

# **FY 2007 RYAN WHITE NEEDS ASSESSMENT: EXECUTIVE SUMMARY REPORT**

Prepared By



## **The Health Councils, Inc.**

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Adopted September 5, 2007

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## BACKGROUND

The Ryan White Care Council conducts an annual needs assessment for the purpose of gathering service need data. The results are utilized in conjunction with other information to prioritize and allocate Ryan White funding throughout an eight-county service area. Covered counties include Hardee, Hernando, Highlands, Hillsborough, Manatee, Pasco, Pinellas and Polk.

The needs assessment is a three-year process and consists of multiple components updated at periodic intervals. The following components were utilized in the FY2007 assessment and the year the component was completed is noted in parentheses:

- ▶ Case Manager Survey (2005)
- ▶ Client Focus Groups (2006)
- ▶ Client Survey (2004)
- ▶ Epidemiologic Profile (2007)
- ▶ Expert Survey (2005)
- ▶ Funding Stream Analysis (2006)
- ▶ Resource Analysis (2006)

The Client Survey, Case Manager Survey, and Expert Survey will be implemented in the Fall of 2007. Updates are provided in this report only on components that were completed during the last year which include Client Focus Groups, Resource Analysis and Epidemiologic Profile.

## II. METHODOLOGY

The needs assessment utilized a variety of techniques to gather information from relevant sources. The specific methodology for each component of the process completed during the last year is explained below.

### A. Client Focus Groups (2006)

Focus groups were conducted with HIV+ persons in the service area in 2006. The targeted hard-to-reach populations included those that were under-represented in previous surveys and focus groups such as Blacks, rural residents and males. In 2006, the target groups included Hillsborough and Manatee males and rural females.

Members of the Planning and Evaluation Committee were trained to facilitate the groups. Sites for the focus groups were chosen based on their accessibility to clients and included locations such as AIDS service organizations, health

departments and a church. Participants were recruited through one-on-one contact with site staff and with posted announcements explaining the purpose of the groups. Participants were offered travel reimbursement, refreshments and door prizes.

Group facilitators used a standard script designed to identify current and future needs, perceived availability of services, and a prioritization of needs. A participant information sheet was used to collect general demographic data of the participants (i.e., county of residence, gender, age, race and mode of transmission).

A total of twenty persons participated in six groups conducted in Highlands, Hillsborough, Manatee and Polk counties in 2006.

## **B. Epidemiologic Profile (2007)**

The demographics and epidemiology report was completed in 2007. As in the past, the report examined the following demographic characteristics: gender, ethnicity, county of residence, mode of transmission and age at diagnosis (which was converted to current age in 2003 data). Information was broken out by geographic area including Total Service Area (TSA), Eligible Metropolitan Area (EMA) and non-EMA counties. Incidence data was provided to assess the increases and decreases in the epidemic.

Some of the findings of the report indicated that as of December 31, 2006, a total of 6,372 living AIDS cases and 4,343 living HIV cases had been reported for the TSA.

### **Race, Ethnicity and Gender (TSA)**

- Overall, White males accounted for the highest percentage of reported living AIDS cases (42%) followed by Black males (22%) and Black Females (14%). The proportional breakdown among the living HIV cases was: White males 33%, Black males 22%, and Black females 21%.
- Among males, Whites accounted for the highest percentage of reported living AIDS cases (57%) and living HIV cases (51%) followed by Blacks (30% and 34%, respectively) and Hispanics (12% and 13%, respectively).
- Among females, Blacks accounted for 55% of reported living AIDS cases and 58% of living HIV cases. Whites accounted for 30% of AIDS cases and 28% of HIV cases followed by Hispanics (14% and 12%, respectively).

- Overall, MSM (men who have sex with men) transmission accounted for the highest percentage of reported living AIDS and HIV cases (44% and 37%, respectively), followed by heterosexual transmission (26% and 29%, respectively), and intravenous drug use (IDU) at 12% and 10%, respectively.
- Among males, MSM transmission accounted for the largest percentage of reported AIDS and HIV cases (59% and 57%, respectively) followed by risk not specified for HIV (16%) and cases reported as heterosexual transmission for AIDS (14%). Injection Drug Use (IDU) ranked third for AIDS cases (10%) and heterosexual transmission ranked third for HIV (14%).
- For female AIDS and HIV cases, heterosexual transmission ranked highest (62% and 57%, respectively) followed by cases reported as IDU for AIDS (19%) and risk not specified for HIV (27%). Risk not specified ranked third for AIDS cases (15%) and IDU ranked third for HIV (14%).

Attachment 1 provides a synopsis of some additional data captured in the report.

