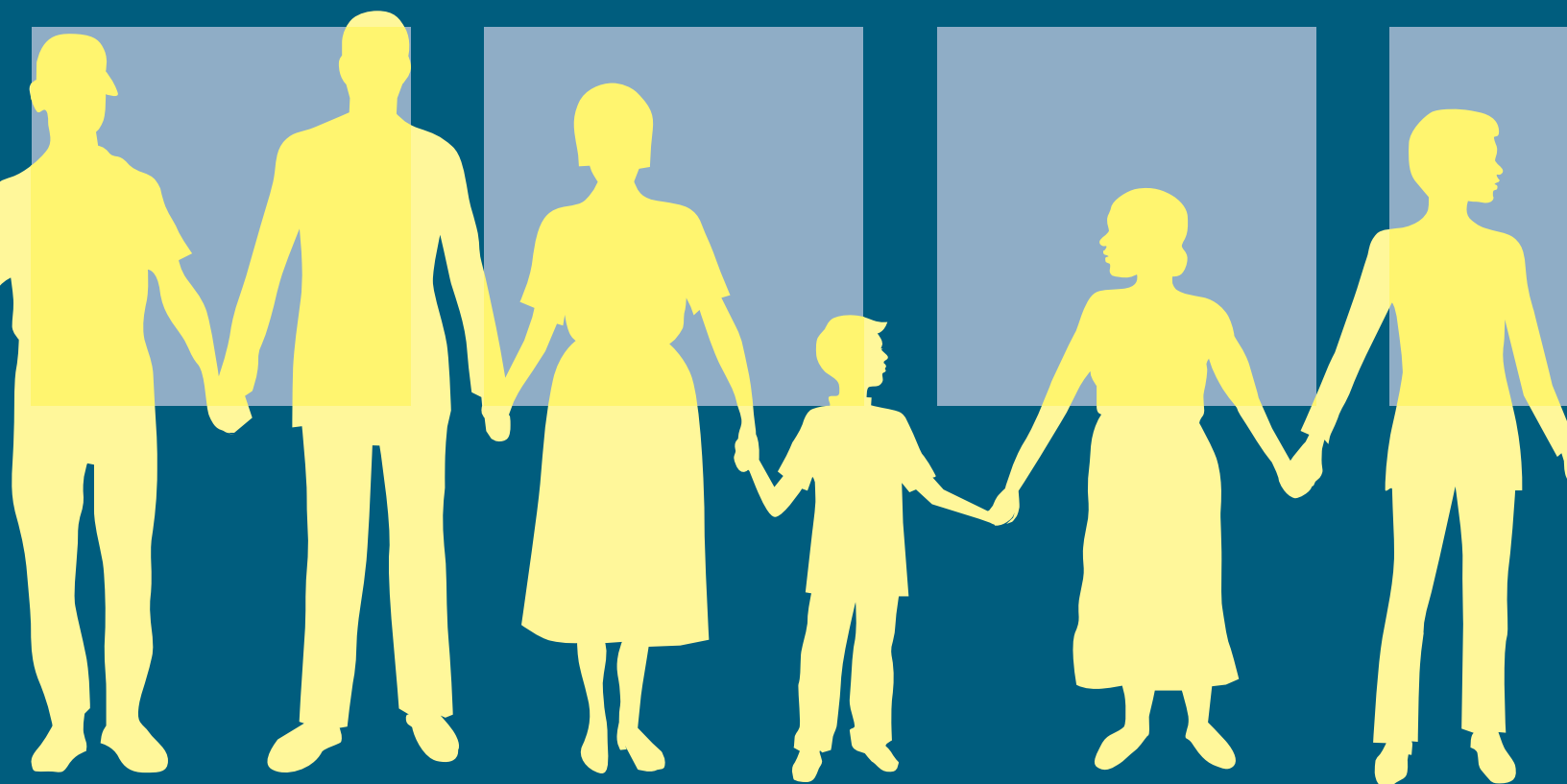
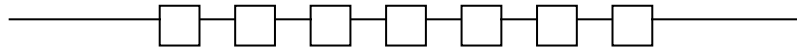

Outcomes Evaluation Technical Assistance Guide



Case Management Outcomes *Titles I and II of the Ryan White CARE Act*



Outcomes Evaluation Technical Assistance Guide



Case Management Outcomes

Titles I and II of the Ryan White CARE Act



Table of Contents

Case Management Guide	1
Background and Rationale	2
Legislative Requirements	2
Need for Outcomes Evaluation	4
Focus on Case Management Services	5
Case Management Definitions and Standards	6
Definition of Case Management	6
Functions of Case Management	7
Setting Case Management Standards of Care	9
HAB Evaluation Questions	11
Using this Guide	12
Issues and Challenges in Outcomes Evaluation	13
Challenges in Obtaining Data	13
Time and Resources	14
Data Reporting versus Sampling Methods	14
Data Systems	15
Consistent Indicators Across Titles	15
Obtaining Clinical Data from Clients	15
Using Quality of Life Indicators	16
Recommended Approaches and Data Sets	16
Suggested Outcomes and Indicators for Case Management Services	20
Figure 1: Suggested Outcomes, Indicators, Data Elements, and Data Sources and Methods for Case Management Programs	21
Aids for Outcomes Evaluation	25
Figure 2: United Way Logic Model	26
Figure 3: Identifying Three Levels of Outcomes	27
Factors in Planning Your Outcomes Evaluation Efforts	28



Table of Contents (continued)

References and Resources30

- HRSA Materials on Evaluation30
- Materials to Assist Grantees in Collecting Client-Reported Quality of Life Data31
- Materials to Assist Grantees in Collecting and Abstracting Outcomes and
Quality of Care Data33
- Other HRSA Materials33
- Guides Providing “How-To” Information on Outcomes Evaluation33
- Journal Articles and Other Documents to Assist Grantees in Researching
Outcomes Evaluation and Standards of Care34
- Treatment Guidelines35

Glossary36

Case Management Guide

This guide has three purposes:

- To clarify the expectations of the Division of Service Systems (DSS), HIV/AIDS Bureau (HAB), Health Resources and Services Administration (HRSA) regarding outcomes evaluation of case management services funded under Title I and Title II of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, and relate these expectations to outcomes evaluation of programs funded under other CARE Act titles.
- To support outcomes evaluation efforts by Title I and Title II programs* that will generate information useful for planning, priority setting, and resource allocation and also meet legislative requirements under the Act.
- To encourage grantees to include some widely used indicators in their case management evaluation efforts that will facilitate comparisons across sites and contribute to HAB national evaluation studies that address the overall effectiveness of CARE Act programs.

The guide provides information designed to assist Title I and Title II programs in conducting outcomes evaluation focusing on case management. Included are specific outcomes indicators and data elements that can be collected by providers, obtained and reported by the grantee, and analyzed and made available for use by the planning body to make decisions regarding case management models, priorities, and funding.

This guide is part of an ongoing and evolving process of building capacity to evaluate the results of the Ryan White CARE Act programs. HAB units are producing other documents to help the CARE Act community to conduct outcomes evaluation and other evaluation efforts. For example, HAB has already completed a similar guide focusing on primary care services and is preparing a third guide designed to help plan outcomes evaluation. The Office of Science and Epidemiology publishes a monograph series on evaluation.

* The terms “CARE Act community” and “CARE Act programs” are used throughout the guide to mean grantees, planning bodies, providers, people living with HIV/AIDS, and other CARE Act stakeholders.



Background and Rationale

Legislative Requirements

After more than a decade of CARE Act services, program evaluation is receiving increasing emphasis. The legislation requires that Title I and Title II programs evaluate program “effectiveness,” which means conducting outcomes evaluation. Legislative language on evaluation is more limited for the other two titles. Title III provisions refer to expenditure of funds for program evaluation, and Title IV provisions instruct the Secretary of Health and Human Services to provide for the evaluation of funded programs. In addition, the 2000 Amendments call for quality management programs to be established by all programs.

The CARE Act Amendments of 1996 included specific evaluation requirements for Titles I and II, which have been retained and slightly modified in the 2000 Amendments:

- Each Title I planning council shall establish priorities for the allocation of funds based on factors including the “demonstrated (or probable) cost effectiveness and outcome effectiveness of proposed strategies and interventions, to the extent that data are reasonably available”; and may, at its discretion, “assess the effectiveness, either directly or through contractual arrangements, of the services offered in meeting the identified needs.” [Section 2602(a)(4)(C)(ii)]
- Each Title II consortium is required to submit to the State an application that “(D) demonstrates that the consortium has created a mechanism to evaluate periodically—(i) the success of the consortium in responding to identified needs; (ii) the cost-effectiveness of the mechanisms employed by the consortium to deliver comprehensive care; and (E) demonstrates that the consortium will report to the State the results of the evaluations described in subparagraph (D) and shall make available to the State or the Secretary, on request, such data and information on the program methodology that may be required to perform an independent evaluation.” [Section 2613(c)(1)(D-E)] State grantees are required to provide for “periodic independent peer review to assess the quality and appropriateness of health and support services provided by entities that receive funds from the State” [Section 2617(b)(4)(C)] and may spend up to 10% of grant funds on “planning and evaluation activities.” [Section 2618(b)(3)]

Outcomes Evaluation Technical Assistance Guide

The CARE Act Amendments of 2000 add new sections establishing quality management programs, applicable to all titles:

- The Amendments require grantees under all four titles to “establish a quality management program to assess the extent to which HIV health services provided to patients under the grant are consistent with the most recent Public Health Service guidelines for the treatment of HIV disease and related opportunistic infections, and as applicable, to develop strategies for ensuring that such services are consistent with the guidelines for improvement in the access to and quality of HIV health services.”
- Title I and II grantees may allocate up to the lesser of 5% of the total grant amount or \$3 million for quality management activities. Funding limits are not specified for Titles III and IV.

