# The 2009 Memphis TGA Ryan White HIV/AIDS Care Needs Assessment

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# Executive Summary

## Research Design

- This year's assessment emphasizes the importance of 1) documenting and analyzing unmet need, 2) directly involving consumers in the planning and implementation of the needs assessment, and 3) organizing and reporting findings in a more easily understood format based on HRSA recommendations.

- Several research methodologies were used to collect data for this needs assessment: 1) a self administered survey for PLWHA who are both in-care (N=280) and not-in-care (N=56); 2) an online provider survey administered to Ryan White (N=8) and non-Ryan White (N=9) area providers; 3) two focus groups completed with male and female PLWHA who are parents; and 4) a secondary analysis of several data sources provided by the Tennessee, Arkansas and Mississippi Health Departments and the Memphis TGA Part A program director.

## Epidemiological Profile

**Number Totals for All 8 Counties in Memphis TGA in 2008**

| *HIV/AIDS Incidence (2008)* [1] | *HIV/AIDS Prevalence (2008)* [2] | *AIDS Incidence (2008)* | *AIDS Prevalence (2008)* | *Cumulative Deaths among PLWHA (2008)* | *Number of PLWHA (2008)* |
|---|---|---|---|---|---|
| 499 | 9,163 | 98 | 3,410 | 2,599 | 6,653 |

- HIV/AIDS incidence, AIDS only incidence, and number of HIV/AIDS deaths decreased in 2008. In 2008 there were 435 newly reported cases of HIV/AIDS in Shelby County, which is 9% lower than HIV incidence in 2007 (479 cases).

- AIDS only incidence has continually declined each year since 2005, and this decline was especially significant in 2008. In 2008 AIDS only incidence in Shelby County declined 50% from 190 cases in 2007 to 95 cases (2008). AIDS only incidence in Shelby County has declined 71% since 2005.

[1] "Incidence" refers to the number of disease cases reported within a specific time period, usually one year. The HIV/AIDS and AIDS (only) incidence figures reported here are for the year ending 12/31/2008.
[2] "Prevalence" is used here in the strict sense of the term and refers to the total number of disease cases ever reported (since cases first became reportable) without adjustments for deaths or relocation. The prevalence totals reported here are for all (cumulative) cases ever reported as of 12/31/2008.

- Number of deaths attributed to HIV/AIDS has declined consistently in Shelby County since 2005. Deaths decreased by 50% between 2007 and 2008 in Shelby County.

- The highest percentage of newly reported cases was among African Americans (88% or 382 cases), followed by Caucasians (8% or 36 cases), and then Hispanics (4% or 17 cases). However, the 17 cases among Hispanics is by far the highest number of new HIV/AIDS cases ever reported for this ethnic group in Shelby County. In 2007 only 2 cases were reported among Hispanics in Shelby County.

- Despite the fact that HIV/AIDS incidence decreased overall by 9% in Shelby County in 2008, incidence increased among 15-24 year olds (while decreasing among 25-44 year olds). Incidence among 15-24 year olds continued to increase steadily for the fifth straight year.

- HIV/AIDS incidence in Shelby County was highest among African-American males (86% or 262 cases) and lowest among white females (5% or 6 cases).

- In 2008 there were 34 new cases of HIV/AIDS reported in the four Northern Mississippi counties included in the Memphis TGA. 68% of these cases were in De Soto County, and all but 2 of these 23 cases were among African Americans. Incidence in De Soto is unique compared to incidence in the other three counties, where cases are much more evenly distributed among African Americans and Caucasians.

## Assessment of Service Needs & Gaps

- Dental care/oral health (42%), utility assistance (37%) and emergency housing (30%) are the services most frequently reported as "needed but not received" reported by consumers in-care with no history of uninterrupted care. When the frequency of "total need" is taken into consideration, emergency housing is the most frequently reported unmet need among these consumers. In addition to emergency housing, respite care, utility assistance and hospice care are the services least likely to be received by in-care consumers reporting a need for such services.

- Consumers who have experienced an interruption in care during the past five years report significantly higher numbers of service needs compared to consumers who do not report interruptions in their HIV medical care. Emergency housing (59%) and utility assistance (59%) are the most frequently reported services that are "needed but not received," followed by dental care/oral health (58%), support group (50%) and non-medical case management (50%). The need for emergency housing and utility assistance among these consumers is approximately *twice* that reported by consumers who have not experienced interruptions in their HIV care.

- The services most frequently reported as "needed and not received" by PLWHA who are not-in-care are dental care/oral health (46%), nutritional therapy (42%), support group (42%), transportation to medical care (36%) and emergency housing (35%). When the degree of "total need" is taken into consideration, emergency housing (90%), nutritional therapy, (74%) outpatient (67%) and residential (62%) drug and alcohol treatment, and support group (60%), are the most frequently reported unmet service needs among not-in-care PLWHA.

- A framework for estimating service gaps is developed in this assessment that uses self-reported consumer data and service utilization data reported from the Memphis TGA to HRSA. According to the framework based estimation of service gaps, the largest service gap is for emergency housing (70%), followed by utility assistance (66%), alcohol and drug outpatient treatment (64%), treatment adherence (58%), medical nutritional therapy (52%), medical transportation (47%) and psychosocial services (45%).

- Survey data collected from consumers with a history of interrupted care (N=81) show that denial, substance use, fear of disclosure and homelessness are the most frequently reported barriers to care. Becoming sick (39%), becoming emotionally ready to deal with illness (34%) and having someone else with HIV/AIDS reach out and help individual get into care (32%) are the most frequently reported reasons as to how consumers were able to get into, or return to, care. This finding underscores the importance of psychosocial support and outreach for addressing unmet need.

## Resource Inventory

- 75% of the non-Ryan White providers responding to an online survey (N=9) reported that their agency is operating below full capacity. 50% of the respondents indicated that their agency would consider applying for Ryan White funding, and 80% of the respondents reported that their agency would be more likely to apply for Ryan White funding if free technical assistance were provided in support the grant application process.

## Provider Capacity and Capabilities

- Responses to an online survey completed by eight Ryan White Memphis TGA providers indicate the need to increase their capacity to provide services (N=8). 50% report that they are presently serving more consumers than they are designed or staffed to serve and 37% report that they are presently at full capacity. Only one of theses providers reports being below full capacity.

- Respondents identified the following factors that undermine client accessibility to services: transportation (67.5%), insufficient staff size (50%), missed appointments (50%), homelessness, substance abuse, and cultural differences (37.5% each).

- Only one Ryan White provider reports having weekend or evening hours.

- Only one provider (a non-medical service provider) is located in Northern Mississippi, and no providers are located in Fayette or Tipton Counties. In short, with the exception of Crittenden County, Arkansas, accessibility is a significant problem in the rural counties that are part of the Memphis TGA.

- 25% of the providers try to hire staff members who speak languages other than English. 75% of the providers ensure that translators are available to clients when needed, and 37.5% of the providers provide patient information materials that are translated into different languages. One provider reports that even though her organization provides translators when services are being provided, language barriers continue to be a barrier to appointment scheduling.

- One provider mentioned that the limited number of specialty providers makes it difficult to provide services to all patients.

## Estimation and Assessment of Unmet Need

- Unmet need (number of identified PLWHA who are not-in-care) was estimated by using a modified version of the framework for estimating unmet need developed by researchers at the University of California at San Francisco and recommended by HRSA. According to the unmet need framework used in this study it is estimated that 3,582 PLWHA (54%) were not-in-care in the Memphis TGA in 2008. This figure is somewhat higher than estimates reported in other Ryan White program areas such as St. Louis, MO, and urban areas of Michigan.

- Assessment of barriers to care for PLWHA who are not-in-care was completed by analyzing responses collected through the PLWHA not-in-care survey (N=56). Denial, substance use, fear of disclosure and homelessness are the most frequently reported barriers to care identified by PLWHA who have experienced interruptions in their HIV medical care. 27% of these PLWHA report that not being "ready to deal with HIV status" (a form of denial) is a barrier to getting into care. Fear of "being identified as HIV positive" (18%), or fear of disclosure, is the second most frequently reported barrier to being in care. 12% report that drug or alcohol use is a barrier to getting into care, and 11% identified homelessness as a barrier to getting into care.

- PLWHA who are out of care were asked how they were able to get into care, or return to care, in the past. Receiving information about getting into care (14%), having someone else with HIV/AIDS reach out and help individual get into care (12%), or being contacted by someone involved in the individual's past care (9%) were the most frequently reported reasons as to how consumers were able to get into, or return to, care. This finding underscores the importance of outreach for addressing unmet need.

# I. Introduction

## Definition and Purpose of the Needs Assessment[3]

The Human Resources Services Administration (HRSA) defines a Ryan White Care Needs Assessment as a systemic process used to 1) collect and analyze information about the number, characteristics, and needs of PLWHA in and out of care, 2) determine unmet needs and service gaps and 3) identify current resources available to meet needs and service gaps. The primary purpose of this needs assessment is to provide the Planning Council (Ryan White Part A) and Mid-South Coalition on HIV/AIDS (Ryan White Part B) with a valid information base in support of planning and decision making related to priority setting and resource allocations.

In addition to meeting the legislative requirements for evidence based planning and decision making, HRSA expects the needs assessment to involve a collaborative partnership lead by the Part A and B planning bodies in coordination with the grantee, the community, and Ryan White consumers. HRSA also expects members of the planning bodies to be comfortable reviewing, critiquing and applying needs assessment data and reports. For this reason it is important that the analysis and presentation of needs assessment data be conducted in a manner understandable by a diverse group of individuals including professionals, non-professionals and consumers.

The data collected and presented in the needs assessment should support a range of planning body activities including comprehensive planning, priority setting, resource allocations, the development of local directives and reviewing and improving the continuum of care.

## Guidelines for Conducting the Needs Assessment

HRSA recommends that the needs assessment utilize both qualitative and quantitative data collected through a variety of research methods such as surveys, interviews, focus groups, and the analysis of existing data (for example, epidemiological data provided by state health departments, service utilization data provided by providers, etc.). The specific research methods used to collect data are determined by the needs assessment committees of the planning bodies and may vary from year to year. Data collected from PLWHA and consumers should reflect the demographic and geographic diversity of the population. Regardless of the particular research methods used to collect data for the needs assessment the assessment should provide solid information in five data areas. These five data areas are summarized in the table below accompanied by a description of the purpose and basic questions addressed by each component.

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[3] This description of the purpose and definition of the needs assessment is based on a review of HRSA technical assistance documents and an interpretation of HRSA needs assessment policy provided in a presentation by Emily Gantz McKay of Mosaica, Inc. I am especially grateful to Ms. Gantz McKay for the consultations she provided during a technical assistance meeting that took place in Memphis, TN, in December 2008.

**Table 1. Description of the Five Parts of a Ryan White Care Needs Assessment[4]**

| *Needs Assessment Component* | *HRSA Description of Needs Assessment Component* | *Basic Questions Addressed by Needs Assessment Component* |
|---|---|---|
| **Epidemiological Profile** | *Information on the number and characteristics of people in your service area who have been diagnosed with HIV or AIDS.* | HIV/AIDS Incidence and prevalence; how many PLWHA; who are they and where do they live? What are the trends and population changes? |
| **Assessment of Service Needs & Gaps** | *Information about the service needs of people with HIV/AIDS, barriers to obtaining these services, and types and extent of needs that are not being met.* | What services do PLWHA need; are these services available; are PLWHA accessing these services; what barriers exist? |
| **Resource Inventory** | *A listing and description of the providers of HIV-related services in the service area, what types of services they provide, where, and to whom.* | Who provides HIV-related services? What types of services do they provide: what, where, when, and to whom? Include Ryan White and non-Ryan White providers |
| **Profile of Provider Capacity and Capabilities** | *Information on the capacity of service providers in the service area to meet the needs of PLWHA, including the extent to which services are available, accessible, and appropriate to PLWHA overall and to specific population groups.* | How *available* are services; are there wait lists? Are services *accessible* (schedule, transportation, etc.)? How *appropriate* are the services given PLWHA diversity (racial, cultural, linguistic, sexual identity, etc.)? |
| **Estimate and Assessment of Unmet Need** | *The estimated number of people in the service area who know they are HIV-positive but are not receiving regular HIV-related primary medical care, and assessment of their characteristics, service needs, gaps and barriers to care.* | How many PLWHA are not in care? Who are they?<br>Where do they live?<br>Why are they not in care?<br>What are their primary care needs and service gaps? |

[4] This description of the purpose and definition of the needs assessment is based on a review of HRSA technical assistance documents and an interpretation of HRSA needs assessment policy provided in a local technical assistance meeting with Mosaica, Inc. in December 2008.

## Changes Made to the Memphis TGA Needs Assessment Process

As a result of technical assistance provided by HRSA to the planning bodies and needs assessment consultant this year's Memphis TGA needs assessment has been significantly changed. In contrast to past area assessments, this year's assessment emphasizes the importance of 1) documenting and analyzing unmet need, 2) directly involving consumers in the planning and implementation of the needs assessment, and 3) organizing and reporting findings in a more easily understood format.

In the past the Memphis area needs assessment focused primarily on the service needs and gaps of consumers (in care PLWHA), and failed to address the importance of documenting and analyzing *unmet need*, that is, the subpopulation of identified PLWHA who are not receiving primary HIV medical care. With the encouragement of the HRSA consultant, the support of the Part A and B planning bodies and needs assessment committees, and the assistance of consumer volunteers, this needs assessment involves a fairly comprehensive assessment of unmet need.

Perhaps the most important change to the Memphis needs assessment process is the involvement of consumers in the collection of needs assessment data. In order to identify and administer surveys to PLWHA who are not in care a strategy was developed that involved recruiting and training consumer volunteers to distribute surveys to out of care PLWHA in the community. This strategy proved to be enormously successful and it recommends itself as a practice worthy of replication and expansion in future needs assessments.

The technical assistance provided by HRSA has also resulted in a fundamental re-design in the organizational format and presentation style of the needs assessment report. This new report format is organized according to the five research components (epidemiological profile, assessment of service needs and gaps, resource inventory, profile of provider capacity and capabilities, and an estimate and assessment of unmet need) and directly focuses on answering the basic questions raised by each of these needs assessment components (as outlined in table 1, page 7).

## Research Design

Several research methodologies were used to collect data for this needs assessment: 1) a self administered survey for PLWHA who are both in-care (N=280) and not-in-care (N=56), 2) a self-administered provider survey administered to Ryan White and non-Ryan White area providers (N=17), 3) two focus groups completed with male and female PLWHA who are parents, and 4) a secondary analysis of several data sources provided by the Tennessee, Arkansas and Mississippi Health Departments and the Memphis TGA Part A program director.

A self-administered survey was developed with the assistance of the needs assessment committees of the Planning Council (Part A) and the Mid-South Coalition on HIV/AIDS (Part B). The survey is essentially a condensed version of the consumer interview survey

that has been used in past years to document needed services and service gaps.[5] The survey also includes several items on barriers to care and factors associated with returning to care.[6]

Two versions of the self-administered survey were distributed to PLWHA in the Memphis TGA. One version was designed to be completed by in-care consumers, and this version was self-administered by consumers when they accessed services at Ryan White funded provider sites. When consumers required assistance in completing the survey help was provided to them by staff or volunteers. Two hundred and forty-one (241) of these surveys were completed throughout the Memphis TGA in the spring of 2009.

A second version of the survey was designed to be completed by PLWHA who are not-in-care. This version was distributed to PLWHA by a team of 12 consumer volunteers who received training in the methods and ethics of community based survey research. Ninety four of these surveys were completed by PLWHA in Memphis in the spring of 2009. Copies of both surveys, and the training curriculum completed by the consumer volunteers, are included in Appendix A.

A self-administered, online surveys was developed to collect data from service providers. Eight (8) Memphis area Ryan White providers completed the online survey designed specifically for Ryan White providers, and nine (9) non-Ryan White providers completed the online survey designed for non-Ryan White providers. The non-Ryan White provider survey included question regarding the provider's interest in applying for Ryan White funds and perceived barriers to doing so.

The needs assessment work plan called for conducting focus groups with male and female PLWHA who are not-in-care, and male and female PLWHA who are parents. The team of consumer volunteers that so successfully distributed self-administered surveys to PLWHA who are out of care were asked to recruit participants from the pool of individuals they to whom they had distributed surveys. The idea was that convening a focus group with these individuals would allow more in depth discussion and analysis of the needs and barriers identified by them in the survey. Unfortunately, despite the best efforts of the consumer volunteers none of the individuals whom they invited agreed to participate. Volunteers and members of the needs assessment committees of the Planning Council and the Mid-South Coalition on HIV/AIDS agreed that fear of disclosure and stigma are significant barriers to conducting focus groups with PLWHA who are not-in-care. It was decided that a more viable strategy to gather in-depth information from this population would be to conduct one-on-one, in-depth interviews with individuals from this population in future needs assessments.

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[5] The new survey was designed to be self-administered by consumers and PLWHA and, on the recommendation of the HRSA consultant, only included questions directly related to the service categories funded by Ryan White Part A and Part B. Two versions of the survey were designed. One version was designed to be administered to in-care Ryan White consumers; the other version was designed to be administered to PLWHA who are not-in-care. Copies of both surveys are included in the appendix.

[6] These survey items were adopted from survey materials provided by the HRSA consultant.

Two focus groups were conducted with male and female PLWHA who are parents and issues specific to parenting and its impact on adherence were discussed in depth (12 males participated in one focus group and six females participated in the other group).

As in year's past, epidemiological data were provided for this needs assessment buy the State Health Departments of Tennessee, Arkansas and Mississippi. Shanell McGoy of the Memphis, Shelby County Health Department served as a liaison to the state health departments and overcame several barriers in order to secure accurate 2008 epidemiological data in the format requested.

An important addition to this year's needs assessment is an analysis of the Ryan White provider report (RDR) that provides detailed information on the number of unduplicated consumers who received services in 2008. These data allowed for the computation of the "unmet need" framework (see table 32 on page 71) and an evidence-based estimate of specific service gaps (see table 25 on page 64).

**Sampling and Data Limitations**

HRSA emphasizes the importance of the representativeness of data used in needs assessments. Survey data, for example, should be collected from all segments of the population of PLWHA in the Memphis TGA and effort should be made to collect samples that approximate the demographic composition of the PLWHA. This means that survey samples should approximate the racial/ethnic, sex and geographic makeup of the PLWHA population.

The convenience survey sample of PLWHA in-care (N=280) closely resembles the racial/ethnic, sex and geographic composition of the PLWHA population in the Memphis TGA. This is not the case, however, regarding the survey sample of PLWHA not-in-care (N=56). This sample over-represents African Americans and residents of Shelby County. Tables 2-4 illustrate the relationship between these samples and the actual population of PLWHA in the Memphis TGA. The main limitation of the survey sample of PLWHA who are not-in-care is that, with the exception of one PLWHA from Crittenden County, it only includes residents of Shelby County. In the future effort should be made to complete surveys with PLWHA from the rural counties in Tennessee and Northern Mississippi.

Another limitation of the data used in this evaluation is the low participation rate of non-Ryan White providers in the provider survey. Effort was made to contact 71 non-Ryan White providers using contact information provided in the resource directory developed by the Community Network. 23 providers were reached by phone and were asked to participate in the online survey. Nine (9) of these providers completed the online survey. Effort should be made to recruit a higher percentage of non-Ryan White providers to participate in future needs assessment surveys.

**Table 2. Comparison of the Demographic Profile of PLWHA in the Memphis TGA in 2008 to Convenience Samples of PLWHA Survey Respondents.**

| **Sex** | Percentage of identified PLWHA living in Memphis TGA in 2008 | Percentage of respondents to consumer (in-care) survey (N=280) | Percentage of respondents to PLWHA not-in-care survey (N=56) |
|---|---|---|---|
| Male | 68% | 65% | 65% |
| Female | 32% | 33% | 35% |
| Transgendered | NR[7] | 2% | --- |
| Total | 100% | 100% | 100% |
| **Race/ethnicity** | | | |
| African American | 84% | 88% | 98% |
| Caucasian | 15% | 10% | 2% |
| Hispanic | 1% | 1% | --- |
| Total | 100% | 100%[8] | 100% |
| **Geographic location within Memphis TGA** | | | |
| Shelby County, TN | 89% | 96% | 98% |
| Tipton County, TN | 1% | 1% | --- |
| Fayette County, TN | <1% | 1% | --- |
| Crittenden County, AR | 3% | 1% | 2% |
| Northern MS (De Soto, Marshall, Tate and Tunica Counties) | 5% | 1% | --- |
| Total | 100% | 100% | 100% |

[7] The epidemiological data provided by the State Health Departments of Tennessee, Arkansas, and Mississippi do not include summary data on transgendered PLWHA.
[8] Figures in this column do not equal 100% due to rounding.

# II. Epidemiological Profile

HRSA requires Ryan White programs to compile an epidemiological profile that describes HIV/AIDS incidence, prevalence, trends and population changes. The epidemiological profile aims to inform us regarding how many people are living with HIV/AIDS in the Memphis TGA, who they are demographically (in terms of race/ethnicity, sex and age) and where they live throughout the 8 county grant area. Table 1 (below) summarizes the most recently available epidemiological HIV/AIDS data for the counties comprising the Memphis Transitional Grant Area for 2008.[9]
The table summarizes the preliminary epidemiological data provided by the Tennessee, Mississippi and Arkansas State Health Departments as of 12/31/2008.

