

NEEDS ASSESSMENTS IN AIDS PATIENTS:
AN EVALUATION OF HEALTH RESOURCES AND SERVICES ADMINISTRATION
FUNDED PILOT NEEDS ASSESSMENTS

by
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CHAPTER ONE: INTRODUCTION

This project will evaluate the Human Immunodeficiency Virus (HIV)/Acquired Immunodeficiency Syndrome (AIDS) services needs assessments developed by recipients of Health Resources and Services Administration (HRSA) Planning Project Grants. The planning project grants were awarded to successful applicants in low to moderate HIV/AIDS incidence areas during the 1989 - 1990 funding cycle. HRSA awarded grants to twenty-two recipients (12 states, two multi-country regions and eight cities or standard metropolitan statistical areas (SMSAs)).

The grants were to be used to develop comprehensive action plans. Plans were constructed to address the health and human service needs of persons with HIV/AIDS. HRSA was interested in providing assistance to communities in the window of opportunity available to low incidence areas before the growing demands of the epidemic overwhelmed the infrastructure of the community. As part of the project, grantees were expected to develop a comprehensive needs assessment of their areas as well as develop community mechanisms for the ongoing oversight of HIV/AIDS planning and service delivery.

There has been no systematic and thorough evaluation of the needs assessment projects developed as a part of the HRSA grants. This study will attempt to evaluate the HRSA projects in an effort to gain insight into HIV/AIDS services needs assessments. Document analysis, supplemented by telephone interviews with the principal

investigators for the projects, will be used to construct a model HIV/AIDS services needs assessment.

Assessment of needs for health and human services has been a standard means of determining the needs and appropriateness of services funded by the federal Department of Health and Human Services for over a decade (U.S. General Accounting Office, 1981). Needs assessments are required for the awarding of both federal and state funding for HIV/AIDS services. The level of funding is determined by a strict formula funding mechanism that considers the number of AIDS cases and per capita income for states or the cumulative number of AIDS cases and per capita incidence of cases for hard hit metropolitan areas. The actual allocation of monies for specific services, however, is tied to demonstration of need in the community.

According to the HIV Division of the Texas Department of Health (TDH), however, the HIV/AIDS consortia of service providers that administer state and federal funding have not adequately complied with or understood the required needs assessment process (Waak, 1992). This lack of understanding of needs assessment undermines current health and social service delivery, weakens planning for future needs and compromises the care and services provided for HIV/AIDS patients in our communities. A better understanding of the needs of HIV/AIDS patients will be required to meet the challenge of the growing epidemic in Texas. It is hoped that the model HIV/AIDS services needs assessment will provide a useful tool to meet this challenge.

Chapter Two, "The AIDS Epidemic" describes HIV/AIDS in the United States and in the state of Texas. The chapter also discusses federal funding for AIDS services. Chapter Three provides a review of relevant needs assessment literature. Chapter Four describes the methodology used in the study. Chapter Five presents the results of the evaluation. Chapter Six presents a discussion of the approaches to needs assessment that appear most successful. Chapter Seven presents the model HIV/AIDS services needs assessment. Appendix A presents a listing of the recipients of the HRSA grants. Appendix B is a glossary of relevant scientific terms.

CHAPTER TWO: THE AIDS EPIDEMIC

This chapter will provide an overview of the evolution of the Acquired Immunodeficiency Disease Syndrome (AIDS)¹ epidemic in the United States and in the state of Texas. AIDS was first recognized in the United States in 1981 and has spread quickly. AIDS is now recognized by many public health authorities as the number one public health problem in the country. As such, it has taxed an already overburdened health and human service system. An understanding of the scope of epidemic is important in understanding health and human service needs.

AIDS in the United States

On June 5, 1981, the first cases of an illness subsequently defined as Acquired Immunodeficiency Syndrome (AIDS) were reported by health care providers in California and the Centers for Disease Control (CDC) (MMWR, 1981). As of December 1991, state and local health departments had reported to the CDC 206,392 AIDS cases among persons of all ages in the United States. The cumulative number of reported deaths associated with AIDS was 133,232 (MMWR, 1992a). Of the estimated one million persons in the United States infected with the human immunodeficiency virus (HIV) that causes AIDS, approximately twenty percent have developed AIDS (MMWR, 1992a). Of those who have developed AIDS, sixty-three percent are reported to have died (MMWR, 1991). The first 100,000 cases were reported

¹ Note: See Appendix B for definitions of scientific terms and abbreviations.

during an eight year period; whereas, the second 100,000 cases were reported during a two year period (MMWR, 1992a).

In 1981, 189 cases of AIDS were reported to the CDC from fifteen states and the District of Columbia. Seventy-eight percent of cases were reported from New York and California. Ninety-seven percent of cases reported were among men, seventy-nine percent of whom reported homosexual/bisexual activity. No cases were reported among children. In contrast, in 1990, more than 43,000 cases were reported, representing all states, the District of Columbia, and the U.S. territories. Nearly two-thirds were reported from outside New York and California. More than eleven percent of adolescent and adult cases were women. Nearly 800 cases were in children less than 13 years of age. These differences between 1981 and 1990 highlight the dramatic growth and increasing complexity of the AIDS epidemic (MMWR, 1991). It was projected that by the end of 1991, AIDS would be the second leading cause of death among men 25 to 44 years of age, and one of the five leading causes of death among women aged 15 to 44 in the United States (MMWR, 1991). AIDS is also a leading cause of death in children from one to five years of age in the United States (MMWR, 1991).

The AIDS epidemic has expanded in scope and magnitude as HIV infection has affected different populations and geographic areas (Gardner et al., 1989). Although homosexual/bisexual men continue to account for most AIDS cases, cases associated with intravenous drug use are more common in several northeastern states (MMWR, 1991). In 1990, the incidence of AIDS increased most rapidly among

persons exposed to HIV through heterosexual contact (MMWR, 1991). In 1992, the CDC reported that the number and proportion of AIDS cases associated with heterosexual transmission was still increasing steadily (MMWR, 1992a). A recent analysis of expected trends in AIDS cases in the United States suggests that by 1995, the infection rate among non-drug using heterosexual men and women may be associated with a doubling of AIDS cases acquired through heterosexual transmission (Brookmeyer, 1991). In addition, the rate of increase in AIDS cases was greatest in the South (MMWR, 1991).

AIDS in Texas

The first case of AIDS appeared in Texas in 1980, although it was not recognized as AIDS for several years (Texas Department of Health, 1991, p. 1). By June 1992, more than 16,000 cases of AIDS in Texas had been reported to the Texas Department of Health. Texas currently ranks fourth (behind New York, California and Florida) among all states in the total number of reported AIDS cases. When state AIDS cases per 100,000 population are examined, Texas ranks ninth in the nation with a rate of 18.3, behind New York (44.8), Florida (38.8), New Jersey (28.4) California (27.5), Georgia (24.0), Maryland (21.2), Nevada (19.6) and Louisiana (19.2) (MMWR, 1992b). Texas also ranks behind the District of Columbia (132.5) and Puerto Rico (50.9) in rate of AIDS cases per 100,000 population (MMWR, 1992b).

For more than a decade, the number of AIDS cases diagnosed each year in Texas has exceeded that of the previous year. By the end of 1992, it is estimated that the cumulative number of AIDS cases will be 20,000 (Texas Department of Health, 1992a, p. 23). It has been estimated that as many as 102,000 Texans are infected with HIV (Texas Department of Health, 1991, p. 2). Most of these persons will eventually be diagnosed with AIDS.

AIDS cases have been reported in 190 of Texas' 254 counties (Texas Preventable Disease News, 1992, p. 2). Since many Texans have HIV but have not yet developed AIDS, the state can expect cumulative cases to continue to rise sharply in the near future, and few counties can expect to remain without cases. In 1991, twelve counties which had formerly never reported an AIDS case reported one or more residents with an AIDS diagnosis. In the six years from 1980 through 1985, rural cases were three percent of all cases reported in Texas. Since 1985, the proportion has increased to four percent (Texas Department of Health, 1992a, p. 18). These statistics clearly show that although high population urban areas have been hit harder by the AIDS epidemic, AIDS is not an urban disease, and rural areas are not immune (Texas Department of Health, 1992a, p. 21).

Texas is fifth in the United States in the total number of AIDS cases reported among children under the age of thirteen (behind New York, California, Florida and New Jersey). Furthermore, pediatric AIDS cases are on the rise in Texas, with a forty-four percent increase in diagnosed cases from 1989 to 1990.

Most Texas children with AIDS were born to HIV infected mothers; sixty-seven percent of all pediatric AIDS cases were exposed perinatally (Texas Department of Health, 1992a, p. 12). HIV seroprevalence surveys that assess the HIV infection rate in women giving birth in the state have shown an average infection rate of 8 per 10,000. This rate has remained stable since 1988 (Texas Department of Health, 1992a, p. 13). However, Texas has a large and growing population of women of childbearing age. From 1980 to 1990, this segment of the population increased by twenty-four percent and the number of births has risen sharply. Thus, a steady rate of maternal infection likely predicts rising numbers of infants born with HIV (Texas Department of Health, 1992a, p. 13). HIV maternal seropositive rates have been higher in urban than in rural counties. However, HIV-positive mothers have been found in all eight public health regions in the state, and the cumulative number of Texas counties reporting at least one maternal infection has increased each year (Texas Department of Health, 1992a, p. 13).

In Texas, as in the United States as a whole, the mode of exposure to the HIV virus that causes AIDS has changed over the course of the epidemic. Seventy-three percent of the cumulative AIDS cases reported to the state are attributed to male homosexual activity. However, when only those cases reported to the Texas Department of Health in the last twelve months are considered, the proportion due to male-to-male sex falls to sixty-eight percent (Texas Department of Health, 1992a, p. 15). Recent cases were more often due to exposure by heterosexual sex or through intravenous

drug use (Texas Department of Health, 1992a, p. 15). Between 1989 and 1990, there was a twenty-seven percent increase in the number of diagnosed AIDS cases reported among heterosexuals exposed to HIV through heterosexual sex or through intravenous drug use (Texas Department of Health, 1992a, p. 16). The number of cases among people exposed to the virus through male-to-male sex and male-to-male sex and intravenous drug use rose only eight percent (Texas Department of Health, 1992a, p. 16). Other changes in the direction of the AIDS epidemic in Texas can be seen in the following statistics for cases diagnosed in 1989 as compared with cases diagnosed in 1990. AIDS cases in children under thirteen years of age increased forty-four percent; AIDS cases in individuals over 39 years of age increased twenty-nine percent; AIDS cases in women increased twenty-nine percent; AIDS cases in African-Americans increased twenty-two percent; AIDS cases in Hispanics increased thirty percent; AIDS cases acquired through heterosexual sex increased twelve percent; AIDS cases acquired through heterosexual sex and intravenous drug use increased thirty-four percent (Texas Department of Health, 1992a, p. 16). Clearly, these are sobering statistics that have serious consequences for the future of the epidemic in the state.

Federal Funding for AIDS

In 1990, in response to the AIDS crisis in the United States, Congress passed the Ryan White Comprehensive AIDS Resources Emergency Act (Ryan White) (PL 101-381). Under provisions of the

act, the federal government makes monies available to states (under Title II) and hard hit metropolitan areas (under Title I) to fund a wide range of services for AIDS patients. The amounts of monies distributed are based on a strict formula funding mechanism that considers numbers of AIDS cases for the two most recent fiscal years and the average per capita income of individuals for Title II or that considers the cumulative number of cases as well as per capita incidence of cases for Title I.