Guidance from HAB indicates that quality management programs are intended to help grantees evaluate and improve the quality of primary care and health-related supportive services provided under the CARE Act. In order to meet the purpose of continuously improving systems of care for individuals and populations, HAB expects evaluations of quality of care to consider the quality of each of the following:

- service inputs (*e.g.*, staffing, resources)
- the service delivery process
- service outcomes

The focus and ultimate goal of quality management is improved health status. Moreover, quality management programs should look beyond clinical services to consider both supportive services and outcomes specific to each grantee’s population and location.

While CARE Act legislation is more specific about outcomes evaluation requirements for Title I and Title II programs, all CARE Act programs are expected to evaluate achievement of goals and objectives and program impact:

- The FY 2001 Title III program guidance requires funded programs to “develop an evaluation strategy with measures that demonstrate achievement of your program goals and objectives and the impact of the program.”
- The FY 2001 Title IV program guidance requires applicants to “outline the evaluation strategy that will be used or has been used to measure 1) achievement of program goals and objectives and 2) impact of the program.”

Since many providers have funding from more than one title, there is a need for shared evaluation approaches as well as common evaluation terms, outcomes indicators, and data elements across titles.



Key Evaluation Terms

Evaluation terms used frequently in this guide are briefly defined and described below for use in reading this document. For more detailed definitions and examples, see the Terms and Definitions section.

Outcomes are benefits or other results (positive or negative) for clients that may occur during or after program participation. Outcomes can be classified as *initial*, *intermediate*, and *longer-term* based on how soon they occur after program participation begins.

Client-level outcomes are results or benefits for an individual client, including psychosocial measures such as improved levels human functional status and/or mental health status, biological measures such as improved CD4 count or viral load or morbidity measures such as reduction in opportunistic conditions; system-level outcomes are results for all clients receiving services, such as reduced morbidity or mortality rates.

Outcome indicators or measures are observable, measurable data sets--such as the number of referrals completed by clients, changes in CD4 counts or non-injury-related emergency room visits over time--that are used to track a program's success in reaching desired outcomes.

Data elements are the specific items of information--such as number of referrals made, number of referrals the client completed, CD4 counts or non-injury-related emergency room visits by clients during a specific period--that are collected and aggregated in order to make measurements using the indicators.

Targets are measurable objectives stating the desired level of outcome achievement for a program, such as "to have X% of HIV-positive clients adhering to medical treatments."

Outputs are measures of the direct products or volume of program operations such as the number of service units that a program delivers; case management examples include the number of clients served, number of referrals completed, or number of intakes completed and assigned to case managers.

Need for Outcomes Evaluation

Many factors in addition to CARE Act legislative requirements contribute to a need for outcomes evaluation. All Federal programs are now expected under the Government Performance and Results Act (GPRA) to document progress towards specific measurable objectives.

Documentation of results is necessary to demonstrate program quality and effectiveness and to support CARE Act appropriations and reauthorization. The Inspector General has recommended the establishment of systems to support outcomes evaluation.

CARE Act programs need outcomes evaluation data to support their work at the State and local levels. Both grantees and lead agencies need guidance on what data requirements to include in their Requests for Proposals (RFPs) for HIV/AIDS services and in provider contracts in order to document results. Planning bodies need outcomes data as input to their planning and priority

setting. States and municipalities require documentation that programs are making a difference, whether they are supported solely through CARE Act resources or by a combination of funders. Providers need to be able to document program outcomes as they seek public and private funds and as they work to improve services.

Evaluation of the CARE Act program at the national level is overseen by the HAB Office of Science and Epidemiology (OSE). Such evaluation can support State and local evaluation activities by documenting national outcomes and assessing the relationship between adherence to standards of care and outcomes (*e.g.*, showing that following HIV-related treatment guide lines leads to reductions in morbidity and mortality). National evaluation studies require standardized local data that record how standards of care are being met and document specific program outcomes.

Focus on Case Management Services

This guide focuses on helping CARE Act programs generate outcomes data for case management services and relate them to primary care, a priority given that case management is seen as the link between the medical and support services that clients can access and receive.

With improvements in medical treatments for HIV/AIDS, care systems are required to move from a social service case management model to a medical model of care--and “provider networks are becoming increasingly aware of the need to redesign their services with primary care at the hub.”* Essential components of the continuum of care include not only primary care and medications, but also supportive services. Ensuring access to and retention in primary care is the primary focus of evaluating the contributions of support services.

Evaluation of case management services is particularly important for several reasons. After primary medical care and medications, case management is often the service category receiving the largest funding allocation from Title I and Title II grantees. Case managers often play a key role in ensuring access to medical care and to the support services clients may require to keep appointments, adhere to medications, and obtain other needed services, from housing to substance abuse treatment. In a medical model, grantees need to measure and understand the client outcomes of case management services.

* Comment from the Pennsylvania Title II program.



Case Management Definition and Standards

Definitions of Case Management

There is no set definition for “case management.” The Ryan White CARE Act Title I Manual defines case management for Title I and Title II programs as:

“A range of client centered services that link clients with health care, psychosocial and other services to insure timely, coordinated access to medically appropriate levels of health and support services, continuity of care, on-going assessment of the client’s and other family members’ needs and personal support systems, and inpatient case management services that prevent unnecessary hospitalization or that expedite discharge, as medically appropriate, from inpatient facilities. Key activities include: initial comprehensive assessment of the client’s needs and personal support systems; development of a comprehensive, individualized service plan; coordination of the services required to implement the plan; client monitoring to assess the efficacy of the plan; and periodic re-evaluation and revision of the plan as necessary over the life of the client. May include client-specific advocacy and/or review of utilization of services.”

In addition to differences in definitions, variations also exist in the type of case manager, services, service units, and location. For example:

- Case managers can be professionals such as social workers and nurses or paraprofessionals such as peer counselors, volunteers, and homeworkers.
- Services can be provided in a variety of sites including (1) hospitals, (2) community-based organizations, (3) State-run social service agencies, (4) health departments, and (5) advocacy organizations.
- Service units can vary by program; for example, 15 minutes equals one unit of service/service encounter or one client visit of any time length equals one unit of service/service encounter.
- Services vary from providing assessments of client needs and referrals for services to the actual provision of services. Case managers typically serve as links to a range of services needed by individual clients.

Case Management Definitions

Following are some definitions for “case management” and for specific types of case management:

- Case management has been defined as:
 - ▼ *a patient-centered process which has been used to augment and coordinate existing care system. (AHCPR, 1994)*
 - ▼ *a clinical service designated to locate, coordinate, monitor, and advocate for necessary and appropriate mental health and social services in the community for a consumer. (Mullen and Magnabosco, 1997)*
 - ▼ *services [that] focus on improving client access to appropriate services, promoting continuity of care by coordinating service delivery arrangements, enhancing clients’ health status and level of functioning, and promoting efficiency by reducing or containing overall costs. (Emlet and Scott Gusz, 1998)*
 - ▼ *a partnership between the case manager and client [which] entails the continual assessment of client needs, addressing those needs by linking the client with available resources, and providing continual care assessment and follow-up. (Sowell and Grier, 1994)*
 - ▼ *Social work case management is a method of providing services whereby a professional social worker assesses the needs of the client and the client’s family, when appropriate, and arranges, coordinates, monitors, evaluates, and advocates for a package of multiple services to meet the specific client’s complex needs. (NASW, 1992)*
 - ▼ *Nursing [medical] case management is a dynamic and systematic collaborative approach to providing and coordinating health care services to a defined population. It is a participative process to identify and facilitate options and services for meeting individuals’ health needs, while decreasing fragmentation and duplication of care and enhancing quality, cost-effective clinical outcomes. The framework for nursing case management includes five components: assessment, planning, implementation, evaluation, and interaction. (ANA, 1996)*

Functions of Case Management

While case management has neither a standard definition nor set guidelines, its main purpose is to provide services that decrease barriers to medical and support services, while increasing quality of life. To do this well, case management services funded through Title I or Title II of the CARE Act should include some or all of the following functions:

1. Client intake and assessment, including:

- Collect initial client information taken at intake (*e.g.*, age, gender, race/ethnicity, presenting problem)

**Outcomes Evaluation Technical Assistance Guide**

- Assess and document the client’s health and psychosocial status, which includes past and present physical health (*e.g.*, CD4 count, viral load, HIV stage), mental health, short- and long-term needs (*e.g.*, ADAP, primary care provider, support services), past and present problems, and needs of family members
 - Assess the client’s level of case management need (*e.g.*, high, moderate, or low) based on the client’s level of functioning and/or needs
 - Develop a client service plan that includes setting objectives for the client (*e.g.*, completion of substance abuse program, finding appropriate housing, increased adherence to medication regimen, completing primary health care appointments)
2. **Service provision planning**, including:
- Identify service availability and client eligibility (*e.g.*, medical providers, drug assistance programs, substance abuse treatment programs, legal services)
 - Identify barriers clients may encounter (*e.g.*, language barriers, eligibility criteria, service fees, geographic location)
3. **Coordination/linkage** of clients to services through the following activities
- Clarify service needs
 - Orient client (*e.g.*, client rights, client responsibilities, service expectations)
 - Identify services (and agencies) that match client needs
 - Contact referral agency(ies)
 - Prepare or assist in preparation of paper work and applications
 - Confirm that client received services
4. **Reevaluation/assessment** through the following activities:
- Maintain consistent contact (*e.g.*, office visits, home visits, phone calls) with clients to determine whether primary care and support services are still appropriate, being completed, and still needed
 - Periodic reevaluation of client’s services, plans, and objectives
 - Periodic reevaluate client’s level of case management need (*e.g.*, high, moderate, or low) to determine if client can function more independently
 - Assess health and functional status through periodic client- and/or provider- administered quality of life surveys