**Table 3. Summary of 2008 Epidemiological Data for 8 Memphis TGA Counties**

| ***County/Sub-region*** | ***HIV/AIDS Incidence (2008)*** [10] | ***HIV/AIDS Prevalence (2008)*** [11] | ***AIDS Incidence (2008)*** | ***AIDS Prevalence (2008)*** | ***Cumulative Deaths among PLWHA (2008)*** | ***Number of PLWHA (2008)*** |
|---|---|---|---|---|---|---|
| Crittenden County | 16 (3%) | 297 (3%) | 0 | 85 (2%) | 83 (3%) | 214 (3%) |
| De Soto County | 23 (5%) | 230 (2.5%) | 0 | 97 (3%) | 62 (2%) | 238 (4%) |
| Fayette County | 9 (2%) | 66 (1%) | 0 | 24 (<1%) | 22 (<1%) | 44 (<1%) |
| Marshall County | NR (<1%) | 81 (1%) | 0 | 29 (<1%) | 31 (1%) | 52 (<1%) |
| Shelby County | 435 (88%) | 8,272 (90%) | 95 (97%) | 3,072 (90%) | 2,323 (89%) | 5,949 (89%) |
| Tate County | NR (<1%) | 36 (<1%) | 0 | 21 (<1%) | 16 (<1%) | 29 (<1%) |
| Tipton County | 5 (1%) | 107 (1%) | NR | 46 (1%) | 33 (1%) | 74 (1%) |
| Tunica County | 5 (1%) | 74 (1%) | 0 | 36 (1%) | 29 (1%) | 53 (<1%) |
| Totals | 499 (100%) | 9,163 (100%) | 98 (100%) | 3,410 (100%) | 2,599 (100%) | 6,653 (100%) |

[9] These data were made available relatively early in the reporting cycle and are *preliminary* and subject to revision.
[10] "Incidence" refers to the number of disease cases reported within a specific time period, usually one year. The HIV/AIDS and AIDS (only) incidence figures reported here are for the year ending 12/31/2008.
[11] "Prevalence" is used here in the strict sense of the term and refers to the total number of disease cases ever reported (since cases first became reportable) without adjustments for deaths or relocation. The prevalence totals reported here are for all (cumulative) cases ever reported within a specified area as of 12/31/2008.

## HIV/AIDS Incidence in Shelby County

In 2008 there were 435 newly reported cases of HIV/AIDS in Shelby County. This number is 9% lower than HIV incidence in 2007, when 479 new cases were reported in Shelby County. Figure 1 (below) shows that 131 cases (30%) were among females and 304 cases (70%) were reported among males.

**Figure 1.**

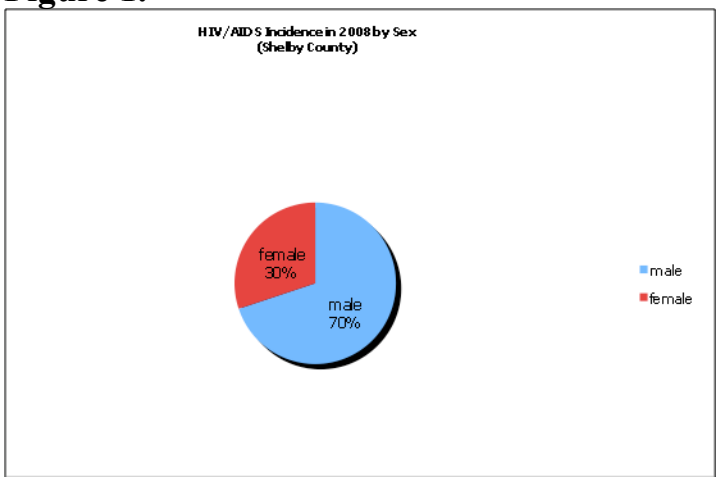



Figure 2 shows the incidence of new HIV cases in 2008 in Shelby County according to race/ethnicity. The highest percentage of newly reported cases was among African Americans (88% or 382 cases), followed by Caucasians (8% or 36 cases), and then Hispanics (4% or 17 cases). However, the 17 cases among Hispanics is by far the highest number of new HIV/AIDS cases ever reported for this ethnic group in Shelby County. In 2007 only 2 cases were reported among Hispanics in Shelby County.

**Figure 2.**

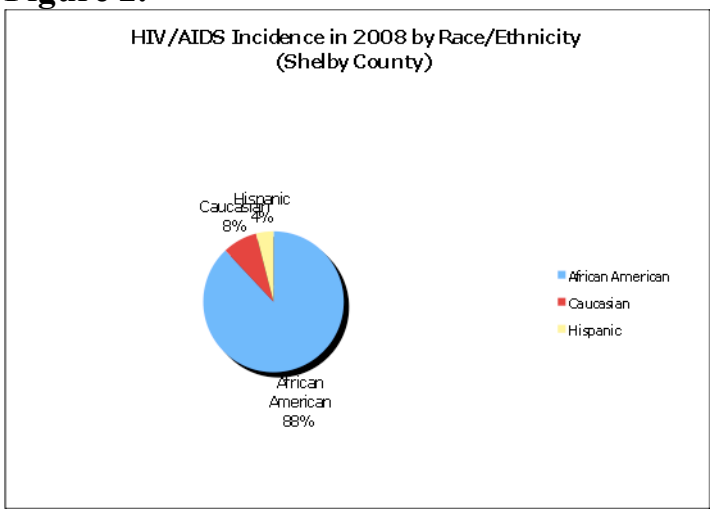


Figure 3 illustrates HIV incidence in 2008 in Shelby County according to sex and race/ethnicity. Incidence was highest among African-American males (86% or 262 cases) and lowest among white females (5% or 6 cases).

**Figure 3.**

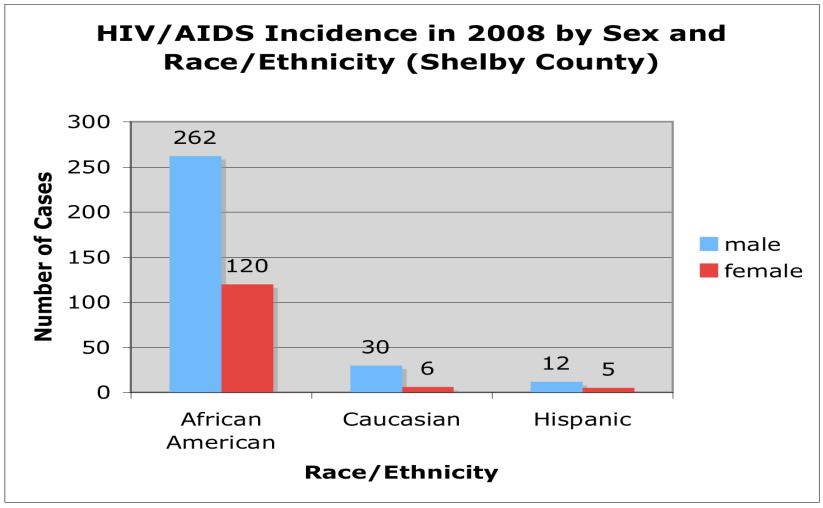



Figure 4 shows the incidence of new HIV cases in Shelby County in 2008 by age. Incidence was highest among 25-34 year olds (29% or 127 cases), followed by 15-24 year olds (26% or 114 cases) and 35-44 year olds (21% or 92 cases). However, despite the fact that HIV/AIDS incidence decreased overall by 9% in Shelby County in 2008, incidence increased among 15-24 year olds while decreasing among 25-44 year olds. (In 2007 there were 113 newly reported HIV/AIDS cases among 15-24 year olds, which amounted to 24% of total HIV/AIDS incidence in 2007.)

**Figure 4.**

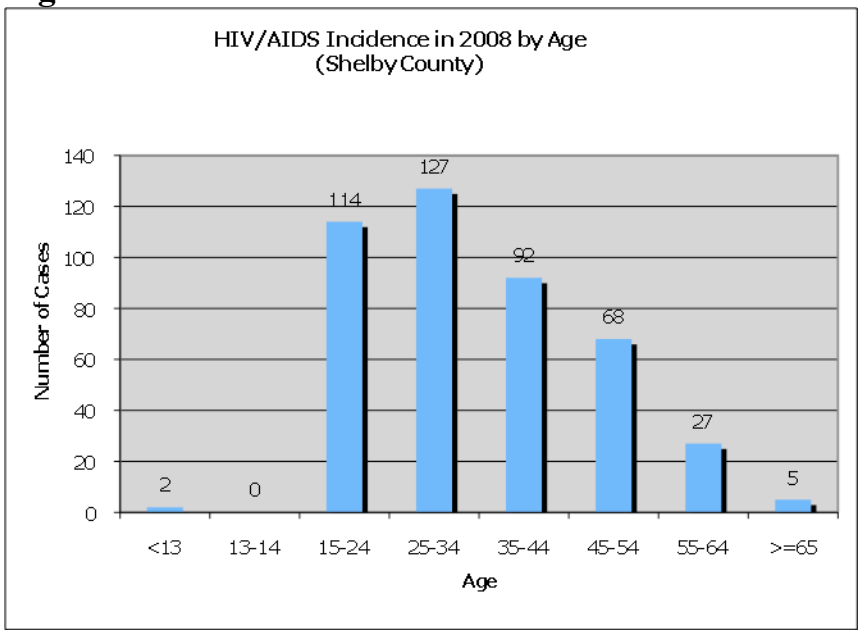


Figure 5 presents HIV/AIDS incidence in 2008 by age and sex. The largest subgroup affected by HIV is males aged 15-24 (20% of the total number of cases or 87 cases). In 2008 males account for 76% (87 cases) of all new cases reported among 15-24 year olds. 25-34 year old males account for 19.5% (85 cases) of all cases reported in 2008, followed by males aged 35-44 (14.7% or 64 cases). Males aged 45-54 account for 10.8% of incidence (47 cases), followed by females aged 25-34 (9.7% or 42 cases), females aged 35-44 (6.4% or 28 cases), and females aged 15-24 (6.2% or 27 cases).

**Figure 5.**

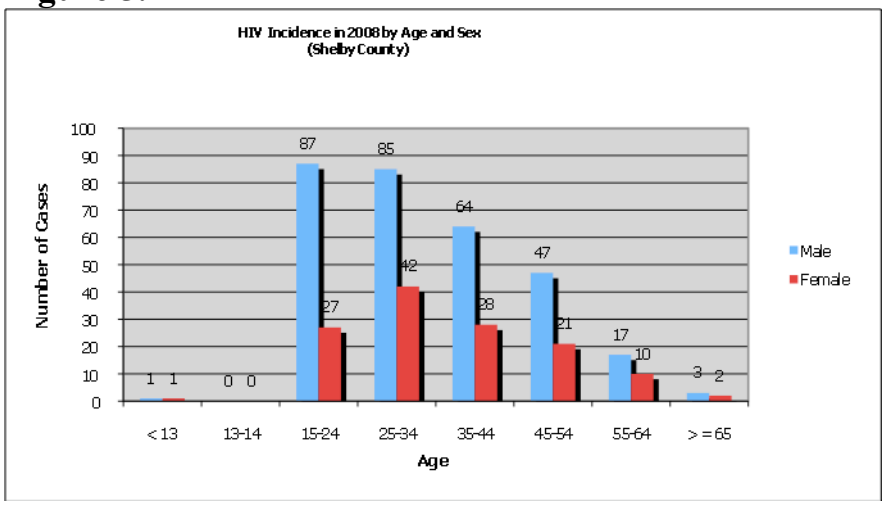
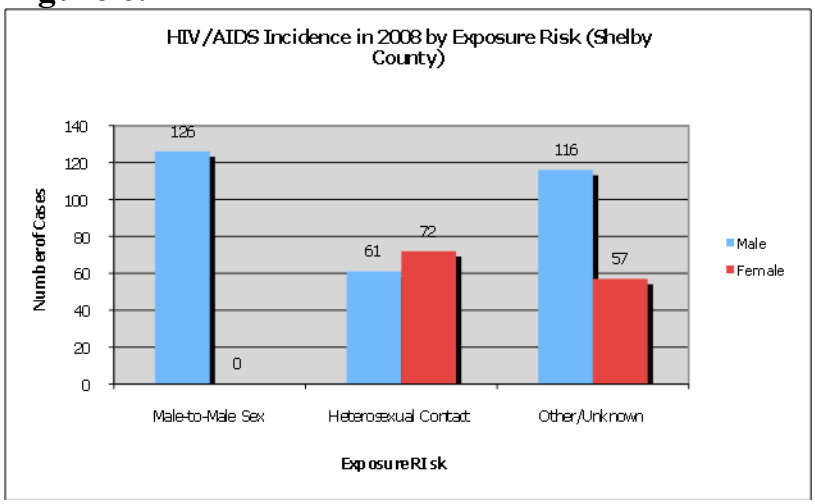



Figure 6 shows that male-to-male sexual contact (29% or 126 cases), heterosexual contact (31% or 133 cases) and "other/unknown" (40% or 173 cases) accounts for virtually 100% of the exposure risks reported by newly diagnosed individuals in Shelby County in 2008 (two people identified as a mother with/at risk for HIV and one person identified injection drug use as an exposure category). The relatively high percentage of "other/unknown" responses may be due in part to the preliminary nature of the epidemiological data.

**Figure 6.**



## People Living With HIV/AIDS in Shelby County

There were 5,949 people living with HIV/AIDS in Shelby County as of 12/31/2008. Figure 7 shows that 4,067 (68%) are males and 1,882 (32%) are females.

### Figure 7.

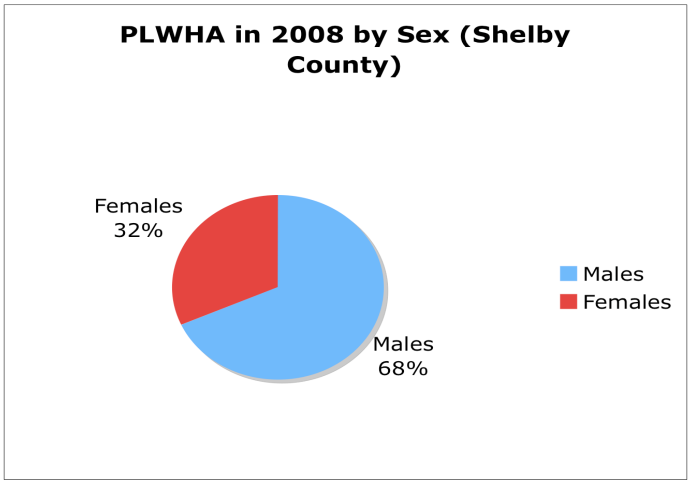



Figure 8 shows that the overwhelming majority (4,935 or 84%) of PLWHA in Shelby County are African American. There are 902 Caucasian PLWHA in Shelby County (15%) and 78 Hispanics (1%).

### Figure 8.

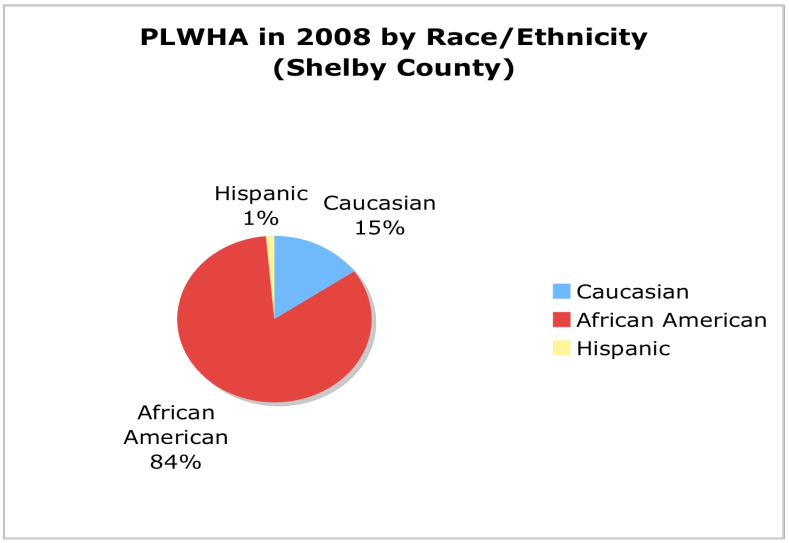
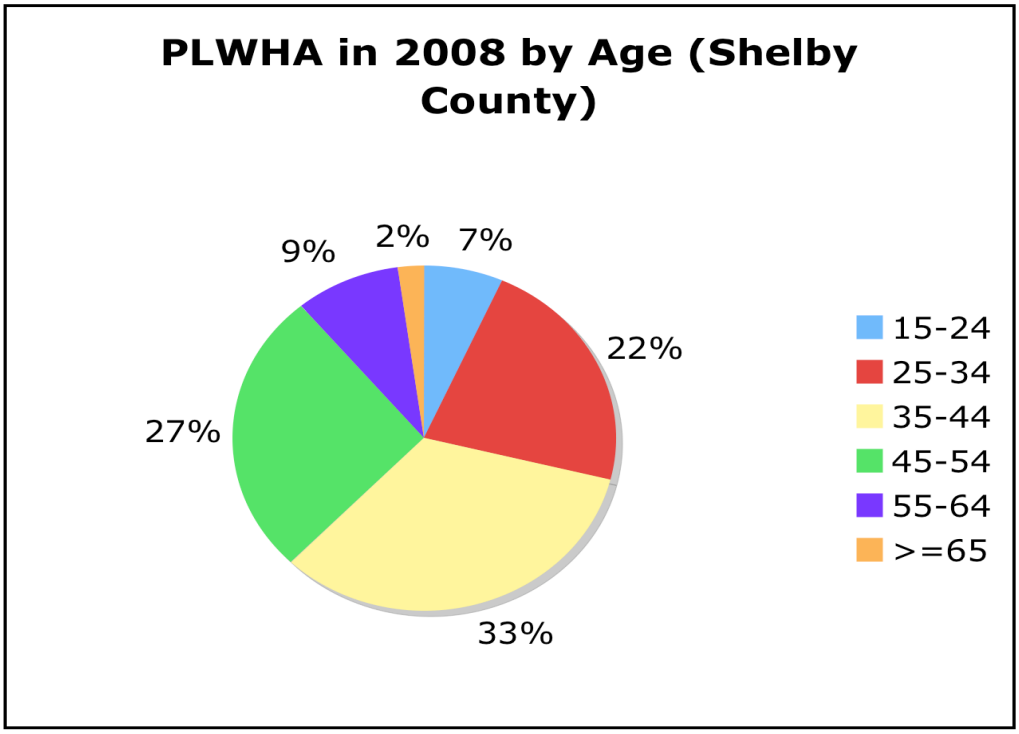


Figure 9 shows the age composition of the population of PLWHA in Shelby County in 2008. The largest age group of PLWHA is 35-44 year olds (1,978 or 33%), followed by 45-54 year olds (1,570 or 27%), and then 25-34 year olds (1,300 or 22%). The smallest age group (not pictured on graph) is 13-14 year olds (6 cases or <1%). Children under the age of 13 years account for <1% of PLWHA in Shelby County (33 cases).

**Figure 9.**



## HIV/AIDS in Fayette and Tipton Counties, TN[12]

Figure 10 summarizes HIV prevalence data for Fayette County by race. The cumulative number of HIV/AIDS cases reported to date in the county is 66. 47 cases (71%) are among African Americans, 18 (27%) are among whites and 1 (2%) is among Hispanics.

**Figure 10.**

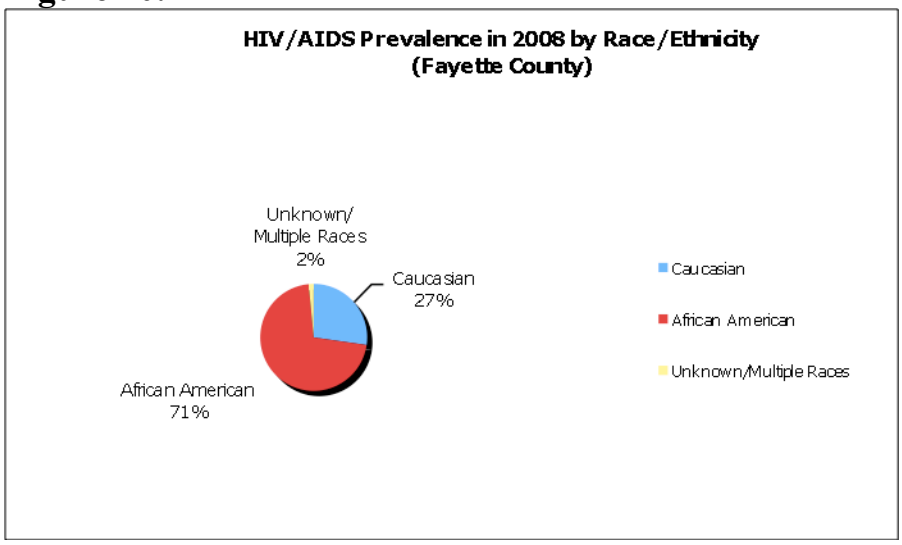
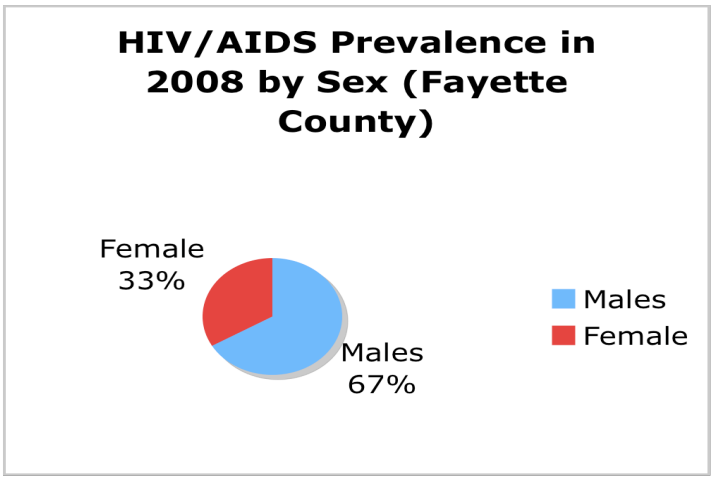



Figure 11 presents a summary of the HIV/AIDS prevalence data for Fayette County by sex. Among the 66 total number of cases, 44 cases (67%) are among males and 22 cases (33%) are among females.

**Figure 11.**




[12] Because of the low numbers of cases typically reported in these counties this section of the epidemiological profile reports prevalence data (cumulative number of cases since HIV/AIDS became reportable) up to and including 2008.

Figure 12 presents a summary of the HIV/AIDS prevalence data for Tipton County by race. The figure shows that the cumulative number of HIV/AIDS cases reported to date in Tipton County is 107. 75 cases (70%) are among African Americans, 29 cases (27%) are among whites, 2 cases (2%) are among Hispanics and 1 case (<1%) is among unknown/multiple races.

