposals (RFPs), monitoring contracts). Not all grantees use a separate administrative or fiscal agent.

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.

AETC (AIDS Education and Training Center): Regional centers providing education and training for primary care professionals and other AIDS-related personnel. AETCs are authorized under Part F of the Ryan White Act and administered by HRSA's HIV/AIDS Bureau's Division of Training and Technical Assistance (DTTA).

Affected Communities: Groups of people who are either infected with the HIV virus or who are family members/significant others of infected individuals.

Aggregate Data: Combined data, composed of multiple elements, often from multiple sources; for example, combining demographic data about clients from all primary care providers in a service area generates aggregate data about client characteristics.

AIDS (Acquired Immunodeficiency Syndrome): A severe immunological disorder caused by a retrovirus and resulting in susceptibility of opportunistic infections and certain rare cancers. This disease is caused by the human immunodeficiency virus (H.I.V.).

AIDS Network: The AIDS Network were established to plan, develop and deliver comprehensive health and support services to meet the identified needs of individuals with HIV/AIDS in a cost effective manner. The Florida Legislature funds the Network. The department is ultimately responsible and accountable to the legislature for the network's appropriate utilization of the funds as established.

Allocation: Total dollar amount that may be expended for a service category.

Antibody: A substance in the blood formed in response to invading disease agents such as viruses, bacteria, fungi and parasites. Antibodies defend the body against invading disease agents. Most HIV tests are antibody test including ELISA, Synthetic Peptide, Western Blot.

Antiretroviral: A substance that fights against a retrovirus, such as HIV.

ASO (AIDS Service Organization): An organization which provides medical or support services primarily or exclusively to populations infected with and affected by HIV disease.

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

Attitude: A state of mind or feeling regarding a particular subject.

Average: A way of describing the typical value or central tendency among a group of numbers, such as average age or average income.

Bar Graph or Bar Chart: A visual way to show and compare scores or values for different categories of variables; for example, a bar chart might be used to show the number of reported AIDS cases who are from each major racial/ethnic group; the taller the bar, the larger the number of AIDS cases.

Behavioral Risk Factor Surveillance System (BRFSS): A telephone survey conducted by most states which 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).

BHRD (Bureau of Health Resources Development): Bureau within the Health Resources and Services Administration (HRSA, [her-sa]), U.S. Department of Health and Human Services, which is responsible for administering the Ryan White Part A, Part B and SPNS (Special Projects of National Significance), among other programs.

Bylaws: Standing rules written by a group to govern their internal function; address issues of voting, quorums, attendance, etc.

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

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

CBO (Community Based Organization): An organization which provides services to locally-defined populations, which may or may not include populations infected with or affected by HIV disease.

CDC (Centers for Disease Control and Prevention): The Department of Health and Human Services (DHHS) agency that administers HIV/AIDS prevention programs, including the HIV Prevention Community Planning process, among other programs. The CDC is responsible for monitoring and reporting infectious diseases, administers AIDS surveillance grants and publishes epidemiologic reports such as the *HIV/AIDS Surveillance Report*.

CD4 or CD4+ Cells: Also known as “helper” T-cells, these cells are responsible for coordinating much of the immune response. HIV’s preferred targets are cells that have a docking molecule called “cluster designation 4” (CD4) on their surfaces. Cells with this molecule are known as CD4-positive (CD4+) cells. Destruction of CD4+ lymphocytes is the major cause of the immunodeficiency observed in AIDS, and increasing CD4 levels appear to be the best indicator for developing opportunistic infections.

CD4 Cell Count: The number of T-helper lymphocytes per cubic millimeter of blood. The CD4 count is a good predictor of immunity. As CD4 cell count declines, the risk of developing opportunistic infections increases. The normal range for CD4 cell counts is 500 to 1500 per cubic millimeter of blood. CD4 counts should be rechecked at least every 6 to 12 months if CD4 counts are greater than 500/mm³. If the count is lower, testing every 3 months is advised. A CD4 count of 200 or less indicates AIDS.

CEO: (Chief Elected Official): The official recipient of the Ryan White Part A funds within the EMA, usually a city mayor, county executive, or chair of the county board of supervisors. The CEO is ultimately responsible for administering all aspects of the Ryan White Act in the EMA and ensuring that all legal requirements are met. In EMAs with more than one political jurisdiction, the recipient of Ryan White Part A funds is the CEO of the city or urban county that administers the public health agency that provides out patient and ambulatory services to the greatest number of people with AIDS in the EMA. In Palm Beach County the CEO is the Board of County Commissioners.

Chronic: A prolonged, lingering or recurring state of disease.

Closed- Ended Questions: Questions in an interview or survey format that provide a limited set of predefined alternative responses; for example, a survey might ask PLWH/A respondents if they are receiving case management services, and if they say yes, ask “About how often have you been in contact with your case manager for services during the past six months, either in person or by telephone?” and provide the following response options: Once a week or more, 2-3 times a month,

about once a month, 3-5 times, 1-2 times, not at all.

Coalesce: To grow together in order to form one whole unit.

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

Coding: The process of “translating” data from one format to another, usually so the information can be entered into a computer to be tabulated and analyzed; often, coding involves assigning numbers to all the possible responses to a question, such as Yes=1, No=2, Not Sure =3, No Response=0.

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 goals.

Community: A group of people living in a defined area who share a common language, ethnicity, geographic area, behavior or belief.