Setting Case Management Standards of Care

While there are guidelines for HIV-related primary care*, no required procedures or treatment guidelines exist for establishing standards of care for HIV case management. Standards of care can define the policies and procedures of a case management program (*e.g.*, who gets services, how services are provided, how services are monitored, the role of the case manager, who can be a case manager, units of service), and the objectives of the services provided. Many States have established standards that must be met before payment for services is allowed under programs such as Medicaid. Finally, service standards and objectives can provide the basis for outcomes evaluation and suggest outcome indicators. In developing standards, program directors and case management staff may want to review existing literature on case management of HIV clients. In addition, HAB Project Officers may be able to guide programs and refer them to grantees that are currently working on or have established standards of care (see box). In general standards, should:

- Address the current practice of the program
- Define standard units of service for the program (*e.g.*, 15-minute face to face visit=1 unit, telephone communication to follow up with client's health/service progress=1 unit, face-to-face visit of any length=1 unit)
- Identify the problem (for example, clients will be evaluated to assess their current need for primary health care services or support services that allow the client to maintain their primary health care services)
- Define the process of case management, including:
 - ▼ Factors to consider when providing services (*e.g.*, does the client have a primary care provider, client's current stage of HIV disease, client's ability to pay for medical services, client's eligibility for ADAP and/or Medicaid)
 - ▼ Identify client's role (*e.g.*, client will complete referrals, client will identify other service needs, client will notify case manager of any changes in health/social status)
 - ▼ Identify case manager's role (*e.g.*, case manager will identify available support services, case manager will follow up with client to assess service needs, case manager will evaluate client's progress on meeting service plan objectives)
 - ▼ Identify criteria for which client services are appropriate and relevant to the client's presented needs
- Identify resources (*e.g.*, community-based clinic, AIDS service organization, AIDS drug assistance programs)
- Identify outcomes (for example: number and percent of clients receiving primary health care services) and evaluation criteria (for example, change in the number of new clients connected to primary health care service)

* HIV-related treatment guidelines outlining optimal HIV/AIDS treatment strategies have been formulated by various national panels. See the References and Resources section of this guide for more detailed information and sources for guidelines.



Outcomes Evaluation Technical Assistance Guide

Example of a Support Service Referral Standard									
<p>Standard: (1) Each client will be evaluated to determine his/her support service needs. (2) Client will receive needed service referrals upon identification. (3) Referrals will be made to mental health, substance abuse, rehabilitation, and other support services. (4) Case manager will follow up to determine whether referral was completed and service obtained. (5) Reassessment and review is ongoing and can be client initiated.</p>									
<p>Factors to Consider:</p> <table border="0"> <tr> <td>• Medical considerations</td> <td>• Financial status</td> <td>• Needs of family/significant others</td> </tr> <tr> <td>• Mental health history</td> <td>• Age of client</td> <td>• Available support system</td> </tr> <tr> <td>• Substance abuse history</td> <td>• HIV stage</td> <td>• Language and cultural factors</td> </tr> </table>	• Medical considerations	• Financial status	• Needs of family/significant others	• Mental health history	• Age of client	• Available support system	• Substance abuse history	• HIV stage	• Language and cultural factors
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• Mental health history	• Age of client	• Available support system							
• Substance abuse history	• HIV stage	• Language and cultural factors							
<p>Client’s Role <i>Client will:</i></p> <ul style="list-style-type: none"> • Assist case manager at intake and periodically to assess/identify support service needs • Help identify convenient, available, and affordable support services when needed • Notify case manager of changes in physical/mental health and substance abuse status that may impact support services status • Follow through with referral appointments • Notify case manager when services are no longer appropriate, needed or not available • Complete necessary applications to acquire services 									
<p>Case Manager’s Role <i>Case manager will:</i></p> <ul style="list-style-type: none"> • Complete all intake and assessment forms • Orient client on eligibility for services • Assess client’s level of service needs (e.g., high, moderate, low level) • Coordinate access to primary health care services if client is not enrolled • Follow up with client and provider to determine whether client is completing primary health care appointments (retention) and adhering to treatment • Identify and confirm availability of eligible support services, within 48 hours • Follow up with clients to confirm that services were received • Assess client’ and client’s family’s support service needs • Follow up with client and provider at least once a month to inquire that client is complying with support service guidelines (e.g., appointments, participation) • Follow up with client and provider at least once a month to assess the appropriateness or continued need of support service • Evaluate client’s health status every three months and functional status (quality of life indicators) every 6 months 									
<p>Outcome Criteria:</p> <ul style="list-style-type: none"> • Client access to and retention in primary health care • Number of referrals completed by client • Client’s functional status (as measured by quality of life indicators) increases over time 									

Outcomes Evaluation Technical Assistance Guide**HAB Evaluation Questions**

HAB has developed five key evaluation questions to guide CARE Act evaluation efforts (see box); they address many of the same evaluation questions that Title I and Title II grantees and planning bodies are likely to want answered. These questions address program processes, quality, and outcomes.

EMA and State outcomes data related to case management can provide needed information on service quality and outcomes to address these questions:

- The numbers of underserved minority and vulnerable populations that were connected to primary health care services through case management referral systems and those clients that maintained their primary health care services (Evaluation Question #1).
- The number and types of support services provided and in some cases their relationship to reducing barriers to care (Evaluation Questions #2 and #3).
- The support services that have had direct effects on client's ability to connect and retain their primary health care (Evaluation Question #3).
- Outcomes indicators based on quality of life instruments can assess whether services are improving self-reported quality of life (Evaluation Question #4)
- Case management programs situated in medical/clinical facilities may be able to address whether quality of care meets care standards and is affecting client morbidity and mortality (Evaluation Question #4).

HIV/AIDS Bureau Evaluation Questions

1. **Assessing Unmet Need.** To what extent are CARE Act programs identifying HIV infected populations who are not in primary health care (not accessing available services)? To what extent are grantees identifying HIV-infected populations who are not remaining in primary health care and the reasons for this lack of continued service utilization?
2. **Removing Barriers to Care.** Are grantees determining the specific reasons why individuals are not in care and removing barriers to their care? What are grantees/providers doing to enroll and retain identified underserved populations in primary health care?
3. **Optimizing Local Service Delivery Systems.** Have CARE Act grantees identified the most effective combinations or models of integrated services that improve the use of primary health care, taking into account the characteristics of local health care delivery systems and affected populations?
4. **Providing Quality Care.** To what extent are CARE Act grantees/providers providing quality care to clients as defined by Public Health Service and other care standards? Is this care having optimal effects on morbidity and mortality, and is it improving health-related quality of life?
5. **Adapting to Change.** To what extent are CARE Act grantees adapting their service priorities and allocations to a changing and sometimes chaotic health delivery and reimbursement environment?



Using this Guide

HAB does not require Title I or Title II programs to conduct a specific type of outcomes evaluation; this guide provides recommendations, not requirements. Every grantee and planning body may determine how it will evaluate program results. However, many grantees and planning bodies have indicated a need for guidance from HAB on outcomes evaluation; this guide was developed to address this need.

Issues and Challenges in Outcomes Evaluation

In preparing this and other guides in this series, HAB sought input and review from Title I and Title II grantees. As summarized below, some of these issues have already been addressed by HAB while others require additional attention by HAB and by CARE Act programs.

Challenges in Obtaining Data

Successful implementation of outcomes evaluation is dependent upon appropriate systems for consistent collection, aggregation, and reporting of data. HAB recognizes that obtaining the service data needed for outcomes evaluation of case management services is likely to be especially challenging under certain conditions. For example:

- The grantee and providers are not using a client-level data system or unique client identifiers that would allow case managers to track client service usage over time.
- Case managers are not consistently following up with clients and providers to document completion of referrals, and access to services especially access to and retention in primary care which is essential for evaluation of outcomes.
- Case management providers may not have computerized systems in place to report aggregate case management data on clients, which is essential to evaluate system level outcomes.
- The grantee has a large number of case management providers with different recordkeeping systems (paper and/or computerized), types of client records, and types of service data making aggregation of client and program data difficult.
- Case management providers serve a relatively small number of CARE Act clients and receive limited CARE Act funds (*e.g.*, in many rural areas).
- Clients have more than one case manager that provides different and/or similar services making data gathering and reporting difficult.



Time and Resources

Establishing procedures to collect outcomes data takes considerable time and resources. This is particularly true in States and EMAs that face many of the data-related challenges described above. Extensive planning is needed to assist providers in collecting consistent outcomes data and to establish the data systems needed for reporting agreed-upon data.

States and eligible metropolitan areas (EMAs) have estimated that it will typically take 18 months to two years to fully implement the systems needed to provide for outcomes evaluation. This includes time to work with providers and planning bodies to decide on appropriate outcomes and indicators; develop, test, and implement provider recordkeeping systems that collect needed data; and develop and test client records abstraction or other methods of aggregating and reporting data.

