

Estimating, Assessing and Addressing Unmet Need for HIV Primary Medical Care: What Planning Bodies Need to Know

**The Mosaica Unmet Need TA
Center of the TAC**

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Topics

- Definition of “unmet need”
- Legislative requirements and HRSA expectations for Title I programs
- Overview on estimating unmet need (*grantee responsibility*)
- Assessing unmet need
- Decision making to address unmet need – *to help PLWH/A get into care and stay in care*



Defining Unmet Need

- **Unmet need** = the unmet need for HIV-related primary health care among individuals who know their HIV status but are **not in care**
- **Estimate of unmet need** = the number of people living with HIV and AIDS in your service area (Los Angeles County) who know they are HIV-positive but are not receiving HIV-related medical care



Legislative Background: CARE Act Amendments of 2000

- **Secretary of HHS required to** develop epidemiologic measures “for establishing the number of individuals living with HIV disease who are not receiving HIV-related health services” and prepare State and national estimates of unmet need as input to Congress
- **Title I and II grantees required to** assess PLWH service needs and gaps “with particular attention to individuals with HIV disease who know their HIV status and are not receiving HIV-related services” and “disparities in access and services among affected subpopulations and historically underserved communities”



HRSA/HAB Expectations for Grantees and Planning Bodies

1. **Provide estimates** of unmet need each year (once you have a sound estimate, you should provide a new estimate at least every 2 years)
2. **Assess unmet need** as part of needs assessment, to learn *who* is out of care, *where* they live, and *barriers* to care
3. **Use information on unmet need** in decision making and planning
4. **Address unmet need:** set objectives, then help PLWH/A enter primary medical care and stay in care
5. **Monitor progress in addressing unmet need** -- look at changes in unmet need



Current Status of HRSA/ HAB Unmet Need Work

- **As of January 2007: Third year of estimates** submitted by Title I programs in their FY 2007 applications – along with plans & progress for using unmet need data in decision making to address unmet need
- **CARE Act reauthorization** expected to reinforce emphasis on unmet need (getting people into care; funding for core services, “demonstrated need”)



Estimating Unmet Need: Using the Unmet Need Framework

Framework uses a clear, logical concept:

- Determine the total number of people diagnosed with HIV/non-AIDS and AIDS in your service area – *population data*
- Subtract the number of PLWH/A who are receiving primary medical care – *care patterns data*
- Difference = number with unmet need

In other words: assume that the individuals you cannot identify as “in care” are “out of care”



Working Definition of Unmet Need for Use with the Framework

An individual 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 recent 12-month time frame:

1. viral load (VL) testing,
2. CD4 count, or
3. provision of anti-retroviral therapy (ART)

Sample Title I Unmet Need Framework Table – FY 2007

Population Sizes	Value		Data Source(s)
A Number of persons living with AIDS (PLWA), 01/01–12/31/05	4,896		2005 HARS adjusted
B Number of persons living with HIV (PLWH)/non-AIDS/aware, 01/01–12/31/05	5,298		2005 HARS adjusted
C Total number of HIV+/aware, 1/1/-12/31/05	10,194		
Care Patterns	Value		Data Source(s)
D Number of PLWA who received the specified HIV primary medical care services, 01/01–12/31/05	4,072		2005 HARS, ADAP, Medicaid, Title I service database, private care and VA adjustments
E Number of PLWH/non-AIDS/aware who received the specified HIV primary medical care services, 01/01–12/31/05	2,992		2005 HRS, ADAP, Medicaid, Title I service database, private care and VA adjustments
F Total number of HIV+/aware who received the specified HIV primary medical care services, 1/1/–12/31/05	7,064		
Calculated Results	Value	%	Calculation
G Number of PLWA who did not receive primary medical services	824	17%	Value = A - D. Percent = G/A
H Number of PLWH/non-AIDS/aware who did not receive primary medical services	2,306	44%	Value: B – E. Percent = H/B
I Total HIV+/aware not receiving specified primary medical services	3,130	31%	Value: G + H. Percent = I/C ⁹



Level of Unmet Need: FY 2006

National Estimates: Title I*

- Estimated number of people with HIV and AIDS – 51 EMAs: **594,342**
- Median estimated % not in care, HIV/AIDS: **36%**
 - HIV/non-AIDS: **42%**
 - AIDS: **29%**
- *Aggregate* estimated % not in care, HIV/AIDS: **37%**
 - HIV/non-AIDS: **47%**
 - AIDS: **27%**
- Range of estimates, HIV/AIDS: **16% to 71%**