Funds are awarded to consortia of service providers within a metropolitan statistical area (MSA) or to consortia of service providers in each Health Service Delivery Area (HSDA) of the state through the HIV Division of the state Department of Health. According to federal statute (Ryan White Section 2613 c1(B)), the allocation of these funds within each HSDA must be based on "an assessment of service needs within the geographic area to be served." No guidelines for the needs assessment are given in the enabling legislation or any accompanying regulations.

According to the requirements established by the HIV Division of the Texas Department of Health, applications to the state for Ryan White Title II funding must survey the target population to assess current service needs within the HSDA. The survey should be designed to assist in determining where gaps in service exist and addressing those needs in the continuum of care. The survey must be client-based, conducted within the last three months, and include a client assessment regarding the continuing need for currently funded services (Texas Department of Health, 1992b).

A needs assessment, as required by the federal government and the Texas Department of Health in the Ryan White funding process, is a standard means of evaluating health and human service programs as well as awarding and evaluating funding. As a formal process, needs assessment has been discussed and described in the social science literature for many years. The following chapter reviews the available literature on needs assessment in order to provide a framework for the project.

CHAPTER THREE:

REVIEW OF RELEVANT NEEDS ASSESSMENT LITERATURE

This chapter will review the abundant social science literature on needs assessment. The chapter will consider the theories that underlie needs assessment and the conceptual framework that is provided by them. The conceptual framework of needs assessment provides the structure for the HIV/AIDS needs assessment project.

Introduction

Needs assessment as a formal and systematic process for identifying, describing, measuring, analyzing and/or evaluating needs is a relatively recent development that has been discussed in the social science literature since the early 1970s. Although particularly prominent in writings in the education and training fields, assessment of needs for health and human services has been a standard means of determining the need for and appropriateness of services funded by the federal Department of Health and Human Services for over a decade (U.S. General Accounting Office, 1981). The precise origin of needs assessment as a defined analytical tool, however, is obscure (United Way, 1982, p. 1).

While the term "needs assessment" may be relatively modern, it is clear that the needs assessment process is ancient. The principles and objectives of present day needs assessments can be seen in the sixth chapter of the Book of Acts in the New Testament. Jesus' disciples, in consideration of a report of hunger among

widows in the community said, "Identify seven men of honest report, full of the Holy Ghost and wisdom, whom we may appoint over this business." (Acts 6:3.) The public identification of society's needs, together with a commonly held sense of obligation to address at least some of those needs, have created a long history in many different cultures of both a formal and an informal needs assessment processes.

Indian tradition held it customary for the raja or his designates to visit his subjects' homes incognito to uncover their problems. The findings of such visits resulted in the amelioration of problems (United Way, 1982, p. 2).

In the eighteenth century, the prison reformer John Howard used the survey method to document repugnant practices in British prisons and hospitals. He was then able to use his data, together with his field observations, to bring about much needed reforms (Polansky, 1971, p. 1100). In the nineteenth century, the American social reformer Dorothea Dix carefully documented the condition of the mentally ill. As a result of her work, she petitioned Congress for federal funding to support mental health services. In her petition, she was able to document that available institutions at that time could not accommodate more than eight percent of those in need of immediate care (Polansky, 1971, p. 1100). The work of social pioneers like Howard and Dix laid the foundation for recognition that the systematic and objective study of community needs may help to bring about changes needed to address those needs.

A dramatic increase of interest in a formal needs assessment process can be documented in the late 1960s and early 1970s (United Way, 1982, pp. 2 - 6). Much of this interest can be traced to federal funding for the Great Society's numerous new health and human service programs. A requirement for needs assessments was built into the funding mechanisms for many of the new federal programs. It was hoped that the formal evaluation process that should accompany needs assessments would provide a mechanism for increased efficiency and accountability in resource allocation. The growing federal influence that accompanied the flow of federal dollars helped to firmly establish and validate the needs assessment process in the community setting. This chapter will attempt to review the theories and conceptual framework provided by the general needs assessment literature.

Needs Theory

Definition of Need

The definition of the word "need" is widely variable. It can be said to refer not to something in particular, but rather to something which does not exist. Need is basically an empty term, one without conceptual boundaries, subject to many shades of meaning, intent and interpretation. It is both emotion- and value-laden and greatly influenced by social, political, and economic conditions (United Way, 1982, p. 9). This confusion over the meaning of "need" follows the term into its application in the needs assessment field. The result may be that researchers who

argue over the appropriate model or uses for needs assessment work are really differing over the much more fundamental issue of the true nature of need.

The literature on needs assessment suggests that most individuals conceive of need as expressing a gap between a present state and an ideal or satisfactory state (Sell and Segal, 1978, p. 5). Lenning defined need as "a necessity or desirable condition, state, or situation -- whether it be a needed end result that is actuality (met need) or a discrepancy that needs to be closed between a current or projected actuality and a needed end result (unmet need) -- as defined by a relevant person or group." (Lenning, 1980, p. 20.) Lenning's definition highlights some of the conundrums encountered in the determination of need. The first is the recognition that the definition of need involves value judgements. A second is that the choice of individuals or groups that participate in the definition of need is also a value judgement. A third is the confusion of needs with wants, desires, preferences, and demands.

Bradshaw's Typology of Needs

Bradshaw identified four types of expectations that support judgements of need (Bradshaw, 1972, pp. 640 - 643). The first is normative need, an expectation based on an expert definition of adequate levels of performance or service. Although particularly useful to inexperienced individuals and groups, the guidance of experts can impose elitist views and expectations on needs

analysis. Bradshaw's second type of expectation led to felt needs, synonymous with wants. These needs arise from the expectations that members of a group have for themselves. Felt needs are grounded in the insight that a group has into its own problems and its desire to achieve a different end result. The expectations that give rise to felt needs can often be unrealistic and are often influenced by the knowledge of availability of services. The third type of need identified by Bradshaw was expressed need, synonymous with demand, and based on the behavior of the group. Expressed needs can be assessed by looking at utilization rates for current services. Support of expressed needs, therefore, serves to continue the status quo without consideration of the appropriateness of current services. Bradshaw's fourth need was comparative need, which is based in expectation of the performance of a group other than the target group. That is, a person or group similar to the target group is receiving a good or service that the target group is failing to receive. Also termed relative need, comparative need looks at the situation of one group compared with another, usually without reference to any standard of service. Studies of comparative needs may utilize the means of populations on a performance measure and thus may neglect unique characteristics that invalidate generalizations (McKillip, 1987, p. 12). To this list, other researchers have added anticipated need, having to do with projected demands for the future (Sell and Segal, 1978, p. 2).

All of these needs express a recognition of and response to a gap between present reality and a future ideal. The study and assessment of the discrepancy between what is now and what is desired forms the conceptual basis for the needs assessment process.

Needs Assessment Models

The conscious attempt to describe goals, measure differences in performance, and prescribe appropriate remediation is typical of most problem solving techniques. In needs assessment, this analytical process is formalized. However, repeated use and familiarity serve to obscure the assumptions that may be embedded in the needs assessment process (Miles, 1979, p. 170). Such assumptions bear closer scrutiny and may differ, depending on the needs assessment model that is used.

Models may also differ on the scope of inquiry appropriate to needs assessment. Some models incorporate the identification of community goals prior to the needs assessment process itself as well as the ranking of identified needs at the end of the process. Other models suggest that identification of needs without analysis -- inquiry into causes and solutions -- make goal setting and prioritization meaningless (Benjamin, 1989, p. 12).

Discrepancy Model

The most widely used needs assessment model is the discrepancy model of Kaufman (Kaufman and English, 1979). According to

Kaufman, needs assessment is a formal process for determining gaps between what is and what should be in terms of organizational or individual performance and setting priorities for closing those gaps. The prime function of needs assessment is to identify, define, document, and justify gaps in results and select those of highest priority for closure (Kaufman, 1986, p. 24). The Kaufman model emphasizes normative expectations and generally relies on experts to derive performance expectations during a preliminary goal-setting phase (Kaufman, 1977, pp. 60 - 64). Performance expectations are then compared to performance measurements to identify discrepancies. Need is indicated by gaps between performance and goal, larger gaps indicating greater need. Alternatively, an expert panel may rate the importance of the gaps, the most important gap revealing the most important need (McKillip, 1987, p. 21).

The discrepancy model involves the implicit assumption that the identification of a discrepancy is tantamount to the identification of a need (Heath, 1985, p. 11). The discrepancy model usually does not distinguish the recognition of problems from the choice of solutions. Problems are identified with specific solutions in mind (McKillip, 1987, p. 21). The Kaufman model has been criticized for directing attention to the assessment of the degree of discrepancy but not addressing the identification and definition of need (Heath, 1985, p. 12). Because of its dependence on experts, the discrepancy model is often criticized as elitist (McKillip, 1987, p. 21).

Needs Analysis

In later writings, Kaufman proposed two additional processes, needs analysis and methods-means analysis to supplement his needs assessment model and apparently to answer some of the criticisms of his approach (Kaufman and Valentine, 1989, pp. 10 - 14). Needs analysis identifies the bases and causes of needs. Methods-means analysis identifies and selects appropriate ways and means for meeting those needs (Kaufman and Valentine, 1989, p. 11).

Some researchers have charged that the tendency to view needs assessment and needs analysis as separate processes is antithetical to a systems approach to organizational development (Benjamin, 1989, p. 12). Benjamin contends that the prioritization of needs before analysis and understanding of those needs increases the possibility that incorrect solutions will be proffered for incorrectly identified needs (Benjamin, 1989, p. 15). Benjamin then formally proposes a new model derived from the classic Kaufman discrepancy model. Based on a systems approach to the problem, Benjamin advocates combination of identification and resolution stages of the process, and suggests the term "situational analysis" for this approach (Benjamin, 1989, p. 15). The blending of the assessment and analysis techniques has been proposed by other theorists (Mattimore-Knudson, 1983; and Griffith, 1978) and has been practiced for some time by workers in the needs assessment field without an accompanying theoretical or philosophical analysis (United Way, 1982).

Coffing Client Model or Demand Model

The Coffing client needs assessment model is similar in many respects to Kaufman's model (Coffing, 1977). Both are discrepancy models, concerned with gaps, and prioritizing those gaps (Selvadurai, et al. 1989, p. 7). However, Coffing centers his needs assessment model around client not expert perceptions. Thus the Coffing model, using a client centered approach that avoids the problem of cultural imperialism implicit in an expert approach, is equivalent to what has been termed the demand model (Heath, 1985, pp. 14 - 15).

Heath, in his description of the demand model, acknowledges that a survey of client perceptions about need will elicit felt needs or wants (Heath, 1985, p. 14). Thus, the demand needs assessment model utilizes a fundamentally different approach than the Kaufman model which is based on normative concepts of need. The differing definitions of need on which the two models are based reflect different values. Who participates in determining need reflects the root issue of power over goal setting and whose issues are represented (Miles, 1979, p. 173).

Experts and organizations frequently have their own agendas which they may represent as taking precedence over client interests. However, it can be argued that experts are able to appreciate issues and needs that clients cannot. People often express needs for things they do not need (e.g.: cigarettes) and do not want things they manifestly need (e.g.: root canal). People may truly need things but be unaware of their need (e.g.:

potassium). People may also be reluctant to express needs out of embarrassment or fear (Heath, 1985, p. 15).

Marketing Model

Nickens, Purga and Noriega define needs assessment as a feedback process useful for groups and organizations, allowing them to adapt to the needs of their client populations (Nickens, Purga, and Noriega, 1980, pp. 3 - 5). Kotler further developed the concept of needs assessment as feedback using marketing principles and suggested use of a private sector marketing perspective in non-profit sector needs analysis (Kotler, 1982). A marketing orientation holds that the main task of an organization is to determine the needs and wants of a target population (Kotler, 1980, p. 37). A marketing strategy of needs analysis has three components: selection of target population, choice of competitive position, and developing of an effective marketing mix. The marketing model leads to needs analysis that is responsive to the desires of the target population (McKillip, 1987, pp. 22 - 25).