Co-Morbidity: A disease or condition, such as mental illness or substance abuse, co-existing with HIV disease.

Comprehensive Planning: The process of determining the organization and delivery of HIV services. This strategy is used by planning bodies to improve decision making about services and maintain a continuum of care for PLWH/As.

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

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*.

Confidentiality: Keeping information private or secret.

Consortium/HIV Care Consortium: A regional or Statewide planning entity established by many State grantees under Ryan White Part B to plan and sometimes administer Part B services. An association of health care and support service providers that develops and delivers services for PLWH/A under Ryan White Part B.

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

Continuum of Care: An approach that helps communities plan for and provide a full range of

emergency and long-term service resources to address the various needs of PLWH/A.

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

County Health Department AIDS Patient Care: This funding is used for patient care services. An allocation is received by 29 of the 67 County Health Departments (CHD). The CHDs send Annual Plans to the Bureau of HIV/AIDS and report regularly as to the spending by category of these funds.

Cultural Competence: The knowledge, understanding and skills to work effectively with individuals from differing cultural backgrounds.

Data: Information that is used for a particular purpose.

Data Analysis: Careful, rigorous study of data; usually involves studying various elements of information and their relationships.

DCBP (Division of Community Based Programs): The division within HRSA's HIV/AIDS Bureau that is responsible for administering Ryan White Part C and Part D, and the HIV/AIDS Dental Reimbursement Program.

Decimal Places: Number of digits to the right of the decimal point, which separates numbers with a value greater than one from numbers with a value of less than one; the more numbers or decimal places used, the more precise the number; for example, 34.03 has two decimal places.

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

Dementia: The loss of mental capacity that affects a person's ability to function.

Department of Health and Human Services (DHHS): The U.S. government's principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves. DHHS includes more than 300 programs, covering a wide spectrum of activities. The Department's programs are administered by 11 operating divisions such as the Centers for Disease Control and Prevention, the Food and Drug Administration and the National Institutes of Health (see the entries for these agencies). DHHS works closely with state and local governments, and many DHHS-funded services are provided at the local level by state or county agencies, or through private-sector grantees. **Internet address:** <http://www.hhs.gov/>.

DHS (Division of HIV Services): The entity within Bureau of Health Resources Development (BHRD) responsible for administering Ryan White Part A and B.

Diagnosis: Confirmation of illness based on an evaluation of a patient's medical history.

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

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

Double blind Study: A clinical trial design in which neither the participating individuals nor the study staff know which patients are receiving the experimental drug and which are receiving a placebo or another therapy. Double-blind trials are thought to produce objective results, since the expectations of the doctor and the patient about the experimental drug do not affect the outcome. See Blinded Study.

Drug Resistance: The ability of some disease-causing microorganisms, such as bacteria, viruses, and mycoplasma, to adapt themselves, to grow, and to multiply even in the presence of drugs that usually kill them. See Cross-Resistance.

DSS (Division of Service Systems): The division within HRSA's HIV/AIDS Bureau that is responsible for administering Part A and B (including the AIDS Drug Assistance Program, ADAP).

DTTA (Division of Training and Technical Assistance): The division within HRSA's HIV/AIDS Bureau that is responsible for administering the AIDS Education and Training Centers (AETC) Program and technical assistance and training activities of the HIV/AIDS Bureau.

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.

ELISA (Enzymes-Linked Immunosorbent Assay): The most common test used to detect the presence of HIV infection. A positive ELISA test result must be confirmed by another test called a Western Blot.

EMA (Eligible Metropolitan Area): The geographic area eligible to receive Ryan White Part A funds. The boundaries of the eligible metropolitan area are defined by the Census Bureau. Eligibility is determined by AIDS cases reported to the Centers for Disease Control and Prevention (CDC). Some EMAs include just one city and others are composed of several cities and/or counties. Some EMAs extend over more than one state.

Encephalitis: A brain inflammation of viral or other microbial origin. Symptoms include headaches, neck pain, fever, nausea, vomiting, and nervous system problems. Several types of opportunistic infections can cause encephalitis.

Epidemic: A disease that occurs clearly in excess of normal expectation and spreads rapidly through a demographic segment of the human population. Epidemic disease can be spread from person to person or from a contaminated source such as food or water.

Epidemiologic Profile: A description of the current status and projected future spread of an

infectious disease (an epidemic) in a specified geographic area; one of the required components of a needs assessment.

Epidemiology: The branch of medical science that studies the incidence, distribution, and control of disease in a population.

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

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

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

Exposure Category: In describing HIV/AIDS cases, same as transmission categories; how an individual may have been exposed to HIV, such as injecting drug use, men who have sex with men, and heterosexual contact.

Family Centered Care: A model in which systems of care under Ryan White Title IV are designed to address the needs of PLWH/As and affected family members as a unit, providing or arranging for a full range of services. The family structures may range from the traditional, biological family unit to non-traditional family units with partners, significant others, and unrelated care givers.

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

FDA (Food and Drug Administration): The DHHS agency responsible for ensuring the safety and effectiveness of drugs, biologic, vaccines, and medical devices used (among others) in the diagnosis, treatment, and prevention of HIV infection, AIDS, and AIDS-related opportunistic infections. The FDA also works with the blood-banking industry to safeguard the nation's blood supply.

Financial Status Report (Form 269): A report that is required to be submitted within 90 days after the end of the budget period that serves as documentation of the financial status of grants according to the official accounting records of the grantee organization.