* 2 EMAs did not provide separate estimates for HIV/non-AIDS and AIDS



Level of Unmet Need: FY 2006

National Estimates: Title II*

- Estimated number of people with HIV and AIDS – 53 States and territories: **764,988**
 - CDC 2003 midpoint estimate: **816,000**
- *Median* estimated % not in care, HIV/AIDS: **45%**
 - HIV/non-AIDS: **53%**
 - AIDS: **38%**
- *Aggregate* estimated % not in care, HIV/AIDS: **43%**
 - HIV/non-AIDS: **52%**
 - AIDS: **33%**
- Range of estimates, HIV/AIDS: **9% to 87%**

* No estimate for 1 State/territory; no HIV/non-AIDS estimate for 4; no separate HIV/non-AIDS and AIDS estimates for 2



What do the nationwide estimates tell us?

- PLWH/non-AIDS more likely than PLWA to be out of care
- Reported unmet need generally lower in EMAs than in States
- Estimates of % unmet need among PLWA most often in the 30s
- Estimates of % unmet need among PLWH most often 40s or low 50s
- Combined estimate in 30s or 40s
- Considerable range of estimates



What Comes after the Estimate?

- Next step is **assessing** unmet need
- Estimate shows size and proportion of population not in care
- Decision making about resources and services requires more information about who they are and why they aren't in care – to plan strategies for finding them and getting them into care



Assessing Unmet Need Requires Analysis of:

- **Characteristics** of PLWH/A not in care – e.g., race/ethnicity, gender, age, risk behaviors, co-morbidities – with focus on special needs populations
- **Where they live** within the State or EMA
- Their **barriers** to care
- Their other **service gaps** – what services are needed and for whom
- **What subpopulations/groups are most likely to be out of care**



Demographic Analysis

Need demographic or “subpopulation” analysis to determine the characteristics of PLWH/A in and out of care, and identify subpopulations most likely to be out of care

- Helps if your estimation method provides demographic data on people in care
- HARS (HIV/AIDS Reporting System) includes demographics, with limits on geographic data
- Linked claims and RWCA client databases often include client characteristics – helps to link with HARS
- Some jurisdictions expanding demographic reporting by funded providers
- Mapping often useful in presenting findings



How EMAs and States Assess Unmet Need

- **Demographic analysis** – analysis of data from the HARS database, Medicaid, Ryan White, etc.
- **Surveys or interviews** – as part of *PLWH/A surveys* [Always include a question to find out if people are “in care”] or through *special studies* targeting people not in care
- **Community outreach** – outreach workers or peer advocates do mini-interviews as part of outreach to people not in care
- **Provider and key informant interviews** – to gain their perspectives on barriers, etc.



PLWH/A Surveys

Go beyond “consumer surveys” to PLWH/A surveys:

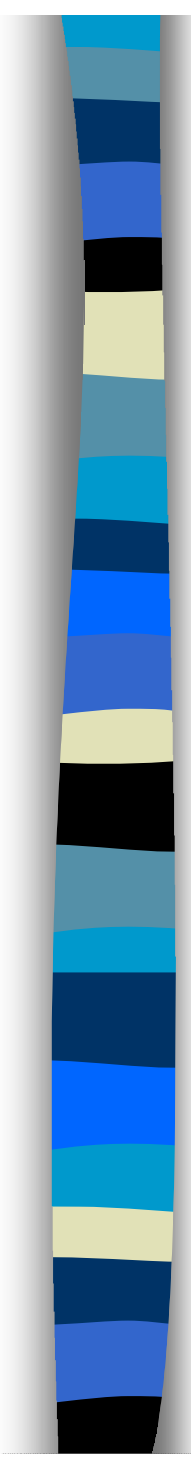
- Deliberately a specified number of people not in care consistent with your unmet need rate (e.g., if 33% are out of care, target 33% in your survey)
- Set targets for specific groups, including those especially likely to be out of care
- Include providers that are not a part of the funded CARE Act system
- Ask everyone surveyed whether s/he was out of care for a year or more in the past five years – and if so, about barriers and why/how s/he got back into care



Special Needs Assessment Studies

Do special studies targeting people out of care

- Consider RARE (Rapid Assessment, Response, and Evaluation) approach
- Do targeted interviews with people not in care
- Target different categories of people not in care – by risk factor, location, and degree of connection to the care system
- Have outreach workers do mini-surveys year-round
- Ask outreach workers to help with special studies



To Successfully Assess Unmet Need:

- **Involve CARE Act providers** – some of their current or recent clients may be out of care
- **Involve non-CARE Act providers** – including homeless shelters, drug treatment centers, food banks – they often have clients who are not in primary care
- **Go to “points of entry”** – places where people get tested or referred into care
- **Do *interviews*** – PLWH/A out of care rarely complete self-administered surveys or attend focus groups
- **Target populations with high rates of HIV/AIDS** – based on your epi data
- **Involve PLWH/A who sit on planning bodies** – they can help find people not in care and design tools to assess their needs



Addressing Unmet Need

- **Joint effort** by grantees, planning bodies like the Commission, consumers, and providers
- **Planning body involvement in decision making about strategies to:**
 - Ensure equitable access to care regardless of characteristics or place of residence
 - Help PLWH/A get into care
 - Keep them in care
 - Ensure that supportive services contribute to primary care entry and retention



Planning Body Roles in Addressing Unmet Need

- **Comprehensive Plan** – leadership in developing goals and objectives for getting people into care
- **Continuum of care** refinement
- **Service priorities** that focus on access to care
- **Resource allocations** to support access to care (*may mean funding fewer service categories*)
- Use of Minority AIDS Initiative (MAI) funds to facilitate entry into care for specific groups – for example, through targeted outreach
- **Directives to the grantee** (*often for specific models, populations, and/or geographic areas*)
- **Standards of care** that help reduce barriers



Data-based Decision Making

Requires review of needs assessment, service utilization, quality management, and evaluation data on:

- Size of the unmet need population
- Who is out of care, where, and why
- Current system of care – especially points of entry and points where people fall out of care
- How continuum of care works for specific groups of PLWH/A
- How current priorities, resource allocations, and service models help address unmet need
- Current efforts to get people into care and their success
- Costs of bringing an individual into care – for medical and other services



Developing Strategies to Address Unmet Need

- Different strategies needed for different groups of PLWH/A
- Strategies must address your identified barriers
- Some changes to the continuum of care may be needed
- Strategies extremely varied -- should involve planning body efforts, contract requirements, grantee leadership and monitoring, MOUs, provider initiatives, consumer involvement



Categories of Individuals Who Are Not in Care

1. Newly diagnosed
2. Receiving other HIV/AIDS services (*often in the CARE Act system*) but not in primary care
3. Formerly in care – dropped out (*and known to primary care providers*)
4. Never in care



Strategies: Newly Diagnosed

Requires improved links between prevention and care, and strategies such as:

- Joint committees focusing on unmet need
- Referral to primary care or case management on same day person receives test results and counseling
- Peer advocates to make contact immediately after diagnosis and take people to first few appointments
- Joint outreach workers, jointly funded
- Links with Prevention for Positive programs
- Use of rapid testing and immediate referral
- Primary care and case management provider agreements with testing sites and prevention programs (including Prevention for Positives)



Strategies: Receiving Other CARE Act Services

- All funded providers expected to ask clients if they are in primary care
- Arrangements for immediate referral for those not in care
- Requirement that anyone receiving non-core services and not in care be offered one primary care appointment
- Primary care provided at the sites of other providers – use of mobile units or off-site services
- Outreach at support service providers



Strategies: Dropped Out of Care

- Contractual requirements that primary care providers follow up on clients who miss appointments
- Case manager follow up through arrangements with primary care providers
- Use of peer advocates to get people back in care
- Follow up by insurer (public or private)
- Discharge planning and outreach to recently incarcerated (including jails)
- Focus for all: identify and overcome barriers to care that contributed to dropping out



Strategies: Never in Care

- Hardest group to reach
- Street outreach targeted to specific populations and locations
- Continuation of outreach worker support through first 2-3 medical visits
- Use of peer advocates from underserved groups
- Primary care provider agreements and active links with points of entry such as homeless shelters, substance abuse treatment programs
- Training of non-AIDS-focused providers
- Education efforts – often peer-led
- Consumer leadership in finding people not in care



Challenges of Addressing Unmet Need

- **Increased demand for services** -- Knowing that addressing unmet need means increased demand for primary care, medications, and other core services
- **Changes in service priorities and resource allocations** – With level or reduced funding, more people needing and using core services means less funds available for other services
- **Strategies needed to get people into care** – Requires changes in the continuum of care, new perspectives and pilot efforts, contractual changes, QM and evaluation



Importance of Addressing Unmet Need

- **So people live longer and healthier lives:** Current treatments can mean long-term survival and good health – but this requires getting care as early as possible
- **To reduce transmission:** Studies indicate people in care are much *less* likely to infect others than those not in care



For more information...

- ✓ Check the HRSA/HAB TARGET Center website (<http://careacttarget.org>), or use www.hab.hrsa.gov and click on Tools for Grantees and go to the new TARGET Center: TA Library
- ✓ Download materials from the Mosaica website - www.mosaica.org/unmetneedta.asp