Evaluation requires human and financial resources. HAB is aware that current administrative caps can make it difficult for grantees and planning bodies--especially those in low-incidence States and small EMAs--to carry out evaluation with CARE Act funds. However, planning bodies are permitted to prioritize evaluation as a program support function and allocate non-administrative funds if they feel that this is a high priority use of CARE Act funds. Title II includes a provision to support planning and evaluation activities up to 10 percent of the grant award, or up to a total of 15 percent in combination with administrative costs. Some grantees use State or local funds or do fundraising to obtain additional resources for evaluation. HAB provides some competitive funding for evaluation through special requests for proposals.

Data Reporting versus Sampling Methods

Many grantees have indicated that providers collect much of the information needed for outcomes evaluation, but do not report these data on a regular basis. One of the greatest challenges of outcomes evaluation is how to get existing data aggregated and reported. One approach is to develop a client-level or an expanded provider-based data system that can report outcomes data. Other, more immediate approaches include review and abstraction of data from a sample of client records and special studies of a sample of selected providers or clients.

Valuable outcomes data can be obtained without 100 percent reporting by providers. If providers collect needed outcomes data and record them in case management or client medical records, the grantee can use client records abstraction procedures to sample clients from various providers and generate outcomes data without requiring providers to regularly aggregate and report their outcomes data. Similarly, the grantee can conduct special studies involving collection of data from a sample of providers.

Outcomes Evaluation Technical Assistance Guide

Grantees, lead agencies, planning bodies, and providers need to work together to decide how best to obtain data needed for outcomes evaluation, with attention given to both immediate and longer-term methods. A desirable approach is to work towards the establishment of systems for consistent reporting of outcomes data, while using records abstraction or special studies as an interim approach.

Data Systems

Outcomes data are most easily reported through client-level data systems. To meet the needs of grantees and providers, HAB has supported the development of a database, RW CAREWare. This new software package is designed to provide grantees and providers with a clear and easy-to-use tool for collecting, managing and reporting Annual Administrative Report (AAR) data. RW CAREWare allows users to collect client-level, encounter-based data that can be used to support outcomes evaluation. A built-in “Crosstab Wizard” enables users to conduct extensive analysis of the data to address their own needs. While RW CAREWare allows client-level analysis of data at the local level, the software package contains modules that will summarize and aggregate data to create the AAR.

Consistent Indicators Across Titles

Providers often receive funds from multiple CARE Act titles. Outcomes evaluation is most efficient if the same case management indicators and data elements can be used across titles. A small number of clinical status data elements are already collected for CARE Act clients, making it easier to select clinical indicators that are consistent across titles. In the same way, case management programs (funded by different titles) need to work together to develop consistent case management indicators that work across titles.

Obtaining Clinical Data from Clients

Obtaining clinical data on clients can be difficult, especially in cases where medical records are not accessible to case managers. However, case managers can often obtain some clinical data (*e.g.*, CD4 count, opportunistic conditions, HIV/AIDS status) where they affect service eligibility criteria. For example, in some cases ADAP eligibility is not only based on finances but on medical eligibility, similarly eligibility for Social Security Disability Insurance (SSDI) is based on specific medical conditions. Some medical data may be available for clients whose medications are paid for with ADAP funds. Sometimes specific medical data can be released to clients and then shared with the case manager.



Where providers believe that they cannot obtain reliable, valid data using such methods, an alternative approach is needed. For example, a provider might use of validated instruments for obtaining self-reported client clinical data.

Using Quality of Life Indicators

Quality of life indicators evaluate the client's perceptions of his/her physical, social, and mental health functioning. These indicators can be used to enhance existing clinical data (*e.g.*, HIV status, CD4 count, and/or morbidity and mortality data) or when case management programs cannot access clinical data. Quality of life (QoL) indicators do not measure clinical outcomes, but do evaluate functional status. For example, QoL indicators can evaluate the client's current mental health status (*e.g.*, depressed, not depressed) and ability to perform activities of daily living (*e.g.*, ability to work, go to appointments), but cannot provide biological indicators such as CD4 counts or incidence of opportunistic conditions. A number of quality of life instruments have been validated with and/or are frequently used with HIV/AIDS clients. The box lists some of these instruments.

Quality of Life Measurement Instruments

The following are some examples of quality of life measurement instruments:

- **MOS-HIV Health Survey** assesses client-reported HIV health-related quality of life
- **Multidimensional Quality of Life Questionnaire for Persons with HIV** measures ten major quality of life domains that are specific to people living with HIV/AIDS
- **Karnofsky Performance Scale** assists clinicians and other providers to measure client's ability to carry out activities of daily living
- **Health and Opinions Questionnaire** addresses client views about their own health status and the health care they receive
- **Quality of Well-being Scale** measures well-being in individuals based on the social preferences that are generally associated with an individual's level of functioning
- **WHOQOL-100 and WHOQOL-BREF** assess quality of life in a variety of situations and population groups

See the References and Resources section of this guide for more detailed information and sources for instruments.

Recommended Approaches and Data Sets

HAB recommends that Title I and Title II grantees and planning bodies conduct outcomes evaluation activities related to CARE Act-funded HIV/AIDS services. Following are specific recommended approaches that grantees and planning bodies can use to implement outcomes evaluation with regard to case management services. Several categories of recommended actions are described below:

Outcomes Evaluation Technical Assistance Guide

1. **Case management providers:** Include requirements in case management contracts specifying that Ryan White CARE Act-funded case managers consistently collect the following demographic and outcomes data about clients. The case manager should:
 - As part of the client’s record, maintain the following data:
 - ▼ **Support service data**, including:
 - Service needs at intake
 - Assessment of client’s level of need (*e.g.*, high-, moderate-, low-level)
 - Service plans objectives contracted by client and case manager
 - Service plan objectives met by client and case manager
 - Number and types of service referrals made
 - Number and types of service referrals completed
 - Number of clients who accessed primary health care services
 - Number of clients who maintained their primary health care services
 - Number of clients who maintained their support services
 - Barriers to services reported by clients
 - Number of service units and types of case management client contacts (*e.g.*, office visits, home visits, phone contacts)
 - Quality of life indicators
 - As part of the intake form, obtain and maintain data regarding where clients obtain their primary care services.
 - Maintain data on the source(s) of funding for client’s medical care (*e.g.*, type of health insurance or no insurance) to the extent possible.
 - Maintain pertinent client demographic information (at a minimum: gender, race/ethnicity*, age, risk factors for HIV infection, and whether the client meets program-established poverty criteria).

* The Federal Office of Management and Budget has called for changes in race/ethnicity categories used by Federal agencies. Race and ethnic (*e.g.*, Hispanic) origin questions will be separate, and clients will have the option of checking more than one race option. HRSA/HAB has revised the race and ethnicity categories in cross title reporting systems, the Annual Administrative Reports (AAR), and the RW CAREWare. Programs should make sure that race/ethnicity categories are the same ones used by their State in reporting HIV/AIDS cases to the Centers for Disease Control and Prevention, and/or that they are prepared to change their categories at the same time the State does, so that client profiles can be compared with epidemiologic data.



- Medical case management programs and/or case management programs that are co-located with primary care providers can obtain primary care data. Programs planning to collect primary care data should review the Primary Medical Care Outcomes Guide (see References and Resources), which provides detailed information on the process of outcomes evaluation for primary care providers. The following data can be included as part of a medical case management program’s evaluation data:
 - ▼ **Biological markers and quality of care data**, including:
 - Date, type of facility/provider providing test, and method of documentation for the client’s earliest HIV-positive test date the client received an AIDS diagnosis, if applicable
 - CD4 count and viral load at the time of first test, and dates of first tests, if known
 - Most recent CD4 count test results and date, if known, and lowest CD4 count test results and date; most recent viral load test results, with date and type of test if known; highest viral load test results and date; and lowest test results and date
 - ▼ **Health care utilization data**, including:
 - Number and reasons for non-injury-related emergency room visits
 - Number and reasons for hospitalizations for AIDS-related conditions and number of days per hospitalization
 - ▼ **Morbidity and mortality data**, including:
 - Occurrence of opportunistic conditions
 - If the client dies, date of death and whether death was HIV-related (to be obtained from a family member or other provider)
2. **Grantee or lead agency monitoring, data analysis and reporting:** The grantee or other designated lead agency should:
- Include requirements in provider contracts that they collect, maintain, and report outcomes-related data.
 - Recommend collection of specific, defined clinical and quality of life data where appropriate to ensure shared outcomes indicators across service categories.

Outcomes Evaluation Technical Assistance Guide

- Include as standard language in provider contracts a form permitting reviews of client records by either grantee representatives or a professional consultant or review organization under contract to the grantee, with appropriate confidentiality protections.
 - Conduct contract monitoring sufficient to ensure compliance with stated provider requirements including collection and reporting of outcomes data (*e.g.*, client record audits).
 - Report outcomes in chart and narrative summary form at least annually, in time for use in priority setting and other decision making.
3. **Planning body:** The grantee should ensure the following involvement of planning councils and/or consortia in the review and use of outcomes data:
- Ensure that planning body members understand legislative language and HAB expectations regarding their roles in developing and implementing outcomes evaluation.
 - Collaborate with planning bodies in planning and implementing outcomes evaluation, consistent with their legislative roles and their ability to bring together service providers, consumers, and other “stakeholders” concerned with HIV/AIDS services.
 - Train planning body members to understand and use client outcomes data and charts in planning activities.*
 - Provide planning bodies with outcomes evaluation data in consistent and clear formats each year in time for review and use in priority setting and other decision making.
 - Ensure that planning bodies use outcome data in planning and priority setting.