Focus Group: A method of information collection involving a carefully planned discussion among a small group led by a trained moderator.

Formula Grant Application: The application used by EMAs and States each year to request an amount of Ryan White funding which is determined by a formula based on the number of reported AIDS cases in their location and other factors; the application includes guidance from DHS on program requirements and expectations.

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

Frequency Distribution: A tally of the number of times each score or response occurs in a group of scores or response; for example, if 20 women with HIV provided information about how they were infected with the virus, the frequency distribution might be 8=injection drug use, 5= heterosexual contact with an injection drug user, 3=other heterosexual contact, 1= blood transfusion, and 3=don't know.

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

Generalizability: The extent to which findings or conclusions from a sample can be assumed to be true of the entire population from which the sample was drawn.

Genotypic Assay: A test which analyzes a sample of the HIV virus from the patient's blood to identify actual mutations in the virus that are associated with resistance to specific drugs.

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

Grantee: The recipient of Ryan White funds responsible for administering the funds. (for a full listing of definitions of grants management terms, see the PHS Grants Policy Statement, which can be accessed at [http://www.nih.gov/grants/policy/gps/.](http://www.nih.gov/grants/policy/gps/))

Guidelines: Rules and structures for creating a program.

HAART (Highly Active Antiretroviral Therapy): An aggressive anti-HIV treatment usually including a combination of two or more drugs with activity against HIV whose purpose is to reduce viral load to undetectable levels in the blood. There is a question about the virus "hiding out" in lymph glands, sperm, etc.

HCFA (Health Care Financing Administration): The DHHS agency that is responsible for administering the Medicaid, Medicare, and Child Health Insurance Programs.

Hepatitis: An inflammation of the liver, which may be caused by bacterial or viral infection, parasitic infestation, alcohol, drugs, toxins, or transfusion of incompatible blood. Although many cases of hepatitis are not a serious threat to health, the disease can become chronic and can sometimes lead to liver failure and death. There are four major types of viral hepatitis: (1) hepatitis A, caused by infection with the hepatitis A virus, which is spread by fecal-oral contact; (2) hepatitis B, caused by infection with the hepatitis B virus (HBV), which is most commonly passed on to a partner during intercourse, especially during anal sex, as well as through sharing of drug needles; (3) non-A, non-B hepatitis, caused by the hepatitis C virus, which appears to be spread through sexual contact as well as through sharing of drug needles (another type of non-A, non-B hepatitis is caused

by the hepatitis E virus, principally spread through contaminated water); (4) delta hepatitis, which occurs only in persons who are already infected with HBV and is caused by the HDV virus; most cases of delta hepatitis occur among people who are frequently exposed to blood and blood products such as persons with hemophilia.

HICP (Health Insurance Continuation Program): A program authorized and primarily funded under Ryan White Part B that makes premium payments, co-payments, deductibles, or risk pool payments on behalf of a client to maintain his/her health insurance coverage.

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

HIV (Human Immunodeficiency Virus): The virus that causes AIDS.

HIV/AIDS Bureau (HAB): The bureau within the Health Resources and Service Administration (HRSA) of the DHHS that is responsible for administering the Ryan White funding. Within HAB, the Division of Service Systems administers Part A, Part B, and the AIDS Drug Assistance Program (ADAP); the Division of Community Based Programs administers Part C, Part D, and the HIV/AIDS Dental Reimbursement Program; and the Division of Training and Technical Assistance administers the AIDS Education and Training Centers (AETC) Program. The Bureau's Office of Science and Epidemiology administers the Special Projects of National Significance (SPNS) Program.

HIV/EIS (HIV Early Intervention Services/Primary Care): Applied in the outpatient setting, HIV/EIS assures a continuum of care which include: (1) identifying persons at risk for HIV infection and offering them counseling, testing, and referral services, and (2) providing lifelong comprehensive primary care for those living with HIV/AIDS.

HIV/AIDS Dental Reimbursement Program: The program within HRSA's HIV/AIDS Bureau Division of Community Based Programs that assists accredited dental schools and post-doctoral dental programs with uncompensated costs incurred in providing oral health treatment to HIV positive patients.

HIV-Related Mortality Data: Statistics that represent deaths caused by HIV infection.

Home- and Community-Based Care: A category of eligible services that States may fund under Ryan White Part B.

Homophobia: An aversion to gay, transgender or homosexual person(s).

HOPWA (Housing Opportunities for Persons With AIDS): A program administered by the U.S. Department of Housing and Urban Development (HUD) which provides funding to support housing for PLWH/A and their families.

HRSA (Health Resources and Services Administration): The DHHS agency that is responsible

for administering the Ryan White Act.

HUD (Department of Housing and Urban Development): The federal agency responsible for administering community development, affordable housing, and other programs including Housing Opportunities for Persons with HIV/AIDS (HOPWA).

IDU/IVDU (Injecting Drug User/Intravenous Drug User): A term used to refer to people who inject drugs directly into their blood streams by using a needle and syringe.

IGA (Intergovernmental Agreement): A written agreement between a governmental agency and an outside agency that provides HIV services.

Immune System: An integrated body system of organs, tissues, and cells within the body that protect it from viruses, bacteria, parasites, and fungi.

Incidence: The number of new cases of a disease that occur during a specified time period.

Incidence Rate: The number of new cases of a disease or condition that occur in a defined population during a specified time period, often expressed per 100,000 population. AIDS rates are often expressed this way.