### **C. Resource Analysis (2006)**

Another component of the needs assessment was an analysis of the resources available in the TSA. The purpose of this analysis was to obtain information to help identify services within the continuum of care that may be unable to meet current needs, services that may not exist in certain geographic areas, and services where the number of providers is inadequate or exceeds the need.

The focus of the 2006 analysis was to obtain information on each of the Health Resources and Services Administration (HRSA) service categories. The geographical scope included all eight counties in the TSA.

The rural counties generally had minimal to non-existent public transportation. The large land areas and low population densities of many of these counties make travel to service providers problematic for some clients. The urban counties have bus service, but depending upon where a client lives, it can take several hours to reach a service provider located along a bus line. In addition, crossing county lines for service not readily available in the county of residence can also be problematic.

All counties had at least some services that were available in other languages, primarily Spanish, and all providers can access the state TDD assistance for the speaking and hearing impaired. Creole was available for some services in

areas with concentrations of Haitian populations.

Waiting lists were not indicated for most services, however public housing across all counties indicated waiting lists that are often in excess of one year. The lack of a waiting list should not necessarily be interpreted to mean a service is readily available. Some providers simply do not maintain waiting lists, and access to service may be dependent upon having an acceptable payer source, or in the case of inpatient substance abuse treatment, an available bed.

Most areas also had some services provided after traditional hours (Monday-Friday 8 a.m. to 5 p.m.). Services most likely to have non-traditional hours included ambulatory/outpatient care, case management, counseling and support groups, substance abuse treatment, emergency shelters and food banks. Services less likely to have non-traditional hours included dental, homemaker services, and emergency financial assistance.

### III. RESULTS

#### A. Service Priority Recommendations

The Planning and Evaluation Committee reviewed and accepted each of the components of the FY 2007 Needs Assessment as completed. Because the components used to determine service priorities in previous years had not changed, the Committee reviewed the service priorities that were adopted by Care Council in 2005 and 2006 but did not make changes.

Since the Health Resources and Services Administration (HRSA) has recently published new program service definitions which include a broader range of core services, the committee decided to keep all services in their current priority ranking and designate the services that are core services as opposed to support services. Any new service categories created (home and community-based health services, child care services, and substance abuse services – residential) are not included since there is no data to use in ranking.

The committee recommended that the Care Council adopt the following priority recommendations with core services highlighted:

- 1. Outpatient/Ambulatory Medical Care**
- 2. AIDS Pharmaceutical Assistance (local)**
- 3. Medical Case Management Services (Including treatment adherence)**

4. ***Health Insurance Premium & Cost Sharing Assistance***
5. Medical Transportation
6. Emergency Financial Assistance
7. ***Oral Health Care***
8. ***Mental Health Services***
9. Housing Services
10. Food Bank/ home delivered meals
11. Psychosocial Support Services
12. Rehabilitation Services
13. Legal Services
14. Health Education/Risk Reduction
15. ***Substance Abuse Services (outpatient)***
16. Referral for Health Care/Supportive Services
17. Case Management (non-medical)
18. ***Medical Nutrition Therapy***
19. ***Early Intervention Services***
20. Treatment Adherence Counseling
21. ***Home Health Care***
22. Outreach Services
23. ***Hospice Services***
24. Respite Care
25. Linguistic Services

Mandated Services – HRSA requires that these administrative services be in place to support the local planning effort and to ensure the highest quality services for clients.

26. Quality Management

## **B. Service Barriers**

During the focus groups, clients identified barriers to services and most needed services in the future.

Among the barriers were long waiting periods, lack of specialists for certain services, complex paperwork, lack of public transportation in rural areas, being asked to supply excessive amounts of information, limited availability of housing, fear of discovery of their HIV+ status, and a limited number of culturally appropriate services.

The participants of the focus groups were asked to identify two services most critical to their perceived future needs. The participants selected the following services as most critical.

**TABLE 1**  
**Most Critical Future Service Needs**  
**Rankings and Scores**

<b>Service Category</b>	<b>Ranking</b>	<b>Score</b>
Home Health Care	1	9
Health Insurance	2	8
Housing Assistance	3	4
Emergency Financial Assistance	4	3
Permanency Planning	4	3
Food Bank/Home Delivered Meals/Nutritional Supplements	5	2
Housing Related Services	5	2
Legal Services	5	2
Health Education/Risk Reduction	5	2
Transportation	5	2
Nutritional Counseling	6	1
Mental Health	6	1
Buddy/Companion Services	6	1
Day/Respite Services	6	1