* For assistance in providing this training, see the Training Guide and Using Data to Assess the Needs for HIV/AIDS Services (See References and Resources section for complete references and information on how to obtain these documents).



Suggested Outcomes and Indicators for Case Management Services

Figure 1, below, provides a summary of what to use in conducting outcomes evaluation of case management, it is based upon the data elements and sources listed in the prior section. Included are a number of outcomes, indicators, and data elements that any Title I and Title II program could use in evaluating case management outcomes, including clinical/health status outcomes. The table shows the close relationship between outcomes, outcomes indicators, and the data elements needed to evaluate performance based on these indicators.

The table includes both general and program-level outcomes that are appropriate for all Title I and Title II case management services and for case management services funded through other CARE Act titles or other sources. This list is illustrative rather than exhaustive; you may want to include other outcomes and/or other indicators.

See the Aids for Outcomes Evaluation section for help in developing initial, intermediate, and longer-term outcomes and indicators using the United Way Logic Model, an evaluation approach that some CARE Act grantees and planning bodies have found useful in guiding their outcomes evaluation efforts, and for references that provide sample indicators and specific questions to include in patient records and in records abstraction forms.

Outcomes Evaluation Technical Assistance Guide



Figure 1: Suggested Outcomes, Indicators, Data Elements, and Data Sources and Methods for Case Management Programs

The following examples are applicable for most case management service agencies, although some of the examples (e.g., service outcomes) are more appropriate for case management programs that are not linked or do not have access to information about the client’s primary health care services.

Outcomes	Indicators	Data Elements	Data Sources and Methods
Service Outcomes and Indicators			
Increased number of clients accessing primary health care services Program-level outcome: Number of clients accessing primary health care services increases over time	Change in the number of clients who accessed primary health care programs after a specified time period	Number and percent of HIV-positive clients who did not have primary health care and accessed primary health care during specified time periods	Programs must have a system in place that is capable of recording the number of clients who accessed primary care, either through (1) follow-up communications with individual clients and/or providers or (2) follow-up communications with a sample number of clients or their providers
Increased number of clients maintaining their primary health care services Program-level outcomes: Number of clients maintaining their primary health care services increases over time	Change in the number of clients who maintained their primary health care services after a specified time period	Number and percent of HIV-positive clients who maintained their primary health care services during specified time periods	Programs must have a system in place that is capable of recording the number clients who did/did not maintain services, either through (1) follow-up communications with individual clients and/or medical provider; or (2) follow-up communications with a sample number of clients or their medical provider
Increased number of clients completing service plan objectives Program-level outcomes: Number of clients completing service plans objectives increases over time	Change in the number of clients who successfully complete the objectives contracted by client and case manager in service plans after a specified time period	Number and percent of HIV-positive clients who completed service plan objectives and number and percent of objectives met by clients	Programs must have a system in place that is capable of recording the number clients who did/did not complete the objectives, either through (1) follow-up communications with individual clients and/or other providers; or (2) follow-up communications with a sample number of clients or their other providers



Figure 1 Continued: Suggested Outcomes, Indicators, Data Elements, and Data Sources and Methods for Case Management Programs

Outcomes	Indicators	Data Elements	Data Sources and Methods
<p>Increased number of clients accessing support services that facilitate their access to primary medical care</p> <p>Program-level outcomes: Number of clients accessing support services that facilitate their access to primary medical care increases over time</p>	<p>Change in the number of clients who obtained support services</p>	<p>Number and percent of HIV-positive clients who obtain support services during specified time periods</p>	<p>Programs must have a system in place that is capable of recording the number of services accessed, either through (1) follow-up communications with individual clients and/or providers or (2) follow-up communications with a sample number of clients or their providers</p>
<p>Increased number of clients completing substance abuse treatment services</p> <p>Program-level outcomes: Number of clients completing substance abuse treatment services increases over time</p>	<p>Change in the number of clients who enter substance abuse treatment services and complete them after a specified time period</p>	<p>Number and percent of clients who enter substance abuse treatment services and complete the program</p>	<p>Programs must have a system in place that is capable of recording the number clients who did/did not complete treatment (1) follow-up communications with individual clients and/or provider; (2) follow-up communications with a sample number of clients or their provider)</p>
<p>Increased number of clients adhering to HIV medication regime</p> <p>Program-level outcomes: Number of clients adhering to HIV medication regime increases over time</p>	<p>Change in the number of clients who adhere to their HIV medication regime after a specified time period</p>	<p>Number and percent of HIV-positive clients who adhere to their HIV medication regimen</p>	<p>Programs must have a system in place that is capable of recording the number clients who did/did not follow the regime either through (1) follow-up communications with individual clients and/or medical provider; (2) follow-up communications with a sample number of clients or their medical provider; (3) client medical records abstraction</p>

Outcomes Evaluation Technical Assistance Guide



Figure 1 Continued: Suggested Outcomes, Indicators, Data Elements, and Data Sources and Methods for Case Management Programs

Outcomes	Indicators	Data Elements	Data Sources and Methods
Psychosocial Outcomes and Indicators			
<p>Quality of life is improved or maintained</p> <p>Program-level outcomes: Quality of life of CARE Act clients is improved or maintained over time.</p>	<p>Improved or maintained human functional status as measured over a specified time period.</p>	<p>Initial measurement of human functional status (taken at the time of intake using quality of life instruments) is compared to measures taken over specified periods of time (e.g., every six months)</p>	<p>Use standardized quality of life instruments to measure human functional status, in coordination with review/abstract from case management records</p>
Quality of Care Standards and Indicators			
<p>Case management care standards are met</p> <p>Program-level outcome: Case management services meet the program's case management standards for clients</p>	<p>Change in percent of case management clients for whom HIV-related service needs are being met</p>	<p>Number and percent of clients whose service plans show attainment of requested services</p>	<p>Programs must have a system in place that is capable of recording the number clients who did/did not access services, either through (1) follow-up communications with individual clients and/or other providers; or (2) follow-up communications with a sample number of clients or their other providers</p>
Biological Markers*			
<p>Slowing/prevention of disease progression</p> <p>Program-level outcome: Disease progression among CARE Act clients is slowed or prevented over time</p>	<p>Improved or maintained average CD4 counts, viral loads for clients as measured over a specified time period</p>	<p>Test results needed to calculate changes in CD4 counts, viral load for individual clients over a specified time period</p>	<p>Programs must have a system in place that is capable of recording disease progression, either through (1) follow-up communications with individual clients and/or medical provider; (2) follow-up communications with a sample number of clients or their medical provider; (3) client medical records abstraction</p>



Outcomes Evaluation Technical Assistance Guide

Figure 1 Continued: Suggested Outcomes, Indicators, Data Elements, and Data Sources and Methods for Case Management Programs

Outcomes	Indicators	Data Elements	Data Sources and Methods
Morbidity and Mortality Outcomes and Indicators*			
<p>Reduced mortality rates</p> <p>Program-level outcome: Mortality rates among clients served by Ryan White CARE Act providers are reduced over time</p>	<p>Change in the percent of clients dying from AIDS-related conditions over a specified time period</p>	<p>Number and percent of deaths from AIDS-related conditions during specified time periods</p>	<p>Review/abstract from case management records (or where possible medical records)</p> <p>Reduced incidence of AIDS-defining opportunistic conditions</p>
<p>Program-level outcome: Incidence of opportunistic conditions among CARE Act clients decreases over time</p>	<p>Change in frequency of occurrence of AIDS-defining opportunistic conditions among clients over a specified time period</p>	<p>Number of cases of AIDS-defining opportunistic conditions, incidence of preventable conditions (e.g., PCP, MAC) among individual CARE Act clients over a specified period</p>	<p>Programs must have a system in place that is capable of recording the number clients who did/did not have opportunistic conditions, either through (1) follow-up communications with individual clients and/or medical provider; (2) follow-up communications with a sample number of clients or their medical provider; (3) client medical records abstraction</p>
<p>Reduced number or rate of AIDS-related emergency room visits</p> <p>Program-level outcome: Rates of emergency room visits among clients decrease over time</p>	<p>Change in the rate of AIDS-related emergency room visits among clients over a specified period of time</p>	<p>Number of clients who make non-injury-related emergency room visits, and the total number of non-injury-related emergency room visits made by these clients during specified time period</p>	<p>Programs must have a system in place that is capable of recording the number of AIDS-related emergency room visits of each client, either through (1) follow-up communications with individual clients and/or medical provider; (2) follow-up communications with a sample number of clients or their medical provider; (3) client medical records abstraction</p>

* Medical case managers or case management programs co-located in medical facilities planning to collect biological and morbidity and mortality outcomes data should refer to the Primary Medical Care Outcomes Guide (see References and Resources) for more information on the process of collecting outcomes evaluation data for primary care services.

Aids for Outcomes Evaluation

This section provides an outcomes evaluation model, factors to consider in outcomes evaluation design, sample materials, references, and other information designed to help Title I and Title II programs meet the recommendations in this guide and carry out other outcomes evaluation activities.

Using the United Way Logic Model for Outcomes Evaluation

CARE Act programs use many different models and methods for outcomes evaluation. HAB does not recommend any specific model as best or most appropriate. An increasing number of CARE Act grantees report using a “logic model” developed by United Way of America. This model provides a step-by-step process for outcomes evaluation, and helps clarify the difference between outputs (measurement of the completed program activities) and outcomes (results for clients who participate in those activities). It also differentiates initial, intermediate, and longer-term outcomes. Because a number of grantees have found the logic model useful, this guide provides two figures that demonstrate how this model can be used in outcomes evaluation.