**Figure 12.**

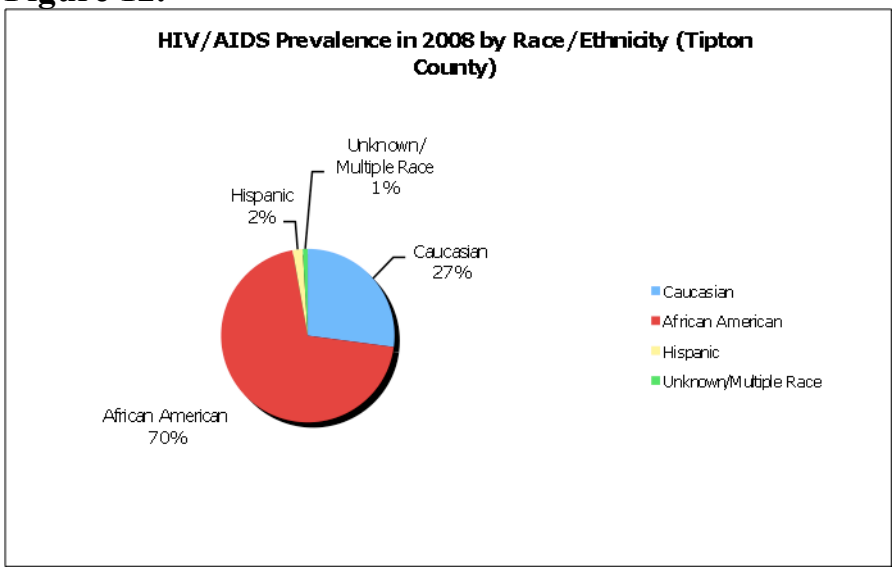
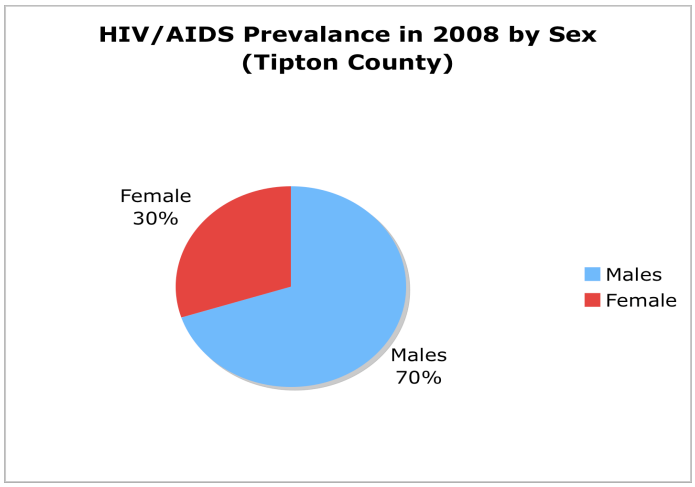



Figure 13 presents a summary of the HIV/AIDS prevalence data for Tipton County by sex. Among the 107 total number of cases, 75 cases are among males (70%) and 32 cases are among females (30%).

**Figure 13.**



**HIV/AIDS in Northern Mississippi (De Soto, Marshall, Tate and Tunica Counties)**

The cumulative number of HIV/AIDS cases reported to date in Northern Mississippi is 421. De Soto County accounts for the majority of HIV/AIDS prevalence in Northern Mississippi, with 230 diagnoses (54% of Northern Mississippi) through 2008. HIV/AIDS Prevalence in Marshall County 81 cases, accounting for 19% of all cases in Northern Mississippi through 2008, followed by Tunica County with 74 cases (18%), and Tate with 36 cases (9%). Figure 14 illustrates the distribution of HIV/AIDS prevalence across the four counties expressed as a percentage of total prevalence in Northern Mississippi.

## Figure 14.

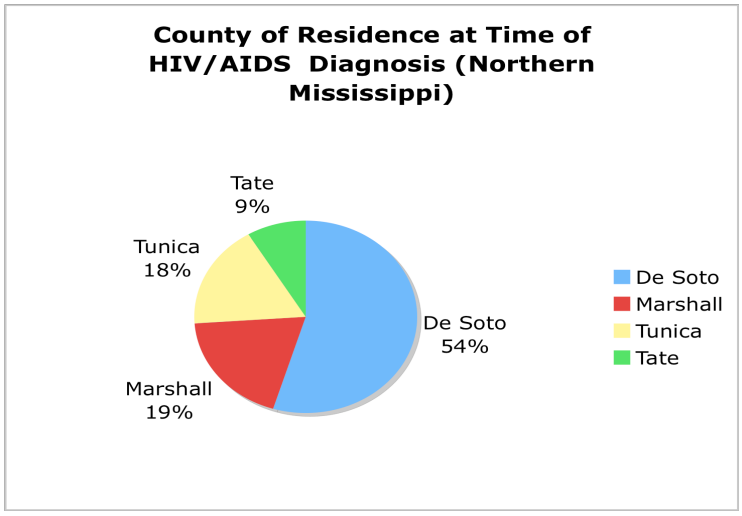



Figure 15 shows that 223 cases in Northern Mississippi are among African Americans (60%), 135 are among Caucasians (36%) and 14 are among other races (4%).

## Figure 15.

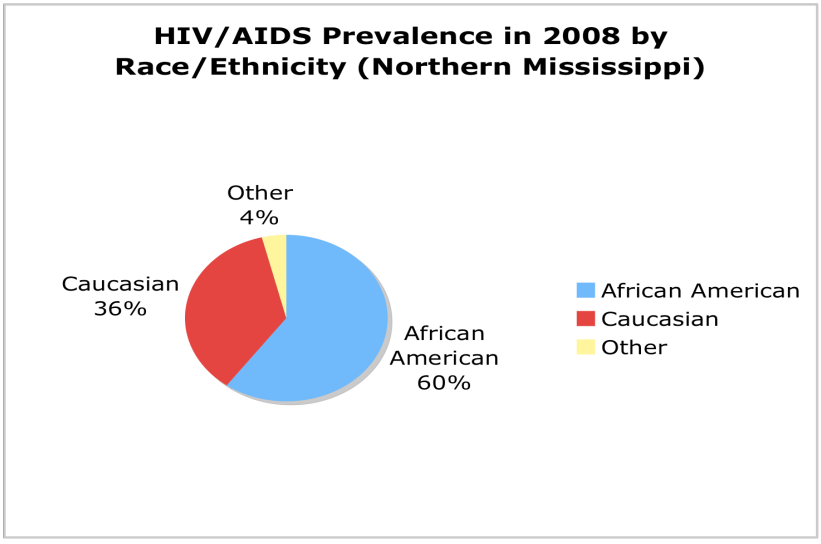


Figure 16 shows the prevalence of HIV in Northern Mississippi broken down by county and race. De Soto County has the highest HIV prevalence, and cases are almost evenly distributed by African Americans and Caucasians. In contrast, African Americans account for the vast majority of HIV/AIDS in the other three counties.

**Figure 16.**

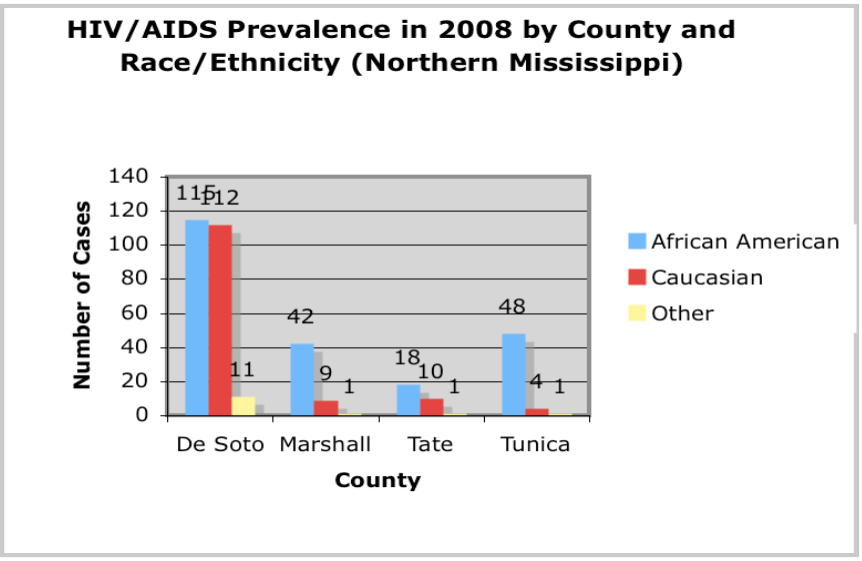
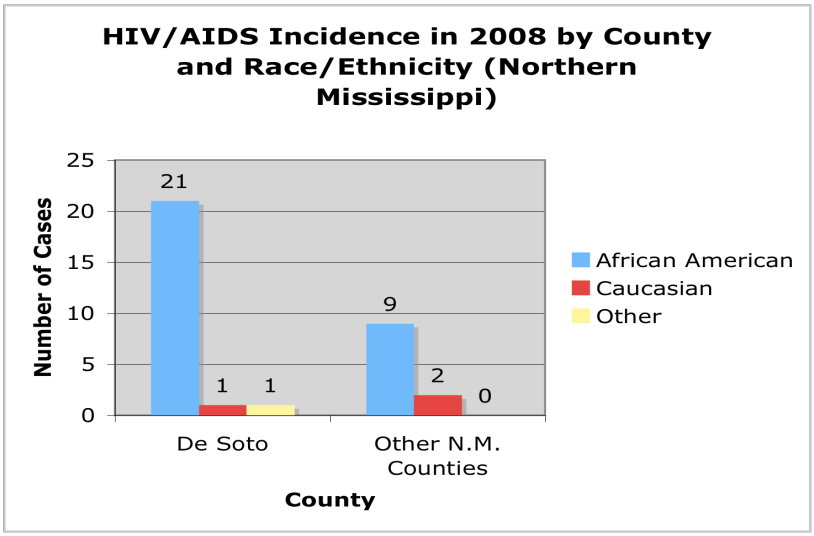


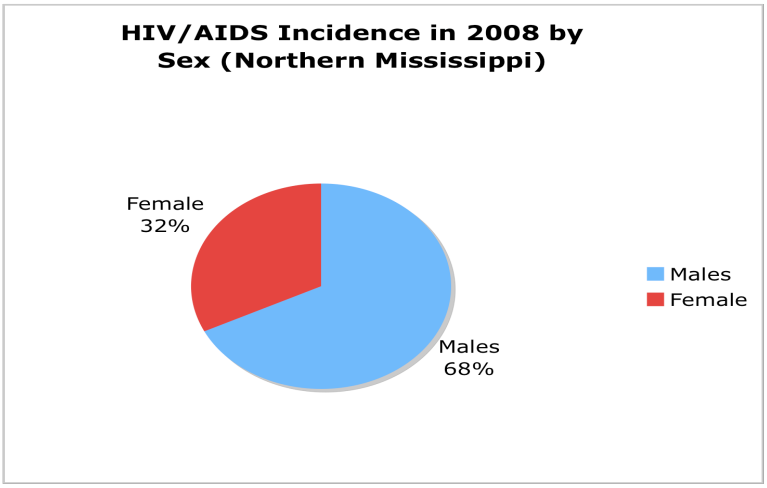

Figure 17 shows the 2008 incidence of new HIV cases in Northern Mississippi broken down by county and race. There were 34 new cases of HIV in Northern Mississippi in 2008. De Soto County had the highest number newly reported cases of HIV/AIDS and all but two of the 23 cases were among African Americans. This is noteworthy when compared to Figure 12, which shows very little difference between prevalence of HIV between African Americans and Caucasians in De Soto County through 2008.

**Figure 17.**



Among the 34 HIV/AIDS incidents reported in 2008 in Northern Mississippi, 23 are among males (68%) and 11 are among females (32%) (see figure 18 below).

**Figure 18.**




## HIV/AIDS and AIDS in Crittenden County, AR

The Arkansas Department of Health provided epidemiological data on HIV/AIDS late in the needs assessment process. For this reason these data are simply presented in table form (see table 4 below).

**Table 4. HIV/AIDS Incidence and Prevalence in Crittenden County, AR**

| | |
|---|---|
| 2008 HIV/AIDS Incidence<br>(Number of newly reported cases in 2008) | 16 cases |
| HIV/AIDS Prevalence<br>(Cumulative number of HIV/AIDS cases reported as of 12/31/2008) | 297 cases |
| 2008 AIDS (only) Incidence<br>(Number of newly reported cases in 2008) | 0 cases |
| AIDS (only) Prevalence<br>(Cumulative number of AIDS cases reported as of 12/31/2008) | 85 cases |

## Epidemiological Trends and Population Changes in the Memphis TGA

HRSA recommends that the epidemiological profile should include a section on trends and population changes. In this section of the report epidemiological data are analyzed over a five-year period (2004-2008) in an attempt to identify any trends and changes in population.

Figure 19 compares the top three "exposure category" responses reported from 2004-2008. While the number of persons reporting "male-to-male sex" as an exposure category spiked in 2006 and has since gone down, the category "heterosexual contact" spiked in 2007 and decreased in 2008. The "other/unknown" category was low in 2006, but has become one of the top categories in 2007-2008.

**Figure 19.**

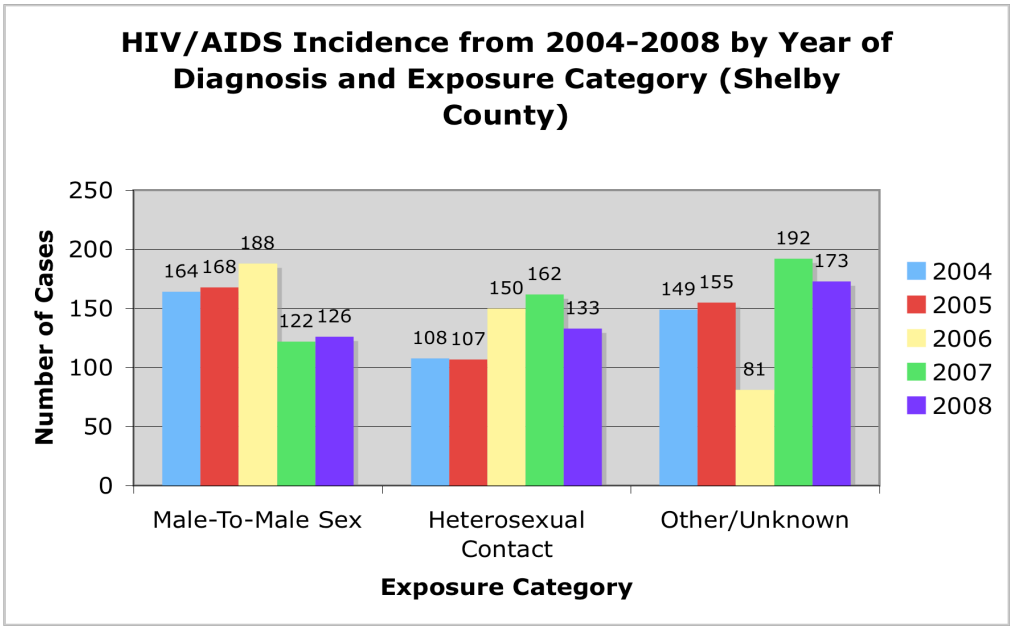



Figure 20 (next page) is a line graph illustrating yearly incidence by race over a five-year period. New cases among African Americans have been consistently and significantly higher than new cases in any other race. For example, in 2007 incidence among African Americans (438 cases) was more than 10 times higher than incidence among whites (39 cases).

Yearly HIV/AIDS incidence among African Americans increased steadily from 2004 to 2007 before decreasing somewhat in 2008. Incidence among Caucasians has declined slightly since 2005. The number of diagnoses among Hispanics had declined between 2004 and 2007 before spiking from 2 to 17 in 2008.

**Figure 20.**

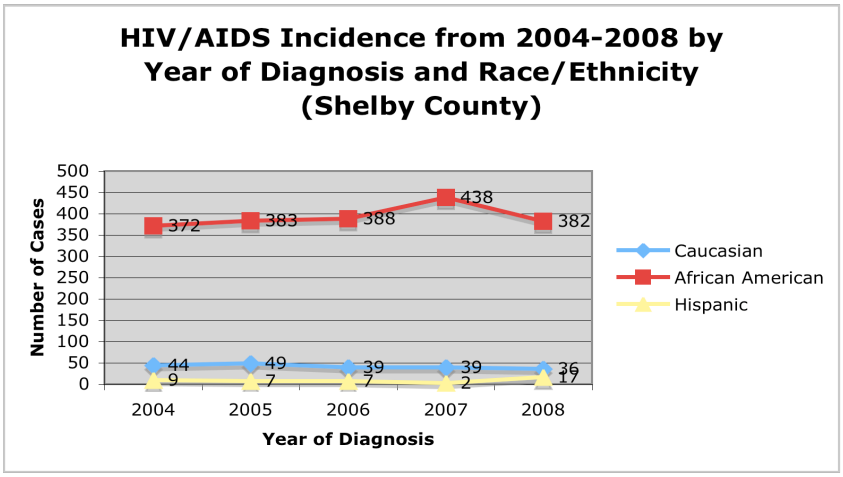



Figure 21 illustrates that in 2008 females accounted for 30% of all newly reported HIV/AIDS cases, compared to 34% in 2007. The number of new female cases in 2008 (131) is the lowest it has been since 2004. The number of new male cases had been rising continually since 2004 before dropping slightly in 2008. As indicated earlier in this section of the report, the total number of newly reported HIV/AIDS cases in Shelby County decreased from 479 in 2007 to 435 in 2008, a decrease of 9%.

**Figure 21.**

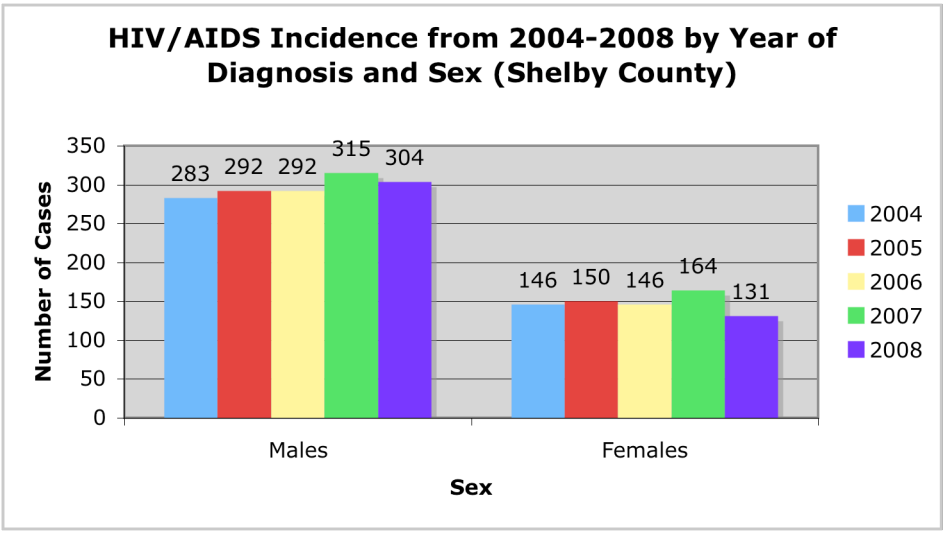


Figure 22 illustrates yearly incidence over a five-year period by sex and race/ethnicity. The figure shows that up until 2007, increases in overall HIV/AIDS yearly incidence have been disproportionately shared by African American males and females, and African American males have accounted for the majority of new cases. However, the number of new cases for African American males dropped slightly in 2008 to 262, and the number of new cases among African American females was the lowest in 2008 (120) than is has been since 2004 (139).

Figure 22 also shows that incidence has slightly and steadily declined over the past five years among Caucasian males (from 38 in 2004 to 20 in 2008) and has declined among white females over the past few years (from 14 in 2005 to 6 in 2008) as well. In contrast, incidence among Hispanic males spiked from 1 case in 2007 to 12 in 2008, and the number of cases among Hispanic females rose from 1 in 2007 to 5 in 2008.