The marketing model is client centered and, thus, is based on felt needs. However, the marketing model is not a discrepancy based model. The marketing model does not measure the gap between what is and what should be but asks what people want and then selects a range and quality of services that will maximize utilization by the target population (McKillip, 1987, p. 23). Prioritization in the marketing model is based on utilization rates and competitive position, not on importance or need. However, in

the post-Reagan world, increasing emphasis is put on the marketplace to determine the availability even of those goods and services traditionally supplied by the non-profit sector. The marketing model may provide a useful perspective as part of a comprehensive approach to needs assessment work.

Dialogue Model

Convergent models of needs assessment attempt to combine aspects of the previously described models. The dialogue model identifies and prioritizes needs based on sustained interaction between investigator and client. Needs are thus identified with people and not for them (Heath 1985, pp. 15 - 16). Unanticipated needs can be clarified and evaluated by both parties. The experience and values of both sides are incorporated into the final recommendations.

Quantitative Models

Some needs assessment models have attempted to address the subjective and arbitrary nature of goal setting and prioritization by the addition of quantitative tools. Harless proposed a client-centered discrepancy model similar to Coffing's model but added a complex scheme in which each problem or need was assigned both a value factor and weight. The final conclusion about the importance of a need was the product of its factor value times its weight (Selvadurai, 1989, p. 9).

A complex more highly quantitative model termed the decision-making model has been proposed by McKillip (McKillip, 1987, pp. 26 - 27 and 105 - 119). The decision-making model has three stages: problem modeling, quantification, and synthesis. In the first stage, needs are identified using multiple indicators or methods. Each need is assessed with each method. During the quantification stage, measurements are transformed to reflect the decision makers' values and interests. During synthesis, an index is produced that orders options. The need index is computed using factors that reflect the decision makers' values and interests and the raw measurement of need. The decision making model is distinguished from discrepancy models and the marketing model because values and their role in needs assessment are made explicit (McKillip, 1987, p. 27). The model is generally implemented using the values of the decision maker, but the values of others, including those of the researcher, can be used instead. A disadvantage of the model is its complexity (McKillip, 1987, p. 28).

The needs assessment model or models chosen for a needs assessment study reflect the values that will underlie the study and will profoundly affect the study's results. The model will also help to determine the type of data that will be gathered and the method or methods that will be employed in the study.

Needs analysis models and their distinguishing characteristics are summarized in Table 1. Characteristics include theoretical

basis, target opinion sampled and type of need according to Bradshaw's typology of need.

TABLE 1

CHARACTERISTICS OF NEEDS ASSESSMENT MODELS

<u>Model</u>	<u>Theoretical Basis</u>	<u>Target Opinion</u>	<u>Type of Need</u>	<u>Additional Characteristics</u>
Kaufman	Discrepancy	Expert	Normative	
Demand	Discrepancy	Client	Felt	
Marketing	Market Demand	Client	Felt	Identification of Target Market
Dialogue	Discrepancy	Expert & Client	Normative & Felt	Identification through Continued Dialogue
Harless	Discrepancy	Client	Felt	Quantitative
Decision Making	Problem Modeling	Expert & Client	Normative & Felt	Quantitative

Types of Data

Many different approaches or methods can be used to gather data in a needs assessment. The data themselves can be classified in several ways -- hard versus soft or impressionistic (Sallis and Henggeler, 1980, pp. 201 - 207), primary versus secondary (Voss, Tordella and Brown, 1987, pp. 156 - 170; United Way, 1982, pp. 14 - 28), and single point versus longitudinal (Heath, 1985, pp. 3 - 5).

Primary/Secondary Data

Primary data are data gathered for the needs assessment by going directly to individuals or selected groups (either clients or experts) and asking them about needs and problems. Primary data can be obtained in population or sub-population surveys, surveys of key informants, surveys of service providers, surveys of service recipients, and public forums (United Way, 1982, p. 14). Secondary data consist of statistical information gathered for a purpose other than the purpose at hand (Voss, Tordella and Brown, 1987, p. 156). Secondary data sources may include previous surveys, census data, administrative records, historical records, epidemiological studies, service statistics, social indicators, economic data, inventory of resources, needs data identified by other planning systems and budgets (Voss, Tordella and Brown, 1987, pp. 157 - 158; United Way, 1982, p. 14).

Hard/Soft Data

Hard data are derived from the more statistical and quantitative approaches to needs assessment. Epidemiological studies, social indicator analyses, and utilization surveys provide hard data. Impressionistic approaches to needs assessment rely on subjective evaluation of needs (Sallis and Henggeler, 1980, p. 201). Impressionistic approaches include surveys, focus groups, and public meetings.

Single Point/Longitudinal Data

Most needs assessments gather data and analyze and prioritize needs during a specified time interval. Although follow-up evaluations may be planned as part of the assessment process, results and conclusions are based on single point analysis. Another type of useful information may be gathered from a panel approach to needs assessment wherein the same group of informants is studied over time. Repeated observations and measurements are made of the same individuals. The intensive information that can be gathered as a result of a continuing dialogue between respondents and investigators can permit refinement of the needs assessment process over time (Heath, 1985, p. 3). This longitudinal approach to data gathering may also provide insights into the evolution of need in a target population, which in turn permits modeling of projected as well as present needs.

Some workers in the needs assessment field have advocated the continuous acquisition of data that can be studied and analyzed

periodically within a needs assessment framework. DeVillaer has asserted that adequate needs assessment information can be obtained by incorporating a few additional questions into an agency's existing intake assessment protocol and can, therefore, provide an ongoing source of prospectively collected needs assessment information (DeVillaer, 1990, p. 211). The format relies on a previously completed comprehensive needs assessment that identifies specific needs and then uses aggregate data collected from many individuals over time to identify service needs.

Needs Assessment Methods

Excellent references are available that describe in detail the many methods or techniques used to gather needs assessment data (Warheit, Bell, and Schwab, 1977; Nickens, Purga and Noriega, 1980; United Way, 1982; Bell et al., 1983; Johnson, Meiller, Miller, and Summers, 1987; McKillip, 1987; Gilmore, Campbell, and Becker, 1989).

Resource Inventory

An inventory of resources describes the services available to a target population and may reveal gaps in services due to lack of availability, lack of continuity, or lack of capacity (McKillip, 1987, pp. 32 - 42). Resource inventories can provide under- and over-utilization information and help to prevent needless duplication of services. A resource inventory cannot by itself indicate need and is inadequate if used as the sole approach.

Inventories should be supplemented with measures of the extent of problems and potential demand for services. Resource inventories indicate solutions that are already being implemented and thus reinforce the status quo. However, the collection of service information provided by a resource inventory is invaluable in evaluating normative and expressed needs revealed by other methods. A successful resource inventory requires the cooperation of all resource providers in an area.

Social Indicators

Social indicators are aggregate statistical measures that depict important aspects of a social situation and of underlying historical trends and developments (McKillip, 1987, pp. 43 - 57). Social indicators are usually gathered by local, state, and federal governments and are therefore relatively easy to access, are available on most topics and for most geographical areas, and are available at relatively low cost. Social indicators are especially useful for describing populations in both absolute and comparative terms. Social indicators can be used as proxy measures of problems (McKillip, 1987, p. 55). The most frequent use of such indicators is in risk factor analysis in which social indicators are chosen for their ability to predict problems or utilization of services (McKillip, 1987, p. 47). However, social indicators have questionable validity as predictors of problems, do not reveal solutions (McKillip, 1987, p. 55), and incorporate the personal and

class biases that enter into the construction of social indicators (United Way, 1982, p. 27).

Utilization Rates

Utilization rates or service statistics provide a well accepted and heavily used indicator of need. Utilization rates are relatively easy to access and can be derived at relatively low cost. Use analysis combines expected use with analysis of actual clients seen and services provided. Use analysis should also include examination of the potential barriers that may explain the discrepancy between expected and actual utilization rates. Barriers to service utilization may include awareness, availability, accessibility, and acceptability (McKillip, 1987, p. 58). Utilization analysis is not helpful in examining the unmet needs of unserved populations (United Way, 1982, p. 27). It is another method that tends to reinforce already existing services and organizations.

Epidemiologic Studies

Epidemiological studies provide estimates of the prevalence of disease and disability (United Way, 1982, pp. 19 - 20). Expectations for use can be developed from epidemiological surveys. Discrepancies between actual use rates for needed services by the identified population and projected rates indicate problems of unmet needs (McKillip, 1987, p. 62). Epidemiological data frequently must be interpreted together with social indicators and

demographic data. Problems may be encountered with epidemiological studies if the available epidemiological data are not appropriate for the target population. Frequently, epidemiological data are available only for large aggregate and heterogeneous populations. Characteristics of the target population may not be equivalent to the population described by available epidemiological data. In addition, prevalence rates may vary among different studies, often because of varying definitions of the problem (United Way, 1982, p. 20).

Surveys

Surveys are a very popular and adaptable method for gathering needs assessment data. Surveys provide a flexible means of assessing expectations of populations, sub-populations, key informants, service providers, and service recipients (United Way, 1982, pp. 15 - 17). Surveys provide a relatively high level of validity and reliability. Survey methods most frequently used in needs assessment are face-to-face interviews, mail surveys, and telephone surveys (McKillip, 1987, pp. 71 - 72). Surveys, however, can be relatively costly. Surveys of experts and service providers tend to elicit information on normative needs and to reinforce the status quo. Surveys of sub-populations may be difficult due to cultural and language barriers. Surveys of service providers have a high probability of cultural and class bias as well as bias in favor of the provider's own services. In addition, service providers are more familiar with the needs of served rather than

unserved populations (United Way, 1982, pp. 16 - 17). Surveys of service recipients elicit information on felt needs and should be used cautiously to predict actual utilization (McKillip, 1987, p. 84). Client surveys, like surveys of service providers, cannot supply information on the unserved populations. Issues of sampling validity and confidentiality are also raised by client surveys.

Delphi Panels

Delphi panels are a special adaptation of survey methodology. The Delphi technique is a type of group process that generates consensus among decision makers and service recipients through a series of survey questionnaires (Gilmore, Campbell, and Becker, 1989, pp. 43 - 48). A questionnaire that contains several broad questions designed to elicit responses about needs are sent to all participants. Responses are analyzed and a second questionnaire developed for clarification. Responses are again analyzed and the process continued until consensus or a limited range of responses is developed. Advantages of the Delphi technique include the absence of face-to-face contact, which reduces conformity, domination, and conflict, the usually high level of motivation of individuals who agree to participate, and a sustained format that encourages the quality and quantity of ideas (Gilmore, Campbell, and Becker, 1989, pp. 43 - 44). Disadvantages of the technique include cost and administrative time, difficulty in identifying participants able to make the extended time commitment, and the

limited opportunities for clarification due to absence of direct contact.

Structured Groups

Structured groups are an alternative as well as a supplement to the other methodologies mentioned. Groups can include organized public meetings or community forums open to selected populations. Such groups are relatively inexpensive, open up the process to the population at large or the targeted community, provide good community relations, but are not statistically representative of the general population or of the targeted group (United Way, 1982, p. 17).

Focus Groups

Focus groups can be adapted well to needs assessment studies. The focus group is an exploratory process that is used for generating hypotheses, uncovering attitudes and opinions, and acquiring and testing new ideas (Gilmore, Campbell, and Becker, 1989, pp. 69 - 74). Focus groups provide an opportunity to hear people speak their minds and may therefore be a useful way to explore the needs of unserved or underserved populations. The group process stimulates a wide range of ideas, emotions, and information, and the group structure enables the moderator to obtain clarification if needed (Gilmore, Campbell, and Becker, 1989, p. 69). Focus groups can be performed with homogeneous or diverse groups, as appropriate. The disadvantages of focus groups

include their dependence on the skill of the moderator, small sample sizes, qualitative data, and potential difficulties in recruiting subjects (Gilmore, Campbell, and Becker, 1989, p. 70).