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

Key Informant Interview: A non-survey information collection method involving in-depth interviews with a small number of individuals carefully selected because of their experiences and/or knowledge related to the topic of interest. An interview guide or checklist is used to guide the discussion. Also called a key person interview.

KS (Kaposi's Sarcoma): A cancer that can involve the skin, mucous membranes, and lymph nodes; appears as grayish purple spots.

Lead Agency: The agency responsible for contract administration; also called a fiscal agent. An incorporated consortium sometimes serves as the lead agency. The lead agency for HOPWA is the City of West Palm Beach, the lead agency for Part B is Treasure Coast Health Council, the lead agency for County Health Department Patient Care and AIDS Network is the Department of Health.

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.*

Lipodystrophy: A disturbance in the way the body produces, uses, and distributes fat. Lipodystrophy is also referred to as "buffalo hump," "protease paunch," or "Crixivan potbelly." In HIV disease, lipodystrophy has come to refer to a group of symptoms that seem to be related to the

use of protease inhibitor drugs. How protease inhibitors may cause or trigger lipodystrophy is not yet known. Lipodystrophy symptoms involve the loss of the thin layer of fat under the skin, making veins seem to protrude; wasting of the face and limbs; and the accumulation of fat on the abdomen (both under the skin and within the abdominal cavity) or between the shoulder blades. Women may also experience narrowing of the hips and enlargement of the breasts.

Macrophage: A type of white blood cell that surrounds and consumes infected cells, disease agents, and dead material.

Maintenance of Effort: The Part A and Part B requirement to maintain expenditures for HIV-related services/activities at a level equal to or exceeding that of the preceding year.

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

Mean: Arithmetic average calculated by adding up all the values or the responses to a particular question and dividing by the number of cases; for example, to determine the mean age of 12 children in a pediatric AIDS program, add up their individual ages and divide by 12.

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

Median: A type of average which calculates the central value, the one that falls in the middle of all the values when they are listed in order from highest to lowest; for example, if the annual incomes of seven families were \$37,231, \$35,554, \$30,896, \$ 27,432, \$24,334, \$19,766, and \$18,564, the median would be \$27,432.

Minority: A racial, religious, political, national or other group regarded as different from the larger group of which it is a part.

Mode: A type of average which identifies the most frequently occurring value; for example, suppose a prevention project included 13 youth of the following ages: 16,16,15,14,14,14,14,13,13,12,12,11,10; the mode would be 14, which occurs four times.

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

Mutation: In biology, a sudden change in a gene or unit of hereditary material that results in a new inheritable characteristic. In higher animals and many higher plants, a mutation may be transmitted to future generations only if it occurs in germ -- or sex cell -- tissue; body cell mutations cannot be inherited. Changes within the chemical structure of single genes may be induced by exposure to radiation, temperature extremes, and certain chemicals. The term mutation may also be used to include losses or rearrangements of segments of chromosomes, the long strands of genes. Mutation, which can establish new traits in a population, is important in evolution. As related to HIV: During the course of HIV disease, HIV strains may emerge in an infected individual that differ widely in

their ability to infect and kill different cell types, as well as in their rate of replication. Of course, HIV does not mutate into another type of virus.

Myopathy: Progressive muscle weakness. Myopathy may arise as a toxic reaction to AZT or as a consequence of the HIV infection itself.

Needs Assessment: A process of obtaining and analyzing findings about the needs of the community. 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 studying the needs of persons with HIV (PLWH) (both those receiving care and those not in care), identifying current resources (Ryan White Act and other) available to meet those needs, and determining what gaps in care exist.

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

NIH (National Institute of Health): The federal agency that includes 24 separate research institutes and centers, among them the National Institute of Allergy and Infectious Diseases, National Institute of Mental Health, and National Institute of Drug Abuse. Within the Office of the NIH Director is the Office of AIDS Research, which is responsible for planning, coordinating, evaluating, and funding all NIH AIDS research.

NGO (Non-Governmental Organization): A private group that is not associated with federal, state, or local agencies; however, they often have 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.

NNRTI (Non-Nucleoside Reverse Transcriptase Inhibitor): The newest class of antiretroviral agents (e.g., delavirdine, nevirapine). NNRTIs stop HIV production by binding directly onto an enzyme (reverse transcriptase) in a CD4+ cell and preventing the conversion of the HIV virus' RNA to DNA.

Nucleoside Analog: Also called NRTI (Nucleoside Reverse Transcriptase Inhibitor) is the first effective class of antiviral drugs (e.g., AZT, ddI, ddC, d4T). NRTIs act by incorporating themselves into the HIV DNA, thereby stopping the building process. The resulting HIV DNA is incomplete and unable to create new virus.

OMB (Office of Management and Budget): The office within the executive branch of the Federal government which prepares the President's annual budget, develops the Federal government's fiscal program, oversees administration of the budget, and reviews government regulations.

Open-Ended Questions: Questions in an interview or survey format that allow those responding to answer as they choose, rather than having to select one of a limited set of predefined alternative responses.

Opportunistic Infection (OI): An infection or cancer that occurs in persons with weak immune systems to fight off bacteria, viruses and microbes due to AIDS, cancer, or immunosuppressive drugs such as corticosteroids or chemotherapy. Kaposi's Sarcoma (KS), pneumocystis pneumonia (PCP), toxoplasmosis, and cytomegalovirus are all examples of opportunistic infections.