**Figure 22.**

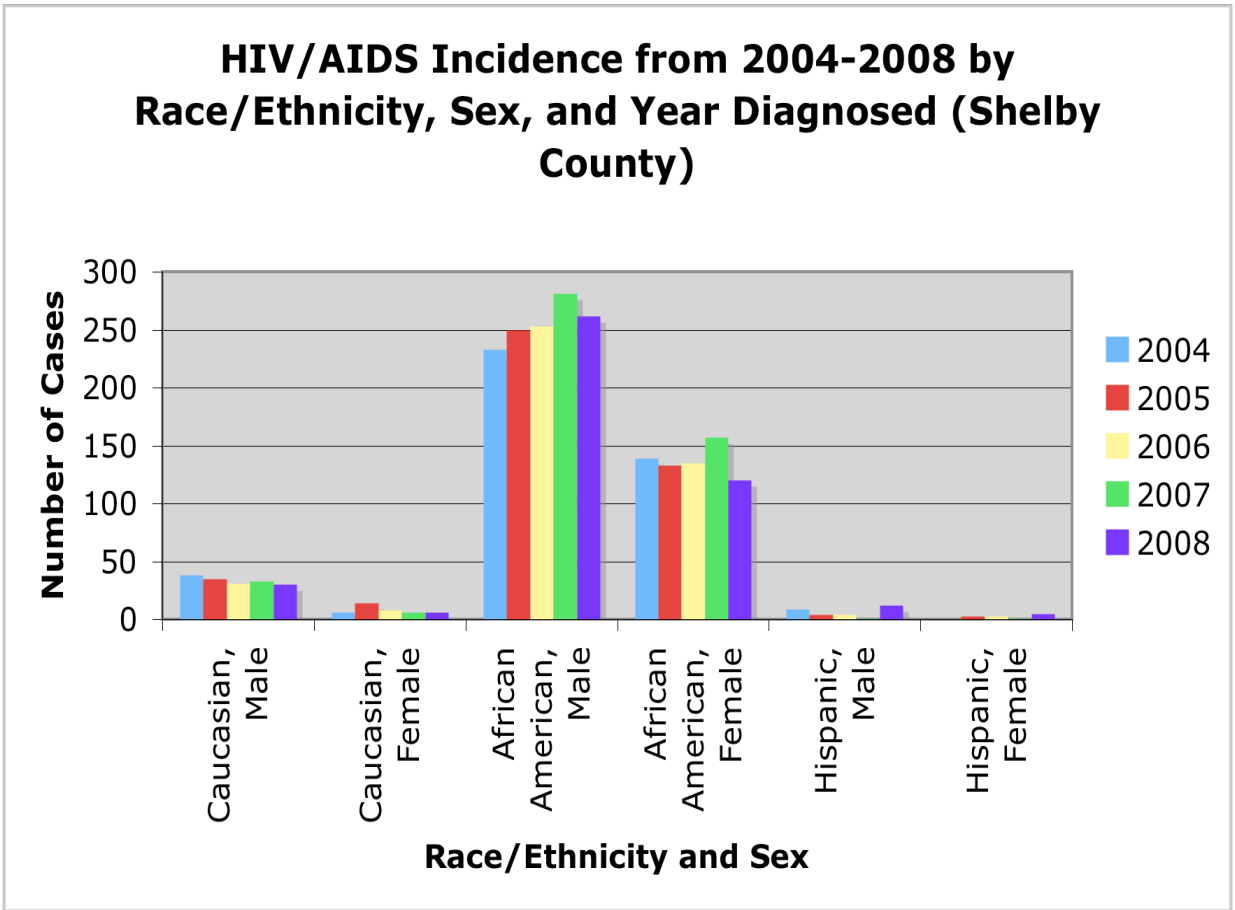
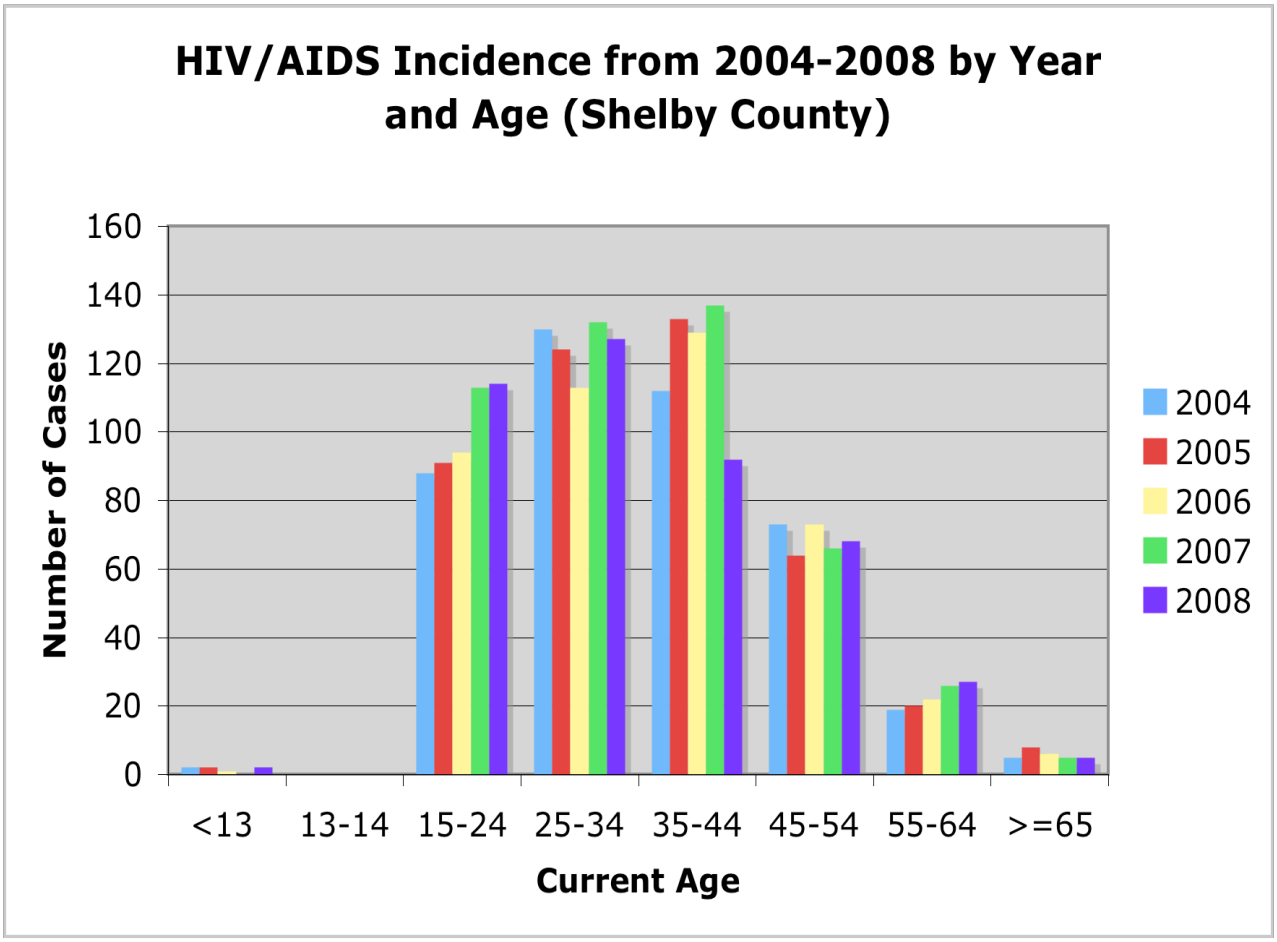


Figure 23 shows that over the past five years the number of newly reported HIV/AIDS cases has increased consistently among youth (age 15-24) and older adults (age 55-64) in Shelby County. Although incidence has fluctuated year to year among people age 25-34 years, and among people age 35-44 years, incidence for both groups was highest in 2007. However, incidence has dropped in 2008, especially among adults aged 35-44 years.

As stated earlier in this section of the report, in 2008 HIV/AIDS in Shelby County incidence was highest among 25-34 year olds (29% or 127 cases), followed by 15-24 year olds (26% or 114 cases) and 35-44 year olds (21% or 92 cases). However, despite the fact that HIV/AIDS incidence decreased overall by 9% in Shelby County in 2008, incidence increased among 15-24 year olds. In 2007 there were 113 newly reported HIV/AIDS cases among 15-24 year olds, which amounted to 24% of total HIV/AIDS incidence in 2007. The figure also illustrates how incidence among youth has increased significantly during the past two years when compared to incidence between 2004 and 2006.

**Figure 23.**



## AIDS (only) Incidence in Shelby County

Figure 24 illustrates that after increasing dramatically from 258 cases in 2004 to 327 cases in 2005 (a 27% increase), AIDS only incidence has continually declined each year since 2005, and this decline was especially significant in 2008. In 2008 AIDS only incidence in Shelby County declined 50% from 190 cases in 2007 to 95 cases (2008). AIDS only incidence in Shelby County has declined 71% since 2005.

**Figure 24.**

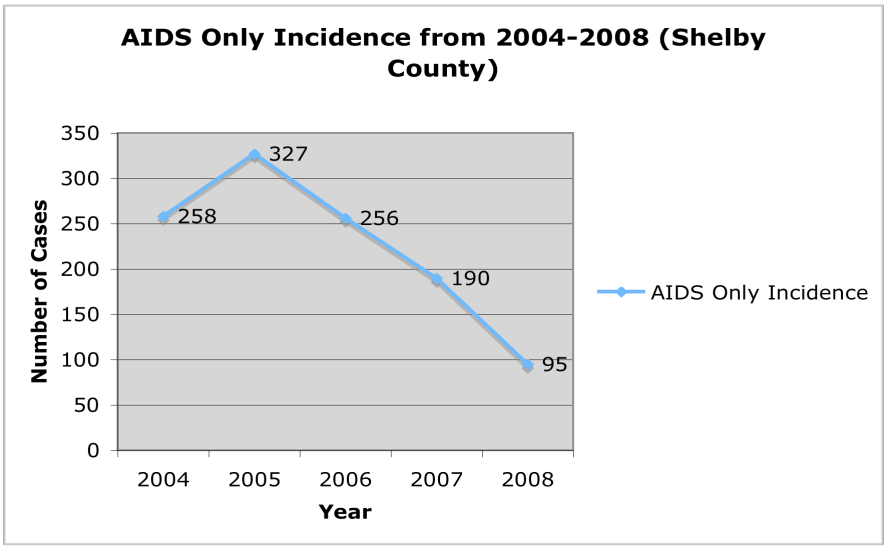



Figure 25 illustrates that AIDS only incidence among males has declined significantly among since 2005, and it has declined considerably among females since 2006. There was a 35% decrease in AIDS incidence among males between 2007 and 2008 and a 70% decrease in AIDS incidence among females from 2007 to 2008.

**Figure 25.**

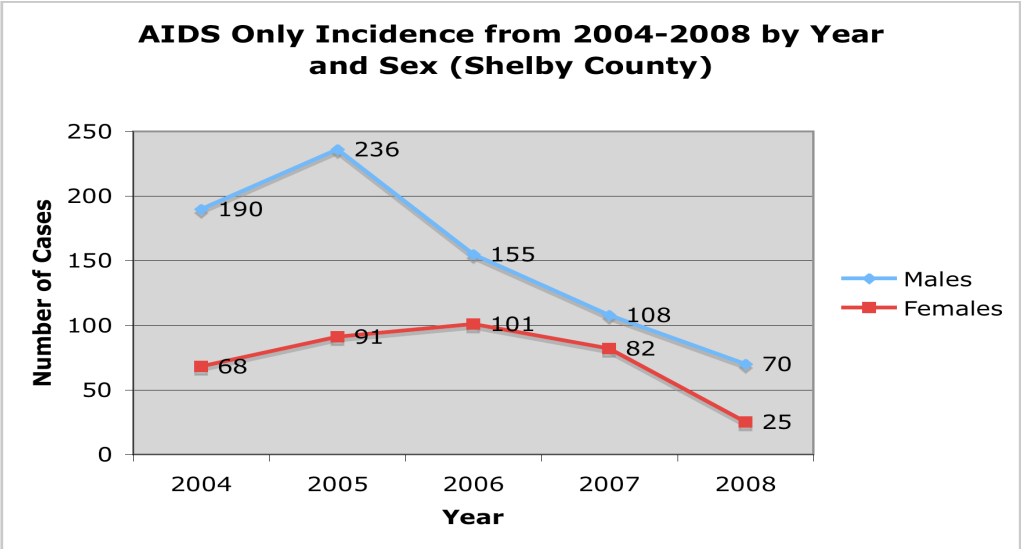
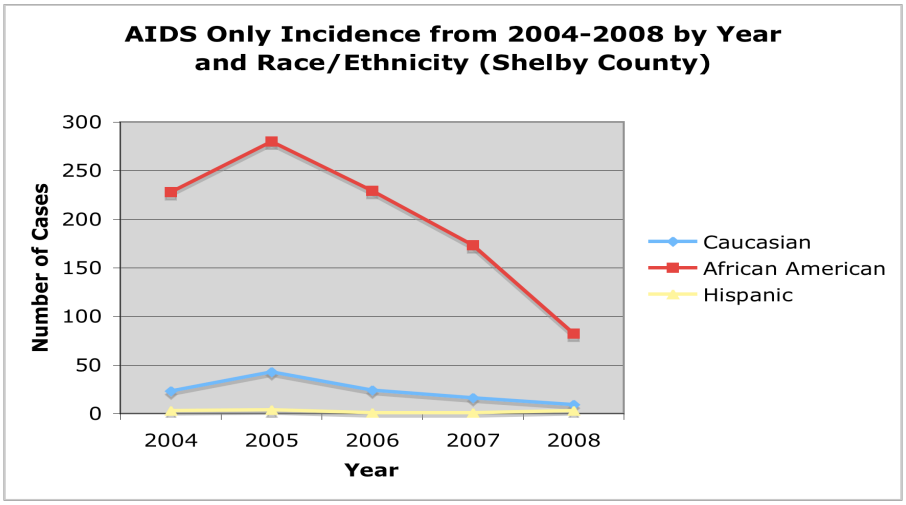


Figure 26 shows that the decline in AIDS only incidence since 2005 occurred among both African Americans and Caucasians. In 2008 AIDS only incidence (82 newly reported cases) among African Americans was 71% lower than it was in 2005 (when there were 280 newly reported cases. AIDS incidence among Caucasians decreased by 79% during the same period, from 43 cases in 2005 to 9 cases in 2008.

**Figure 26.**




## PLWHA in Shelby County

Despite declines in HIV/AIDS and AIDS only incidence during the past year the number of people living with HIV/AIDS in Shelby County continues to increase (see figure 27 below). Over the past five years the number of PLWHA in Shelby County has increased 22% from 4,653 PLWHA in 2004 to 5,949 PLWHA in 2008.

**Figure 27.**

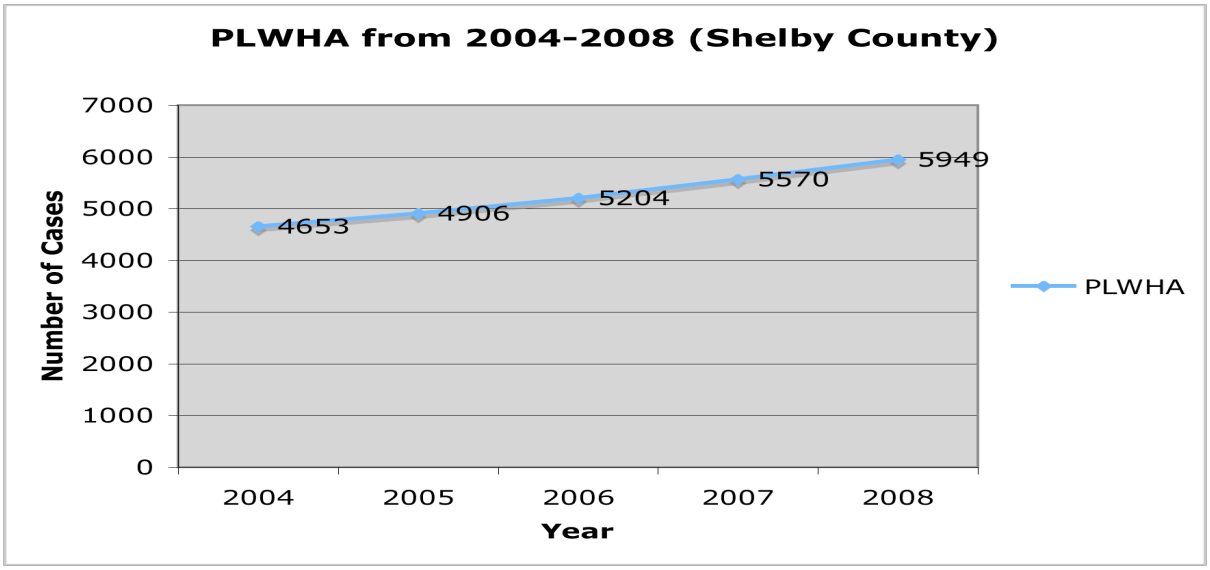


Figure 28 shows that the number of PLWHA has steadily grown since 2004 for both males (by 21%) and females (by 24%).

**Figure 28.**

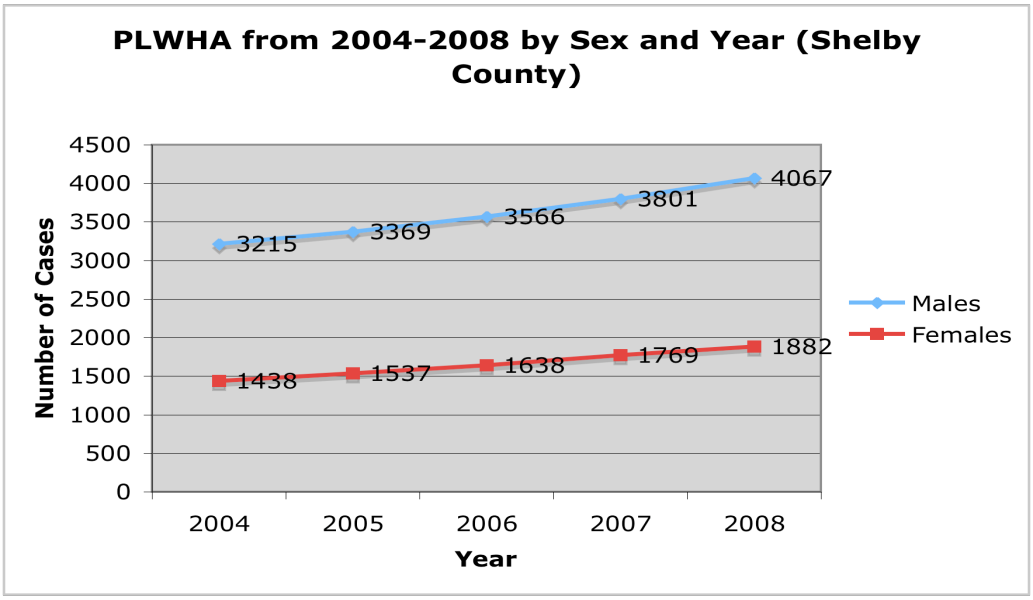



Figure 29 illustrates the steady increase of PLWHA among people between the ages of 15 and 44 years over the past five years. This pattern is most likely produced by a number of factors, including relatively high incidence among these age groups (compared to older groups) and relatively low incidence of co-morbidity among younger and middle-aged adults, among other factors.

**Figure 29.**

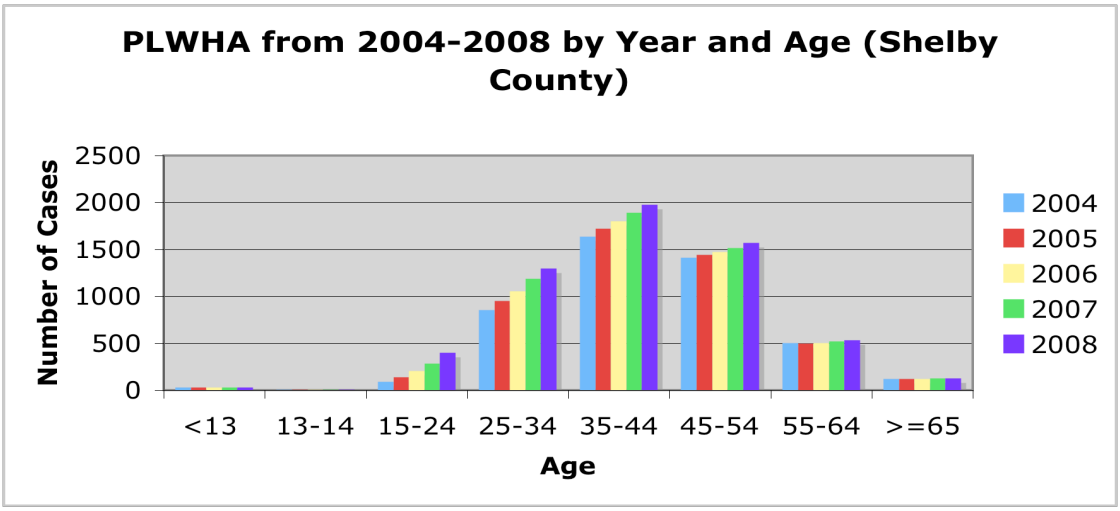
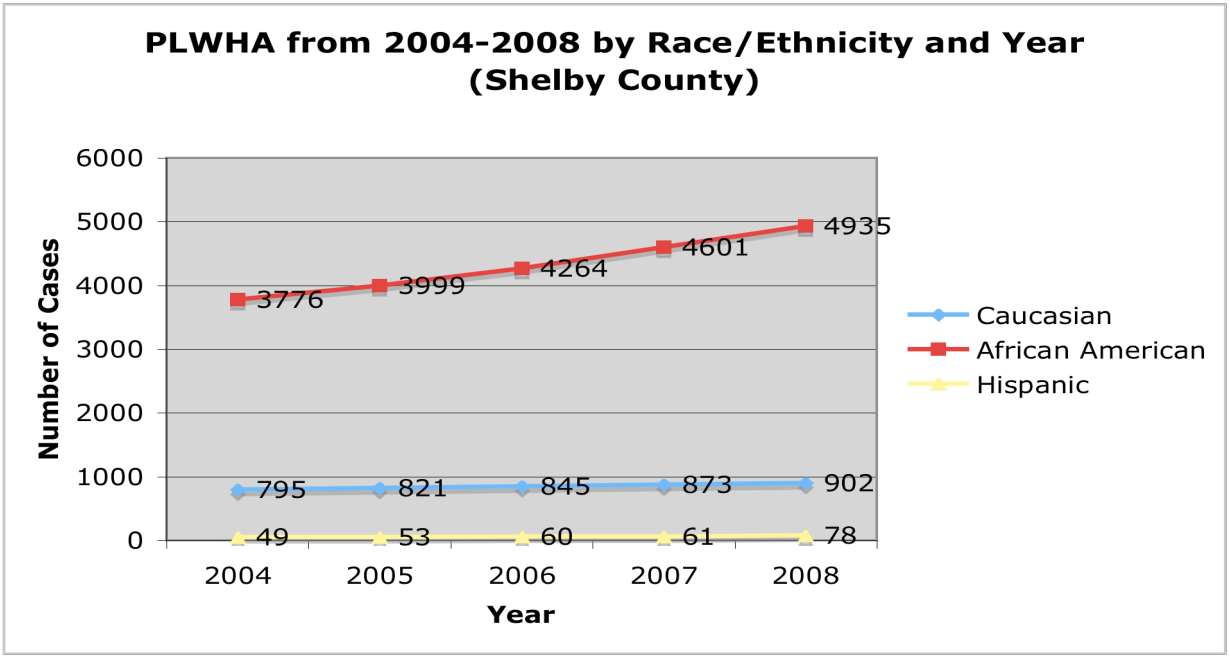


Figure 30 presents the yearly number of PLWHA by race between 2004 and 2008. In 2008, there were 4,935 identified African American PLWHA (83%), 902 Caucasian PLWHA (15%), 78 Hispanic PLWHA (1%), and 27 PLWHA who were identified as unknown/multiple race (<1%). Although the scale of the figure does not illustrate the dramatic increase in the number of Hispanic PLWHA it should be noted that this number increased by 17 (from 61 to 78) between 2007 and 2008, and increase of 29%. The figure does illustrate the steady increase in the number of PLWHA in Shelby County over the past five years.

**Figure 30.**



## Deaths Among PLWHA in Shelby County

Figure 31 illustrates the trend in the number of deaths among PLWHA in Shelby County from 2004 to 2008. There was a slight increase in deaths from 2004 to 2005 (10%), but deaths have declined consistently since then. There was a 26% decrease in deaths between 2005 and 2006, a 19% decrease in deaths between 2006 and 2007, and a 50% decrease in deaths between 2007 and 2008.