Nominal Groups

Nominal groups are more structured groups of five to seven people who have some knowledge of the issues to be discussed. Participants write responses to pre-selected questions and then share their responses in turn. Ideas are clarified through discussion and then ranked by each individual. After another round of clarification and discussion, ideas are ranked and an overall tally constructed. Thus, the result of a nominal group is a priority ranking of answers to various needs assessment questions (McKillip, 1987, p. 89).

The choice of participants for a nominal group (i.e.: providers and/or clients) greatly affects the character of the group and the results obtained. Advantages of nominal groups include equal opportunity for all members to participate. The more disciplined structure ensures tolerance for minority views, reduces the potential for control of the group by a single individual or the use of hidden agendas, and avoids arguments (Gilmore, Campbell, and Becker, 1989, p. 62). A disadvantage of nominal groups can be the introduction of bias because the method encourages expressions of personal opinions, beliefs, and experiences (Gilmore, Campbell, and Becker, 1989, p. 62). Nominal group responses may also deviate from the direction intended by the original question.

Needs assessment methods and their characteristics are summarized in Table 2. Characteristics include type of data (primary or secondary; hard or soft) and the advantages and disadvantages of each method.

TABLE 2

NEEDS ASSESSMENT METHODS

<u>METHOD</u>	<u>DATA*</u>		<u>DATA HARD/SOFT</u>	<u>ADVANTAGES</u>	<u>DISADVANTAGES</u>
	<u>PRIMARY 1°</u>	<u>SECONDARY 2°</u>			
Resource Inventory	1° & 2°		Hard	Provides under & over utilization data; clues to access & duplication.	Inadequate if sole approach; requires cooperation and common language.
Social Indicators	2°		Hard	Relatively easy access & low cost; flexibility.	Reliance on record; bias in indicator construction.
Utilization Rates	1° & 2°		Hard	Relatively easy access & low cost.	Not show unmet needs; reinforce status quo.
Epidemiologic Studies	2°		Hard	Relatively inexpensive.	Inadequate if sole approach; appropriateness to target population.
Surveys	1°		Soft	Relatively high level of reliability and validity.	Relatively costly; not all populations amenable to study; cultural & language barriers; reinforce status quo.

TABLE 2 (Continued)

<u>METHOD</u>	<u>DATA*</u> <u>PRIMARY 1°</u> <u>SECONDARY 2°</u>	<u>DATA</u> <u>HARD/SOFT</u>	<u>ADVANTAGES</u>	<u>DISADVANTAGES</u>
Delphi Panels	1°	Soft	Relatively costly; time required; no direct contact.	High level of participant motivation; no direct contact.
Structured Groups	1°	Soft	Community relations; opens up process; relatively inexpensive.	Non-representative open to political agendas.
Focus Groups	1°	Soft	In depth study; clarification of opinion; able to overcome cultural and language barriers.	Dependent on skill of facilitator; small sample size; recruiting subjects; relative cost and time.
Nominal Groups	1°	Soft	In depth study; clarification of opinion.	Dependent on skill of facilitator; small sample size; recruiting experts; relative cost and time.

*Primary (1°) Data: Data obtained for the purposes of the study at hand.
 Secondary (2°) Data: Data originally obtained for other purposes.

Criticisms of the Needs Assessment Process

Many of the biases and disadvantages of needs assessments models and methods can be mitigated by the combination of several methods in the needs assessment process (Steadham, 1980; Evans, 1985). Client-centered methods can be balanced with provider-centered methods. Methods can be chosen that will represent normative, felt, expressed, comparative, and anticipated needs. By combining methods, the values and perspectives of clients, experts, service providers and the community can be represented. Needs identified by one method can be cross-validated by the results from other methods (Miles, 1979). Heath termed this more complex methodological framework convergent analysis (Heath, 1985, pp 5 - 6). In convergent analysis, information is gathered from a range of methods, deployed both systematically and sequentially. The term "convergent" is used to convey the combination of information from different sources and different strategies as well as the cumulative nature of an ideal assessment procedure viewed across time (Heath, 1985, p. 6). The convergence of multiple perspectives permits the approximation of a more valid description of community needs.

Difficulties in the needs assessment process may be encountered due to the characteristics of special populations under study. The tendency of some needs assessment methods to impose cultural bias and elitist attitudes has been described. If special population groups need to be included in a needs assessment, careful consideration should be given to the techniques employed.

Some population groups, such as Hispanics, do not respond well to impersonal methods of data collection (Delgado, 1979). More personal methods that respect cultural needs should be chosen. Problems may also be encountered due to language or illiteracy barriers. The use of interpreters and translators may be helpful. Interviews or focus groups may help to overcome illiteracy. Interviewers or facilitators from similar racial, ethnic, or cultural backgrounds may facilitate information gathering.

A 1981 study by the General Accounting Office (GAO), Health Service Program Needs Assessments Found Inadequate, is one of the most comprehensive studies available of the needs assessment process (U.S. General Accounting Office, 1981). The Department of Health and Human Services (HHS), in administering federal grants in a variety of programs, requires that an assessment of need for services be made to support and evaluate grant proposals. The GAO concluded that little benefit was obtained from the needs assessment process. A portion of the criticism was directed at the needs assessment process itself, but the majority of the problems the GAO described were attributed to HHS's guidance and supervision of the needs assessment process.

An eight-year study of the needs assessment experience of United Way agencies documented significant advances and success in applying the technology of needs assessment to the private sector (Center for Social Research and Development, 1974). A more recent examination of the United Way experience supports the usefulness of needs assessment work in identifying and prioritizing need if the

project is carefully planned, and the inherent biases of methods are balanced and considered in project design (United Way, 1982).

Conclusions

Although a relatively recent analytical technique, needs assessment provides useful tools for the systematic identification, analysis, and prioritization of problems and needs in a community. Although value judgements are deeply embedded in the needs assessment process, balanced and useful information can be derived from a well-planned and comprehensive needs assessment plan.

Needs Assessments in AIDS

There are no complete presentations of needs assessment work for AIDS patients in the formal scientific or social science literature. Presentations were made at the Fifth, Sixth and Seventh International Conferences on AIDS, and abstracts of those presentations appear in the appropriate conference materials.

In 1989, the Health Resources and Services Administration (HRSA) awarded contracts for HIV/AIDS planning project grants to twenty-two principal investigators around the country. A portion of the funds awarded were to be used for development of the needs assessment process in the AIDS field. HRSA was particularly interested in helping states and metropolitan areas outside of the hardest hit areas, such as New York and San Francisco, to gear up to meet the growing demands of the AIDS epidemic. The HRSA grants were also planned to assist communities in developing their

infrastructure to meet the requirements of what was to become the Ryan White funding (Soliz, 1992). When written into law, the Ryan White statutes, as previously stated, required the performance of needs assessments in AIDS patients to qualify for funding. The in-house needs assessment projects that have been performed under Ryan White requirements have tended to stay in-house and have not been published or made available to the general AIDS scientific or service communities.

It has been the experience of the HIV Division of the Texas Department of Health that AIDS/HIV service consortia within the state have not adequately complied with or understood the required needs assessment process in applications for Ryan White funding (Waak, 1992). No guidance is provided by federal or state authorities. The experience of the Texas Department of Health suggests that most AIDS service providers lack knowledge of the needs assessment process or the funding to perform needs assessments well. This lack of understanding of the needs assessment process undermines current health and social service delivery, weakens planning for future needs, and compromises the care and services provided for AIDS patients in their communities. A better understanding of the needs of HIV/AIDS patients will be required to meet the challenge of the growing HIV/AIDS epidemic in Texas.

The review of needs assessment literature provides the structural framework and the evaluation elements necessary for analysis of the needs assessments that form the core of the AIDS

needs assessment project. The next chapter will discuss the methodology used for the project.

CHAPTER FOUR: RESEARCH METHODOLOGY

This chapter explains the methodologies used to analyze the HRSA funded needs assessments. The AIDS needs assessment project is an exploratory descriptive study that attempts to identify and describe the optimal components of an HIV/AIDS services needs assessment and then to utilize the identified components to construct a model needs assessment. No hypothesis has been tested in this work. The study has been carried out using document analysis of the twenty-two HRSA funded needs assessment studies, supplemented by open-ended telephone interviews with the principal investigators of the projects.

Document Analysis

The primary method chosen for this study is document analysis of the final reports of the twenty-two HRSA funded projects. (The projects are listed in Appendix A.) Document analysis is an appropriate method to answer questions of a descriptive nature (Yin, 1989, p. 25).

A project will be considered evaluable for the purposes of this study if access is available to the final report for the project, including methods, survey instruments, results and conclusions. The documents will be analyzed for their content using the evaluation elements of needs assessments identified in Chapter Three.

All evaluable needs assessments will be analyzed for target client study populations, efforts to include or consider

underserved minority populations, provider study populations, methods of data collection and methods of analysis.

Target study populations to be considered include people with AIDS; symptomatic HIV+ individuals, asymptomatic HIV+ persons, family members, significant others and caregivers of HIV+ persons, and the bereaved family, significant others and caregivers of deceased HIV+ persons. Underserved minority populations to be considered include African-Americans, Hispanics, Native Americans, women, children, adolescents, migrant workers, undocumented aliens, persons in rural areas, homeless persons, substance abusers and incarcerated persons. Persons from these minority communities are traditionally underserved and under-represented in HIV/AIDS studies and planning.

Provider populations to be considered include the following: physicians, dentists, case managers, key informants, hospitals, home health agencies, clinics, community based organizations, mental health providers, long term care facilities, hospices, housing facilities, drug treatment programs, transportation services, legal services, benefits counseling, food or meals and emergency financial assistance.

Methods of data collection that were used in analysis of the needs assessment documents included the following: resource inventories, utilization studies, epidemiological projections, surveys, interviews, focus groups, committees or workshops, and public forums.

Methods of analysis that were used in analysis of documents included the following: definition of services, definition of service units, utilization statistics, analysis of utilization patterns by stage of disease, presence and type of epidemiologic projections, attempts to identify services in a continuum of care, identification of gaps in services in the continuum of care, discussion of barriers to accessing care, recommendations (general or specific) and prioritization of recommendations.

Results of the analysis will be presented in narrative form. Results will also be described in the percentages of time each client study population, provider type, method of data collection and method of analysis was used.

A weakness of document analysis is limitation to what has been recorded. All aspects of a process or all conclusions may not be accessible to a researcher who has only the written record available for study. This limitation of document analysis has been addressed by the addition of interviews with principal investigators of the projects.

Investigator Interviews

Open-ended telephone interviews with principal investigators of the projects supplemented information obtained by analysis of the project reports. If the principal investigator was no longer available, an associate knowledgeable about the project was interviewed.

Interviews consisted of obtaining responses to the following questions:

- 1) Do you consider that the needs assessment project was successful?
- 2) Has the consortium established for the project continued to function in your community?
- 3) Have any of the goals that were established in your report been accomplished?
- 4) How have you used the results of the project in your community?
- 5) What worked best about the project?
- 6) What worked least?
- 7) How would you change any of the procedures or methods if you had to repeat the process?
- 8) What was the community's reaction to the process and to your results? How did you involve the community in the process?

The results of the interviews are summarized in narrative form.

The open-ended interviews attempted to compensate for some of the limitations of document analysis. An advantage of interview surveys is their ability to collect more complex information and impressions. A disadvantage of interview surveys, however, is that information obtained from interviews may be difficult to analyze due to its subjective and often erratic nature. In addition, it can be difficult to ensure a high degree of consistency in the conduct of the interview. The current study used a clearly defined

format and list of questions and a single interviewer to minimize variability in the interview process.