Figure 2 shows how the United Way Logic Model categorizes the work of a service agency; examples provided are appropriate for an HIV/AIDS primary care provider. Figure 3 shows how to use the logic model approach to develop three levels of client-level outcomes related to primary care. Two types of primary care programs are used as examples: treatment to prevent perinatal transmission of HIV and primary care services for adults with HIV.



Figure 2: United Way Logic Model

Inputs	Activities	Outputs	Client-Level Outcomes	Program-Level Outcomes
<p>Resources dedicated to or consumed by the program</p> <ul style="list-style-type: none"> › money › staff › volunteers › equipment and supplies › medications <p>Constraints (if any)</p> <ul style="list-style-type: none"> › laws › regulations 	<p>Services - what the program does with inputs to fulfill its mission</p> <ul style="list-style-type: none"> › outreach › case management visits › biopsychosocial assessments › client needs assessment › primary care referrals › specialty services referrals › support services referrals › care plans 	<p>Products of program activities</p> <ul style="list-style-type: none"> › clients served › intake › case management visits completed › referrals made › referrals followed up › primary care visits completed › support services visits completed › medications prescribed › treatments provided 	<p>Benefits to or changes in participants during or after involvement in program activities</p> <p>Initial:</p> <ul style="list-style-type: none"> › new knowledge › increased skills › completed referrals › changed attitudes or values <p><i>(e.g., awareness of HIV support services available)</i></p> <p>Intermediate:</p> <ul style="list-style-type: none"> › modified behavior <p><i>(e.g., clients ask for referrals; clients complete referrals; clients obtain services)</i></p> <p>Longer-term:</p> <ul style="list-style-type: none"> › improved health and social condition or status <p><i>(e.g., increased number of clients who maintained their primary health care services; reduced HIV-related morbidity; slowed disease progression; increased quality of life)</i></p>	<p>Program-level benefits to participant group during or after program involvement</p> <p>Initial:</p> <ul style="list-style-type: none"> › new knowledge › increased skills › changed attitudes or values <p><i>(e.g., number of clients referred to primary health care services and/or support services)</i></p> <p>Intermediate:</p> <ul style="list-style-type: none"> › modified behavior <p><i>(e.g., clients advocate for themselves; percent of clients successfully receiving services; decreased number of missed service visits)</i></p> <p>Longer-term:</p> <ul style="list-style-type: none"> › improved health and social condition or status <p><i>(e.g., percent of clients who maintained their primary health care services; reduced HIV-related morbidity; percent of clients with slowed disease progression; increased quality of life)</i></p>

Figure 3: Identifying Three Levels of Outcomes

Program	Initial	Intermediate	Longer-Term
<p>Program: Case Management for Adults/Adolescents with HIV</p>	<p>Specific targeted populations of adults with HIV enter case management service</p> <p>Adults with HIV receive intake, biopsychosocial assessment, and needs assessment.</p> <p>Adults understand that primary health care and support services can increase their health status.</p>	<p>Adult patients receive referrals to primary health care and support services.</p> <p>Adult clients complete referrals to primary health care and support services.</p> <p>Adult clients complete goals documented on client service plan.</p>	<p>Adult clients maintain their primary health care and support services.</p> <p>Adult clients research available services on their own and advocate for themselves.</p> <p>Adult clients report increased levels of human functional status.</p>



Factors to Consider in Planning Your Outcomes Evaluation Efforts

Many factors should be considered in choosing the outcomes and outcomes indicators you will use to evaluate case management outcomes and planning your outcomes evaluation efforts. (These factors are similarly useful in determining outcomes and indicators for other service categories.) The following are especially important:

- 1. Look for a model or approach to guide you in developing outcomes and indicators and implementing outcomes evaluation.** Many practical models exist, among them the United Way Logic Model. You may want to use one or combine approaches from several. Often most useful are the definitions of terms, steps, and suggested ways to approach the development of outcomes and indicators. The reference section provides several sources of information about evaluation models and approaches.
- 2. Develop case management standards of care for units of service.** Standardized “treatment guidelines” for HIV case management are not available, nor are there guidelines on who should be providing case management services, what services should be provided, and how to document a unit of service. Programs must develop their own standards of care in order to define their policies and procedures (*e.g.*, clients will be connected to primary health care services, case managers will follow up with clients and providers to confirm that clients are maintaining primary health care services), and identify the outcomes for the services provided. Using the standards and outcomes case management providers can evaluate outcomes.
- 3. Include a mix of case management, clinical, and quality of care indicators.** Outcomes and indicators can focus on support service utilization, health care utilization/retention, quality of life indicators, morbidity and mortality, and standards of care measures (*e.g.*, evidence from client charts that appropriate support services were offered depending on the level of client needs [*i.e.*, high-, moderate-, low-need]).
- 4. Include initial, intermediate, and longer-term outcomes.** Recognize that initial and intermediate outcomes indicators are available sooner and are often easier to collect. Initial outcomes may seem more like outputs (such as clients are aware of services available, and clients receive referrals to services). To become comfortable with the distinction, focus on changes in the client, but recognize the need for flexibility. Intermediate and longer-term measures provide more information about the effects of services on client social, mental, and/or health status, such as increased number of primary care visits, reduced number of hospital visits, increased levels of client self advocacy, and increased level of human functional status.
- 5. Carefully consider the time and effort required to establish your outcomes data system, including the efforts required of providers.** If your providers do not use the same client flow charts or other shared recordkeeping systems, you will have to agree on data elements and a consistent format and approach for collecting and reporting service access and retention and quality of life data, including specific data to be collected and the methods and frequency of reporting or records review and abstraction. Providers need not use the same forms to collect support service data, but should be recording the same data elements, for example number of clients connected to primary health care, number of clients maintaining primary health care

services, number of clients adhering to treatment regimen. Providers do need to agree upon the quality of life measurement instrument that will be used and the frequency of use. A phase-in period will be required to test and refine the agreed-upon systems--including methods to be used in periodic case management records abstraction or aggregation and reporting of data.

6. **Consider the ongoing time and effort required to collect, maintain, and aggregate required client-level data.** Even after the system is established, the data are useful only if they are regularly abstracted from case management and medical records, used for special studies, and/or aggregated and reported through an appropriate data system. In planning your approach, consider not just development time and efforts but also the resources required to monitor and follow up with clients, maintain the data collection and records abstraction, collect quality of life measures, and/or manage reporting systems. For example, you might plan for regular use of staff or consultants to carry out case management records abstraction for a sample of providers and clients using standardized forms. This will reduce the burden on providers; they will need to collect but not aggregate or report client outcomes data. Consider limiting your initial outcomes evaluation efforts to a small number of outcomes and indicators, such as the ones suggested in this guide, and set up procedures for collecting and reporting them. Once you have experience with them, consider expanding outcomes and indicators.
7. **Consider desired analysis when you choose indicators and make plans for data collection and analysis.** Be sure you make plans to collect, record, and aggregate data both overall and by population group (including the underserved populations identified in your service area), geographic area, and/or funding source.
8. **After you have gained some experience with measuring client-level outcomes, develop program-level objectives or targets you want to meet--**for example, “to increase the number of clients maintaining primary health care service met by X% among population Y.” For example, if your outcome involves increased number of clients accessing primary health care services, your target might be to have 100 percent of clients will be connected to a regular source of primary health care services or 100 percent of eligible clients enrolled in ADAP. Each outcome needs a measurable objective or target of performance. It may be difficult to decide what level of performance you should try to attain during the first year of outcomes measurement, but the only way to determine your success is to have measurable objectives or targets that set the standards your program hopes to meet. Recognize that the targets will need to be refined over time. To decide what constitutes a challenging but achievable outcome target, get a year of experience in measuring outcomes at the individual client level, then aggregate the information to see program-level outcomes. Comparable information from other programs, national data, or Public Health Service standards can help you determine or adjust your targets.
9. **Request assistance through your Project Officer.** A number of CARE Act programs have valuable experience and in many cases written reports documenting their work in developing outcomes indicators and implementing outcomes evaluation activities. Some have used particular models such as the United Way Logic Model. Even if their indicators and systems are not yet fully validated, you can learn about processes and models and about how they met challenges you are likely to face. Contact your HAB Project Officer for referrals to other programs, advice about outcomes evaluation, and where appropriate arrangements for an evaluation consultant through the Ryan White Technical Assistance Contract (TAC).



References and Resources

Following are some references and resources that may be helpful to grantees, planning bodies, and providers in developing and implementing outcomes evaluation and other evaluation efforts. Some focus on clinical outcomes of primary care, while others address quality of life, quality of care, or more general evaluation topics.

HRSA Materials on Evaluation

The following materials are available from HRSA; to obtain them, contact your Project Officer unless otherwise noted.

The Primary Care Assessment Tool (PCAT), an evaluation tool originally developed for Title III and updated in 1998 by a cross-title working group coordinated by the Primary Care Services Branch, Division of Community Based Programs, HIV/AIDS Bureau. Includes modules that focus on clinical services, administration, finance, and support services. Designed for use by a multidisciplinary team making a site visit to a primary care site funded through the CARE Act to assess whether it is meeting legal requirements, HIV-related treatment guidelines, grantee requirements, and other accepted quality standards. Available by downloading from HRSA/HAB website at <http://www.hab.hrsa.gov>.