**Figure 31.**

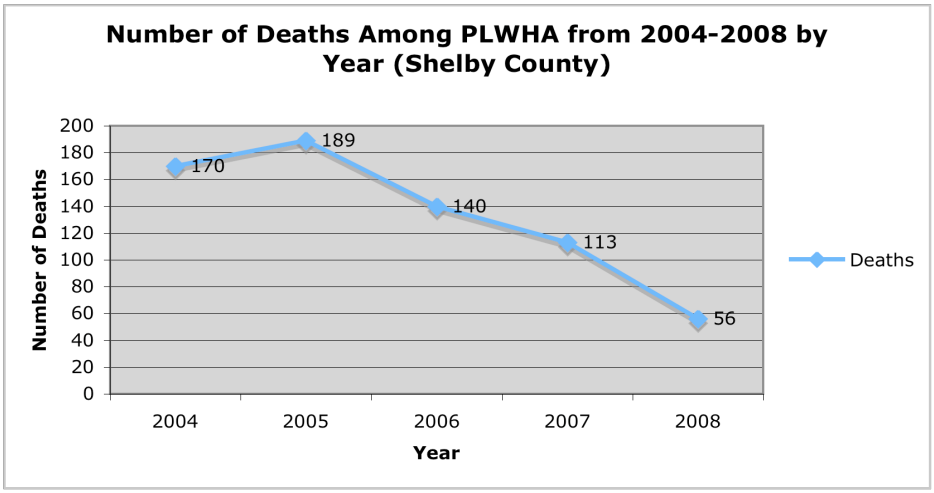



Figure 32 illustrates that deaths among male PLWHA have decreased since peaking in 2005. There has been a 72% increase in yearly deaths among male PLWHA since 2005. Deaths among female PLWHA have also declined during this period.

**Figure 32.**

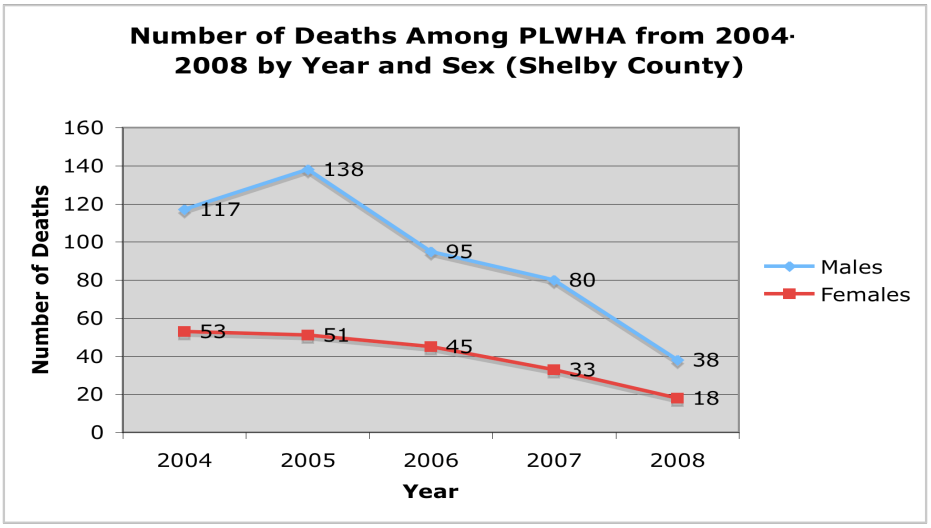


Figure 33 shows that the decrease in mortality among PLWHA in 2008 occurred among people in ever age category besides those 65 years of age or older. Yearly deaths among PLWHA aged 35-44 years of age decreased by 70% between 2007 and 2008, and deaths among 45-54 year olds decreased by 48% from 2007 to 2008. Deaths among PLWHA 65 years or older increased slightly between 2007 and 2008 from 2 to 5.

**Figure 33.**

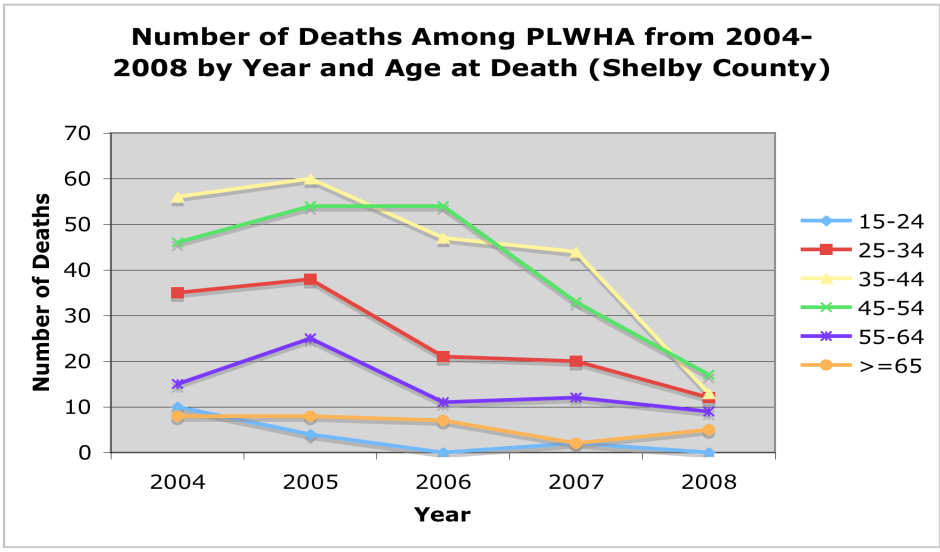
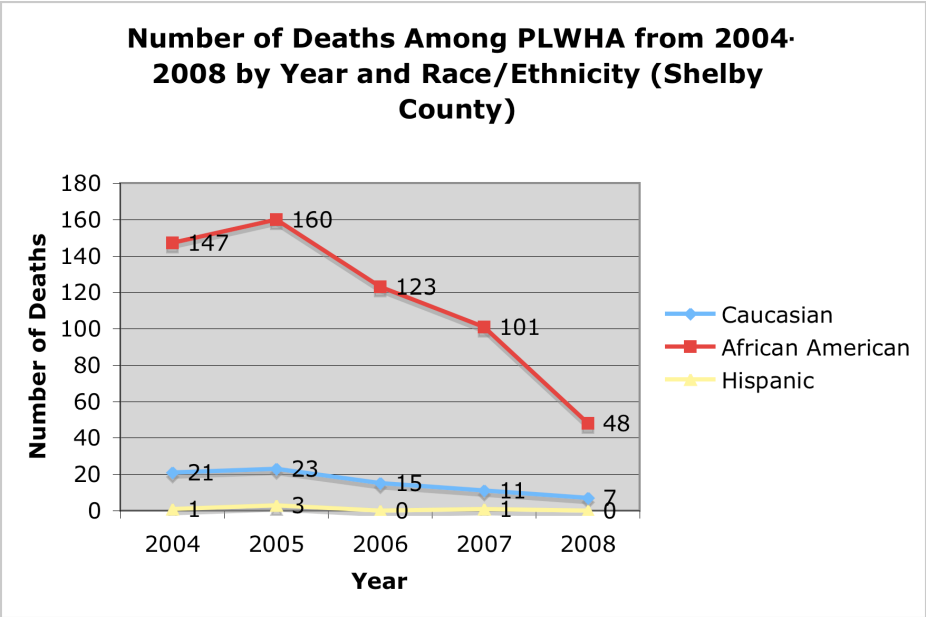



Figure 34 shows that in 2007 deaths among Caucasian PLWHA declined by 31% and deaths declined by 18% among African American PLWHA.

**Figure 34.**



## Summary of Key Findings

- HIV/AIDS incidence, AIDS only incidence, and number of HIV/AIDS deaths decreased in 2008. In 2008 there were 435 newly reported cases of HIV/AIDS in Shelby County, which is 9% lower than HIV incidence in 2007 (479 cases).

- AIDS only incidence has continually declined each year since 2005, and this decline was especially significant in 2008. In 2008 AIDS only incidence in Shelby County declined 50% from 190 cases in 2007 to 95 cases (2008). AIDS only incidence in Shelby County has declined 71% since 2005.

- Number of deaths attributed to HIV/AIDS have declined consistently in Shelby County since 2005. Deaths decreased by 50% between 2007 and 2008 in Shelby County.

- The highest percentage of newly reported cases was among African Americans (88% or 382 cases), followed by Caucasians (8% or 36 cases), and then Hispanics (4% or 17 cases). However, the 17 cases among Hispanics is by far the highest number of new HIV/AIDS cases ever reported for this ethnic group in Shelby County. In 2007 only 2 cases were reported among Hispanics in Shelby County.

- Despite the fact that HIV/AIDS incidence decreased overall by 9% in Shelby County in 2008, incidence increased among 15-24 year olds (while decreasing among 25-44 year olds). (In 2007 there were 113 newly reported HIV/AIDS cases among 15-24 year olds, which amounted to 24% of total HIV/AIDS incidence in 2007.) Incidence among 15-24 year olds continued to increase steadily for the fifth straight year.

- HIV/AIDS incidence in Shelby County was highest among African-American males (86% or 262 cases) and lowest among white females (5% or 6 cases).

- In 2008 there were 34 new cases of HIV/AIDS reported in the four Northern Mississippi counties included in the Memphis TGA. 68% of these cases were in De Soto County, and all but 2 of these 23 cases were among African Americans. Incidence in De Soto is unique compared to incidence in the other three counties, where cases are much more evenly distributed among African Americans and Caucasians.

# III. Assessment of Service Needs & Gaps

This section of the needs assessment provides information about the service needs of people with HIV/AIDS, the types of needs and the extent to which they are not being met and the barriers to obtaining these services.

## What services do PLWHA need and are these service-needs being met?

Data pertaining to needed services were collected through self-administered surveys completed by Ryan White consumers who are in-care who report no history of interrupted care (N=160) and Ryan White consumers who are in-care who report that their HIV care has been interrupted for at least one twelve month period during the past five years (N=81). Data pertaining to services reported as "needed," "needed and received," and "needed but not received" for these two consumer populations are presented in the tables below.

What services do PLWHA need and are these service needs being met? The self-administered surveys provided consumers with a list of Ryan White service categories and asked them to indicate whether they "needed," "needed and received," and "needed but not received" specific services.

## Service Needs Reported by Consumers (In-Care) With No History of Interrupted Care

Table 5 (next page) rank orders the percentages of responses given to this survey item by consumers with no reported history of interrupted care. Table 5 indicates that Dental care/oral health (93%), HIV doctor (91%) and prescription drug assistance (88%) as the services most frequently reported by these consumers.

**Table 5. Services Reported as Needed by Consumers (In-Care) With No Reported History of Interrupted Care.**

| | **Service** | Total % of consumers who report **service as needed** | % of consumers who report that they **need and receive service** | % of consumers who report that they **need but do not receive service** |
|---|---|---|---|---|
| 1 | Dental care and oral health | 93% | 51% | 42% |
| 2 | HIV Doctor | 91% | 90% | 1% |
| 3 | Prescription drug assistance | 88% | 80% | 8% |
| 4 | HIV health insurance assistance | 79% | 60% | 19% |
| 5 | Food pantry | 78% | 66% | 12% |
| 6 | Medical care case management | 68% | 60% | 8% |
| 7 | Utility assistance | 63% | 26% | 37% |
| 6 | Support group | 55% | 35% | 20% |
| 8 | Transportation to medical care | 51% | 34% | 17% |
| 9 | Non-medical case management | 46% | 37% | 9% |
| 10 | Mental health care/counseling | 43% | 31% | 12% |
| 10 | Emergency housing | 43% | 13% | 30% |
| 11 | Nutritional therapy | 37% | 21% | 16% |
| 12 | Treatment adherence services | 22% | 15% | 7% |
| 13 | Home health care | 15% | 9% | 6% |
| 14 | Respite care | 14% | 5% | 9% |
| 15 | Hospice services | 12% | 6% | 6% |
| 16 | Alcohol/drug outpatient treatment | 9% | 6% | 3% |
| 17 | Alcohol/drug residential treatment | 8% | 6% | 2% |

Consumers indicated a need for several additional services that were not included in the list of Ryan White service categories that were provided to consumers. Two (2) consumers listed that they need but do not receive "HIV awareness classes." Two (2) also need but do not receive the care of an "eye doctor." One (1) consumer needs but does not receive the care of a neurologist, one (1) reports the need for assistance in picking up HIV medication, one (1) reports a need physical therapy, and one (1) reports a need for foot care.

Table 6 presents the same data presented in Table 1 but rank-orders the data in terms of the frequency of "needed but not received" responses. Presenting the data in this format allows us to appreciate which services are most frequently reported as needed but not received. Table 6 indicates that dental care/oral health (42%), utility assistance (37%) and emergency housing (30%) are the services most frequently reported as "needed but not received."

**Table 6. Services Reported as "needed but not received" by "In-Care" Consumers With No Reported History of Interrupted HIV Care.**

| | **Service** | % of consumers who report that they **need but do not receive service** | % of consumers who report that they **need and receive service** | Total % of consumers who report **service as needed** |
|---|---|---|---|---|
| 1 | Dental care and oral health | 42% | 51% | 93% |
| 2 | Utility assistance | 37% | 26% | 63% |
| 3 | Emergency housing | 30% | 13% | 43% |
| 4 | Support group | 20% | 35% | 55% |
| 5 | HIV health insurance assistance | 19% | 60% | 79% |
| 6 | Transportation to medical care | 17% | 34% | 51% |
| 7 | Nutritional therapy | 16% | 21% | 37% |
| 8 | Food pantry | 12% | 66% | 78% |
| 8 | Mental health care/counseling | 12% | 31% | 43% |
| 9 | Non-medical case management | 9% | 37% | 46% |
| 9 | Respite care | 9% | 5% | 14% |
| 10 | Prescription drug assistance | 8% | 80% | 88% |
| 10 | Medical care case management | 8% | 60% | 68% |
| 11 | Treatment adherence services | 7% | 15% | 22% |
| 12 | Home health care | 6% | 9% | 15% |
| 12 | Hospice services | 6% | 6% | 12% |
| 13 | Alcohol/drug outpatient treatment | 3% | 6% | 9% |
| 14 | Alcohol/drug residential treatment | 2% | 6% | 8% |
| 15 | HIV Doctor | 1% | 90% | 91% |

During the process of completing past needs assessments in Memphis it has been learned that some services are greatly needed but only by a relatively small percentage of consumers. For this reason it is important to look not only at the frequency of responses across service categories, but also, the percentage of "needed and not received" responses relative to "needed and received" responses within service categories. For example, hospice care is only reported as "needed" by 12% of the in-care consumers, however, among these consumers 50% report this service as "needed but not received." It is important to document such service needs, especially when they pertain to services associated with frailty, high acuity or non-ambulatory service needs.

In addition to reporting the percentages of survey respondents who "need but do not receive" a particular service, it is worthwhile to consider the unmet need for services in relation to the total number of respondents identifying the service as "needed." For example, only 43% of the respondents identified "emergency housing" as a need (see table 5, page 43). However, among these consumers 70% report that their need for emergency housing has not been met (this is done by expressing the percentage of "needed but not received" as a percentage of "total need"). Calculating the data in this manner shows us the degree of unmet service need *among* consumers reporting a need for specific services. This is an important consideration when the overall need for a service is low (for example, respite care) but the percentage of consumers who need but do not receive the service is relatively high. The first column in Table 7 rank orders the "needed but not received" responses provided by in-care consumers as a percentage of "total need." In addition to emergency housing, respite care, utility assistance and hospice care are the services least likely to be received by in-care consumers reporting a need for such services.

**Table 7. Services Reported as "needed but not received" by "In-Care" Consumers With No Reported History of Interrupted HIV Care Expressed as a Percentage of "total need."**

| | **Service** | **need but do not receive** expressed as a % of **total need** | % of consumers who report that they **need but do not receive service** | Total % of consumers who report **service as needed** |
|---|---|---|---|---|
| 1 | Emergency housing | 70% | 30% | 43% |
| 2 | Respite care | 64% | 9% | 14% |
| 3 | Utility assistance | 59% | 37% | 63% |
| 4 | Hospice services | 50% | 6% | 12% |
| 5 | Dental care and oral health | 45% | 42% | 93% |
| 6 | Nutritional therapy | 43% | 16% | 37% |
| 7 | Home health care | 40% | 6% | 15% |
| 8 | Support group | 36% | 20% | 55% |
| 9 | Alcohol/drug outpatient treatment | 33% | 3% | 9% |
| 9 | Transportation to medical care | 33% | 17% | 51% |
| 10 | Treatment adherence services | 32% | 7% | 22% |
| 11 | Mental health care/counseling | 28% | 12% | 43% |
| 12 | Alcohol/drug residential treatment | 25% | 2% | 8% |
| 13 | HIV health insurance assistance | 24% | 19% | 79% |
| 14 | Non-medical case management | 20% | 9% | 46% |
| 16 | Food pantry | 15% | 12% | 78% |
| 17 | Medical care case management | 12% | 8% | 68% |
| 18 | Prescription drug assistance | 9% | 8% | 88% |
| 19 | HIV Doctor | 1% | 1% | 91% |

## Service Needs Reported by In-Care Consumers Who Report an Interruption in Their HIV Medical Care During the Past Five Years

Tables 8, 9 and 10 present responses provided in response to the service category question by Ryan White consumers who are in-care who report that their HIV care has been interrupted for at least one twelve month period during the past five years (N=81). These data are presented according to the same format used to present the responses provided by the in-care consumers.

Consumers who have experienced an interruption in care during the past five years report significantly higher numbers of service needs compared to consumers who do not report interruptions in their HIV medical care. Table 8 shows that more than 50% of these consumers report a need for all but two of the 19 Ryan White fundable services categories. HIV doctor (96%), prescription drug assistance (93%), dental care/oral health (91%) and food pantry (91%) are the most frequently identified service needs reported by consumers with a history of interrupted care.

**Table 8. Services Reported as Needed by "In-Care" Consumers Who Report a History of Interrupted HIV Care.**

| | **Service** | Total % of consumers who report **service as needed** | % of consumers who report that they **need and receive service** | % of consumers who report that they **need but do not receive service** |
|---|---|---|---|---|
| 1 | HIV Doctor | 96% | 69% | 27% |
| 2 | Prescription drug assistance | 93% | 57% | 36% |
| 3 | Dental care and oral health | 91% | 33% | 58% |
| 3 | Food pantry | 91% | 50% | 41% |
| 4 | HIV health insurance assistance | 88% | 40% | 48% |
| 5 | Medical care case management | 79% | 34% | 45% |
| 5 | Utility assistance | 79% | 20% | 59% |
| 6 | Emergency housing | 77% | 18% | 59% |
| 6 | Support group | 77% | 27% | 50% |
| 7 | Non-medical case management | 74% | 24% | 50% |
| 8 | Transportation to medical care | 73% | 28% | 45% |
| 9 | Mental health care/counseling | 68% | 25% | 43% |
| 10 | Nutritional therapy | 60% | 18% | 42% |
| 11 | Alcohol/drug outpatient treatment | 56% | 13% | 43% |
| 11 | Alcohol/drug residential treatment | 56% | 12% | 44% |
| 12 | Respite care | 52% | 12% | 40% |
| 13 | Treatment adherence services | 50% | 11% | 39% |
| 14 | Home health care | 47% | 12% | 35% |
| 15 | Hospice services | 44% | 10% | 34% |

Table 9 shows that emergency housing (59%) and utility assistance (59%) are the most frequently reported services that are "needed but not received," followed by dental care/ oral health (58%), support group (50%) and non-medical case management (50%). The need for emergency housing and utility assistance among these consumers is approximately *twice* that reported by consumers who have not experienced interruptions in their HIV care. This finding is consistent with findings reported in the research literature that associate housing and housing conditions with ability to access and remain in HIV medical care.[13]

**Table 9. Services Reported as "needed but not received" by "In-Care" Consumers Who Report a History of Interrupted HIV Care.**

| | **Service** | % of consumers who report that they **need but do not receive service** | % of consumers who report that they **need and receive service** | Total % of consumers who report **service as needed** |
|---|---|---|---|---|
| 1 | Emergency housing | 59% | 18% | 77% |
| 1 | Utility assistance | 59% | 20% | 79% |
| 2 | Dental care and oral health | 58% | 33% | 91% |
| 3 | Support group | 50% | 27% | 77% |
| 3 | Non-medical case management | 50% | 24% | 74% |
| 4 | HIV health insurance assistance | 48% | 40% | 88% |
| 5 | Medical care case management | 45% | 34% | 79% |
| 5 | Transportation to medical care | 45% | 28% | 73% |
| 6 | Alcohol/drug residential treatment | 44% | 12% | 56% |
| 7 | Mental health care/counseling | 43% | 25% | 68% |
| 7 | Alcohol/drug outpatient treatment | 43% | 13% | 56% |
| 8 | Nutritional therapy | 42% | 18% | 60% |
| 9 | Food pantry | 41% | 50% | 91% |
| 10 | Respite care | 40% | 12% | 52% |
| 11 | Treatment adherence services | 39% | 11% | 50% |
| 12 | Prescription drug assistance | 36% | 57% | 93% |
| 13 | Home health care | 35% | 12% | 47% |
| 14 | Hospice services | 34% | 10% | 44% |
| 15 | HIV Doctor | 27% | 69% | 96% |

[13] For a review of this literature see Aidala, A. A. and Quattrochi, R. , 2007-08-11 "Housing is Prevention and Care: Using Research to Change the HIV Risk Paradigm" *Paper presented at the annual meeting of the American Sociological Association, TBA, New York, New York City Online* <PDF>. 2009-03-04 from http://www.allacademic.com/meta/p184780_index.html

Table 10 shows that when the degree of "total need" is taken into consideration, outpatient and residential drug and alcohol treatment, treatment adherence services, hospice, respite and home health care, and emergency housing are the most frequently reported unmet service needs among consumers with a history of interrupted care. These findings are consistent with research that demonstrate a causal association among substance abuse, housing access and the ability of PLWHA to access and remain in care.