Limitation of the Study

A limitation of the study is the relatively small number of projects funded by HRSA for this grant cycle. Because Ryan White funding, available since 1990, mandates needs assessments, it is likely that other AIDS needs assessments have been performed. The experience of the Texas Department of Health, which has found needs assessments in the state deficient, however, suggests that most HIV/AIDS service providers and consortia lack knowledge of the needs assessment process or the funding to perform needs assessments well. Study of the HRSA funded needs assessments has the advantage of using a defined population of documents from needs assessment projects that were well funded and performed by individuals and organizations that were highly motivated to perform the job well in order to meet the requirements of their funding.

The twenty-two HRSA needs assessment projects were analyzed with the framework and evaluation elements listed. The findings of the analysis are presented in the next chapter.

CHAPTER FIVE: RESEARCH FINDINGS

This chapter presents the findings of the document analysis in narrative form as well as in table format, the methods of data collection used and the methods of analysis. The results of the investigator interviews are also presented in narrative form.

Projects Evaluable

Eighteen of the twenty-two HRSA funded projects were considered evaluable. The full final reports from three of the projects (New Haven, Connecticut; Milwaukee, Wisconsin; and Texas) were unavailable. A fourth project (Jacksonville, Florida) did not include a needs assessment. Community needs assessment had been performed by the Jacksonville AIDS Coalition with funds received from an earlier grant. HRSA funds were used to address community needs that were identified in the earlier project.

Evaluable projects included eleven state-wide assessments, one regional project, and five city-wide (or standard metropolitan statistical areas (SMSA)) assessments. See Appendix A for a listing of all of the HRSA funded projects.

Difficulties in the Analysis

Difficulties were encountered in evaluating the population of the eighteen needs assessment projects as a group because of the different terminology used for data collection methods, provider types and methods of analysis. The different terms used may mask identical methods and approaches. The differing terms may,

however, represent different approaches and different groupings used in the needs assessment process.

Evaluation elements chosen for the study represent the most frequently used elements in needs assessment processes. The definitions of those elements and groupings of the elements were the commonly understood definitions of those terms. For example, substance abuse programs were understood to include chemical dependency programs, alcohol treatment programs and intravenous drug abuse programs. Mental health programs were understood to mean individual counseling, group counseling, peer support groups and in-patient psychiatric care. Long term care facilities were understood to include traditional nursing homes, skilled nursing facilities and intermediate nursing care facilities.

Client Study Populations

The client populations that were studied in the needs assessment projects are summarized in Table 3. As expected, self-administered surveys were the most common method of obtaining client data.

The majority of the projects provided for direct client input in the needs assessment process. All projects included not only people with AIDS, but also both symptomatic and asymptomatic HIV+ individuals.

Approximately half of the needs assessments utilized randomly distributed self-administered surveys to study clients. Surveys were distributed by providers and returned by mail or both

distributed and returned by mail. About a quarter of the projects utilized interview surveys administered to randomly chosen individuals. Other methods, including random telephone surveys, client focus groups, targeted surveys and committees with client participation, were utilized by a minority of the needs assessment projects. One third of the projects used more than one method of data input from clients. Self-administered surveys combined with focus groups and interview surveys combined with focus groups were the most frequent combinations. One project did not specify the type of client input used. Only a minority of projects provided for input from families, significant others and caregivers of HIV/AIDS patients. None of the projects provided for input from bereaved survivors of deceased HIV/AIDS patients.

Results of client study populations are summarized in Table 3. The type of population and the method used to study the population group are presented.

TABLE 3

CLIENT STUDY POPULATIONS
(Total number projects studied = 18)

<u>Population</u>	<u>Method</u>	<u>Number of Projects Using Method</u>
Client	Random self-administered survey	10
	Random interview survey	5
	Random telephone survey	1
	Targeted self-administered survey	1
	Focus Groups	4
	Committees	1
	Random self-administered survey with focus groups	2
	Random interview survey with focus groups	2
	Random self-administered survey with telephone survey	1
	Random self-administered survey with focus groups and committees	1
	Not specified	1
	None	2
Family, Significant Others and Caregivers	Focus groups	1
	Random interview surveys	1
Bereaved	Any Method	0

Efforts to Consider Minority Populations

Efforts to consider minority populations are summarized in Table 4. Both direct input from the minority population, and consideration of the needs of minority communities without direct input were considered. The specific minority populations were also considered.

Three quarters of the projects made some effort to consider if not specifically include minority populations. Almost one quarter of the projects actually sought input from members of an appropriate minority community. Three quarters of the projects attempted to devote some thought and planning to the needs of minority communities but did not consult the minority community directly during the development of the project. The extent of these planning and discussion efforts varied widely.

Half of the projects considered the needs of African-Americans. One quarter of the projects considered the needs of Hispanic clients. One half of the projects considered the needs of substance abusers. Just under one half of the projects considered the special needs of women. One half of the projects considered the special needs of children. One third of the projects considered the special needs of adolescents. Just over one quarter of the projects considered the needs of incarcerated persons. Just over one quarter of the projects considered the special needs of rural populations. Only a minority of projects gave special consideration to Native Americans, migrant workers, undocumented aliens and the homeless.

The willingness of an Advisory Committee to plan and consider the special needs of various minority populations may reflect the political power of the various communities or their advocates. Willingness to consider special needs may also reflect the size of the problem the particular minority may pose for the community at large. Results for consideration of the special needs of minority populations are summarized in Table 4.

TABLE 4

EFFORTS TO CONSIDER MINORITY POPULATIONS
(Total Number of Projects Studied = 18)

<u>Consideration</u>	<u>Number of Projects Studying Minority Population</u>
Type	
Any type	14
Direct input from minority	4
Planning and deliberations	14
Population	
African-American	9
Hispanic	5
Substance abusers	10
Women	8
Children	9
Adolescents	6
Incarcerated persons	5
Migrant workers	2
Undocumented aliens	1
Native Americans	2
Rural clients	5
Homeless	3

Provider Study Populations

Details of the study of providers in the needs assessment projects are presented in Table 5. Each provider type is broken down by the methods used to study it.

Three quarters of the projects provided information on the provider populations studied. Among the projects providing information, the principal method of studying providers was by survey. Return rates for the surveys varied dramatically, from five to ninety percent.

One half of the projects surveyed physicians about their willingness to treat and their attitudes towards HIV/AIDS patients. One quarter of the projects surveyed dentists about their willingness to treat and attitudes towards HIV/AIDS patients. A small number of the projects used focus groups, committees or public forums to assess the attitudes of these professionals.

Over one half of the projects surveyed hospitals about their history, policies and attitudes towards accepting HIV/AIDS patients. Small numbers of projects used other methods to obtain input from hospitals, including hospital record reviews, hospital administrator interviews and a committee format that included hospital administrators. One half of the projects surveyed home health agencies about their willingness to serve HIV/AIDS clients. Other methods of obtaining information from home health agencies used by a minority of projects included statistics from third party review, interviews and a committee format. Ambulatory care clinics were surveyed in one half of the projects. Community based

organizations (CBOs) were also surveyed in one half of the projects. Other methods used by a minority of projects for obtaining information from clinics and CBOs included interviews and committees.

Mental health service providers were surveyed in one half of the projects. Methods used by a minority of projects to obtain information from mental health providers included statistics from third party review, committees and interviews with mental health administrators.

Housing was surveyed in one half of the projects. Long term care facilities were surveyed in over half of the projects. Hospice facilities were surveyed in one third of the projects. Other methods used by a minority of projects to obtain data from housing, long term care or hospice facilities included interviews with administrators or the participation of administrators on committees.

Drug treatment programs were surveyed in one half of the projects. Methods used by a minority of projects to obtain information from drug treatment facilities included third party statistics, interviews with administrators and committees.

A minority of projects surveyed funeral homes about their policies for accepting persons who have died from HIV/AIDS. One project utilized a public forum that included input from directors of funeral homes.

One half of the projects surveyed transportation services. One quarter of the projects surveyed emergency financial assistance

services available to HIV/AIDS clients. One third surveyed legal assistance services. A minority of projects surveyed benefits counseling services, job counseling services and food pantry or meal services.

One third of the projects surveyed case managers about gaps in services, access barriers and community needs and priorities. Outside of the structure of the Advisory Committee and officially designated subcommittees, a few projects specifically provided for input from key informants and community leaders.

Accurate interpretation of information on provider input may be difficult. Review of the final reports does not reveal if input from certain classes of providers was not obtained because it was known that the provider type did not exist in the community or because input from the provider type in question was not considered important or possible. In general, the largest providers or most important provider types (e.g., hospitals, clinics, physicians) were surveyed by the highest proportion of projects. However, other very important services such as food pantry or meal services were surveyed by a relatively small proportion of projects.

TABLE 5

PROVIDER STUDY POPULATIONS
(Total Number of Projects Studied = 18)

<u>Provider</u>	<u>Method</u>	<u>Number of Projects Using Method</u>
Physician	Survey	9
	Public forum	1
	Committee	1
Dentist	Survey	5
	Focus group	1
	Committee	1
Hospital	Survey	11
	Record review	2
	Interview	1
	Committee	1
Home Health	Survey	9
	Third party statistics	1
	Interview	2
	Committee	1
Ambulatory Care Clinics	Survey	9
	Interview	1
CBO	Survey	3
	Interview	1
	Committee	2
Mental Health	Survey	9
	Third party statistics	1
	Committee	2
	Interview	1
Housing	Survey	9
	Interview	1
Long Term Care	Survey	11
	Committee	2
	Interview	1
Hospice	Survey	6
	Interview	1
	Committee	1

TABLE 5 (Continued)

<u>Provider</u>	<u>Method</u>	<u>Number of Projects Using Method</u>
Drug Treatment	Survey	9
	Third party statistics	1
	Interview	1
	Committee	1
Funeral Home	Survey	3
	Public forum	1
Transportation	Survey	9
Emergency financial aid	Survey	5
Legal help	Survey	6
Benefits help	Survey	3
Job counseling	Survey	2
Food/meals	Survey	4
Case manager	Survey	6
Community leaders	Public forum	1
	Committee	1
Key informants	Committee	3
	Public forum	1
	Interview	1
	Focus group	1
	Survey	1

Methods of Data Collection

Details of the methods of data collection are summarized in Table 6. All projects provided specific information on their methods of data collection for either client or provider populations. In addition, nearly all of the projects used surveys. One third of the projects used third party statistics and one third used focus groups. Almost a quarter of the projects used an interview format as well as a committee format.

The statistics on method of data collection reflect the popularity of the methods in the social sciences as well as popular familiarity with use of the methods. Figures may also reflect the expense and expertise required to utilize each of the methods. More expensive methods or methods that require technical skill would be less likely to be widely used.

TABLE 6

METHOD OF DATA COLLECTION
(Total Number of Projects Studied = 18)

<u>Method</u>	<u>Number of Projects Using Method</u>
Survey	17
Focus Groups	6
Interviews	4
Committees	4
Third Party Statistics	3
Public Forum	1

Methods of Data Analysis

Services needed by HIV/AIDS clients were defined in over one quarter of the projects. Units of service provision were defined in over one third of the projects. A continuum of care can be defined as a system of health care provision, a line of services that continues throughout an illness, that is integrated, comprehensive and consistent, providing continuity and choices. A continuum of care with component needed services was established in just over one half of the projects.

