

Unmet Need Case Studies: Best Practices in the Estimation Process

Introduction

Among the FY 2005 Ryan White CARE Act Title I and II unmet need estimates, the consultants found several jurisdictions whose methods included many of the best practices in estimating unmet need. Among these jurisdictions were the following:

- Los Angeles – a large Title I EMA
- Illinois – a large State that also has a Title I grantee
- Iowa – a small State with no Title I grantee

Many of these “best practices” were not required components of the unmet need estimate submitted in the FY 2005 Title I and Title II applications. For example, the Program Guidance did not require a narrative explanation of the estimate, use of the unmet need Framework table, or subpopulation analysis. Some jurisdictions did not include such information in their applications, but these three jurisdictions did. It is likely that a number of other jurisdictions had similarly sound estimates. The Unmet Need Center selected these three jurisdictions on the basis of the unmet need estimates as submitted, because they represent three different types of jurisdictions, and because they provide some new “good examples” to add to case studies presented in prior unmet need meetings.

The actual unmet need estimate included in the FY 2005 application is included for each jurisdiction, along with a brief summary of best practices reflected in the estimate and accompanying narrative.

Los Angeles

The Los Angeles Title I application included the following best practices:

- **Narrative:** The grantee provided a narrative to explain its unmet need estimate. It's important to document your process, assumptions, and limitations – the estimate has to be used by the planning council, and other entities in the jurisdiction, for the process of assessing and addressing unmet need (i.e., getting people into care). The better the process is documented – the more readable and easy to understand it is – the easier it can be used by others, and the easier it is to improve it in the future.
- **Use of Framework:** The grantee used the correct operational definition of unmet need, and the unmet need Framework table developed by the University of California-San Francisco (UCSF) and listed the correct data sources in the table. The grantee provided the unmet need estimate in both a whole number and a percentage in a table footnote.
- **Population Estimate:** The grantee used HIV/AIDS Report Reporting System (HARS) surveillance data for its population estimate.
- **Use of Linked Databases:** The grantee linked and unduplicated both private and public databases, including client-level CARE data (the Office of AIDS Programs and Policy's Casewatch database), client-level ADAP data, Veteran's Administration (VA) estimate, Medi-Cal (California's Medicaid program), Medicare, and an estimate from Kaiser-Permanente (California's largest private health care system).
- **Separate Estimates for HIV and AIDS:** The grantee provided separate care patterns and estimates for HIV\non-AIDS and AIDS.
- **Title I-Title II Collaboration:** The grantee collaborated with the California Title II program to get HARS and Medi-Cal data, and with all other eight EMAs in California to develop a common Medi-Cal data reporting format and methods to link client records – both for improving the estimate and future use.
- **Limitations:** The grantee explained its limitations, saying, "The linked data set is likely to over-estimate the number of clients in care, and under-estimate the unmet need, due to relatively high proportions of clients who are undocumented residents, uninsured or both."
- **Next Steps:** The grantee outlined next steps.

Areas for improvement in this application included:

- **Source of Data used in Estimate:** The grantee did not explain how it obtained the estimate from Medi-Cal – whether it was two separate estimates for HIV and AIDS, or one combined estimate, and if one, how it was separated.
- **Time Period:** The grantee did not specify what time period was used for care patterns data.

Illinois

The Illinois Title I application included the following best practices:

- **Narrative:** The grantee provided a narrative to explain the unmet need estimate. It's important to document your process, assumptions, and limitations – the estimate has to be used by the planning council, and other entities in the jurisdiction, for the process of assessing and addressing unmet need (i.e., getting people into care). The better the process is documented – the more readable and easy to understand it is – the easier it can be used by others, and the easier it is to improve it in the future.
- **Use of Framework:** The grantee used the correct operational definition of unmet need, and used the unmet need Framework table developed by UCSF and listed the correct data sources in the table. The grantee provided the unmet need estimate in both a whole number and a percentage in the narrative.
- **Legal Context:** The grantee explained what reporting is required by law in Illinois with regard to CD4 and viral load tests.
- **Population Estimate:** The grantee used HARS surveillance data for its population estimate.
- **Use of Linked Databases:** To obtain care pattern data, the grantee linked and unduplicated (with a patient code number – PCN) both private and public databases, including HARS data, client-level ADAP data, and large Title III and IV provider client data.
- **Time Period:** The grantee used the same time period for its population and care data sources.
- **Separate Estimates for HIV and AIDS:** The grantee provided separate care patterns and estimates for HIV and AIDS.
- **Cross-title Collaboration:** The grantee collaborated with the other Illinois Title programs, included Titles I, II, III., and IV, Illinois Department of Public Aid (IDPA) and the Midwest AIDS Training and Education Center (MATEC), in an All-Titles Meeting in Chicago in October 2003. The grantee requested joint technical assistance for all Titles for estimating unmet need from HRSA.
- **Demographic/subpopulation Breakdown:** The grantee included two tables providing a demographic and a geographic breakdown of its unmet need estimate. The geographic estimate showed unmet need for each consortium area in the State.
- **Limitations:** The grantee explained its limitations: it was unable to get Medicaid data, and is still trying; it was unable to get VA data or Title III and Title IV clinic date; and that its “unique client identifier” is not 100% unique.
- **Next Steps:** The grantee outlined next steps.

Areas for improvement in this application included:

- **Adjustment for In-migration but not Out-migration:** The grantee used only individuals who were definitely diagnosed in Illinois in its estimate, excluding in-migration. It did not mention any adjustment for those who may have moved out of State.

Iowa

The Iowa Title II application included the following best practices:

- **Narrative:** The grantee provided a narrative to explain the unmet need estimate. It's important to document your process, assumptions, and limitations – the estimate has to be used by the planning council, and other entities in the jurisdiction, for the process of assessing and addressing unmet need (i.e., getting people into care). The better the process is documented – the more readable and easy to understand it is – the easier it can be used by others, and the easier it is to improve it in the future.
- **Use of Framework:** The grantee used the unmet need framework table developed by UCSF and listed the correct data sources in the table.
- **Legal Context:** The grantee explained what reporting is required by law in regards to CD4 and viral load tests.
- **Population Estimate:** The grantee used HARS surveillance data for its population estimate.
- **Time Period:** The grantee used the same time period for its population and care patterns data.
- **Use of Surveillance Data:** The grantee used lab tests from surveillance data to provide care patterns data. Where such data are complete, this is generally the simplest and most comprehensive source of care patterns data, since it involves a single source and includes lab reports from individuals receiving care from both public and private sources.
- **Separate Estimates of HIV and AIDS:** The grantee provided separate care patterns and estimates for HIV and AIDS.
- **Limitations:** The grantee explained its limitations: the estimate was based on cleaned up data for 81% of people in care.

Areas for improvement in this application included:

- **Adjustment for In-Migration Unclear:** The grantee checked its local data against the Interstate Duplication Evaluation Project (IDEP) list, which helps to weed out people diagnosed some time ago who show up as out of care, but are most likely living out of State or have died. This provided an adjustment for out-migration. However, it is not clear whether the grantee also adjusted for in-migration. Typically a surveillance system flags individuals when there is no record of their being diagnosed in the State. It is not clear whether the grantee included in its estimate all cases in the HARS system or only those not flagged.
- **Identifying People Who Have Died:** The grantee would have found it useful to check its data against the National Death Index as well as IDEP, since this would identify individuals who may be listed as out of care but have died. It is usually most valuable to check individuals who were diagnosed with AIDS and were diagnosed some years ago – for example, all individuals in the surveillance system who were diagnosed with AIDS before 1995. This is less expensive than attempting to match all names in the surveillance system.