HIV/AIDS Evaluation Monograph Series. The Evaluation Monograph Series is a group of periodic publications that are developed by the HRSA's HIV/AIDS Bureau (HAB) under the coordination of the Office of Science and Epidemiology to assist Ryan White Comprehensive AIDS Resources Emergency (CARE) Act grantees in designing and implementing evaluation studies. The series consists of concise reports which provide guidance on a wide range of issues relating to program evaluation. Available through the HRSA/HAB website at <http://www.hab.hrsa.gov>.

- ***Choosing and Using an External Evaluator***, Report #1, September 1997. Describes a seven-step process for defining the purpose and scope of an evaluation, selecting an external evaluator, and working with the evaluator to plan and implement a methodologically sound study.

Outcomes Evaluation Technical Assistance Guide

- *Using Data to Assess HIV/AIDS Service Needs: A Guide for Ryan White CARE Act Planning Groups*, Report #2, August 1998. Designed for use in training community members of CARE Act planning bodies, including PLWH, on basic statistics terms and methods and needs assessment, so they can participate actively in activities involving the use of statistics and research reports. Includes self-tests.
- *Cost and Performance-Based Contracting: A Guide for Ryan White CARE Act Grantees*, Report #3, October 1998. Designed to introduce grantees and planning bodies to the concepts of cost and outcome effectiveness and the ways in which cost and performance indicators can be incorporated into priority setting, resource allocation, and procurement processes. Includes useful definitions as well as guidance on developing performance-based provider contracts and monitoring service providers to identify fiscal and performance problems and facilitate quality improvement.
- *A Practical Guide to Evaluation & Evaluation Terms for Ryan White CARE Act Grantees*, Report #4, September 1999, Designed to help CARE Act grantees & planning groups become familiar with the “language” of evaluation. Defines evaluation and explains how evaluation differs from needs assessment, monitoring, research, and continuous quality improvement. Describes the steps involved in designing & conducting evaluations and defines the terms associated with each step. Defines terms related to quality management and improvement.
- *An Approach to Evaluating HAART Utilization & Outcomes in CARE Act-Funded Clinics*, Report #5, June 2000, Description of the approach used by two Title III-funded clinics to evaluate the therapeutic benefits and resource requirements of implementing HAART. Study findings are presented, but the primary focus is on the process of designing and conducting an outcomes evaluation, the problems encountered, and the “lessons learned.”
- *Delivering HIV Services to Vulnerable Populations: What Have We Learned?*, Report #6, October 2000, A summary of recent research on the accessibility, quality, and outcomes of health & support services provided to low-income and medically underserved populations with HIV disease. Focus is on evaluation and research studies funded by the HRSA’s HAB and studies that directly relate to the Ryan White CARE Act. Additional empirical studies that have been conducted or published since 1996 are summarized in the Appendix.

Materials to Assist Grantees in Collecting Client-Reported Quality of Life Data

Following are quality of life tools and supporting information:

- **Medical Outcomes Trust Instruments:** The following instruments from the Medical Outcomes Trust can be used to obtain client-reported health-related quality of life data. Copies and permission to use these questionnaires can be obtained from the Medical Outcomes Trust, 20 Park Plaza, Suite 1014, Boston, MA 02116, telephone (617) 426-4046, and website <http://www.outcomes-trust.org>.
 - ▼ “Health and Opinions Questionnaire.” Available are three client-reported health status instruments that have been tested and found to be reliable and valid. The SF-12 consists of 12 items addressing client views about their own status and the health care they receive. Also available are the SF-20 and the SF-36.



- ▼ “MOS-HIV Health Survey.” The questionnaire adapted from the Medical Outcomes Study (MOS) for persons diagnosed with HIV/AIDS assesses client-reported health-related quality of life. See Wu, et al., below, for information about the uses and validation of this study.
- ▼ “Quality of Well-being Scale.” The instrument measures well-being in individuals based on the social preferences that society generally associates with an individual’s level of functioning at a specific point in time, the scale rates: mobility, physical activity, and social activity, and rates symptomatic complaints that might inhibit function.
- **Karnofsky Performance Scale.** An assessment tool used to assist clinicians and caretakers to measure the patient’s ability to carry out activities of daily living. Client’s ability to carry out activities of daily living is assessed by provider and documented in client records at each visit. The scale is available through the Southeast AIDS Training and Education Center as part of the manual: *Clinical Management of the HIV-infected Adult: A Manual for Mid-level Clinicians*. The manual and scale can be accessed online at <http://www.seatec.emory.edu/default.htm> or can be ordered through the Southeast AIDS Training and Education Center, Emory University School of Medicine, Dept. of Family and Preventive Medicine, 735 Gatewood Road NE, Atlanta, GA 30322-4950, e-mail: seatec@emory.edu, phone (404) 727-2929, and fax (404) 727-4562.
- **Multidimensional Quality of Life Questionnaire for Persons with HIV (MQOL-HIV).** A brief questionnaire that measures ten major quality of life domains (physical function, medical care, social support, physical health, cognitive functioning, intimacy, social functioning, finance, sexual functioning, and mental health) and addresses issues especially relevant for people with HIV and AIDS. The MQOL-HIV can be used as a supplement to clinical measures such as immune status and viral load. Available through the New England Research Institutes, telephone (617) 923-7747 x560, fax (617) 923-4176, and e-mail Media@neri.org.
- **WHOQOL-100 and WHOQOL-BREF.** Two quality of life measurement instruments designed by the World Health Organization (WHO). The WHOQOL instruments can assess quality of life in a variety of situations and population groups. Additional modules are being developed that concentrate on specific population (e.g., people living with HIV/AIDS). Information is available by contacting Dr. Donald Patrick, Department of Health Services F-346, Health Sciences Centre, SC-37, Seattle, Washington 98195, telephone (206) 543-8866, fax (206) 543-3964, and e-mail uswhoqol@u.washington.edu.
- **The American Thoracic Society (ATS) database.** A detailed database on many different quality of life instruments and resources including those listed above. For more information contact ATS at 1740 Broadway, New York, NY 10019, telephone (212) 315-8700, fax (212) 315-6498, or access ATS webpage at <http://www.atsqol.org/>.
- **Using Health-Related Quality of Life Measures:** Article providing guidance on how to use health-related quality of life measures and questionnaires: A.W. Wu, R.D. Hays, S. Kelly, F. Malitz, and S.A. Bozzette, “Applications of the Medical Outcomes Study: Health-Related Quality of Life Measures in HIV/AIDS,” *Quality of Life Research*, Vol. 6, 1997. This article describes health status measures from the Medical Outcomes Study (MOS) and other studies, providing a reference for researchers in selecting an instrument to use, comparing health-related quality of life findings from different studies, or interpreting and analyzing the use of these measures in studies of HIV.

Outcomes Evaluation Technical Assistance Guide**Materials to Assist Grantees in Collecting and Abstracting Outcomes and Quality of Care Data**

Abstracting Medical Records Data: HAB has developed a Medical Records Abstraction form and instructions that can be used to abstract client demographic and medical data, including outcomes data, from medical records. “Impact of RWCA Title I Funding in Newly Funded EMAs: Medical Record Abstraction Form” and “Instructions for Completing the Ryan White EMA Record Abstraction Form” are now being tested in two newly funded Eligible Metropolitan Areas (EMAs). These materials will be available from the Office of Science and Epidemiology, HIV/AIDS Bureau after the instruments are adequately tested and revised.

Other HRSA Materials

Training Guide: A Resource for Orienting and Training Planning Council and Consortium Members. HRSA, March 1997. Includes information on legislative requirements for evaluation and materials for preparing planning council members with limited statistical training to use research and evaluation data. Available from the HRSA Information Center at 1-888-ASK-HRSA or <http://www.hab.hrsa.gov>.

RW CAREWare. HRSA. An ACCESS database developed by HAB. This software package provides grantees and providers with a clear and easy-to-use tool for collecting, managing and reporting Annual Administrative Report (AAR) data. RW CAREWare allows users to collect client-level, encounter-based data that can be used to support outcomes evaluation. A built-in “Crosstab Wizard” enables users to conduct extensive analysis of the data to address their own needs. Data elements include race, gender, age, disease status, primary medical care information, specialty care, case management information, and support service information. The package includes software, manual, and data dictionary for Ryan White CARE Act grantees and providers. Available from Office of Science and Epidemiology, HRSA/HAB, Parklawn Building, Room 7-90, 5600 Fishers Lane, Rockville, MD 20857 or download from <http://www.hrsa.gov/hab/CAREWare>.

Guides Providing “How-To” Information on Outcomes Evaluation

Measuring Program Outcomes: A Practical Approach. Alexandria, Virginia: United Way of America, 1996. This is the “how-to” guide presenting the United Way Logic Model of evaluation, currently being used by at least four Title I EMAs. Available as item number 0989; from Sales Service/America, (800) 772-0008. Cost \$5.

W.K. Kellogg Foundation Evaluation Handbook. Battle Creek, Michigan: W.K. Kellogg Foundation, 1998. Provides practical information on evaluation, including project-level, cluster, and program-level evaluation using several models including logic models. Available as item 1203 from Collateral Management Company, 1255 Hill Brady Road, Battle Creek, MI 49015, (616) 964-0700 or download from <http://www.wkkf.org/Publications/evalhdbk>.



Journal Articles and Other Documents to Assist Grantees in Researching Outcomes Evaluation and Standards of Care

An Integrated Case Management Model: Developing Standards, Evaluation, and Outcome Criteria. Sowell, R. and Meadows, T. The journal article provides information about the case management model used by AID Atlanta. Using an integrated, multisite, multiprofessional (social workers, nurses, pastoral counselors, and therapists) model to develop client-centered plans of care across a continuum of need. The article presents the integrated model and describes the standards of service and outcome evaluation criteria that the AID Atlanta case management program developed. *Nursing Administration Quarterly* 18(2), (1994) pp. 53-64.