Epidemiological considerations were discussed in all projects with regard to present and projected incidence of AIDS as well as the seroprevalence of HIV in the community. Over one third of the projects provided no specifics on the epidemiological methods used in the project. Over half of the projects cited the epidemiological methods employed in their calculations. Almost half of the projects used more than one method to project a future range for AIDS cases and HIV seroprevalence. The methods cited included the following: Brookmeyer back calculation, Centers for Disease Control proportional method, forward projection, doubling time, cumulative reported cases, linear regression with and without transformation, Public Health Service transmission category method, actuarial formula, extrapolation, life table analysis, cross sectional method, newborn screening, infection progression, and extrapolation method. It is certain that some of these methods are the same. However, because different names have been used, and

most often no references for the methods are cited, it is not possible to be certain from review of the project reports.

One half of the projects analyzed the data collected to provide client utilization statistics for all services. Over one third broke down the utilization patterns by stage of disease or T cell number because it is known that utilization patterns and T cell numbers vary by stage of disease.

All of the projects considered gaps in services in their final report. Two of the projects, however, did not perform a resource inventory. Therefore, reports of gaps in service were based on impressions from client surveys and provider discussion groups. Over one third projects considered barriers to access in their report.

All of the projects proposed general recommendations in the analyses of their projects. More than half of the projects made very specific recommendations involving monies or personnel required to implement the recommendations. General priorities within broad categories of recommendations were presented in half of the projects after extensive considerations of Advisory Committees. None of the projects presented a precise listing of numbered priorities in their final analysis.

There was a significant amount of variation in the approaches taken towards the analysis and reporting in the projects. The variation may reflect the very general requirements placed on the grant recipients by HRSA. A needs assessment was required but no precise instructions were given to grant recipients as to how that

must be performed. Similarly, a final report was required but no specifications were provided on the format or scope of the needs assessment efforts and the final reports varied widely. Some of the variation in emphasis among the reports likely reflects the differing requirements of the states or areas studied as well as the varying expertise and experiences of the individuals involved in the project.

Principal Investigator Interviews

Telephone interviews were conducted with over half of the principal investigators or knowledgeable associates familiar with the project. Seven of the eighteen projects either had no one still employed who was familiar with the HRSA grant process, or the author was unable to speak with an appropriate knowledgeable individual.

Certain trends were clear in the responses of the principal investigators to the general questions asked about their experiences with the needs assessment project. All investigators felt that one of the most valuable results of the grant process was the building and operation of the broadly based Advisory Committees in their communities. The committees continue to function in some capacity in almost all of the communities. The investigators felt that the inclusive nature of the Committees helped to assure support for the work of the Committees and that the coalition building required for the Committees to function benefitted the communities.

All investigators felt that the needs assessment process had been useful to their communities by helping to educate various sectors of the community. State or community-wide planning that resulted in a formal document by which communities can now develop their services and measure their progress was considered by all investigators to be a very significant result of the project.

All investigators had used the project as a basis for providing direction, documentation and data in applications for funding from both public and private sources. All had been successful in obtaining at least some funding for their work at the close of the HRSA funding cycle.

The knowledge acquired from a review of the needs assessment literature, from study of the HRSA-funded needs assessment project reports and from conversations with the principal investigators for the projects have been used to identify the methods and approaches that should prove most successful in HIV/AIDS needs assessment projects. These methods and approaches are discussed in the following chapter.

CHAPTER SIX: DISCUSSION

Careful review and analysis of the materials from all eighteen HRSA funded projects was combined with discussions with the principal investigators. The efforts provide some very clear information and some distinct impressions about the needs assessment process and ways in which such a project can be approached that will enhance the likelihood of a successful outcome.

Needs assessment must be understood as a process. The initial project is a process for determining gaps between "what is" and "what should be." A needs assessment should identify, define and document gaps between actual performance and defined goals. After studying the differences between how things are and defining how things should and will be, recommendations about priorities should be developed to help direct resources and efforts to the greatest needs. After tackling the initial process, however, needs assessment should be seen as an ongoing process or evaluation.

The needs assessment process, like many human endeavors, is undertaken with certain assumptions on the part of the individuals responsible for setting up the project and the individuals participating in it. The assumptions depend on the reasons for doing the needs assessment, the requirements and expectations of the communities that are supporting the process and the people involved in the project. Some discussion about the assumptions that underlie the process before beginning may help to clarify, focus and structure the goals and projected uses of the needs

assessment. Clarification of previously unspoken agendas and motivations can also help to establish consensus and teamwork.

The needs assessment process must be overseen by a responsible body that is given the authority to structure the process and make necessary decisions about the conduct of the project. Creation of a broadly based Advisory Committee to provide such oversight is critical in bringing to the process the support of various provider, client, professional, business and community constituencies. Participation on the Advisory Committee helps to assure input and support and the variety of viewpoints is critical to success. Particular attention should be paid to participation on the Advisory Committee of representatives from minority communities affected by HIV/AIDS that have been traditionally underserved or under-represented.

A good needs assessment requires input from several different sources. Each source provides a different dimension to the final picture. The perspective of clients is pivotal and is best understood as including infected individuals as well as family members, significant others and caregivers who are profoundly impacted by HIV/AIDS. The needs of such "affected" clients must be considered in the HIV/AIDS care delivery system that relies so heavily on community and family supports. For the same reasons, bereaved survivors of deceased HIV/AIDS clients may be able to provide a valuable perspective on service needs.

In collecting information on service needs, individuals other than clients and providers may be in pivotal positions to be able

to provide valuable insight on unmet needs and barriers to access. Any valuable source of information that can be relatively easily accessed should not be overlooked. In particular, case managers, who coordinate and access care systems for clients, can provide valuable insight that can inform and illuminate the needs assessment process.

Clients, providers, case managers and key informants provide to the needs assessment process different types of information about different types of need. The process should endeavor to obtain and balance different types of input. Inclusion of both objective quantitative data as well as more impressionistic, qualitative and subjective information on need will result in assessment of need that is more accurate and useful.

The Advisory Committee should discuss what services will be included in the continuum of care within the community. The discussions should include a definition of the services as well as agreement on how the services will be measured. Agreement on such logistical details is vital to be certain that all participants in the process have the same understanding and the same rules by which to play. Meaningful data in the final analysis of the project depend on clear definitions and agreement at the beginning of the project.

Agreement on and definition of the epidemiological considerations that will be used in the needs assessment process are also critical. All such considerations and assumptions should

be clearly stated so that interpretations and subsequent work are not confused by misunderstanding and misinterpretations.

All needs assessment projects should include a resource inventory. Knowledge of what exists is critical before need can be convincingly demonstrated. The level of detail and sophistication of data collection in a needs assessment project may vary with the resources of the agency or area undertaking the inventory. However, some level of knowledge about resources and capacity for service is vital.

Many different methods of data collection can be used in a needs assessment project. Although surveys are the most popular method for acquiring data, other methods may be important ways to supplement a data base. Other methods may provide more subjective and qualitative information to flesh out a comprehensive understanding of service needs in a community. In addition to surveys, data can be obtained by focus groups, interviews, workshops, committees and public forums. No one method or combination of methods is always appropriate. The choice of method should consider the populations that need to be investigated, as well as balancing different types of data, i.e., combining methods that use qualitative subjective data with those that measure objective quantitative criteria.

Collection of data from clients must include consideration of ways in which the needs of underserved minority populations can be included in the process. Minority population groups may require extra effort and different approaches, but it is imperative that

assessment of need in a community does not just reflect the desires of individuals and providers that are already a part of the process. The fastest growing segments of the epidemic are in unserved and under-represented minority communities. Ways must be found to provide services and care to minorities.

The Advisory Committee must establish procedures for the analysis and integration of all the data collected in the needs assessment process. The level of detail in analysis and recommendation may vary, depending on the needs and capabilities of the Committee and the objectives of the project. It is useful to provide for review of a draft version of the final report and recommendations. In addition, public presentation of the reports' findings accompanied by expressions of support for the final recommendations from various leaders and experts can help to assure community recognition for the accomplishments and future goals of the project.

Review of the needs assessment literature, study and analysis of the HRSA-funded needs assessment project reports and conversations with the principal investigators for the projects have been used to construct a model HIV/AIDS services needs assessment. Such a model could be used by communities or organizations unfamiliar with the needs assessment process to assist in conducting a needs assessment. The model HIV/AIDS services needs assessment is presented in the following chapter.

CHAPTER SEVEN

MODEL HIV/AIDS SERVICES
NEEDS ASSESSMENT

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MODEL HIV/AIDS SERVICES NEEDS ASSESSMENT

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PREFACE

This model HIV/AIDS services needs assessment has been put together to provide all the information and tools needed to perform a needs assessment. The model can be adapted for use by small community-based organizations (CBOs), large providers, cities, or entire health service delivery areas (HSDAs).

A needs assessment should be much more than a client opinion survey. To be useful, a good needs assessment requires input from several different sources. Needs assessments should combine objective quantitative information with subjective and qualitative information.

In addition, needs assessment should be an ongoing process. Although needs assessments are most often performed on a periodic basis, after mastering the process in periodic evaluations, plans should be made to collect some needs assessment information on an ongoing basis.

The model needs assessment first addresses what a needs assessment is, who is involved in its development, what assumptions are involved, what services are included and how those services are measured. The epidemiology of HIV/AIDS must also be considered. The model then reviews the methods most frequently used in a needs assessment for HIV/AIDS services, how to analyze and combine all of the data, as well as how to write and present the final report.

I. What is a Needs Assessment and How is it Used?

Needs assessment is a process for determining gaps between "what is" and "what should be" and for setting priorities for closing those gaps. The function of a needs assessment is to identify, define and document gaps between actual performance and goals/forecasts. A needs assessment also studies and documents barriers to accessing services. After studying the differences between how things are and defining how things should and will be, priorities are established for directing resources and efforts to the greatest needs.

Needs assessments are used to illustrate needs, to justify funding and to support requests for future funding.

II. Assumptions Underlying the Needs Assessment Process

There are always assumptions made. The assumptions depend on the reasons for doing the needs assessment, the requirements and expectations of the community and the people involved in the project. Discussion before beginning the project helps to clarify, focus and structure the goals and projected use of the needs assessment.

The assumptions may include but are not limited to the following issues.

1. HIV/AIDS presents unique problems that other diseases do not, including fear and discrimination against those infected.

2. HIV/AIDS will affect everyone in the community, not just people in traditionally labelled high-risk groups.
3. The entire community shares an obligation to address the problem of HIV/AIDS. The costs of that obligation should be distributed appropriately among all segments of the community.
4. An effective community response to HIV/AIDS requires ongoing planning.
5. Persons with HIV/AIDS have dignity and worth. Services provided to them must reflect that principle.
6. Persons with HIV/AIDS need a comprehensive range of accessible services. Vital services should be provided in local communities whenever possible.
7. Services should give affected persons choices for their care and should encourage individuals to maintain responsibility for and control over their own lives.
8. Problems of access to services in rural areas and in traditionally underserved communities require special attention. Such communities include gay men and lesbians, African-Americans, Hispanics, Native Americans, women, children, homeless persons, substance abusers, people with disabilities, imprisoned persons, migrant workers and undocumented aliens.
9. HIV/AIDS-related services should be provided in a manner that is sensitive to all cultures, races and ethnic minorities.

10. A compassionate care delivery system should include consumers at all levels of planning. Services should be efficient, effective and accountable to the community that supports them.
11. Existing community networks for HIV/AIDS services should be maintained and strengthened.
12. The resources of traditional community health and human service providers should also be used to deliver support and care to minimize unnecessary duplication of services and to make the best use of scarce resources.
13. Although not addressed in the model HIV/AIDS service needs assessment, prevention and education are a vital component in the continuum of care.

III. Who is Involved in the Needs Assessment Process?

A. For Advice and Oversight

To provide for advice and oversight of the needs assessment process, an Advisory Committee should be created. The committee should include many different types of people because many different viewpoints are needed. This approach may require expanding membership of an existing Consortium or Board of Directors. Members should be individuals who will be motivated to really participate in and contribute to the process. Members of the Advisory Committee help to bring support and input from the groups they represent, cooperation and participation in the process and support for the findings.