OSE (Office of Science and Epidemiology): The office within HRSA's HIV/AIDS Bureau that administers the SPNS Program, HIV/AIDS evaluation studies, and the Annual Administrative Report (AAR).

Over-representation/Under-representation: Term often used to indicate that a particular sub-population makes up a larger proportion- or a smaller proportion - of a particular group than would be expected, given its representation in the total population; for example, Hispanics and African Americans are both over represented among AIDS cases, compared to their percentage in the U.S. population, while Asians/Pacific Islanders are under-represented.

Over-sampling: A procedure in stratified random sampling in which a larger number of individuals from a particular group (or stratum) are selected than would be expected given their representation in the total population being sampled; this is done in order to have enough subjects to permit separate tabulation and analysis of that group; for example, minorities are often over sampled to permit separate analyses of data by racial/ethnic group as well as comparisons among racial/ethnic groups.

Palm Beach County Board of County Commissioners: The PBC Board of County Commissioners is the CEO (grantee) of Ryan White Part A funds.

Palm Beach County Department of Community Services (DCS): The DCS acts as fiscal agent for the PBC Board of County Commissioners and is responsible for the disbursement of Ryan White Part A funds.

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

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

Partner Notification: The confidential process of informing the sexual and needle sharing partners of an HIV infected person that they may also be infected.

Part A: The part of the Ryan White Act that provides emergency assistance to localities (EMAs) disproportionately affected by the HIV epidemic.

Part B: The part of the Ryan White Act that enables States and Territories to improve the quality, availability, and organization of health care and support services to individuals with HIV and their families.

Part C: The part of the Ryan White Act that supports outpatient primary medical care and early intervention services to people living with HIV disease through grants to public and private non-profit organizations.

Part D: The part of the Ryan White Act that supports coordinated services and access to research for children, youth, and women with HIV disease and their families.

Part F: The part of the CARE Act that includes the AETC Program, the SPNS Project, and the HIV/AIDS Dental Reimbursement Program.

PCP (Pneumocystis Carinii Pneumonia): A form of pneumonia caused by a parasite that does not usually cause infection in people with fully functioning immune systems; the leading cause of death in people with AIDS.

Percent: Literally, per hundred; a proportion of the whole, where the whole is 100; the percent is calculated by dividing the part of interest by the whole, and then multiplying by 100; for example, if you want to know what percent of recently reported AIDS cases are women, take the number of women AIDS cases (the part of interest), divide by the number of total AIDS cases (the whole), and multiply by 100; if your community has a total of 70 recently reported AIDS cases and 14 are women, divide 14 by 70 ($=.2$) and multiply by 100, and you get 20%.

Percentage Point: One one-hundredth; term used to describe numerical differences between two percent without comparing relative size; for example, if 16% of AIDS cases are Hispanic and 32% are African American, the difference is 16 percentage points (32 minus 16).

Perinatal: of, involving, or occurring during the period closely surrounding the time of birth.

Phenotypic Assay: A procedure whereby a sample DNA of a patient's HIV is tested against various antiretroviral drugs to see if the virus is susceptible or resistant to these drugs.

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

Planning Council/HIV Health Services Planning Council: A planning body appointed or established by the Chief Elected Official of an EMA whose basic function is to establish a plan for the delivery of HIV care services in the EMA and establish priorities for the use of Ryan White Part A funds.

Planning Process: Steps taken and methods used to collect information, analyze and interpret it, set priorities, and prepare a plan for rational decision making.

Population Count: Data which describe an entire population and were obtained from that entire population without sampling; the U.S. Census conducted every ten years is a population count since it attempts to obtain information from everyone living in the United States.

Prevalence: The total number of persons living with a specific disease or condition in a defined population at a given time (compared to the incidence, which refers to the number of new cases).

Prevalence Rate: The proportion of a population living at a given time with a condition or disease (compared to the incidence rate, which refers to new cases).

Primary Source Data: Original data that you collect and analyze yourself.

Priority Setting: The process used by a planning council or consortium to establish numerical priorities among service categories, to ensure consistency with locally identified needs, and to address how best to meet each priority.

Probability: The likelihood that a particular event or relationship will occur.

Probability Value: The probability that a statistical result- an observed difference or relationship- would have occurred by chance alone, rather than reflecting a real difference or relationship; statistical results are often considered to be significant if the probability, or **p value**, is less than .05, which means that there is less than a 5 % chance - 5 out of 100- that the result would have occurred by chance alone.

Profile of Provider Capability/Capability: A description of the extent to which the various services offered by a network of providers in the service area are available, accessible, and appropriate for PLWH/A, including particular populations.

Procurement: The process of selecting and contracting with providers, often through a competitive RFP process. For Part A, a responsibility of the grantee, not the planning council; for Part B, consortia are sometimes involved.

Prophylaxis: Treatment to prevent the onset of a particular disease (primary prophylaxis) or recurrence of symptoms in an existing infection that has been brought under control (secondary prophylaxis).

Proportion: A number smaller than one, which is calculated by dividing the number of subjects having a certain characteristic by the total number of subjects; for example, if 35 new AIDS cases have been reported in the community in the past year and 7 of them are women, the proportion of female AIDS cases is 7 divided by 35 or $1/5$ (.2).

Protease: An enzyme breaks apart long strands of viral protein into separate proteins constituting the viral core and the enzymes it contains. HIV protease acts as new virus particles are budding off

a cell membrane.