**Table 10. Services Reported as "needed but not received" by "In-Care" Consumers Who Report a History of Interrupted HIV Care Expressed as a % of "total need."**

| | **Service** | **need but do not receive** expressed as a % of **total need** | % of consumers who report that they **need but do not receive service** | Total % of consumers who report **service as needed** |
|---|---|---|---|---|
| 1 | Alcohol/drug residential treatment | 78% | 44% | 56% |
| 1 | Treatment adherence services | 78% | 39% | 50% |
| 2 | Hospice services | 77% | 34% | 44% |
| 2 | Alcohol/drug outpatient treatment | 77% | 43% | 56% |
| 2 | Respite care | 77% | 40% | 52% |
| 3 | Emergency housing | 76% | 59% | 77% |
| 4 | Utility assistance | 75% | 59% | 79% |
| 5 | Home health care | 74% | 35% | 47% |
| 6 | Nutritional therapy | 70% | 42% | 60% |
| 7 | Non-medical case management | 68% | 50% | 74% |
| 8 | Support group | 65% | 50% | 77% |
| 9 | Dental care and oral health | 64% | 58% | 91% |
| 10 | Mental health care/counseling | 63% | 43% | 68% |
| 11 | Transportation to medical care | 62% | 45% | 73% |
| 12 | Medical care case management | 57% | 45% | 79% |
| 13 | HIV health insurance assistance | 54% | 48% | 88% |
| 14 | Food pantry | 45% | 41% | 91% |
| 15 | Prescription drug assistance | 39% | 36% | 93% |
| 16 | HIV Doctor | 28% | 27% | 96% |

## Service Needs Reported by PLWHA Who are Not-In-Care

PLWHA who are not-in-care, by definition, need primary HIV medical care. However, HRSA emphasizes the importance of assessing the needs of these PLWHA beyond their unmet need for medical care.[14] What services are needed PLWHA beyond their unmet need for medical care? This question is answered in this needs assessment by analyzing responses from self-administered surveys completed by PLWHA who report that they are not-in-care (N=56). Table 11 shows that dental care/oral health (92%), food pantry (82%), HIV health insurance assistance (78%) and prescription drug assistance (77%) are the most frequently reported services needed by PLWHA who are not-in-care.

**Table 11. Needed Services Reported by PLWHA Who are Not In HIV Care Rank Ordered According to "total need."**

| | **Service** | Total % of consumers who report **service as needed** | % of consumers who report that they **need and receive service** | % of consumers who report that they **need but do not receive service** |
|---|---|---|---|---|
| 1 | Dental care and oral health | 92% | 46% | 46% |
| 2 | Food pantry | 82% | 56% | 26% |
| 3 | HIV health insurance assistance | 78% | 59% | 19% |
| 4 | Prescription drug assistance | 77% | 51% | 26% |
| 5 | Support group | 70% | 28% | 42% |
| 6 | Transportation to medical care | 69% | 33% | 36% |
| 7 | Medical care case management | 61% | 36% | 25% |
| 8 | Respite care | 60% | 20% | 20% |
| 9 | Non-medical case management | 59% | 28% | 31% |
| 10 | Nutritional therapy | 57% | 15% | 42% |
| 11 | Mental health care/counseling | 55% | 33% | 22% |
| 12 | Utility assistance | 54% | 27% | 27% |
| 13 | Emergency housing | 39% | 24% | 35% |
| 14 | Treatment adherence services | 38% | 16% | 22% |
| 14 | Home health care | 38% | 20% | 18% |
| 15 | Alcohol/drug outpatient treatment | 36% | 12% | 24% |
| 16 | Alcohol/drug residential treatment | 34% | 12% | 21% |
| 17 | Hospice services | 33% | 18% | 15% |

[14] It is worth noting that it is only in reference to the service category "primary HIV medical care" that HRSA uses the term "unmet need."

Table 12 shows that the services most frequently reported as "needed and not received" by PLWHA who are not-in-care are dental care/oral health (46%), nutritional therapy (42%), support group (42%), transportation to medical care (36%) and emergency housing (35%). These findings are somewhat similar to those reported by consumers who have experienced interruptions in their HIV medical care (for example, emergency housing and transportation are extensively reported as "needed but not received" by both groups.)

**Table 12. Needed Services Reported by PLWHA Who are Not-In-Care Rank Ordered According to Services "needed but not received."**

| | **Service** | % of consumers who report that they **need but do not receive service** | % of consumers who report that they **need and receive service** | Total % of consumers who report **service as needed** |
|---|---|---|---|---|
| 1 | Dental care and oral health | 46% | 46% | 92% |
| 2 | Nutritional therapy | 42% | 15% | 57% |
| 2 | Support group | 42% | 28% | 70% |
| 3 | Transportation to medical care | 36% | 33% | 69% |
| 4 | Emergency housing | 35% | 24% | 39% |
| 5 | Non-medical case management | 31% | 28% | 59% |
| 6 | Utility assistance | 27% | 27% | 54% |
| 7 | Prescription drug assistance | 26% | 51% | 77% |
| 7 | Food pantry | 26% | 56% | 82% |
| 8 | Medical care case management | 25% | 36% | 61% |
| 9 | Alcohol/drug outpatient treatment | 24% | 12% | 36% |
| 10 | Mental health care/counseling | 22% | 33% | 55% |
| 10 | Treatment adherence services | 22% | 16% | 38% |
| 11 | Alcohol/drug residential treatment | 21% | 12% | 34% |
| 12 | Respite care | 20% | 20% | 60% |
| 13 | HIV health insurance assistance | 19% | 59% | 78% |
| 14 | Home health care | 18% | 20% | 38% |
| 15 | Hospice services | 15% | 18% | 33% |

Table 13 (next page) shows that when the degree of "total need" is taken into consideration, emergency housing (90%), nutritional therapy, (74%) outpatient (67%) and residential (62%) drug and alcohol treatment, and support group (60%), are the most frequently reported unmet service needs among PLWHA who are not-in-care.

**Table 13. Needed Services Reported by PLWHA Who are Not-In-Care Expressed as a % of "total need."**

| | Service | **need but do not receive** expressed as a % of **total need** | % of consumers who report that they **need but do not receive service** | Total % of consumers who report **service as needed** |
|---|---|---|---|---|
| 1 | Emergency housing | 90% | 35% | 39% |
| 2 | Nutritional therapy | 74% | 42% | 57% |
| 3 | Alcohol/drug outpatient treatment | 67% | 24% | 36% |
| 4 | Alcohol/drug residential treatment | 62% | 21% | 34% |
| 5 | Support group | 60% | 42% | 70% |
| 6 | Treatment adherence services | 58% | 22% | 38% |
| 7 | Transportation to medical care | 52% | 36% | 69% |
| 7 | Non-medical case management | 52% | 31% | 59% |
| 8 | Dental care and oral health | 50% | 46% | 92% |
| 8 | Utility assistance | 50% | 27% | 54% |
| 9 | Home health care | 47% | 18% | 38% |
| 10 | Hospice services | 45% | 15% | 33% |
| 11 | Medical care case management | 41% | 25% | 61% |
| 12 | Mental health care/counseling | 40% | 22% | 55% |
| 13 | Prescription drug assistance | 34% | 26% | 77% |
| 14 | Respite care | 33% | 20% | 60% |
| 15 | Food pantry | 32% | 26% | 82% |
| 16 | HIV health insurance assistance | 24% | 19% | 78% |

The data reported above suggest that considerable differences exist among the service needs and service gaps of the three different PLWHA survey samples (PLWHA in-care, PLWHA in-care who have experienced interruptions in their HIV care, and PLWHA who are not-in-care). These differences are worthy of further analysis because they may help us to understand the differences between these three different PLWHA populations, their service needs and gaps, and their respective barriers to care.

Tables 14, 15 and 16 (next several pages) compare the top responses provided by the three different PLWHA survey samples. These comparisons show that the service gap differences among these groups is subtle but evident. Service-need differences are most apparent when the responses provided by consumers with a history of interrupted care are compared to those of consumers with no history of interrupted care.[15] Services

[15] One might expect the differences to be greatest between consumers with no history of interrupted care and PLWHA who are not-in-care. However, PLWHA who are not-in-care consistently reported lower frequencies of needed services, services needed but not received, and services needed and received, relative to the two consumer groups. The counter-intuitive nature of this finding suggests that the validity of the service data provided by this group may be low.

associated with housing needs and social support are especially high among consumers with a history of interrupted care as compared to consumers with no history of interrupted care.

**Table 14. Comparison of Services Reported as "needed" by PLWHA Not-In-Care, PLWHA In-Care with a History of Interrupted Care, and PLWHA In-Care.**

| **Services Identified by PLWHA Not-In-Care** | Percentage reporting the service as "**needed**" (total need) |
|---|---|
| Dental care and oral health | 92% |
| Food pantry | 82% |
| HIV health insurance assistance | 78% |
| Prescription drug assistance | 77% |
| Support group | 70% |
| Transportation to medical care | 69% |
| Medical care case management | 61% |
| Respite care | 60% |
| **Services Identified by PLWHA In-Care with a History of Interrupted Care** | |
| HIV Doctor | 96% |
| Prescription drug assistance | 93% |
| Dental care and oral health | 91% |
| Food pantry | 91% |
| HIV health insurance assistance | 88% |
| Medical care case management | 79% |
| Utility assistance | 79% |
| Emergency housing | 77% |
| **Services Identified by PLWHA In-Care** | |
| Dental care and oral health | 93% |
| HIV Doctor | 91% |
| Prescription drug assistance | 88% |
| HIV health insurance assistance | 79% |
| Food pantry | 78% |
| Medical care case management | 68% |
| Utility assistance | 63% |
| Support group | 55% |

**Table 15. Comparison of Services Reported as "needed but not received" by PLWHA Not-In-Care, PLWHA In-Care with a History of Interrupted Care, and PLWHA In-Care.**

| **Services Identified by PLWHA Not-In-Care (N=56)** | Percentage reporting the service as "**needed but not received**" |
|---|---|
| Dental care and oral health | 46% |
| Nutritional therapy | 42% |
| Support group | 42% |
| Transportation to medical care | 36% |
| Emergency housing | 35% |
| Non-medical case management | 31% |
| Utility assistance | 27% |
| Prescription drug assistance | 26% |
| **Services Identified by PLWHA In-Care with a History of Interrupted Care (N=81)** | |
| Emergency housing | 59% |
| Utility assistance | 59% |
| Dental care and oral health | 58% |
| Support group | 50% |
| Non-medical case management | 50% |
| HIV health insurance assistance | 48% |
| Medical care case management | 45% |
| Transportation to medical care | 45% |
| **Services Identified by PLWHA In-Care (N=160)** | |
| Dental care and oral health | 42% |
| Utility assistance | 37% |
| Emergency housing | 30% |
| Support group | 20% |
| HIV health insurance assistance | 19% |
| Transportation to medical care | 17% |
| Nutritional therapy | 16% |
| Food pantry | 12% |

**Table 16. Comparison of Services Reported as "needed but not received" expressed as a percentage of "total need" by PLWHA Not-In-Care, PLWHA In-Care with a History of Interrupted Care, and PLWHA In-Care.**

| **Services Identified by PLWHA Not-In-Care** | **Service "needed but not received"** expressed as a % of "**total need**" |
|---|---|
| Emergency housing | 90% |
| Nutritional therapy | 74% |
| Alcohol/drug outpatient treatment | 67% |
| Alcohol/drug residential treatment | 62% |
| Support group | 60% |
| Treatment adherence services | 58% |
| Transportation to medical care | 52% |
| Non-medical case management | 52% |
| **Services Identified by PLWHA In-Care with a History of Interrupted Care** | |
| Alcohol/drug residential treatment | 78% |
| Treatment adherence services | 78% |
| Hospice services | 77% |
| Alcohol/drug outpatient treatment | 77% |
| Respite care | 77% |
| Emergency housing | 76% |
| Utility assistance | 75% |
| Home health care | 74% |
| **Services Identified by PLWHA In-Care** | |
| Emergency housing | 70% |
| Respite care | 64% |
| Utility assistance | 59% |
| Hospice services | 50% |
| Dental care and oral health | 45% |
| Nutritional therapy | 43% |
| Home health care | 40% |
| Support group | 36% |

## Service Needs Identified in Focus Groups with PLWHA Parents

Two separate focus groups were held with PLWHA male (N=12) and female (6) parents to identify services that are needed but not received. The following is a summary of the service needs identified by both male and female PLWHA parents:

- Psychosocial support for dealing with issues of fear of disclosure to children
- Emergency and long-term housing services, especially services that do not disqualify clients due to criminal records
- HIV/AIDS educational and psychosocial supportive services for their children
- Job training and employment opportunities, especially services that do not disqualify clients due to criminal records
- Community level education and awareness programs to reduce HIV/AIDS stigma

## Identifying Barriers to Accessing Needed Services

Why is the need for services often not being met? What are the barriers that keep consumers form accessing needed services? What do we know about how these barriers might be overcome?

These questions are addressed in this section of the report by using information provided by survey data provided by PLWHA who are in-care but who report that they experienced an interruption in their HIV medical care during at least one 12-month period during the past five years. By analyzing barriers identified by these consumers with a history of leaving, and returning to, care, we may be able to learn something about barriers to care and the things that help people return to care.[16]

Table 17 (page 53) shows that denial, substance use, fear of disclosure and homelessness are the most frequently reported barriers to care identified by PLWHA who have experienced interruptions in their HIV medical care. 48% of these PLWHA report that not being "ready to deal with HIV status" (a form of denial) is a barrier to staying in care. 38% report that drug or alcohol use is a barrier to staying in care. Fear of "being identified as HIV positive" (36%), or fear of disclosure, is also a barrier to staying in care. Homelessness is reported by 34% of the consumers as a barrier to accessing HIV care.

Table 18 (page 54) shows that becoming sick (39%), becoming emotionally ready to deal with illness (34%) and having someone else with HIV/AIDS reach out and help individual get into care (32%) are the most frequently reported reasons as to how consumers were able to get into, or return to, care. This finding underscores the importance of psychosocial support and outreach for addressing unmet need.

[16] A similar analysis of barriers to care and factors associated with returning to care was conducted with data collected from surveys completed by PLWHA who are not-in-care. However, because this population falls under the heading "unmet need" analysis of its barriers to care is presented in the section titled "assessing unmet need" in Section VI of this report.

**Table 17. Barriers to Care Identified by In-Care Consumers Who Report a History of Interrupted Care**

| Barriers to Care Identified by Consumers Who Experienced Interrupted Care in the Paste | Percentage of PLWHA who Identified Barrier (N=81)[17] |
|---|---|
| Individual was not ready to deal with HIV status. | 48% |
| Individual was using drugs or alcohol. | 38% |
| Individual was afraid of being identified as HIV positive. | 36% |
| Individual was homeless. | 34% |
| Individual couldn't afford care and didn't know I could get it without paying. | 33% |
| It was too hard to get services without transportation. | 32% |
| Individual had too many other things to worry about in life. | 20% |
| Individual had mental health problems. | 18% |
| Individual was in jail or prison and did not want to ask for care there. | 17% |
| Individual didn't know where to get care. | 16% |
| Individual had heard bad things about the medications and their side effects. | 15% |
| Individual had a bad experience with medications and did not want to take them. | 14% |
| It was too hard to get services due to long waits or inconvenient clinic hours. | 12% |
| Individual had a bad experience with doctors and other medical care providers. | 11% |
| There wasn't a medical facility near where individual lived. | 10% |
| The medical facility wasn't a good "fit" for individual's needs. | 7% |

[17] Percentages do not add up to 100% because respondents could select up to three of the most important barriers to accessing care.

**Table 18. How Individuals Who Experienced Interruptions in Care Were Able to Get Into or Return to Care**

| How Individual Was able to Get into or Return to Care in the Past | Percentage of Responses (N=81)[18] |
|---|---|
| Individual got sick and knew he/she needed care. | 39% |
| Individual was ready to deal with illness. | 34% |
| Someone else with HIV/AIDS reached out to individual and helped individual get into care. | 32% |
| Individual found a doctor or medical facility he/she liked. | 21% |
| Someone involved in individual's care followed up and got individual back in care. | 20% |
| A family member or friend helped individual get into care. | 20% |
| Individual was able to deal with other problems in his/her life that had kept individual out of care. | 20% |
| Individual got the information needed to get into care. | 18% |
| Individual got out of jail or prison. | 15% |
| Individual was able to get transportation to access care. | 15% |
| An outreach worker found individual and helped individual get into care. | 11% |
| Individual was able to access care because of more convenient clinic hours. | 11% |

[18] Percentages do not add up to 100% because respondents could select up to three of the most important factors that helped them to access care.

## Summary of Key Findings

- Dental care/oral health (42%), utility assistance (37%) and emergency housing (30%) are the services most frequently reported as "needed but not received" reported by consumers in-are with no history of uninterrupted care. When the frequency of "total need" is taken into consideration, the emergency housing is the most frequently reported unmet need among these consumers. In addition to emergency housing, respite care, utility assistance and hospice care are the services least likely to be received by in-care consumers reporting a need for such services.

- Consumers who have experienced an interruption in care during the past five years report significantly higher numbers of service needs compared to consumers who do not report interruptions in their HIV medical care. Emergency housing (59%) and utility assistance (59%) are the most frequently reported services that are "needed but not received," followed by dental care/ oral health (58%), support group (50%) and non-medical case management (50%). The need for emergency housing and utility assistance among these consumers is approximately *twice* that reported by consumers who have not experienced interruptions in their HIV care.

- The services most frequently reported as "needed and not received" by PLWHA who are not-in-care are dental care/oral health (46%), nutritional therapy (42%), support group (42%), transportation to medical care (36%) and emergency housing (35%). When the degree of "total need" is taken into consideration, emergency housing (90%), nutritional therapy, (74%) outpatient (67%) and residential (62%) drug and alcohol treatment, and support group (60%), are the most frequently reported unmet service needs among PLWHA who are not-in-care.

- A framework for estimating service gaps is developed in this assessment that uses self-reported consumer data and service utilization data reported from the Memphis TGA to HRSA. According to the framework based estimation of service gaps, the largest service gap is for emergency housing (70%), followed by utility assistance (66%), alcohol and drug outpatient treatment (64%), treatment adherence (58%), medical nutritional therapy (52%), medical transportation (47%) and psychosocial services (45%).

- Survey data collected from consumers with a history of interrupted care (N=81) show that denial, substance use, fear of disclosure and homelessness are the most frequently reported barriers to care. Becoming sick (39%), becoming emotionally ready to deal with illness (34%) and having someone else with HIV/AIDS reach out and help individual get into care (32%) are the most frequently reported reasons as to how consumers were able to get into, or return to, care. This finding underscores the importance of psychosocial support and outreach for addressing unmet need.

- The following services were identified as needed but not received by both male and female PLWHA parents in focus group discussions: 1) psychosocial support for dealing with issues of fear of disclosure to children, 2) emergency and long-term housing services, especially services that do not disqualify clients due to criminal records, 3) HIV/AIDS educational and psychosocial supportive services for affected children, 4) job training and employment opportunities, especially services that do not disqualify clients due to criminal records, and 5) community level education and awareness programs to reduce HIV/AIDS stigma.

# IV. Resource Inventory

HRSA requires Ryan White program needs assessments to include a resource inventory of both Ryan White and non-Ryan White area providers. This inventory allows the community to be aware of the types of services available in the grant area, where providers are located, and the client populations they serve.

While the resource inventory includes detailed descriptive information about Ryan White providers, the information it provides regarding non-Ryan White providers is especially important from the perspective of assessing, and addressing, service gaps and limited provider capacity. HRSA identifies two basic ways to increase provider capacity and address unmet need and service gaps: 1) service line expansion and 2) system expansion.[19] Service line expansion involves increasing funding to existing Ryan White funded agencies to increase the quantity of the services provided. In contrast, system expansion typically involves adding new Ryan White providers to the existing care network in order to address service gaps. Information collected from non-Ryan White providers provide is important because it allows planning bodies to a gain a general sense of the potential for system expansion.

The Community HIV Network maintains a detailed resource directory of service providers located throughout the Memphis TGA, which it has made available to the Memphis community. The resource directory is updated annually and aims to be exhaustive. At present the directory provides descriptive and contact information for 196 non-Ryan White and Ryan White programs and providers covering a wide range of medical and supportive services relevant to HIV care. This resource directory may be downloaded from the Friends for Life Corporation website at the following link: http://www.friendsforlifecorp.org/directory.htm

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[19] See the following article for a discussion of the difference between "service line expansion" and "system expansion": "Impact of the Ryan White CARE Act on the Availability of HIV/AIDS Services Journal," by Thomas G. Rundall, Jennafer Kwait, Katherine Marconi, Stephanie Bender-Kitz, David Celentano; Policy Studies Journal, Vol. 27, 1999.

**Inventory of Services Provided by Part A and Part B Providers in 2008**

Table 19 provides a summary of the services provided in the Memphis TGA by Part A and Part B providers in 2008.

**Table 19. Services Provided by Part A and Part B Providers in the Memphis TGA**

| Provider | Ryan White Services Provided | Location within TGA |
|---|---|---|
| Regional Medical Center- Adult Special Care | HIV outpatient care, medical care case management, medical transportation, mental health, medical nutritional therapy | **Shelby County, TN** (877 Jefferson Avenue, Memphis TN) |
| Christ Community Health Services | HIV outpatient care, medical care case management, medical transportation | **Shelby County, TN** (2953 Broad Avenue Memphis, TN) |
| East Arkansas Family Health Center, | HIV outpatient care, medical care case management, medical transportation, oral health, medical nutritional therapy, treatment adherence, food bank | **Crittenden County, AR** (215 East Bond Street West Memphis, AR) |
| Memphis Health Center | HIV outpatient care, medical care case management, medical transportation | **Shelby County, TN** 360 E. H. Crump Blvd. Memphis, TN |
| St, Jude Children's Research Hospital | HIV outpatient care, medical care case management, medical transportation, treatment adherence, mental health, psychosocial, medical nutritional therapy, health education/risk reduction | **Shelby County, TN** 262 Danny Thomas Place Mall 600, Memphis, TN |
| Friends For Life Corporation | Food bank, treatment adherence, psychosocial, medical nutritional therapy, health education/risk reduction, utility assistance, emergency housing, non-medical case management | **Shelby County, TN** 43 North Cleveland Memphis, TN |
| Family Services of the MidSouth, | Non-medical case management | **Shelby County, TN** 2430 Poplar Avenue Memphis, TN |
| Cocaine Alcohol Awareness Program | Substance abuse outpatient treatment | **Shelby County, TN** 4041 Knight Arnold Road, Suite 300, Memphis, TN |
| BioScrip Pharmacy | Treatment adherence, prescription drug assistance | **Shelby County, TN** 1424 Union Avenue Memphis, TN |
| Sacred Heart Southern Missions | Food bank | **De Soto County** 6050 Highway 161 North Walls, MS |

Table 20 (below) describes the distribution of Ryan White Part A and Part B services provided throughout the Memphis TGA in 2008 according to race/ethnicity, sex and age of consumers who received services.