Community and business leaders bring community and business support and local charitable foundation dollars to local service and prevention efforts. Creation of a successful community coalition to plan and conduct the needs assessment project can provide the basis for an ongoing HIV/AIDS Planning Coalition in the community.

The following groups should be represented, as appropriate:

- HIV/AIDS service organizations
- Traditional health care providers including, but not limited to,
 - Physicians
 - Dentists
 - Nurses
 - Hospitals
 - Clinics
 - Pharmacists
- Social service providers
- Mental health care providers
- Local public health agencies
- Government and political leaders
- Community and business leaders
- Appropriate specialists such as transportation and public utility experts
- HIV+ individuals and people with AIDS (PWA)
- Significant others, families and caregivers of HIV+/PWA
- Consumer advocates
- Representatives of pharmaceutical firms

- Representatives of affected communities with particular attention to people who can speak for traditionally under-represented populations such as
 - Gay Men and Lesbians
 - African-Americans
 - Hispanics
 - Native Americans
 - Women
 - Children
 - Homeless Persons
 - Substance Abusers
 - Incarcerated Persons
 - Migrant Workers
 - Undocumented Aliens

B. For Data and Insight

A goods needs assessment requires input from several different sources. Each source provides a different dimension to the final picture.

1. Clients (Infected, Affected and Bereaved)

The perspectives of clients are a pivotal part of any needs assessment project. Clients of HIV/AIDS service agencies include not only those infected with HIV, but families, significant others and caregivers who are also affected by the disease. Those who have lost a loved one to HIV infection are also included. A survey of clients produces what are called expressed needs which are the same thing as desires. Although it is vital that the client's interests and issues are represented so that clients have significant input into setting goals and priorities, people may express need for things they do not actually need (e.g., cigarettes) and do not want

things they need (e.g., root canal). Client input is vital but is only a part of the overall needs assessment process.

2. Providers/Key Informants

Providers and key informants can often appreciate issues and needs that clients cannot. Key informants may include technical experts as well as individuals with extensive political or personal experience with HIV/AIDS. Expert opinion gives a different viewpoint on need (called normative need) that is based on experience and expert definitions of adequate performance and service. The opinions of providers and key informants are an important part of a good needs assessment when combined with the opinion of clients.

3. Case Managers

Because of their pivotal role in coordinating care for HIV/AIDS clients, caregivers and families, case managers are in a unique position to see gaps in services and barriers to accessing services. For these reasons, the Advisory Committee may wish to supplement input from clients, providers, and key informants with the insights and opinions of case managers.

IV. What Services and Included in the Continuum of Care and How are They Measured?

A. Service Categories

The Advisory Committee must clearly define the service categories within which capacity and need will be measured. Basic services should be defined as the critical components of care that should be available in every community. Additional services should be placed in an expanded level of care. There are currently no standards or minimum requirements for services in the continuum of care. Basic services should be defined and should serve as goals for services to be made available within each HSDA.

If needs assessments performed in various localities may be combined or compared to establish regional or state-wide need, equivalent service categories must be used. Please see Appendix 1 for definitions of services.

Possible categories may include but are not limited to the following services:

- Case Management
- Physician Services
 - General Physicians
 - Specialist Physicians
- Acute In-patient Medical Care
- Ambulatory Medical Care
- Home Health Services
 - Skilled Nursing Care
 - Respite Services
 - Home Health Aide Services

- Attendant Care
- In-home Hospice Care
- Home Support Services
 - Transportation
 - Homemaker Services
 - Meals
 - Food Bank
 - Nutrition Counseling
- Volunteer Support Services
 - Buddy Program
 - Helper Program
 - Home Care Teams
- Medication Services
- Medical Equipment
- Dental Care
- Rehabilitation Services
- Mental Health Services
 - In-patient services
 - Out-patient services
 - Individual Counseling
 - Support Groups
- Pastoral Services
- Housing
 - Emergency Shelter
 - Temporary Shelter
 - Independent Living
 - Assisted Living
 - Adult Day Care
- Pediatric Foster Care
- Long Term Care Facilities
 - Skilled Nursing Facilities
 - Intermediate Care Facilities
- Residential Hospice/Special Care Facilities

- Benefits Advocacy
 - Information and Referral
 - Legal Services
 - Emergency Assistance
 - Insurance Assistance
 - Rent Assistance
- Substance Abuse Services
 - Out-patient
 - Residential
- Street Outreach
- Outreach to Correctional Facilities

B. Service Units

Estimates of capacity and need for services should be expressed in precise and reproducible terms. If needs assessments performed in various localities may be combined or compared to establish regional or state-wide need, capacity and need must be expressed in equivalent terms.

The Advisory Committee should adopt and clearly define service units for all services in the continuum of care.

Possible service units may include but are not limited to the following listing:

<u>Service Category</u>	<u>Units/Month</u>
Ambulatory Care including	
Physician care	visits
Dental care	visits
Outpatient drug therapy	visits
Mental Health Treatment Services including	
Support Group	hours
Individual Counseling	hours
Pastoral Care	hours

<u>Service Category</u>	<u>Units/Month</u>
Housing Services including	
Emergency Shelter	days
Temporary Shelter	days
Independent Living	days
Assisted Living	days
Adult Day Care	days
Home Health Care including	
Skilled Nursing Care	visits
Home Health Aide Services	visits
Attendant Care	visits
In-home Hospice Care	visits
Home Support Services including	
Homemaker Services	visits
Meals	visits
Transportation	hours
Volunteer/Support Services	
Buddy Program	visits
Helper Program	visits
Home Care Team	visits
Acute Institutional Care including	
Medical Care	days
Psychiatric Care	days
Long Term Care including	
Skilled Nursing Facility	days
Intermediate Care Facility	days
Pediatric Foster Care	days
Residential Hospice/Special Care Facility	days
Substance Abuse Services including	
Residential Programs	slots
Out-patient Programs	days
	slots
	visits
	hours
Rehabilitation Services	visits

Service CategoryUnits/Month

Case Management

15 minutes
slots
visits

Benefits Advocacy including

Information and Referral
Legal Services
Emergency Assistance
Insurance Assistance
Rent Assistancevisits
visits
dollars
dollars
dollars

V. Epidemiology of HIV/AIDS

A. Current Status of HIV/AIDS

Investigation of community needs must start with the best data available about current incidence of HIV/AIDS in the community. Data source and method for determining current HIV seroprevalence should be cited. The HIV Division of TDH will be the sole data source for figures of current incidence of HIV/AIDS. TDH currently uses cumulative reported cases to define HIV seroprevalence and incidence of AIDS.

All assumptions that have a direct or possible impact on the data should be stated. Assumptions that have a direct impact are:

- incidence of under-reporting including region-specific or population-specific under-reporting
- delay in reporting

Assumptions that have a possible impact are:

- migration of HIV+ individuals and PWA after diagnosis
- trends in spread of HIV/AIDS across the state

- percent of HIV+ population who will develop AIDS in a given year

TDH will define the assumptions to be used. If data will be compared or combined, assumptions and methods should be the same.

B. Future Trends of HIV/AIDS

Needs assessments use projections of future incidence of HIV/AIDS to help estimate future needs. The method used to project future incidence should be stated. The HIV Division of TDH, which uses regression analysis, will be the sole source for estimates of future incidence of HIV/AIDS.

Assumptions may also be made which have a possible impact on projections of future incidence of HIV/AIDS. These include:

- the progression of the epidemic
- cumulative mortality
- effects of earlier intervention in progression of disease and of increasingly effective drugs

TDH will define the assumptions to be used. If data will be compared or combined, assumptions and methods should be the same.

VII. What Methods are Used?

We have discussed what kinds of information are needed and how to measure them. We will now look at methods of obtaining

information, the process of data collection, and finally data analysis.

A. Resource Inventory

1. General Comments

a. Purpose

An inventory of resources describes the services and service capacity currently available for all service categories in the continuum of care. Resource inventories need to be routinely updated.

b. Advantages

A resource inventory may reveal gaps in services due to absence of services, inadequate capacity of facilities or providers or barriers to accessing services. Resource inventories can show what services are under- or over-utilized and help to prevent duplication of services.

c. Disadvantages

A resource inventory cannot by itself indicate need. Resource inventories look at solutions and approaches that are already being implemented and therefore reinforce the status quo.

d. Target Population

A resource inventory should look at the resources of all services included in the continuum of care and chosen for study by the Advisory

Committee. For example, a survey of dentists may provide useful information about availability of dental services, as well as the knowledge and attitudes of dentists in an area. However, the Advisory Committee may decide that such a survey is outside the scope of the needs assessment.

A successful inventory requires the cooperation of all providers. Cooperation can be fostered through the members of the Advisory Committee that represent the provider groups.

2. What to Ask in a Resource Inventory

What to ask should be discussed and clearly stated by the Advisory Committee before beginning the project. Resource inventories are most often done by survey and the objectives dictate how the survey is customized, the type of questions included and the data derived from the inventory. Small groups or areas with limited resources may only be able to cover a few subjects with a limited number of questions.

Possible subjects and types of questions useful in a resource inventory are listed below.

<u>Subject</u>	<u>Types of Questions</u>
Provider description	Provider data
Client description	Client data
Services offered	List services
Service capacity	Current capacity
Capacity used	Service provided
Capacity not used	Service capacity minus capacity used
Current need	Average wait for services
Client use of services	Average times used
Planned expansion	Plans for services and capacity
Access Barriers	Policies/Eligibility

3. How to Perform a Resource Inventory

Resource inventory surveys should be mailed with a postage paid return mailer and a requested return date two weeks from receipt. If not returned within three weeks from date of receipt, a reminder (perhaps with a second copy of the survey) should be mailed to each delinquent respondent. If not received within another two weeks, a phone call should be made to those who have not returned their surveys. Phone calls made by members of the Advisory Committee from the provider community may be helpful.

In order to make the survey format more "user friendly" and thus more likely to be completed, survey

instruments tailored to different types of care providers should be used.

Resource inventories have most often been performed on a periodic basis. Needs assessment is most meaningful when performed on an ongoing and continual basis. Larger providers and areas with more resources may be able to begin planning for ongoing collection of the pivotal data used in a resource inventory (e.g., services offered, service capacity, capacity used). The ongoing or monthly collection of this data could be done by expansion of quarterly report activities. Ongoing collection of data permits more frequent analysis and better response to community needs.

B. Survey

1. General Comments

a. Purpose

Surveys are a popular and relatively easy way to gather information from large groups of people about a variety of subjects. Surveys can be self-administered or can be administered by another person. Self-administered questionnaires provide complete anonymity and are generally successful if the survey is concise, relatively simple and written clearly. A survey is generally given by another person if it is lengthy or complex or if

the target population needs more personal contact to make the survey successful.

b. Advantages

Surveys are generally easy to perform and are adaptable to many different types of subjects and circumstances. They have a relatively high level of validity (they give correct answers) and reliability (they give the same answer if done more than once).

c. Disadvantages

Surveys can be relatively costly, especially if administered by another person or if postage costs are high. A significant problem with client surveys, particularly for HIV/AIDS services, is that not all populations can be easily studied. The groups generally surveyed are those currently receiving services. Often, cultural and language barriers affect survey outcome. For these reasons, surveys tend to reinforce the status quo.

d. Target Population

Many different types of populations can be studied by survey: clients, providers, case managers and key informants. There are different ways to do the survey after the target population is chosen. Possible methods include blanket distribution to all individuals in a group, random

sampling and directed sampling (special effort to get representatives of special populations). Blanket distribution and random sampling will probably give poor representation of underserved special client population groups. Directed sampling may be necessary to adequately sample all client groups.