Protease Inhibitor: A drug that binds to and blocks HIV protease from working, thus preventing the production of new functional viral particles.

Public Health Service (PHS): An administrative entity of the U.S. Department of Health and Human Services; until October 1, 1995, HRSA was a division of the PHS.

Public Health Surveillance: An ongoing, systematic process of collecting, analyzing, and using data on specific health conditions and diseases, in order to monitor these health problems, such as the Centers for Disease Control and Prevention surveillance system for AIDS cases.

QA (Quality Assurance): A system of establishing standards and measuring performance in the attainment of those standards and with feedback of results in order to better meet those standards.

QI (Quality Improvement): A system of repetitive analysis of areas of potential improvement, ever increasing standards of performance, measurement of performance, and systems change to improve performance.

Ratio: A combination of two numbers that shows their relative size; the ratio of one number to another is simply the first number divided by the other, with the relation between the two numbers expressed as a fraction (x/y) or decimal ($x:y/1$), or simply the two numbers separated by a colon ($x:y$); for example, the ratio of minority to white pediatric AIDS cases in a community with 75 total cases, 45 among Hispanic and Black children and 30 among white children, would be 45/30 (45:30), $3/2$ (3:2), or 1.5:1.

Raw Data: Data that are in their original form, as collected, and have not been coded or analyzed; for example, if a woman participating in an HIV nutrition workshop is tested to determine her knowledge of nutrition need and gets a score of 11, that is her raw score; if the score represented 11 correct answers out of 20, then the score could be converted to 11 divided by 20 times 100 or 55%, which is not a raw score.

Reliability: The consistency of a measure or question, in obtaining very similar or identical results when used repeatedly; for example, if you repeated a blood test three times of the same blood sample, it would be reliable if it generated the same results each time. For example, a positive HIV test result is reliable because there are three tests on the blood sample.

Representative: Term used to indicate that a sample is similar to the population from which it was drawn, and therefore can be used to make inferences about that population.

Resource Allocation: The legislatively mandated responsibility of planning councils to assign the Ryan White Act funding amounts or percentages to established priorities across specific service categories, geographic areas, populations, or sub-populations.

Retrovirus: A type of virus that, when not infecting a cell, stores its genetic information on a single stranded RNA molecule instead of the more usual double stranded DNA. HIV is an example of a retrovirus. After a retrovirus penetrates a cell, it constructs a DNA version of its genes using a special enzyme, reverse transcriptase. This DNA then becomes part of the cell's genetic material.

Reverse Transcriptase (RT): A uniquely viral enzyme that constructs DNA from an RNA template, which is an essential step in the life cycle of a retrovirus such as HIV. The RNA-based genes of HIV and other retro viruses must be converted to DNA if they are to integrate into the cellular genome.

RFP (Request for Proposal): An open and competitive process for selecting providers of services (sometimes called RFP or Request for Proposal).

Rounding: Presenting numbers in more convenient units; rounding is usually done so that all numbers being compared have the same level of precision (one decimal place, for example); usually numbers under 5 are rounded down while 5 and over are rounded up; for example, you would round 3.08 to 3.1 and 4.14 to 4.1.

Ryan White HIV/AIDS Treatment and Modernization Act: The Federal legislation created to address the health care and service needs of people living with HIV/AIDS (PLWH/As) disease and their families in the United States and its Territories. The Act was enacted in 1990 (Pub. L. 101-381) and reauthorized in 1996, 2001 and 2006.

Salvage Therapy: A treatment effort for people who are not responding to, or cannot tolerate the preferred, recommended treatments for a particular condition. In the context of HIV infection, drug treatments that are used or studied in individuals who have failed one or more HIV drug regimens, including protease inhibitors. In this case failed refers to the inability to achieve or sustain low viral load levels.

SAMs (Self Assessment Modules): Self-assessment tools for planning bodies.

SAMHSA (Substance Abuse and Mental Health Services Administration): The DHHS agency that administers programs in alcohol abuse, substance abuse, and mental health.

Sample: A group of subjects selected from a total population or universe with the expectation that studying the group will provide important information about the total population.

SCSN (Statewide Coordinated Statement of Need): A written statement of need for the entire State developed through a process designed to collaboratively identify significant HIV issues and maximize CARE Act program coordination. The SCSN is legislatively mandated and the process is convened by the Part B grantee, with equal responsibility and input by all programs. Representatives must include all Ryan White Part A, B, C, D and Part F managers, providers, PLWH/As, and public health agency(s).

Secondary Source Data: Information that was collected by someone else, which can be analyze or re-analyze.

Secondary Analysis: Re-analysis of data or other information collected by someone else; for example, you might obtain data on AIDS cases in your metro area from the Centers for Disease Control and Prevention, and carry out some additional analyses of those data.

Serology: The study of blood serum and its component parts; blood serum is the fluid that separates from clotted or blood plasma that is allowed to stand. HIV testing is conducted using blood serum from the person being tested.

Seroconversion: The development of detectable antibodies of HIV in the blood as a result of infection. It normally takes several weeks to several months for antibodies to the virus to develop after HIV transmission. When antibodies of HIV appear in the blood, a person will test positive in the standard ELISA test for HIV. This is also referred to as the “window period”.

Seroprevalence: The number of persons in a defined population who test HIV-population based on HIV testing of blood specimens. (Seroprevalence is often presented as a percent of the total specimens tested or as a rate per 100,000 persons tested.)