**Table 20. Distribution of Ryan White Part A and Part B Services Provided Throughout the Memphis TGA According to Race/Ethnicity, Sex and Age of Consumers who Received Services in 2008**

| **Race/ethnicity** | Number of consumers who received Part A and Part B services in the Memphis TGA in 2008 reported by race/ethnicity | Number expressed as a percentage of total number |
|---|---|---|
| African American | 4,652 | 87% |
| Caucasian | 597 | 11% |
| Hispanic | 87 | 2% |
| Total | 5,336 | 100% |
| **Sex** | | |
| Male | 3,422 | 62% |
| Female | 2,051 | 37% |
| Transgendered | 23 | <1% |
| Total | 5,496 | 100% |
| **Age** | | |
| 13-24 years of age | 585 | 11% |
| 25-44 years of age | 2,941 | 55% |
| 45-64 years of age | 1,789 | 33% |
| ≥ 65 years of age | 68 | 1% |
| Total | 5,383 | 100% |

## Survey Data Collected from non-Ryan White Providers

A self-administered, online surveys was developed to collect data from non-Ryan White service providers. Effort was made to contact 71 non-Ryan White providers using contact information provided in the resource directory developed by the Community HIV Network. 23 providers were reached by phone and were asked to participate in the online survey. Nine (9) of these providers completed the online survey.[20]

[20] The Non-Ryan White area provider survey may be reviewed online at:

http://www.surveymonkey.com/s.aspx?sm=g9Jy7_2bcZHiv99prDgMcpXg_3d_3d

Non-Ryan White funded service providers were asked whether they presently provide any HIV/AIDS care or supportive services. Table 21 (below) shows that more than half of these providers presently offer HIV/AIDS services to their clients.

**Table 21. Does Agency Provide any HIV/AIDS Care or Supportive Services?**

| | **Percentage of Non-Ryan White Provider Responses (N=9)** |
|---|---|
| Yes | 57% |
| No | 43% |

Survey responses were also used to compare provider service capacity (the maximum number of clients the provider can serve) to the actual number of consumers presently served by the provider.[21] Table 22 shows that 75% of the providers are presently operating below full capacity.

**Table 22. Is Provider Serving At, Below, or Above its Service Capacity?**

| **Is provider serving at, below, or above its service capacity?** | **Percentage of Ryan White Provider Responses (N=9)[22]** |
|---|---|
| Provider is presently serving *at* full capacity | 12.5% |
| Provider is presently serving *above* full capacity more clients than it is staffed to serve | 12.5% |
| Provider is presently serving *below* full capacity | 75% |

[21] The amount of services a provider can deliver (i.e., the number of service units and the estimated number of clients who can be served).
[22] One provider did not respond to the survey questions that were compared to determine whether the provider is serving at, below, or above service capacity.

The non-Ryan White providers were asked whether their agency would consider applying for Ryan White Care Act funding to provide services to people living with HIV/AIDS. Only four of the nine providers responded to this question, and 2 of them (50%) indicated that their agency would consider would consider applying for Ryan White funding (see Table 23 below).

**Table 23. Would Provider Consider Applying for Ryan White Care Act Funding to Provide Services to People Living with HIV/AIDS?**

| | **Percentage of Ryan White Provider Responses (N=9)** |
|---|---|
| Yes | 50% |
| No | 50% |

Non-Ryan White Providers were also asked what barrier or concerns might make it difficult for their agency to consider applying for Ryan White Care Act funding. "Insufficient information about the program" and "limited size and relative newness of program" were two reasons provided by respondents to this question.

Non-Ryan White providers were also asked whether they thought their agency would be more likely to apply for Ryan White funding if free technical assistance were provided in support of completing the grant application process. Four of the five respondents answered "yes" to this question (see table 24 below).

**Table 24. Would Agency be More Likely to Apply for Ryan White Funding if Free Technical Assistance were Provided in Support of Completing the Grant Application Process?**

| | **Percentage of Ryan White Provider Responses (N=9)** |
|---|---|
| Yes | 80% |
| No | 20% |

## Summary of Key Findings

- 75% of the non-Ryan White providers responding to an online survey (N=9) reported that their agency is operating below full capacity. 50% of the respondents indicated that their agency would consider applying for Ryan White funding, and 80% of the respondents reported that their agency would be more likely to apply for Ryan White funding if free technical assistance were provided in support the grant application process.

# V. Provider Capacity and Capabilities

This section of the needs assessment provides information on the capacity of service providers in the Memphis TGA to meet the service needs of PLWHA. To what extent are needed services *available*, *accessible,* and *appropriate* to PLWHA overall and to specific population groups? In this section of the needs assessment a variety of data sources are used to assess the availability, accessibility and appropriateness of needed services.

## Assessing the *Availability* of Needed Services

How are we to determine the availability of needed services? In this needs assessment availability of needed services is estimated by using a two-step logical framework.[23] In step one service utilization data provided in the Ryan White HIV/AIDS Program Annual Data Report (RDR) are used to document the number of unduplicated consumers that accessed each service in the Memphis TGA in 2008.[24] The RDR is a valuable resource because it documents the unduplicated number and type of consumers that actually received specific services during the past calendar year. In step two, findings from the consumer survey (presented earlier in section III of this report) pertaining to services identified as "needed and received" and "needed and not received" are used to generate estimates of the provider capacity that is needed to meet the need for services reported by area consumers. Although the framework used for estimating service gaps relative to present service availability is limited (for example, it utilizes self-reported data from a convenience survey sample of consumers, N=81) it nevertheless provides a baseline for charting future progress regarding care system and service line expansion.

Table 25 (next page) presents an estimation of service gaps based on the estimation framework described above. The largest service gap is for emergency housing (70%), followed by utility assistance (66%), alcohol and drug outpatient treatment (64%), treatment adherence (58%), medical nutritional therapy (52%) and psychosocial services (45%).

[23] The principal researcher attempted to identify established frameworks for estimating service gaps, such as the one advocated by HRSA to estimate unmet need. However, this attempt was unsuccessful. For this reason a framework was developed that uses self-reported consumer data to derive estimated projections of service needs based on present service utilization data reported in the RDR.

[24] As part of its funding requirements, HRSA requires service providers funded by the Ryan White HIV/AIDS Program to complete the Ryan White HIV/AIDS Program Annual Data Report (RDR) detailing information on all the clients they served during the course of the calendar year.

## Table 25. Estimation of Service Gaps (Rank Ordered)

| Service Category | Total # of Unduplicated Clients Who Received Service in the Memphis TGA in 2008 | % of consumers who "need and receive" service expressed as a % of "total need"(N= 280) | Estimate of total number of consumers in Memphis TGA who need service | Formula Based Estimate of Service Gap[25] |
|---|---|---|---|---|
| Emergency housing (rent assistance) | 74 | 30% | 247 | 173 (70%) |
| Utility assistance (EFA) | 120 | 34% | 352 | 232 (66%) |
| Alcohol/drug outpatient treatment | 9 | 36% | 25 | 16 (64%) |
| Treatment adherence services | 752 | 42% | 1,790 | 1,038 (58%) |
| Medical nutritional therapy | 956 | 48% | 1,992 | 1,036 (52%) |
| Transportation to medical care | 792 | 53% | 1,494 | 702 (47%) |
| Psychosocial services (support groups, counseling) | 373 | 55% | 678 | 305 (45%) |
| Non-medical case management | 673 | 56% | 1,202 | 529 (44%) |
| Mental health care | 396 | 59% | 671 | 275 (41%) |
| Medical care case management | 2,856 | 71% | 4,022 | 1,166 (29%) |
| Food pantry | 1,035 | 73% | 1,418 | 383 (27%) |
| ADAP & IAP | 624 | 74% | 843 | 219 (26%) |
| Primary HIV medical care | 2,073 | DNA | DNA | DNA |
| Health education/risk reduction | 742 | NA | NA | NA |
| Oral health | NA[26] | NA | NA | NA |

[25] This estimation is based on the following formula: A = number of unduplicated consumers receiving service in 2008; B = % of consumers reporting service as "needed and received" expressed as a % of "total need" reported for service; C = 100/B; D (estimated number of total consumers that need service) = A x C; E (estimated service gap) = D – A.

[26] Due to changes in the management of Ryan White dental funding in fiscal 2008 a total number of clients receiving Ryan White funded oral health in the Memphis TGA is not available. Due to an increase in funding in this service category funding did not run out during the grant year and there was no need to

Assessing the availability of needed services also involves an analysis of data provided by local Ryan White providers who completed a self-administered online survey (N=8). Survey responses are used to compare provider service capacity (the maximum number of clients the organization can presently serve) and the actual number of consumers presently served by the organization.[27]

A self-administered, online survey was completed by eight Ryan White Memphis TGA providers.[28] Survey respondents were asked to specify the number of Ryan White consumers its agency presently serves, and also, the total number of clients the provider could serve (provider capacity). Responses to these two questions to determine the capacity status of the providers. Table 26 (below) indicates that only one of theses providers reports being below full capacity. 37% of he providers report that they are presently at full capacity, and 50% report that they are presently serving more consumers than they are designed or staffed to serve.

**Table 26. Self-reported Capacity Status of Ryan White Providers**

| | **Percentage of Ryan White Provider Responses (N=8)** |
|---|---|
| Provider is presently serving at full capacity | 37.5% (3 providers) |
| Provider is presently serving more clients than it is staffed to serve | 50% (4 providers) |
| Provider is presently serving below full capacity | 12.5% (1 provider) |

## How easy is it for PLWHA to *access* services?

HRSA emphasizes the importance of assessing the accessibility of services. The accessibility of services was assessed in this study by analyzing data collected from an online survey completed by providers (N=8). Providers were asked to identify barriers that their organization has experienced which limit client access to services. Responses to this question are summarized Table 27 (next page). Transportation was identified by 67.5% of the providers, followed by insufficient staff size (50%) and missed appointments (50%).

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create a "wait list" for oral health care as there had been in past years.

[27] The amount of services a provider can deliver (i.e., the number of service units and the estimated number of clients who can be served).

[28] The Ryan White provider survey may be reviewed online at: http://www.surveymonkey.com/s.aspx?sm=FcWykzE9TA3l2I9NTgMBiQ_3d_3d

**Table 27. Barriers Identified by Providers That Limit Access to Services**

| Barriers that Limit Access to Services | Percentage of Ryan White Provider Responses (N=8) |
|---|---|
| Transportation | 62.5% |
| Insufficient staff | 50% |
| Missed appointments | 50% |
| Substance abuse | 37.5% |
| Cultural differences | 37.5% |
| Homelessness | 37.5% |
| Lack of community partnerships | 25% |
| Distrust or suspicion among clients | 12.5% |
| Confidentiality or HIPPA issues | 12.5% |
| Insurance provider restrictions or limits | 12.5% |

Ryan White providers were also asked whether they provide evening or weekend hours to their clients. Only one provider has weekend or evening hours (12.5%) (see table 28 below).

**Table 28. Does Provider Offer Evening or Weekend Hours?**

| | Percentage of Ryan White Provider Responses (N=8) |
|---|---|
| Yes | 12.5% |
| No | 87.5% |

Providers were also asked whether they provide walk-in or same-day appointments. All but one provider reported that they do provide walk-in or same-day appointments (see Table 29 below).

**Table 29. Does Provider Offer Walk-in or Same Day Appointments?**

| | Percentage of Ryan White Provider Responses (N=8) |
|---|---|
| Yes | 87.5% |
| No | 12.5% |

## Sub-Population Accessibility to Services in the Memphis TGA

Providers were asked to describe the demographic profile of the consumer populations they serve. This information was used to help assess the accessibility of services among special populations in the Memphis TGA. The following is a summary of main observations drawn from the data provided:

- On average the demographic profile of the populations served by providers is similar to the demographic profile of the population of people living with HIV/AIDS. For example, on average the population served by all providers is approximately 85-90% African American and 10-15% Caucasian; and 65% male and 35% female. This profile is consistent with the demographic profile documented in the RDR report provided by Shelby County cited earlier in this report.

- Only one provider (a non-medical service provider) targets consumers living in the four Northern Mississippi Counties, and no providers specifically target consumers living in the rural counties of Fayette and Tipton, Tennessee. In short, with the exception of Crittenden County, Arkansas, accessibility is a significant problem in the rural counties that are part of the Memphis TGA.

## How *Appropriate* Are Services for Specific Populations of PLWHA?

HRSA emphasizes the importance of assessing the cultural appropriateness of the services provided to clients, especially with regard to diverse client sub-populations.[29]

The appropriateness of services includes but is not limited to the languages spoken by clients. Providers were asked to identify the different ways it accommodates the language needs of non-English speaking clients. Table 30 (next page) shows that 25% of the providers tries to hire staff members who speak languages other than English. 75% of the providers ensure that translators are available to clients when needed, and 37.5% of the providers provide patient information materials that are translated into different languages. One respondent commented that even though her organization provides translators when services are being provided language barriers continue to be a barrier to appointment scheduling.

[29] Considerations of appropriateness include client sub-populations that are unique in terms of minority ethnic identity, sexual identity and any identifying characteristic that might require culturally sensitive treatment.

**Table 30. Ways in Which Provider Serves Non-English Speaking Clients**

| Ways in Which Provider Serves Non-English Speaking Clients | Percentage of Ryan White Provider Responses (N=8) |
|---|---|
| Provider hires staff members who speak languages other than English | 25% |
| Provider ensures that translators are available to clients when needed | 75% |
| Provider translates patient materials into different languages | 37.5% |

Providers were asked to list the languages of any client populations whose language needs are proving difficult for their agency to meet. 37.5% of the providers responded that they are not experiencing difficulty serving non-English speaking clients. 37.5% of the providers report that Spanish speaking clients are proving difficult to serve, and 25% report difficulty meeting the language needs of French clients (see Table 31 below).

**Table 31. Ways That Provider Serves Non-English Speaking Clients**

| Ways in Which Provider Serves Non-English Speaking Clients | Percentage of Ryan White Provider Responses (N=8) |
|---|---|
| None | 37.5% |
| Spanish | 37.5% |
| French | 25% |

Providers were also asked to provide any comments they might have regarding provider capacity and barriers to care. The comments provided are listed below:

- One provider stated that limited staff makes it difficult to meet the transportation needs of clients.
- The scarcity of transportation options in Northern Mississippi was identified by one provider as a significant barrier to care for clients living in that area.

- One provider stated that untimely program reimbursements undermined the provider's ability to provide services as planned.

- One provider mentioned the need to document the service needs of recently incarcerated and homeless PLWHA in order to support funding requests for programs and services that target these sub-populations.

- One provider mentioned that the limited number of specialty providers makes it difficult to provide services to all patients.

## Summary of Key Findings

- Responses to an online survey completed by eight Ryan White Memphis TGA providers indicate the need to increase their capacity to provide services (N=8). 50% report that they are presently serving more consumers than they are designed or staffed to serve and 37% report that they are presently at full capacity. Only one of theses providers reports being below full capacity.

- Respondents identified the following factors that undermine client accessibility to services: transportation (67.5%), insufficient staff size (50%), missed appointments (50%), homelessness, substance abuse, and cultural differences (37.5% each).

- Only one Ryan White provider has weekend or evening hours (12.5%).

- Only one provider (a non-medical service provider) is located in Northern Mississippi, and no providers are located in Fayette or Tipton Counties. In short, with the exception of Crittenden County, Arkansas, accessibility is a significant problem in the rural counties that are part of the Memphis TGA.

- 25% of the providers try to hire staff members who speak languages other than English. 75% of the providers ensure that translators are available to clients when needed, and 37.5% of the providers provide patient information materials that are translated into different languages. One respondent commented that even though her organization provides translators when services are being provided language barriers continue to be a barrier to appointment scheduling.

- One provider mentioned that the limited number of specialty providers makes it difficult to provide services to all patients.

# VI. Estimation and Assessment of Unmet Need

The Ryan White HIV/AIDS Treatment Modernization Act of 2006 requires all Grantees and planning bodies to estimate how many people in their service areas know they are HIV- positive but are not receiving regular HIV-related primary medical care. The technical term used by HRSA to refer to the care-status of this population is *unmet need. "Unmet need" refers to the segment of the PLWHA population that knows its HIV-positive status but is not receiving primary medical care.*

Estimating unmet need is important because it provides a starting point for developing a strategy for identifying PLWHA who are out of care, determining the barriers that prevent them from accessing care, and developing a process for addressing these barriers and bringing them into care.

HRSA's policy regarding *unmet need* may be summarized in terms of three specific requirements:[30]

1. *Estimating* the number of people in the TGA service area who know they are HIV-positive but are not in care.

2. *Assessing* the service needs and barriers to care for such people, including finding out who they are and where they live.

3. *Addressing* unmet need by finding these individuals and getting them into care.

This needs assessment addresses the first two of these HRSA requirements – estimating unmet need and assessing their service gaps and barriers to care. It is the responsibility of the Part A and Part B planning bodies to utilize this information to identify PLWHA who are out of care and get them back into care.

## Estimation of Unmet Need

A framework for estimating unmet need was developed by the University of California at San Francisco (UCSF) and is used by the HIV/AIDS Bureau to estimate unmet need. The framework involves three steps: 1) determining the total number of PLWHA identified as HIV-positive in the service area, 2) determining the total number of PLWHA who have received primary HIV related medical care during the past 12 months, and 3) subtracting the number of people in care from the total number of PLWHA and expressing this difference as a percentage. This framework is presented below in table 2.

[30] This summary of HRSA's policy on *unmet need* and the framework for estimating *unmet need* is based on technical assistance documents provided by HRSA and materials provided to local planning bodies and the needs assessment consultant by Emily Gantz McKay of Mosaica, Inc.

**Table 32. Estimation of Unmet Need for Memphis TGA 2008**

| Input | Value | Data Sources |
|---|---|---|
| **Population Sizes** | | |
| A. Number of persons living with HIV/AIDS in the eight county Memphis TGA as of December 31, 2008.[31] | 6,653[32] | TN, MS and AR State Health Departments/ HIV/AIDS Reporting System |
| **Care Patterns** | | |
| B. Number of PLWHA who met the definition of "in care" during 2008 and received HIV medical care from Ryan White providers. | 2,073 | RDR service unit utilization numbers as entered by Provider agencies |
| C. Number of PLWHA who met the definition of "in care" during 2008 and received HIV medical care from non-Ryan White providers. | 998 | Estimate based on 15% of identified PLWHA population (15% of 6,653). |
| **Calculations** | | |
| D. Estimated Number of PLWHA in-care in 2008 | 3,071 | B + C = 3,071 |
| E. Estimated number and percentage of identified PLWHA who were not "in care" during 2008. | 3,582<br>54%[33] | A – D = 3,582<br>3,582/6,653 = 54% |

[31] HRSA recommends that a distinction be maintained between People Living with HIV (non-AIDS/aware) and People Living with AIDS and that these values be presented separately before being combined in order to estimate total unmet need. The reason for this recommendation is that AIDS care is more expensive than HIV (non-AIDS) care and knowing the respective sizes of these out of care populations is an important planning consideration. In this analysis a distinction between people living with HIV (non-AIDS/aware) and people living with AIDS is not made because the data were only available in combined form.

[32] This figure was computed by adding the 2008 PLWHA data from Shelby, Fayette and Tipton Counties in Tennessee (6,067), Tate, Marshall, De Soto and Tunica Counties in Mississippi (372), and Crittenden County, Arkansas (214).

[33] This estimate becomes reduced if the estimate of the % of PLWHA in private care is increased. For example, if the estimate of the % of PLWHA in private care is increased from 15% to 20%, then the estimate of the number of out of care identified PLWHA is reduced to 3,250 or 49% of the total number of PLWHA. If the private care estimate is increased to 25%, the estimate of the number of out of care PLWHA is reduced further to 2,917 or 44% of the total PLWHA population.

According to the unmet need framework used in this study it is estimated that 3,582 PLWHA (54%) were not-in-care in the Memphis TGA in 2008. It should be emphasized that this estimate used outpatient medical care utilization data as an indicator of "in-care" status, and not laboratory reported data, as suggested by HRSA (laboratory data are not presently made available to the researchers that conduct this needs assessment).

This percentage of unmet need in the Memphis TGA may be compared in a general sense to estimates of unmet reported by other Ryan White program areas. Unmet need in the state of Michigan between 2007 and 2008 was estimated to be 40%, with certain areas having considerably higher levels of unmet need (for example, 51% in Saginaw Bay, 49% in Benton Harbor and 47% in Jackson).[34] A report published by the State of North Carolina estimated unmet need in the state to be 38% in 2007. The report, however, does not describe how the estimate varies from city to city or regionally within the state.[35]

## Assessment of Unmet Need

Assessing unmet need was accomplished by analyzing self-administered surveys completed by PLWHA who are classified as "not in care" according to HRSA's operational definition.[36] A team of consumer volunteers were trained in the methodology and ethics of community survey research and distributed and returned ninety-four (94) surveys completed by PLWHA in the Memphis TGA. Fifty-six (56) of these survey respondents met the HRSA definition of "not-in-care" and the remainder (38 respondents) met the criteria for not having been in care at some point during the past five years (data from these 38 surveys were are reported in the section on interrupted care in section III).

Table 33 (next page) shows that denial, substance use, fear of disclosure and homelessness are the most frequently reported barriers to care identified by PLWHA who have experienced interruptions in their HIV medical care. 27% of these PLWHA report that not being "ready to deal with HIV status" (a form of denial) is a barrier to getting into care. Fear of "being identified as HIV positive" (18%), or fear of disclosure, is the second most frequently reported barrier to being in care. 12% report that drug or alcohol use is a barrier to getting into care, and 11% identified homelessness as a barrier to getting into care.

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[34] This report may be accessed online at:
http://www.michigan.gov/documents/mdch/Title_II_FY2009_UN_Narrative_259407_7.pdf

[35] This report may be accessed online at:
http://www.epi.state.nc.us/epi/hiv/epiprofile1008/Chapter_7.pdf

[36] According to HRSA an individual identified with HIV or AIDS is considered to have an **unmet need for care** (or to be **out of care**) when there is no evidence that s/he received *any* of the following three components of HIV primary medical care during a defined 12-month time frame: a) viral load (VL) testing, b) CD4 count, or c) provision of anti-retroviral therapy (ART). A person is considered to be **in care** when there is evidence of *any one or more* of these three measures during the specified 12-month time period.

