Measuring What Matters: HRSA/HAB Response to the IOM Study

The Ryan White CARE Act All Grantees' Meeting
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Health Resources & Services Administration
HIV/AIDS Bureau

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Study Issues

- Whether reported HIV cases are adequate, reliable, and sufficiently accurate for inclusion in CARE Act allocation formulas, and how to improve HIV reporting systems;
- What data are available for assessing communities' severity of need and how that information could be used in allocation decisions;
- What data could be used to measure the quality of and access to CARE-Act funded services

Findings on Use of HIV Data & the CARE Act Formulas

- States' HIV reporting systems are neither ready nor adequate for purposes of CARE Act resource allocation;
- Additional studies are needed to examine the comparability of data from HIV case reporting across states and Eligible Metropolitan Areas (EMAs);
- IOM could not confirm the hypothesis that the maturity of the HIV epidemic varies significantly across regions;
- Allocations depart from a nationwide standard of equivalent spending per unit of HIV burden;
- Hold harmless in Title I has a small overall effect on allocations to EMAs, yet a large impact on a single EMA.

Findings on Use of HIV Data & the CARE Act Formulas

- Several structural features of Title I & II funding formulas – the counting of EMA cases in both Titles I & II formula allocations, hold harmless provisions, and set-asides for emerging communities – have a large impact on resulting allocations, and may dampen potential benefits of adding HIV data to the mix;

- Given the "payer of last resort" intent of the CARE Act, formulas do not take into account data to define those for whom such funds were intended (Uninsured, special needs);

- Completeness of HIV data can be improved by counting all HIV cases rather than just those from name-based reporting states, and more fully utilizing data from labs & other sources;

- Techniques exist to estimate the prevalence of HIV infection independently of the HIV case reporting systems;

- Surveillance mechanisms needed that provide information on total population of persons with HIV infection, diagnosed or undiagnosed.

Recommendations on Use of HIV Data & CARE Act Formulas

- Use Estimated Living Cases (ELCs) for next 4 years while pursuing more complete reporting and use of HIV data (Secretarial decision by July 1, 2004), and alternative strategies for estimating HIV cases such as as survey or model-based estimation;

- Improve the consistency, quality, and comparability of HIV case reporting: accept all reported cases, procedures and infrastructure to unduplicate cases, assess & compare completeness & timeliness of HIV reporting, Secretary should provide additional $$$$$ to CDC to assist states;

- CDC should obtain estimates of total HIV prevalence and evaluate methods using an independent body;

- Secretary should engage an independent body to perform “what if” assessments of alternate input data and allocation formulas, and evaluate extent of inter-regional variability.

- Congress should reevaluate formulas to determine whether they allocate resources to those with HIV/AIDS who are uninsured or underinsured.

Conceptual Framework on Assessing Communities' Severity of Need

Resource Needs =

(Disease Burden * Costs of Providing Care) – Available Resources

Findings on Assessing Communities' Severity of Need

- The Title I supplemental award attempts to take into account other factors affecting the complexity and cost of care;
- The supplemental award process relies on nonstandard and unvalidated measures of local need;
- The Title I supplemental application process is burdensome and given the high correlation between grantees' per-ELC supplemental and base formula awards, the effort seems unjustified;
- Many public data could be used to assess resource needs using indicators that are comparable across areas, and direct measures would be more valid but more expensive and perhaps less feasible than indirect measures.

Recommendations on Assessing Communities' Severity of Need

- The Title I supplemental award should be based on quantitative need based on a small # of measures and calculated by HRSA/HAB, w/ locally defined need described buy applicants;
- Predominance of weight should be given to quantitative measures that reflect variations in costs of care and fiscal capacity across EMAs;
- HRSA/HAB should evaluate the feasibility & usefulness of using social area indicator models based on publicly available data to estimate need, & use additional experts to assist in developing this new strategy;
- The Secretary should evaluate the cost & utility of redesigning & coordinating studies conducted by HRSA & CDC to assess need & circumstances of people living w/ HIV, as well as the assessment of the indirect modeling approach recommended above.

Data to Assess the Quality & Access to CARE Act-Funded Services

Four Dimensional Conceptual Framework

- **Population of Interest (undiagnosed & not in care, diagnosed & not in care, diagnosed & in care);**
- **Level of Assessment (individual, provider/clinic, population/area);**
- **Type of Measure (structure, process, outcome);**
- **Spectrum Of Services (prevention to C/T/R to care to service integration & coordination)**

Findings on Data to Assess Quality & Access

- Use of existing outcome measures is appropriate but not sufficient due to factors beyond the control of grantees and because structure & process measures can identify areas for improvement;
- Quality measure sin use are clinically appropriate but not standardized and are limited to patient-level clinical data;
- Measures of access to needed medical and non-medical services are lacking;
- Current efforts to assess overall quality of care are rudimentary and population-based measures, though essential in monitoring HIV care, are not generally in use.

Recommendations on Data to Assess Quality & Access

- Standard definitions & detailed criteria for measures (population, level of assessment, type of measure, spectrum of services) need to be developed by HRSA in collaboration w/ grantees and constituents;

- Secretary should provide additional resources to HRSA & CDC to develop infrastructure for monitoring quality at patient, provider and population level (enhance support for IT & clinic personnel, develop innovative population-based measures, Congress should enhance flexibility of admin caps);

- Secretary should convene a working group to consider strategies for public-private collaboration to establish tools & methods to assess systems of care & quality using other successful models.

HRSA/HAB Response?

- **HRSA/HAB has:**
  - **Met internally to consider the report and action steps;**
  - **Conversed w/ IOM Committee members based on internally derived questions & areas of needed input;**
  - **Provided perspective to DHHS & communicate with CDC on the study recommendations**
  - **Considered the report as input into reauthorization 2005**
  - **Within HAB, and with partners (CDC), develop processes and structure for consultations & studies. More specifically…..**

HRSA/HAB Response Cont.

- Use of HIV data in formulas – will continue to use ELCs; Secretarial decision memo and July 1st decision; assessing structural features of the formulas and their dampening effect by running "what-if" assessments on hold harmless, minimum awards, set-asides, I/II double counting, per capita runs → DHHS & Advisory Committee.
- Severity of Need
  - HIV Morbidity Monitoring project
  - Social Area indicator Model – use small set of publicly available data correlated with important dependent variables (such as late access to care) as indicators for need for HIV care; transparent process with constituency groups, simplified supplemental award processers; funds proposed as part of FY 2004 TA effort but limits on such funds will delay until FY 2005.

HRSA/HAB Response Cont.

- Framework for assessing the quality of funded services
- HAB developing a quality roadmap for the Bureau's quality initiatives.
- Participatory process to reach more data driven set of quality measures
- Could also help focus HAB data collection activities and movement toward client-level data collection.

Challenges Yet to be Overcome

- Capacity, infrastructure and resources necessary at Federal and grantee levels
- Availability & cross-jurisdictional replicability of HIV surveillance and other quantitative data
- Development & implementation of necessary & useful studies
- Other structural features affecting CARE Act allocations;
- Consideration of incentives & disincentives

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The IOM Data Study: Measuring What Matters

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