Seroprevalence Report: A report that provides information about the percent or rate of people in specific testing groups and populations who have tested positive for HIV.

SPNS (Special Projects of National Significance): A health services demonstration, research, and evaluation program funded under Part F of the Ryan White Act. SPNS projects are awarded competitively.

Statistical Significance: A measure of whether an observed difference or relationship is larger or smaller than would be expected to occur by chance alone; statistical results are often considered to be significant if there is less than a 5% chance -5 out of 100- that they would have occurred by chance alone.

Statistics: Information or data presented in numerical terms; quantitative data; often refers to numerical summaries of data obtained through surveys or analysis.

STD (Sexually Transmitted Disease): Infections spread by the transfer of organisms from person to person during sexual contact. Some examples are, Chlamydia, Syphilis, Gonorrhea, Pubic Lice, Herpes, Human Papilloma virus (warts).

Stratified Random Sample: A random sample drawn after dividing the population being studied into several subgroups or strata based on specific characteristics; subsamples are then drawn separately from each of the strata; for example, the population of a community might be stratified by race/ethnicity before random sampling.

Supplemental Grant Application: An application for funding that supplements the Part A formula grant, and is awarded to EMAs on a competitive bases based on demonstrated need and ability to use and manage the resources.

Surrogate Measures: Substitute measures, used to help understand a situation where adequate direct measures are not available; for example, it may be difficult to obtain good HIV surveillance data on teenagers, but incidence rates of sexually transmitted diseases (STDs) among teenagers can be used as surrogate measures of high-risk sexual behavior, since HIV is an STD, and people get STDs when they engage in unprotected sex.

Surveillance: An ongoing, systematic process of collecting, analyzing, and using data on specific health conditions and diseases (e.g. Centers for Disease Control and Prevention surveillance system for AIDS cases).

Surveillance Reports: Reports providing information on the number of reported cases of a disease such as AIDS, nationally and for specific locations and subpopulations; the Centers for Disease Control and Prevention issues such reports, providing both cumulative cases and new cases reported during a specific reporting period, such as each of the last two years.

Survey: Data collection method in which a number of individuals (often a probability sample) are asked the same set of questions, which are usually largely multiple choice or short-answer, and their responses are tabulated, analyzed, and compared to provide quantitative data about the population surveyed..

Survey Research: Research in which a sample of subjects is drawn from a population and then interviewed or otherwise studied to gain information about the total population from which the sample was drawn.

T-cell: A type of white blood cell essential to the body's immune system; helps regulate the immune system and control B-cell and macrophage functions.

Tabulation of Data: Ordering and counting of quantitative data to determine the frequency of responses, usually the first step in data analysis; typically involves entering data into a computer for manipulation through some form of data analyses program.

Target Population: Populations to be reached through some action or intervention; may refer to groups with specific characteristics (e.g., race/ethnicity, age, gender, socioeconomic status) or to specific geographic areas.

TA (Technical Assistance): Training and skills development, which allows people and groups to perform their jobs better. This includes education and knowledge development in areas that range from leadership and communication to creating an effective needs assessment tool and understanding statistical data.

TOPWA: (Targeted Outreach for Pregnant Women Act): A Florida General Revenue funded HIV prevention intervention project.

Transmission Category: A grouping of disease exposure and infection routes; in relation to HIV disease, exposure groupings include injection drug use, men who have sex with men, heterosexual contact, perinatal transmission, etc.

Trend: Movement in a particular direction in the value of variables over times.

Trend Charts: Line charts which show changes or movement in the values of a particular variable over time; usually, values are recorded periodically as points on a graph, and then connected to show how the values are changing; often used to provide comparisons, such as separate lines showing reported AIDS cases among different population groups over time.

Tuberculosis (TB): A bacterial infection caused by *Mycobacterium tuberculosis*. TB bacteria are spread by airborne droplets expelled from the lungs when a person with active TB coughs, sneezes, or speaks. Exposure to these droplets can lead to infection in the air sacs of the lungs. The immune defenses of healthy people usually prevent TB infection from spreading beyond a very small area of the lungs. If the body's immune system is impaired because of infection with HIV, aging, malnutrition, or other factors, the TB bacterium may begin to spread more widely in the lungs or to other tissues. TB is seen with increasing frequency among persons infected with HIV. Most cases of TB occur in the lungs (pulmonary TB). However, the disease may also occur in the larynx, lymph nodes, brain, kidneys, or bones (extrapulmonary TB). Extrapulmonary TB infections are more common among persons living with HIV. See Multidrug Resistant TB.

Universe: The total population from which a sample is drawn.

Unmet Needs: Service needs of those individuals not currently in care as well as those in care whose needs are only partially met or not being met. Needs might be unmet because available services are either inappropriate for or inaccessible to the target population.

URS (Uniform Reporting System): Data collection system designed by HRSA to document the use of Title I and Title II funds.

Vaccine: A liquid made from modified or denatured viruses or bacteria that is injected in to the body and produces or increases immunity and protection against a particular disease.

Validity: The extent to which a survey question or other measurement instrument actually measures what it is supposed to measure; for example, a question which asks PLWH/A with TB whether they are taking their medication every day is valid if it accurately measures their actual level of medication use (as with directly observed therapy programs in which they are observed taking the medication), and it is not valid if they are not giving honest answers, and the question is really measuring the extent to which they realize that they should take their medication.

