

# Central Issues Across Service Categories

## STIGMA OF HIV/AIDS

The stigma of HIV disease is a significant barrier to care within the Houston EMA/HSDA. Stigma prevents people from seeking proper medical and psychological care for HIV disease.

## FINDINGS

Across all consumer focus groups, except white MSM, participants described being ostracized by family and friends after their HIV diagnosis. The memories were so painful, that many cried as they spoke.

- ⌘ Significant misconceptions exist about HIV transmission. Misinformation is found in both the general community and the social service provider community.
- ⌘ Stigma leads to homelessness for a number of the homeless focus group participants. These consumers described being alienated and sent away from their family homes after diagnosis.
- ⌘ “I was worried someone might find out my HIV status if I went there” was identified as a barrier to care by over 15% of out-of-care consumers. Other disclosure-related barriers to getting HIV medical care identified by out-of-care consumers included:
  - ◆ I’m worried about my partner finding out I am positive (20%);
  - ◆ I’m worried about my children finding out I am positive (9%); and
  - ◆ I’m worried about my partner abusing me (11%).
- ⌘ The consumer survey found for PLWH with children, the number of children is proportional to the percentage out-of-care. Although not the only barrier confronted, stigma has been documented to be a critical barrier to care for women with children.
  - ◆ In an August 2004 HRSA publication, the observation is made: “The researchers found that the stigma related to maternal HIV disclosure to children and family members, combined with the complexity of treatment regimens, limited access to care, and disparities in health, posed huge barriers to care for women, most of whom have children to care for.”<sup>16</sup>

<sup>16</sup> Joan Holloway, et.al. “HIV/AIDS Stigma: Theory, Reality and Response.” Health Resources Services Administration. August 2004. pg. 71.

### RECOMMENDATIONS

- ⌘ An integrated approach to combating stigma in the Houston EMA/HSDA is needed. HRSA has identified successful strategies for combating stigma that should be considered. These include:
  - ◆ Provide knowledge and education to the public;
  - ◆ Humanize the stigmatized population;
  - ◆ Challenge the social acceptability of stigma;
  - ◆ Help people affected by stigma develop tools to survive it—and combat it;
  - ◆ Develop legal and regulatory responses to protect people from stigma and discrimination; and
  - ◆ Provide effective HIV/AIDS care and treatment.
  
- ⌘ For each of these strategies, HRSA has identified specific interventions that may be employed. These should be considered in defining integrated interventions for combating stigma within specific populations and neighborhoods in the Houston EMA/HSDA.
  
- ⌘ A comprehensive approach to combating stigma in the EMA/HSDA is needed. This may be one component of a public relations plan that is undertaken by the partners of this needs assessment.

### **SYSTEM LINKAGES AND INTERACTIONS**

As HRSA increasingly focuses CARE Act funding on “core services,” enhanced linkages with community resources for other supportive services will be required. Collaborative relationships and service development with other organizations and funding sources should be strengthened with the goals of filling gaps in care and enhancing service access for PLWHA.

### **FINDINGS**

With more people diagnosed with HIV disease, PLWHA living longer with a disease that was once considered terminal and case finding to bring out-of-care PLWHA into medical care system, the demands on HIV-specific funding are growing. Although the needs are increasing, HIV-specific funding has experienced limited increases.

In order to effectively adapt to these new demands, HIV planning bodies and funded agencies need to leverage available funds to not only best meet needs but also to bring other funding sources to bear for PLWH. In Houston, this can be accomplished by effectively linking with community providers’ whose services complement those provided with HIV-specific funds. The Non-HIV specific providers’ focus group discussed possibilities in detail:

*“The issues are growing, the need is growing, the funds aren’t growing to that length. Let’s create these comprehensive programs where these groups buy in, where it’s not just the organizations that are partnering, the funding sources are partnering.”*

Although HIV-specific funded agencies have a wide range of collaborative relationships and agreements, focus group participants advocated a global approach in which representatives from funding sources “come to the table to solve problems for individuals. They suggested the Ryan White Planning Council take the lead in developing collaborative partnerships to expand and enhance services for PLWHA.

The Commonwealth Fund recently published suggestions for establishing and maintaining collaborative partnerships. Pertinent suggestions included:

- ⌘ Identify an unbiased facilitator and an active coordinator;
- ⌘ Build consensus from the ground up;
- ⌘ Obtain agreement among participants that there is a clear need for communitywide intervention;
- ⌘ Require in-kind or financial contributions from each participant, so they become vested in the project; and
- ⌘ Design a long-range plan with intermediate goals that provide early success.

### RECOMMENDATIONS

- ⌘ Identify opportunities to collaborate with other funding sources to leverage HIV-specific funds. Services may blend HIV care or supportive services, housing, substance abuse treatment, etc, and may target specific populations.
- ⌘ Consider beginning with a visible, beneficial, low-cost intervention that can be accomplished within the first year.
- ⌘ Build upon successes with the ultimate goal of an integrated, balanced HIV service continuum with non-HIV-specific agencies and funding sources contributing at least as much as HIV-specific funding.

### **INFORMATIONAL BARRIERS TO CARE**

Consumer survey respondents consistently identified informational barriers to accessing services. Enhancing service information targeting both in-care and out-of-care consumers will promote service utilization.

### **FINDINGS**

For all services, information barriers were the most frequently identified response to the question “What keeps you from getting it?” Examples of information barriers to care included, “I didn’t have the information I needed about these services—that it existed, where to get it, how to qualify, etc.

For the total consumer survey sample, informational barriers to care were the most frequently identified for all services. Only two services, childcare and child welfare, had access barriers identified more frequently than informational.<sup>19</sup>

Informational barriers to care were also the most frequently identified for in-care consumers. The only services with access barriers identified more frequently than informational barriers were vision care, oral health care, OB/GYN services and food bank.

Out-of-care consumers most frequently reported informational barriers for all services. The percentage of responses identifying informational barriers ranged from 68% for drug reimbursement and legal services to 49% for vision care and 48% for OB/GYN services.

### **RECOMMENDATIONS**

- ⌘ Develop a work group that evaluates informational barriers to care across services and populations. Consider targeted informational needs of in-care and out-of-care priority populations. If appropriate, coordinate efforts with anti-stigma informational activities.

<sup>19</sup> Access barriers were defined as services are too far from my home or work, services were not open at the hours I could get there, there was not child care, waiting times for appointments or to see the person I needed to see were too long.