**Table 33. Barriers to Care Identified by PLWHA Who Are Not in Care**

| Barriers to Care Identified by PLWHA Who Are Not in Care | Percentage of PLWHA who Identified Barrier (N=56)[37] |
|---|---|
| Individual was not ready to deal with HIV status. | 27% |
| Individual was afraid of being identified as HIV positive. | 18% |
| Individual was using drugs or alcohol. | 12% |
| Individual had too many other things to worry about in life. | 12% |
| Individual didn't know where to get care. | 12% |
| Individual was homeless. | 11% |
| It was too hard to get services without transportation. | 9% |
| Individual couldn't afford care and didn't know I could get it without paying. | 7% |
| Individual had heard bad things about the medications and their side effects. | 7% |
| Individual was in jail or prison and did not want to ask for care there. | 7% |
| Individual had a bad experience with medications and did not want to take them. | 7% |
| Individual had a bad experience with doctors and other medical care providers. | 4% |
| The medical facility wasn't a good "fit" for individual's needs. | 4% |
| There wasn't a medical facility near where individual lived. | 2% |
| Individual had mental health problems. | 2% |
| It was too hard to get services due to long waits or inconvenient clinic hours. | 1% |

[37] Percentages do not add up to 100% because respondents could select up to three of the most important barriers to accessing care.

PLWHA who are out of care were asked how they were able to get into care, or return to care, in the past. Table 34 (below) shows that receiving information about getting into care (14%), having someone else with HIV/AIDS reach out and help individual get into care (12%), or being contacted by someone involved in the individual's past care (9%) were the most frequently reported reasons as to how consumers were able to get into, or return to, care. This finding underscores the importance of outreach for addressing unmet need.

**Table 34. How Individual Was Able to Get into or Return to Care in the Past**

| How Individual Was able to Get into or Return to Care in the Past | Percentage of Responses (N=56)[38] |
|---|---|
| Individual got the information needed to get into care. | 14% |
| Someone else with HIV/AIDS reached out to individual and helped individual get into care. | 12% |
| Someone involved in individual's care followed up and got individual back in care. | 9% |
| Individual found a doctor or medical facility he/she liked. | 7% |
| A family member or friend helped individual get into care. | 7% |
| Individual got sick and knew he/she needed care. | 7% |
| Individual was ready to deal with illness. | 7% |
| Individual got out of jail or prison. | 5% |
| Individual was able to deal with other problems in his/her life that had kept individual out of care. | 2% |
| An outreach worker found individual and helped individual get into care. | 2% |
| Individual was able to get transportation to access care. | 0% |
| Individual was able to access care because of more convenient clinic hours. | 0% |

[38] Percentages do not add up to 100% because respondents could select up to three of the most important factors that helped them to access care.

## Summary of Key Findings

- Unmet need (number of identified PLWHA who are not-in-care) was estimated by using a modified version of the framework for estimating unmet need developed by researchers at the University of California at San Francisco and recommended by HRSA. According to the unmet need framework used in this study it is estimated that 3,582 PLWHA (54%) were not-in-care in the Memphis TGA in 2008. This figure is somewhat higher than estimates reported in other Ryan White program areas such as St. Louis, MO, and urban areas of Michigan.

- Assessment of barriers to care for PLWHA who are not-in-care was completed by analyzing responses collected through the PLWHA not-in-care survey (N=56). Denial, substance use, fear of disclosure and homelessness are the most frequently reported barriers to care identified by PLWHA who have experienced interruptions in their HIV medical care. 27% of these PLWHA report that not being "ready to deal with HIV status" (a form of denial) is a barrier to getting into care. Fear of "being identified as HIV positive" (18%), or fear of disclosure, is the second most frequently reported barrier to being in care. 12% report that drug or alcohol use is a barrier to getting into care, and 11% identified homelessness as a barrier to getting into care.

- PLWHA who are out of care were asked how they were able to get into care, or return to care, in the past. Receiving information about getting into care (14%), having someone else with HIV/AIDS reach out and help individual get into care (12%), or being contacted by someone involved in the individual's past care (9%) were the most frequently reported reasons as to how consumers were able to get into, or return to, care. This finding underscores the importance of outreach for addressing unmet need.

## Appendix A

# The 2009 Memphis "Consumer – in Care" Needs Assessment Survey

Taking this survey is completely voluntary. The information you provide will be used to improve services for people living with HIV/AIDS in our area. In order to protect your privacy and ensure that the information you provide is anonymous, do not put your name on the survey.

**PLEASE DO NOT COMPLETE THIS SURVEY IF YOU HAVE ALREADY COMPLETED ONE!**

1. What is your race/ethnicity? (You may check more than one category.)

___ [1] African American/Black
___ [2] White
___ [3] Hispanic
___ [4] Asian/Pacific Islander
___ [5] American Indian/Native American
___ [6] Other:_____

2. Are you male, female or transgendered?

___ [1] Male ___ [2] Female ___ [3] Transgendered

3. What year were you born? _____

4. In the table below please put a check in the space that indicates whether you need and receive a particular service, need but do not receive the service, or do not need the service.

| Medical and Supportive Services | I need and receive service | I need but I don't receive service | I don't need this service |
|---|---|---|---|
| HIV doctor | | | |
| Prescription drug assistance | | | |
| Dental care and oral health | | | |
| HIV health insurance assistance | | | |
| Home health care | | | |
| Nutritional therapy | | | |
| Hospice services | | | |
| Mental health care/counseling | | | |
| Treatment adherence services | | | |
| Alcohol/drug outpatient treatment | | | |
| Alcohol/drug residential treatment | | | |
| Medical care case management | | | |
| Non-medical case management | | | |
| Transportation to medical care | | | |

| | | | |
|---|---|---|---|
| Respite care | | | |
| Utility Assistance | | | |
| Emergency housing | | | |
| Food pantry | | | |
| Support group | | | |
| Other (specify) | | | |

5. During the past 12 months, have you had at least one of the following: a CD4 count, a viral load test, or a prescription for HIV medication?

___ No If you answered "NO" please turn this sheet over and continue this survey.

___ Yes If you answered "YES," has there been a period of at least 12 months over the past 5 years when you *did not* receive one of the following: a CD4 count, a viral load test, or a prescription for HIV medication?

___ Yes If "YES," please turn this sheet over and complete page two.

___ No If "NO," you have now completed this survey. Please return the survey to the person who gave it to you. Thank you for completing this survey!

6. What best describes your situation during that period in which you were not receiving HIV medical care? Check the response that best fits your situation.

___ I had recently been diagnosed with HIV, and had not entered primary care.
___ I had been receiving medical care for HIV, but I dropped out of care.
___ Other (please explain _____)

7. What zip code or neighborhood did you live in during the period when you were out of care? _____ What zip code or neighborhood do you live in now? _____

8. Why were you not receiving primary medical care during that period? Please identify up to three reasons that you consider the most important in explaining why you were not in care.

___ I couldn't afford care and didn't know I could get it without paying.
___ I didn't know where to go to get care.
___ I was not ready to deal with my HIV status.
___ I was afraid of being identified as HIV-positive.
___ I had heard bad things about the medications and their side effects.
___ I was in jail or prison and didn't want to ask for care there.
___ There wasn't a medical facility near where I lived.
___ It was too hard to get services without transportation.

___ It was too hard to get services due to long waits or inconvenient clinic hours.
___ I had too many other things to worry about in my life.
___ I was homeless.
___ I was using drugs or alcohol.
___ I had mental health problems.
___ I had a bad experience with a doctor or other medical staff.
___ The medical facility wasn't a good "fit" for my needs.
___ I had a bad experience with my medications and didn't want to take them.
___ Other (please explain _____)

9. Tell us more about what caused you to be out of care.

10. What caused you to get back into care? Please identify and check up to three main reasons.

___ I got sick and knew I needed care.
___ I was ready to deal with my illness.
___ I got the information I needed to get into care.
___ I found a doctor or medical facility I liked.
___ A family member or friend helped me get into care.
___ Someone else with HIV/AIDS reached out to me and helped me get into care.
___ An outreach worker found me and helped me get into care.
___ Someone involved in my care followed up and got me back in care.
___ I was able to get transportation to access care.
___ I was able to access care because of more convenient clinic hours.
___ I got out of jail or prison.
___ I was able to deal with other problems in my life that had kept me out of care.
___ Other (explain _____)

11. Tell us more about how you got back into care.

**YOU HAVE NOW COMPLETED THE SURVEY! PLEASE RETURN THE COMPLETED SURVEY TO THE PERSON WHO GAVE IT TO YOU. THANK YOU!**

## Appendix B

### The 2009 Memphis "PLWHA – Not in Care" Needs Assessment Survey

Taking this survey is completely voluntary. The information you provide will be used to improve services for people living with HIV/AIDS in our area. In order to protect your privacy and ensure that the information you provide is anonymous, do not put your name on the survey.

**PLEASE DO NOT TAKE THIS SURVEY IF YOU HAVE ALREADY COMPLETED ONE!**

1. During the past 12 months, have you had at least one of the following: a CD4 count, a viral load test, or a prescription for HIV medication?

___ No If you answered "NO" please go to question # **2** and continue the survey.

___ Yes If you answered "YES," has there been a period of at least 12 months over the past five years when you were *not* receiving one of the following: a CD4 count, a viral load test, or a prescription for HIV medication?

___ Yes If "YES," please go to question # **2** and continue the survey.

___ No If "NO," you have now completed this survey. Please return the survey to the person who gave it to you. Thank you for completing this survey!

2. What best describes your situation during that period in which you were not receiving HIV medical care? Check the response that best fits your situation.

___ I had recently been diagnosed with HIV, and had not entered primary HIV care.
___ I had been receiving primary medical care for HIV, but I dropped out of care.
___ Other (please explain
_____ )

3. What zip code or neighborhood did you live in during the period when you were out of care? _____ What zip code or neighborhood do you live in now? _____

4. Why were you not receiving primary medical care during that period? Please identify up to three reasons that you consider the most important in explaining why you were not in care.

___ I couldn't afford care and didn't know I could get it without paying.
___ I didn't know where to go to get care.
___ I was not ready to deal with my HIV status.
___ I was afraid of being identified as HIV-positive.
___ I had heard bad things about the medications and their side effects.
___ I was in jail or prison and didn't want to ask for care there.
___ There wasn't a medical facility near where I lived.
___ It was too hard to get services without transportation.
___ It was too hard to get services due to long waits or inconvenient clinic hours.
___ I had too many other things to worry about in my life.
___ I was homeless.
___ I was using drugs or alcohol.
___ I had mental health problems.
___ I had a bad experience with a doctor or other medical staff.
___ The medical facility wasn't a good "fit" for my needs.
___ I had a bad experience with my medications and didn't want to take them.
___ Other (please explain _____ )

5. Tell us more about what caused you to be out of care.

6. What caused you to get back into care? Please identify and check up to three main reasons.

___ I got sick and knew I needed care.
___ I was ready to deal with my illness.
___ I got the information I needed to get into care.
___ I found a doctor or medical facility I liked.
___ A family member or friend helped me get into care.
___ Someone else with HIV/AIDS reached out to me and helped me get into care.
___ An outreach worker found me and helped me get into care.
___ Someone involved in my care followed up and got me back in care.
___ I was able to get transportation to access care.
___ I was able to access care because of more convenient clinic hours
___ I got out of jail or prison.
___ I was able to deal with other problems in my life that had kept me out of care.
___ Other (explain _____)

7. Tell us more about how you got back into care.

8. What is your race/ethnicity? (You may check more than one category.)

___ [1] African American/Black
___ [2] White
___ [3] Hispanic
___ [4] Asian/Pacific Islander
___ [5] American Indian/Native American
___ [6] Other:_____

9. Are you male, female or transgendered?

___ [1] Male ___ [2] Female ___ [3] Transgendered

10. What year were you born? _____

11. In the table below please put a check in the space that indicates whether you need and receive a particular service, need but do not receive the service, or do not need the service.

| **Medical and Supportive Services** | **I need and receive service** | **I need but I don't receive service** | **I don't need this service** |
|---|---|---|---|
| HIV doctor | | | |
| Prescription drug assistance | | | |
| Dental care and oral health | | | |
| HIV health insurance assistance | | | |
| Home health care | | | |
| Nutritional therapy | | | |
| Hospice services | | | |
| Mental health care/ counseling | | | |
| Treatment adherence services | | | |
| Alcohol/drug outpatient treatment | | | |
| Alcohol/drug residential treatment | | | |
| Medical care case management | | | |
| Non-medical case management | | | |
| Transportation to medical care | | | |
| Respite care | | | |
| Utility Assistance | | | |
| Emergency housing | | | |
| Food pantry | | | |
| Support group | | | |
| Other (specify): | | | |

**THANK YOU FOR COMPLETING THIS SURVEY!**
**PLEASE RETURN IT TO THE PERSON WHO GAVE IT TO YOU**

## Appendix C

**Training Session for Consumer Volunteers**
**Administering the Memphis "PLWHA – Not in Care" Survey**

February 2, 2009

Prepared by
Thomas G. McGowan, Ph. D.

Presented at Friends For Life Corporation

## Training Session Outline

I. Introduction and Project Overview

II. Ethical Considerations and Requirements

Tuskegee and the importance of ethics in research
Ethical requirements

III. Procedural Requirements

IV. Reviewing the Survey

Self administering the survey
Survey help sheet

V. Administering the Survey

Role-play
Discussion and questions

VI. Summary, Evaluation and Conclusion

Summary of key points
Volunteer letter of agreement
Review of project calendar

## I. Introduction and Project Overview

Thank you for volunteering to distribute outreach surveys as part of the Memphis Area 2009 HIV/AIDS Needs Assessment. The purpose of the survey is to collect information from people living with HIV/AIDS (PLWHA) who *are not* receiving HIV medical care, and people who have experienced interruptions in their HIV care in the past. Learning *why* these people have trouble accessing care, and *what* might help them access care, will assist the health department and other providers to develop strategies for getting people into care.

Please consider carefully whether you are both willing and able to serve as a consumer volunteer on this project. Your role is not difficult, but it carries a great responsibility. It is very important that you understand these responsibilities and follow them to the best of your ability. Your main responsibility is to carefully follow the ethical and procedural requirements specified in this training session.

You will receive a $50 stipend as an incentive to participate in this project. The stipends will be paid in the form of gift cards. You will receive half of this stipend (a $25 gift card) when we meet to collect completed surveys and discuss our progress on Wednesday, February 18th. You will receive the other half of your stipend (a $25 gift card) when we meet to collect additional surveys and discuss the completion of the project on Wednesday, March 18th. You must return a minimum of 5 completed surveys before the project ends on March 18th to receive the second half of your stipend.

All participants must successfully complete this training session in order to participate in this project. There are no exceptions to this requirement. It is our hope that this project will be successful and that it will mark the beginning of a new strategy of engaging consumer volunteers to assist with the work of our annual needs assessment in Memphis.

## II. Ethical Requirements

It is very important that you administer the survey in an ethical manner. This section defines key ethical requirements and explains their importance.

In order to appreciate the importance of ethics in research we will consider the Tuskegee Syphilis Study.[39] The Tuskegee Syphilis Study was a clinical study, conducted around Tuskegee, Alabama, where 399 poor -- and mostly illiterate -- African American sharecroppers became part of a study on the treatment and normal progression of syphilis.

This study became notorious because it was conducted without due care to its subjects, and led to major changes in how patients are protected in clinical studies. Individuals enrolled in the Tuskegee Syphilis Study did not give informed consent and were not informed of their diagnosis; instead they were told they had "bad blood" and could receive free treatment, a free ride to the clinic, one hot meal per day, and, in the event of death, $35 (later raised to $50) for the funeral.

By 1947, penicillin had become the standard treatment for syphilis. Prior to this discovery, syphilis frequently led to a chronic, painful and fatal multisystem disease. Rather than treat all syphilitic subjects with penicillin and close the study, the Tuskegee scientists withheld penicillin or information about penicillin, purely to continue to study how the disease spreads and kills. Participants were also prevented from accessing syphilis treatment programs that were available to other people in the area. The study continued until 1972, when a leak to the press resulted in its termination.

By the end of the study, only 74 of the test subjects were still alive. Twenty-eight of the men had died directly of syphilis, 100 were dead of related complications, 40 of their wives had been infected, and 19 of their children had been born with congenital syphilis.

Sociological studies show that the Tuskegee Syphilis Study has caused many African Americans to distrust medical and public health providers. The study has likely contributed to low participation of African Americans in clinical trials and organ donation efforts and their tendency not to seek routine preventive care.

The Tuskegee Syphilis Study is often cited as one of the greatest ethical breaches of trust between physicians and patients in the setting of a clinical study in the United States. As a result of Tuskegee, the government created laws to ensure that research conducted with human subjects is ethical. All research involving human subjects must now be overseen by a group of professionals to ensure that researchers comply with established ethical guidelines. This project is overseen by the needs assessment committees of the Planning Council (established by the Memphis Shelby

[39] This description is an edited version of material presented on Wikepedia and other electronic sources.

County Health Department) and the Mid South Coalition on HIV/AIDS (convened by the United Way of the Mid South).

The lessons learned from Tuskegee include:

- **informed consent** [people must be told the truth about the purpose of the research and the risks associated with participation in the research]

- **voluntary participation** [people must be given the freedom to refuse participation; they must not be pressured or coerced into participation]

- **privacy protection** [personal information, especially identifying information, of people participating in research must be protected]

    - Confidential research: the researcher knows the identity of the person but is bound to protect the person's identity and personal information.
    - Anonymous research: the researcher does not know the person's identity and ensures that no identifying information is written on surveys or forms completed by the respondent.

- **special protection for vulnerable groups**: [special consideration must be given to ethnic minorities and vulnerable groups when conducting research.]

In order to provide **informed consent** you must make sure that respondents know the purpose and content of the survey. In order to ensure that their participation is **voluntary** you must emphasize the voluntary nature of the survey. It is ok to explain why you think their participation is important (to collect information needed to improve care services and consumer health outcomes), but you must not coerce or pressure people to participate.

In order to protect privacy you must follow these requirements:

1. It is unethical to approach someone and ask them their HIV status. Guessing one's HIV status is unethical and dangerous. You must only approach people whose HIV status is known to you because the person is familiar to you and has disclosed their status to you by choice. Since you know the person's identity, and you are a researcher, you must keep the person's identity confidential.

2. You should focus your efforts on friends or acquaintances that you already know. This will significantly limit the number of people you may be able to approach, but this is a limitation we must accept and deal with. IT IS BETTER TO COMPLETE ONLY A FEW SURVEYS RATHER THAN VIOLATE THIS ETHICAL RULE.

3. It is ethical to give a survey to someone who approaches you because a mutual friend or provider has referred him or her to you. If someone asks you for a survey simply give them a survey and answer any questions they might have as they complete it. Remember, this is an anonymous survey, which means that the person's name must not appear on the survey. You should not ask the person's name; however, if the person tells you his or her name you must keep his or her identity confidential.

If you have any questions about these ethical requirements, or if you find yourself in an awkward situation while distributing surveys, do not hesitate to call Dr. McGowan on his cell phone at (901) 652-3316 to discuss your situation or question.

## III. Procedural Requirements

1. Your role as a consumer volunteer is to:

- distribute outreach surveys and referral information to people living with HIV/AIDS who have difficulty accessing HIV medical care on a consistent basis;
- help people to understand the survey questions and assist them with the completion of the survey when necessary;
- deliver completed surveys to Dr. McGowan on February 18th at our second project meeting (midway through the project) and at our final project meeting on March 18th (at the completion of the project). You must return a minimum of 5 completed surveys on or before March 18th to receive the second half of your stipend.

2. You must follow these procedural requirements:

1. You **must only distribute surveys** a) to people you know personally or b) to people who approach you and express their interest in completing a survey because a friend or provider has referred them to you.

2. You **should not** give this survey to someone who has already completed a 2009 needs assessment survey. Before giving the survey to someone you must ask whether they have already completed this survey or the "consumer – in care" survey. If anyone you encounter has already completed a consumer survey this year do not have him or her complete this survey.

4. You must hold on to completed surveys and deliver them to Dr. McGowan when we meet on Wednesday, February 18th. You must hand-in any additional completed surveys to Dr. McGowan when we meet at the completion of the projection on Wednesday, March 18th.

# Ethical and Procedural Requirement Summary Sheet

I. I will only approach people whose HIV status is known to me because I know the people and they have disclosed their status to me by choice. I understand that I must keep the person's identity, and the information they provide, confidential. This means that I will not discuss with anyone the information provided or the fact that the person completed the survey.

II. In the event that people approach me and ask me for a survey I will give them a survey according to procedure and answer any questions they might have as they complete it. I will not ask people their name, and I will remind them to not write their names on the survey. If a respondent discloses his or her name I will keep it confidential.

III. Before administering the survey I will ask whether the person has already completed the survey, and if so, I will not administer the survey to the person.

IV. I will explain the introductory statement on the survey to the respondent and make sure the person understands the purpose and voluntary nature of the survey (informed consent).

V. I will offer a case management referral form to every person I encounter who completes a survey.

VI. I will not submit a survey unless it has been completed by an actual PLWHA according to the ethical and procedural requirements stated above.

# Ethical and Procedural Requirement Agreement Form

My signature at the bottom of this form expresses my understanding of, and agreement to follow, the following ethical and procedural requirements while administering the 2009 Memphis "PLWHA – Not in Care" survey:

1. I will only approach people whose HIV status is known to me because I know the people and they have disclosed their status to me by choice. I understand that I must keep the person's identity, and the information they provide, confidential. This means that I will not discuss with anyone the information provided or the fact that the person completed the survey.

2. In the event that people approach me and ask me for a survey I will give them a survey according to procedure and answer any questions they might have as they complete it. I will not ask people their name, and I will remind them to not write their names on the survey. If a respondent discloses his or her name I will keep it confidential.

3. Before administering the survey I will ask whether the person has already completed the survey, and if so, I will not administer the survey to the person.

4. I will explain the introductory statement on the survey to the respondent and make sure the person understands the purpose and voluntary nature of the survey (informed consent).

5. I will offer a case management referral form to every person I encounter who completes a survey.

6. I will not submit a survey unless it has been completed by an actual PLWHA according to the ethical and procedural requirements stated above.

I understand and agree to follow the ethical and procedural requirements stated above.

Signature_____Date _____