Value: Individual response or score; for example, if people responding to a survey are asked to state their age, each age is a value.

Variable: A characteristic or finding that can change or vary among different people or in the same person over time; for example, race/ethnicity varies among individuals, and income varies for the same individual over time.

Viral Load Test: In relation to HIV: Test that measures the quantity of HIV RNA in the blood. Results are expressed as the number of copies per milliliter of blood plasma. This test is employed as a predictor of disease progression and later remission.

Viremia: The presence of virus in blood or blood plasma. Plasma viremia is a quantitative measurement of HIV levels similar to viral load but is accomplished by seeing how much of a patient's plasma is required to spark an HIV infection in a laboratory cell culture.

Virus: Organism composed mainly of nucleic acid within a protein coat, ranging in size from 100 to 2,000 angstroms (unit of length; 1 angstrom is equal to 10⁻¹⁰ meters). When viruses enter a living plant, animal, or bacterial cell, they make use of the host cell's chemical energy and protein -- and nucleic acid -- synthesizing ability to replicate themselves. Nucleic acids in viruses are single stranded or double stranded, and may be DNA (deoxyribonucleic acid; see) or RNA (ribonucleic acid; see). After the infected host cell makes viral components and virus particles are released, the host cell is often dissolved. Some viruses do not kill cells but transform them into a cancerous state; some cause illness and then seem to disappear, while remaining latent and later causing another, sometimes much more severe, form of disease. In humans, viruses cause -- among others -- measles, mumps, yellow fever, poliomyelitis, influenza, and the common cold. Some viral infections can be treated with drugs.

Wasting: Severe loss of weight and muscle, or lean body mass, common among AIDS patients. Leads to muscle weakness, organ failure, tissue swelling, muscle and joint pain and contributes to fatal outcomes.

Weighting: A procedure for adjusting the values of data to reflect each group's percent in the total population; for example, race/ethnicity and oversampled minorities so you could compare findings for each group; in order to combine your findings to describe the entire population, you would weight the data to reflect the percentage of the whole population that comes from each racial/ethnic group.

Western Blot: A test for detecting the specific antibodies to HIV in a person's blood. It is commonly used to verify positive ELISA tests. A Western Blot test is more reliable than the ELISA, but it is harder and more costly to perform. All positive HIV antibody tests should be confirmed with a Western Blot test. Synthetic Peptide test has increased the accuracy of the Western Blot test, inconclusive results are rare.

Wild Type Virus: HIV that has not been exposed to antiviral drugs and therefore has not

accumulated mutations conferring drug resistance.

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ACRONYMS

ADAP- AIDS Drug Assistance Program

AHCA- Agency for Health Care Administration

AICP- AIDS Insurance Continuation Program

AITRP (AIDS International Training and Research Program, FIC)

ATIS (HIV/AIDS Treatment Information Service)

B/START (Behavioral Science Track Award for Rapid Transition, NIMH & NIDA)

CAB (Community Advisory Board)

CAMCODA (Center on AIDS and Other Medical Consequences of Drug Abuse)

CAPS (Center for AIDS Prevention Studies)

CBC (Congressional Black Caucus)

CBO- Community-Based Organization

CDC- Centers for Disease Control

CFAR (Center for AIDS Research)

CMS- Children Medical Services

CMV (Cytomegalovirus)

CNS (Central Nervous System)

CMV (Cytomegalovirus)

CNS (Central Nervous System)

CPP- Community Planning Partnership

CPCRA (Community Program for Clinical Research on AIDS)

CSF (Cerebrospinal Fluid)

CTL (Cytotoxic T Lymphocyte)

DHHS (Department of Health and Human Services)

DOH- Department of Health

DNA (Deoxyribonucleic Acid)

DRG (Division of Research Grants, NIH (now the Center for Scientific Review))

EBV (Epstein-Barr Virus)

FIRCA (Fogarty International Research Collaboration Award, FIC)

FY (Fiscal Year)

GCRC (General Clinical Research Center)

HBCU (Historically Black Colleges and Universities)

HCD (Health Care District)

HHV-8 (Human Herpesvirus-8)

HIVIG (HIV Immunoglobulin)

HPV (Human Papillomavirus)

IDU- Injection Drug User

IHS (Indian Health Service)

IVIG (Intravenous Immunoglobulin)

JCV (JC Virus)

MAC (Mycobacterium Avium Complex)

MAI- Minority AIDS Initiative

MCT (Mother-to-Child Transmission)

NAFEO (National Association for Equal Opportunity in Higher Education)

OAR (Office of AIDS Research, NIH)

OARAC (Office of AIDS Research Advisory Council)

OI (Opportunistic Infection)

PBMC (Peripheral Blood Mononuclear Cell)

PIR: (Parity, Inclusion and Representation)

PLWH/A: (Person(s) Living with HIV/AIDS Disease)

PML (Progressive Multifocal Leukoencephalopathy)

PWA/PLWA (Person With AIDS): A person living with AIDS.

RCMI (Research Center in Minority Institution)

RNA (Ribonucleic Acid)

SCID (Severe Combined Immunodeficiency)

SI (Synctia-Inducing)

SRA (Scientific Review Administration)

STI (Structured Treatment Interruption)

TB- Tuberculosis

TOPWA- Targeted Outreach for Pregnant Women Act

VA (Veterans Administration)

WHO (World Health Organization)

ZDV (Zidovudine)

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