**ATTACHMENT 1**  
**Epidemiology Fact Sheet: As of December 31, 2006**

**Proportions of the TSA's People Living with AIDS Population by County (2006)**

<b>County</b>	<b>County Totals</b>	<b>Male</b>	<b>Female</b>	<b>White</b>	<b>Black</b>	<b>Hispanic</b>
Hardee	1%	<1%	<1%	<1%	<1%	<1%
Hernando	2%	1%	<1%	1%	<1%	<1%
Highlands	1%	<1%	<1%	<1%	<1%	<1%
Hillsborough	44%	32%	12%	18%	18%	7%
Manatee	7%	5%	2%	3%	3%	1%
Pasco	5%	4%	1%	4%	<1%	<1%
Pinellas	28%	22%	6%	18%	8%	2%
Polk	12%	8%	4%	5%	6%	1%
<b>TOTAL</b>	<b>100%</b>	<b>74%</b>	<b>26%</b>	<b>50%</b>	<b>37%</b>	<b>12%</b>

**Proportions of the TSA's People Living with HIV Populations by County (2006)**

<b>County</b>	<b>County Totals</b>	<b>Male</b>	<b>Female</b>	<b>White</b>	<b>Black</b>	<b>Hispanic</b>
Hardee	<1%	<1%	<1%	<1%	<1%	<1%
Hernando	1%	<1%	<1%	<1%	<1%	<1%
Highlands	2%	1%	<1%	<1%	1%	<1%
Hillsborough	46%	29%	16%	16%	22%	7%
Manatee	7%	4%	3%	3%	3%	1%
Pasco	5%	3%	2%	4%	<1%	<1%
Pinellas	28%	20%	8%	15%	10%	2%
Polk	11%	6%	5%	4%	6%	2%
<b>TOTAL</b>	<b>100%</b>	<b>65%</b>	<b>35%</b>	<b>43%</b>	<b>43%</b>	<b>13%</b>

**TSA AIDS Incidence\* by Gender**

	<b>2001</b>	<b>2002</b>	<b>2003</b>	<b>2004</b>	<b>2005</b>	<b>2006</b>
<b>Males</b>	467	475	493	560	491	554
	70%	73%	69%	70%	71%	72%
<b>Females</b>	197	175	218	243	197	218
	30%	27%	31%	30%	29%	28%
<b>TOTAL</b>	664	650	711	803	688	772
	100%	100%	100%	100%	100%	100%

\* Incidence refers to the number of new cases grouped by year.

**TSA AIDS Incidence\* by Race and Ethnicity**

	<b>2001</b>	<b>2002</b>	<b>2003</b>	<b>2004</b>	<b>2005</b>	<b>2006</b>
<b>White</b>	306	247	280	349	300	325
	46%	39%	39%	43%	44%	42%
<b>Black</b>	289	301	314	319	274	310
	44%	46%	44%	40%	40%	40%
<b>Hispanic</b>	61	86	104	121	104	123
	9%	13%	15%	15%	15%	16%
<b>Other</b>	8	16	13	14	10	14
	1%	2%	2%	2%	1%	2%
<b>TOTAL</b>	<b>664</b>	<b>650</b>	<b>711</b>	<b>803</b>	<b>688</b>	<b>772</b>
	100%	100%	100%	100%	100%	100%

\* Incidence refers to the number of new cases grouped by year.

**TSA Cases by Mode of Transmission and Gender (2006)**

	TSA AIDS Cases (#)	TSA AIDS		TSA HIV Cases (#)	TSA HIV	
		Cases	(%)		Cases	(%)
<b>MALES</b>		Total	Gender		Total	Gender
MSM	2756	44%	59%	1596	37%	57%
IDU	464	7%	10%	197	5%	7%
MSM/IDU	323	5%	7%	138	3%	5%
Heterosexual	640	10%	14%	398	9%	14%
Pediatric	N/A	N/A	N/A	N/A	N/A	N/A
Other Identified Risk	61	1%	1%	28	1%	<1%
Risk Not Specified	445	7%	9%	451	10%	16%
<b>TOTAL</b>	<b>4689</b>	<b>74%</b>	<b>100%</b>	<b>2808</b>	<b>65%</b>	<b>100%</b>
<b>FEMALES</b>						
IDU	325	5%	19%	222	5%	14%
Heterosexual	1043	16%	62%	870	20%	57%
Pediatric	N/A	N/A	N/A	<3	<1%	<1%
Other Identified Risk	68	1%	4%	31	<1%	2%
Risk Not Specified	247	4%	15%	411	9%	27%
<b>TOTAL</b>	<b>1683</b>	<b>26%</b>	<b>100%</b>	<b>1535</b>	<b>35%</b>	<b>100%</b>
<b>TOTAL for TSA</b>	<b>6372</b>			<b>4343</b>		