Community-Based HIV Case Management: Challenges and Opportunities. Sowell, R. The journal article provides information on the functions and process of case management in HIV/AIDS community settings. Topics covered include outcome evaluation and standards of case management services and providers. *The Journal of the Association of Nurses in AIDS Care (JANAC)* 6(2), (March-April 1995) pp. 33-40.

Case Management of the HIV/AIDS Client. Kucera, K. The journal article examines the many opportunities case managers have to make an impact on clients' lives and long-term outcomes. Topics include case management practice guidelines and outcomes measurements. *Journal of Case Management* 7(2), (Summer 1998) pp. 62-66.

Practice with Highly Vulnerable Clients: Case Management and Community-Based Service. Rothman, J. 1994. Focuses on professional practice involving severely impeded population groups who require comprehensive enhancement service. Outlines an empirically based model of practice that is keyed to 15 specific professional functions and their interrelationships. Prentice-Hall Inc., New Jersey.

Outcomes Measurement in the Human Services: Cross-Cutting Issues and Methods. Mullen E. and Magnabosco, J. 1997. Provides information on theory and practice of outcomes measurement in human services with a specific focus on social work. Available as item 2758 from through the NASW Distribution Center, P.O. Box 431, Annapolis Junction, MD 20701-0431, telephone (800) 227-3590 or online at <http://www.naswdc.org>. Washington, DC: National Association of Social Workers (NASW), cost \$36.95.

NASW Standards for Social Work Case Management. 1992. Developed by NASW's Case Management Standards Work Group, the document provides definitions for ten standards whose purpose are to clarify the nature of social work case management as well as the role of the social work case manager. Available online at <http://www.naswdc.org>.

Outcomes Evaluation Technical Assistance Guide**Treatment Guidelines**

Following is a listing of websites/resource centers (co-sponsored by HRSA) where HIV-related treatment guidelines can be obtained; contact information for accessing HRSA's clinician phone consultation services; and a listing of the various HIV-related treatment guidelines. Guidelines are regularly revised, with changes incorporated most rapidly on the websites.

- **AETC National Resource Center.** Features ability to download guidelines in various formats and a section to “Ask the Experts” guidelines-related questions. Available by telephone (410) 502-7913, fax (410-502-7915, and online at <http://www.aids-ed.org>.
- **HIV/AIDS Treatment Information Service.** Features ability to download PDF files of guidelines and search for other information on HIV/AIDS treatment. Available by telephone (800)448-0440, fax (301)480-3739, and online at <http://www.hivatis.org>.



Glossary

This glossary defines and describes key evaluation terms using explanations and examples designed to make them useful for providers and other non-researchers. For more detailed definitions, see *Glossary of Evaluation Terms for Ryan White CARE Act Grantees*, Report #4 of the HIV/AIDS Evaluation Monograph Series, prepared for the HIV/AIDS Bureau's Office of Science and Epidemiology, September 1999.

Case Management: A range of client centered services that link clients with health care, psychosocial and other services to insure timely, coordinated access to medically appropriate levels of health and support services, continuity of care, on-going assessment of the client's and other family members' needs and personal support systems, and inpatient case management services that prevent unnecessary hospitalization or that expedite discharge, as medically appropriate, from inpatient facilities. Key activities include: initial comprehensive assessment of the client's needs and personal support systems; development of a comprehensive, individualized service plan; coordination of the services required to implement the plan; client monitoring to assess the efficacy of the plan; and periodic re-evaluation and revision of the plan as necessary over the life of the client. May include client-specific advocacy and/or review of utilization of services.

Causality: to establish a cause and effect relationship between the program or intervention and the observed outcomes; to be able to document that the program was the cause (or a cause) of the outcome. This is very difficult. If national studies--such as those conducted by universities or by the HAB Office of Science and Epidemiology--show that ensuring that patients follow an approved HIV-related treatment regimen contributes to positive health outcomes, then it is acceptable for individual grantees and providers to assume that positive longer-term outcomes are at least partially a result of the services provided.

Continuous Quality Improvement (CQI): an ongoing process that involves individuals within an organization in monitoring and evaluating its resources and other service “inputs,” processes, and outputs in order to continuously improve service delivery. CQI focuses on preventing problems and maximizing quality of care. It is a model for improving service delivery that is closely related--and complementary--to program evaluation.

Data elements: the specific items of information that are collected and aggregated in order to make measurements using the indicators. For example, to determine whether the rate of non-injury-related emergency room visits by clients is decreasing over time, required data elements would be the number of non-injury-related emergency room visits by clients during specific periods. To determine whether CD4 counts are being maintained or improved, data elements would be CD4 counts for clients at specific intervals during the stated time period.

Goals: descriptions of desired long-term program impact. It often takes a long time and many programs to achieve a goal. Outcomes objectives measure progress towards goal attainment. For example, one typical goal of Title I and Title II CARE Act programs is to reduce AIDS-related mortality; an outcome objective is to reduce the mortality rate for clients in care.

Outcomes: Benefits or other results (positive or negative) for clients that may occur during or after their participation in a program. **Client-level outcomes** are results for an individual client; examples include biological markers (*e.g.*, improved CD4 count) or morbidity-related outcomes (*e.g.*, reduction in opportunistic conditions). **System-level outcomes** are results stated in terms of all clients receiving services from CARE Act providers, such as reduced rates of perinatal HIV transmission or reduced mortality rates for clients within a particular State or EMA. Outcomes can be categorized along a time continuum, as **initial**, **intermediate**, or **longer-term**; the shorter-term outcomes lead to the longer-term ones. (The Aids for Outcomes Evaluation section includes a sample chart showing the three categories of outcomes that might be expected for two types of primary care services.) Specifically:

- **Initial outcomes** are the first benefits or changes experienced by clients, usually involving changes in knowledge, skills, or attitudes. For example, initial outcomes for a pregnant woman with HIV might be knowledge that treatment is available that can help reduce the transmission of HIV to an unborn child and understanding that she can reduce the probability of perinatal transmission by adhering to and completing this treatment. An initial outcome for an adult entering primary medical care might be to become aware of his/her disease status through determining initial clinical indicators such as viral load and CD4 count.



- **Intermediate outcomes** occur after the initial outcomes and link them to the longer-term outcomes desired for clients. They often involve behavior change. For example, for the pregnant woman with HIV, an intermediate outcome would be beginning or following the treatment regimen to reduce perinatal transmission. An intermediate outcome for an adult in primary care might be compliance with combination antiretroviral therapy. System-level outcomes might include the percentage of pregnant women who adhere to the specified treatment regimen or improved rates of client adherence to combination antiretroviral therapy.
- **Longer-term outcomes** are measurable client results that take longer to achieve such as changes in their condition, clinical health status, or quality of life. They are the long-term results the program was established to accomplish, often related to morbidity and mortality. For example, desired longer-term outcomes for the pregnant woman include completion of the treatment regimen to reduce perinatal transmission and, ultimately, determination that the infant is HIV-negative. System-level longer-term outcomes for primary medical care might include reducing perinatal transmission of HIV, reducing HIV-related mortality, and slowing disease progression (as measured by CD4 count, viral load, or reduced incidence of opportunistic conditions).

Outcomes indicators or measures: the observable and measurable data that are used to measure and track a program's progress in achieving desired outcomes or results. For example, the following individual client-level outcomes indicators might be used by a primary care program to track reductions in morbidity and mortality: biological markers such as changes in CD4 counts and viral loads over time, morbidity indicators such as incidence of new AIDS defining opportunistic conditions, and mortality indicators such as survival during a specified time period. System-level indicators might include reduced rates of non-injury-related emergency room visits or reduced percent of clients dying from AIDS-related conditions over a specified time period.

Outcome objectives or outcome targets: numerical objectives stating the desired level of outcome achievement for the program, such as for all primary care providers or all clients served by a Title I or Title II program. Outcome targets are usually stated for the program rather than for individual clients and are sometimes referred to as **system-level or program-level objectives**. For example, an outcome target might be to have 80 percent of HIV-positive pregnant women complete their treatment regimen or to ensure that 72 percent of adult clients take their medications consistently. In developing outcome targets, it can be helpful to start with targets reached by non-CARE Act providers, or targets specified by the U.S. Public Health Service or other CARE Act grantees. If targets from other locations are used, it is important that they be based on epidemiologic profiles similar to those of your service area.

Outputs: measures of the products or volume of program operations such as the number of service units that a program delivers--the number of clients served, medical examinations provided, CD4 or viral load tests completed, or specialty care consultations provided, etc. For example, a desired output for a primary care program might be to provide primary medical care for 150 adults with HIV disease during the year, or to provide 35 medical examinations for HIV-positive adults each month. Outputs do not measure changes in clients, but without outputs or service units, outcomes would not occur. Sometimes it is difficult to tell the difference between an output and an initial outcome, so judgment is required. It is easier to tell the difference between outputs and intermediate or longer-term outcomes since the latter clearly involve client changes or benefits.

Quality assurance: a formal and systematic process of identifying problems in service delivery, designing activities to overcome these problems, and following up to ensure that correction actions have been effective and no new problems have developed. The emphasis is usually on ensuring that minimum standards of care are met. It is an approach for improving service delivery that is closely related--and complementary--to program evaluation.

System-level or program-level objectives: See **outcome objectives** or **outcome targets**.



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