MSM = Men who have sex with men  
IDU = Injecting Drug Use

**TSA HIV/AIDS Cases by Race, Ethnicity and Gender (2006)**

	TSA AIDS Cases (#)	TSA	AIDS	TSA HIV Cases (#)	TSA	HIV
		Cases	(%)		Cases	(%)
<b>MALES</b>		Total	Gender		Total	Gender
White	2668	42%	57%	1433	33%	51%
Black	1401	22%	30%	952	22%	34%
Hispanic	557	9%	12%	371	9%	13%
Other/Unknown	63	1%	1%	52	1%	2%
<b>TOTAL</b>	<b>4689</b>	<b>74%</b>	<b>100%</b>	<b>2808</b>	<b>65%</b>	<b>100%</b>
<b>FEMALES</b>						
White	497	8%	30%	433	10%	28%
Black	931	14%	55%	894	21%	58%
Hispanic	235	4%	14%	184	4%	12%
Other/Unknown	20	<1%	1%	24	<1%	2%
<b>TOTAL</b>	<b>1683</b>	<b>26%</b>	<b>100%</b>	<b>1535</b>	<b>35%</b>	<b>100%</b>
<b>TOTAL for TSA</b>	<b>6372</b>			<b>4343</b>		

Total Service Area includes Hardee, Hernando, Highlands, Hillsborough, Manatee, Pasco, Pinellas and Polk counties

## ATTACHMENT 2

### Ryan White Program Services Definitions

#### CORE SERVICES

##### Service categories:

- a. *Outpatient/Ambulatory medical care (health services)*** is the provision of professional diagnostic and therapeutic services rendered by a physician, physician's assistant, clinical nurse specialist, 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 include 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. *AIDS Drug Assistance Program (ADAP treatments)*** is a State-administered program authorized under Part B of the Ryan White Program that provides FDA-approved medications to low-income individuals with HIV disease who have limited or no coverage from private insurance, Medicaid, or Medicare.
- c. *AIDS Pharmaceutical Assistance (local)*** includes local pharmacy assistance programs implemented by Part A or Part B Grantees to provide HIV/AIDS medications to clients. This assistance can be funded with Part A grant funds and/or Part B base award funds. Local pharmacy assistance programs are **not** funded with ADAP earmark funding.
- d. *Oral health care*** includes diagnostic, preventive, and therapeutic services provided by general dental practitioners, dental specialists, dental hygienists and auxiliaries, and other trained primary care providers.
- e. *Early intervention services (EIS)*** include 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.

NOTE: EIS provided by Ryan White Part C and Part D Programs should NOT be reported here. Part C and Part D EIS should be included under *Outpatient/Ambulatory medical care*.

- f. *Health Insurance Premium & Cost Sharing Assistance*** is the 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.
- g. *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.
- h. *Home and Community-based Health Services*** include 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.
- i. *Hospice services*** include 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.
- j. *Mental health services*** are 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.
- k. *Medical nutrition therapy*** is 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.
- l. *Medical Case management services (including treatment adherence)*** are 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.

- m. *Substance abuse services outpatient*** is the 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

- n.** 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.
- o.** *Child care services* are the 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.
- p.** *Pediatric developmental assessment and early intervention services* are the provision of professional early interventions by physicians, developmental psychologists, educators, and others in the psychosocial and intellectual development of infants and children. These services involve the assessment of an infant's or child's developmental status and needs in relation to the involvement with the education system, including early assessment of educational intervention services. It includes comprehensive assessment of infants and children, taking into account the effects of chronic conditions associated with HIV, drug exposure, and other factors. Provision of information about access to Head Start services, appropriate educational settings for HIV-affected clients, and education/assistance to schools should also be reported in this category.

- q.** *Emergency financial assistance* is the 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).

- r.** *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.
- s.** *Health education/risk reduction* is the 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.
- t.** *Housing services* are the 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.
- u.** *Legal services* are the 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.
- v.** *Linguistics services* include the provision of interpretation and translation services.
- w.** Medical transportation services include conveyance services provided, directly or through voucher, to a client so that he or she may access health care services.
- x.** *Outreach services* are 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.

- y.** *Permanency planning* is the provision of services to help clients or families make decisions about placement and care of minor children after the parents/caregivers are deceased or are no longer able to care for them.
- z.** *Psychosocial support services* are the 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.
- aa.** *Referral for health care/supportive services* is 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.
- ab.** *Rehabilitation services* are 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.
- ac.** *Respite care* is the 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.
- ad.** *Substance abuse services—residential* is the provision of treatment to address substance abuse problems (including alcohol and/or legal and illegal drugs) in a residential health service setting (short-term).
- ae.** *Treatment adherence counseling* is the 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.

## **ACKNOWLEDGMENTS**

The Ryan White Care Council wishes to recognize the contributions of the

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### **Combined Epidemiologic Profile**

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