2. How to Conduct a Survey

Surveys distributed by mail or through a service provider but to be returned by mail should contain information on target return date. Postage paid return mailers should accompany all such self-administered surveys to encourage people to complete and return them. Surveys distributed by a service provider that are intended to be anonymous (i.e., client, physician, or dentist surveys) can be coded so that analysts can determine which provider distributed the survey. This type of coding, together with a record of the number of surveys distributed at each site, will permit calculation of return rate. Return rates are important in considering the validity of survey results.

If survey questionnaires will be administered by another person, arrangements must be made for space and time for administering the survey. This should be done in the most convenient manner for the individuals taking, not those giving, the survey.

Interviewers should be chosen with some care and given at least a modest amount of training. Individuals chosen should be somewhat knowledgeable about HIV/AIDS, non-judgmental and accepting of other people and other opinions. Interviewers should be informed about the importance and the objectives of the survey. The questionnaire should be reviewed aloud and explained with the interviewers. Potential problems should be discussed. Interviewers must secure the respondent's permission to be interviewed, establish rapport with the respondent and obtain the maximum amount of unbiased information possible about sensitive subjects. Interviewers should be given an opportunity to practice administering the survey before beginning the project.

Before beginning the survey process, utilize the members of the Advisory Committee, especially the representatives of special communities, to get the word out about the project and the importance of participation. It is important to let people know that it is an open process, and that you want to meet their needs but you must know what their needs are in order to meet them.

Confidentiality is discussed under client surveys.

C. Focus Groups

1. General Comments

a. Purpose

Focus groups are small groups (generally 10 or less) led by a facilitator or someone who does not direct the discussion or express opinions. Focus groups are useful in uncovering attitudes and opinions of clients, providers, experts or case managers. These groups can give people a chance to speak their minds and are an especially useful way to explore the needs of unserved or underserved populations. Focus groups may be an important part of an HIV/AIDS needs assessment in which the needs and opinions of special populations must be considered. Focus groups may be useful with people from different cultural backgrounds (e.g., Hispanics and Native Americans) who are known to dislike impersonal surveys. Focus groups can also help by speaking to people in their own language, whether it is a social or cultural variant of English, or Spanish.

b. Advantages

Focus groups are better than surveys for needs assessments in many special populations. Focus groups also are better than surveys in exploring the important issues of barriers to access because

focus groups permit more in-depth discussion and clarification of opinion. Groups provide peer support for expressions of opinion.

c. Disadvantages

Focus groups require a facilitator. Recruiting subjects may be difficult, and only limited numbers of subjects can be used. In addition, participants may be subject to peer pressure to conform. Focus groups produce subjective information which may be difficult to analyze.

d. Target Population

Focus groups can be used with clients, providers, key informants or case managers. Only larger CBOs, or groups and areas with more resources may be able to set up focus groups because of limited resources. However, if possible, serious consideration should be given by the Advisory Committee to the use of focus groups in special client populations.

2. How to Conduct a Focus Group

Focus groups usually range in size from 4 to 12 members. Consider over-recruiting by up to twenty percent to compensate for no-shows.

Members of the Advisory Committee should help with recruitment of members from special population groups.

Focus groups can be put together with people from diverse backgrounds. However, homogeneous backgrounds (if not opinions) foster comfort and discussion. People should have something to say and should feel comfortable saying it. Participants should be informed that their responses will be anonymous when compiled and analyzed. If clients, participants should be reassured that their responses will not influence the care that they receive.

If possible, at least two groups should be conducted for each special population (e.g., women). The optimal number is three or four. Results from a single group may reflect the individuals, not the opinions of the population group.

The site or sites chosen should be comfortable and accessible for the group.

Sessions should be taped and should be closed to outsiders.

Focus group should take no more than one and a half hours. The time constraints of the participants should be respected and the schedule should be followed. It may be useful to plan for one hour to accommodate the unexpected.

The facilitator should be someone who is somewhat knowledgeable about HIV/AIDS, non-judgmental and able to accept other opinions without feeling obliged to express

his/her own. Membership in or ties to the special population can be a real asset.

The facilitator should be flexible, guiding the topics discussed and the group interactions only as much as necessary to make the group successful.

A topic outline of broad questions should be prepared. Topics should overlap and flow into each other. Facilitators should feel free to probe further on one topic or skip another topic if it has already been covered in the discussion.

The group should be opened with a general statement about why the group is being conducted. The facilitator should also state that s/he is there to learn from the participants. Participants should be asked to emphasize their personal experiences to avoid generalizations and inaccuracies. The ground rule should be only one person talking at a time. Everyone should be encouraged to speak.

Group discussion can then be started by asking everyone to say something about themselves. Then the facilitator should introduce the first topic. The facilitator should track responses, look for and create opportunities to develop the discussion (e.g., "That's a good point but we can return to that later.", "I've heard several of you mention X. How do the rest of you feel about that?").

Discussion can be closed after one hour by asking everyone to make a summary statement, or asking if there is anything else they would like to say.

The facilitator should make notes on impressions of the group after it is over.

A transcript of the session is usually made from the tape. However, the costs involved may be prohibitive. A reasonable alternative may be for one or two individuals (usually non-participants) in addition to the facilitator to review the tape and arrive at a consensus on the content of the session.

D. Interview

1. General Comments

a. Purpose

An interview involves face-to-face contact or contact by telephone and interaction between a client, provider, key informant or case manager and a person collecting information.

b. Advantages

Interviews permit a more thorough discussion of issues and exchange of ideas than surveys or focus groups.

c. Disadvantages

The types of information discussed are limited by the time and form of the interview. In

addition, interviews are costly in terms of time and personnel.

d. Target Population

Interviews can be conducted with clients, providers, key informants or case managers. Interviews are most useful, however, in obtaining information from key informants or in following up on information from a resource inventory survey.

2. How to Conduct an Interview

See page 93 for information on recruiting and training interviewers.

Interviews should be scheduled at the convenience of the person to be interviewed. The questions should be planned and written out before the interview. Responses should be written down by the interviewer. If answers are not clear, the interviewer should ask for more information.

E. Workshop/Committee

1. General Comments

a. Purpose

A workshop or committee is a group of individuals brought together by a group leader to discuss issues. These types of groups are larger than focus groups and the leader is more active in directing the group than the facilitator in a focus group. A workshop generally meets once, whereas a

committee meets more than once or on an ongoing basis.

b. Advantages

Workshops and committees are a good way to bring people together to generate discussion, ideas, and cooperation.

c. Disadvantages

Workshops or committees require time, planning and commitment. It may be difficult to get people to participate. Setting up meetings may be relatively costly.

d. Target Population

Workshops or committees can be used with groups of clients, providers, key informants or case managers or mixtures of these groups. For HIV/AIDS needs assessments, provider or case manager workshops/committees are used most frequently. Only larger CBOs, or groups and areas with more resources may be able to set up workshops/committees because of limited resources.

2. How to Conduct a Workshop/Committee

Workshops or committees should be led by someone who is knowledgeable about HIV/AIDS, preferably from the group participating in the workshop/committee.

Location and times should be those best for the participants.

The format should be determined by the leader of the group, in consultation with group members.

Sessions can be taped. Minutes of the proceedings should be taken during the sessions. Tapes can be transcribed for analysis. Alternately, after the sessions, one or two persons (in addition to the group leader) can summarize the group consensus based on their experience in the group as well as the minutes and tapes, if available.

F. Public Forum

1. General Comments

a. Purpose

A public forum is used to obtain information from many interested parties who are invited to express their beliefs and perceptions about needs and services in the community.

b. Advantages

Public forums are generally easy to arrange and conduct and are relatively inexpensive. They increase citizen participation and may be helpful for community relations and in building community support. In a politicized atmosphere, forums can help by providing for very public input from all sides. Forums can also identify individuals who may be valuable resources or additions to the Advisory Committee.

d. Disadvantages

Attendance and input may not be representative of the community at large. The forum may become focused on inappropriate issues or things over which the Advisory Committee has no control. Forums produce subjective data which may be difficult to analyze.

d. Target Population

Community forums can provide input from all segments of the community at large, special population groups, clients and providers, depending on what population is targeted for attendance.

2. How to Conduct a Public Forum

The target population should be identified by the Advisory Committee, and the objectives or questions around which the forum will be structured should be defined.

A location should be chosen that is appropriate for the target population.

Publicize the event liberally with posters and radio announcements. Encourage attendance with special appeals to key individuals in special populations and letters to target individuals and groups.

Announcements and flyers should indicate who is sponsoring the event, the purpose, time, date and place.

Flyers can provide additional information on the hearing and on guidelines for testimony.

Begin the forum on time. Have sign-up sheets available at the entrance to the meeting for people who wish to speak. Ask for name and affiliation on the sheets. The forum should be opened with brief welcoming remarks. State the objectives of the meeting and establish ground rules for testimony (e.g., state name and affiliation, five minutes per speaker, responses from the floor).

Individuals who have signed up to speak should be called on from the podium. After all persons who have signed up have spoken, any additional persons wishing to speak should be called to the front.

A tape of the proceedings can be made. Minutes should be taken. After the forum, at least two individuals who were present should be responsible for compiling a summary, particularly noting demographic information on individuals present and groups represented, high priority items and points on which there was strong consensus.

VII. Collecting the Data

A. From Clients

Surveys, focus groups and community forums are used most often to get information from clients. Advisory Committee members from client communities and special populations should help to promote support for the needs assessment process.

The Advisory Committee must decide if clients will be offered a small sum to reimburse them for possible expenses for participation in long and complicated surveys or in focus groups. Typically, amounts range up to \$20.00.

1. By Survey

a. What to Ask in a Client Survey

What to ask should be discussed and clearly stated by the Advisory Committee before beginning the project. The subjects chosen for study will determine how the survey is set up, the types of questions included and the data derived. Small CBOs, or groups or areas with limited resources may only be able to cover a few subjects with a limited number of questions. Long or complicated surveys may need to be administered to the client by another person.

Possible subjects and types of questions useful in a client survey are listed below.

<u>Subject</u>	<u>Type of Question</u>
Services used	List services used
Frequency services used	Frequency used
Feel services used inadequate to meet needs (satisfaction)	Opinion
Needs not met	Services needed but not available
Knowledge of services available	Knowledge of services
Client description	General client data
Results by disease stage or number of T cells	Health and lab information
Services inadequate	Time wait for services
Barriers to access	Opinion
Most needed services	Opinion

Provision can also be made for obtaining ongoing (in addition to periodic) input from clients. Ongoing routine information gathering on client needs helps to provide faster and better responses and should be a goal for all needs assessments. Ongoing needs assessment surveys can be completed by clients during routine (e.g., monthly) visits.

b. How to Conduct a Client Survey

See pages 92 - 93 for general information.

Clients must be reassured that all surveys are anonymous and that their participation or responses

will in no way affect the quality of the care they receive. If the survey is to be administered by another person, the Advisory Committee must decide whether the client must be unknown to the person administering the survey. Even if known, answers would be anonymous when returned.

2. By Focus Groups

a. What to Discuss in Client Focus Groups

Topics and questions to be discussed should be determined by the Advisory Committee and may include but are not limited to the following subjects:

- What has been the one most helpful thing in your life since you tested positive?
- What has been the most difficult part of your life since you've tested positive?
- What are some of the strengths of the services provided to HIV+/PWAs in this area? What has been the most helpful service you've received?
- What are some of the weaknesses of services for HIV+/PWAs in this area? What kind of problems have you had in getting health and social services?
- What kinds of support do you need? What do you need that you're not getting?

- What part of the problems you experience in being able to receive or access care is connected to membership in your special population? What are the barriers to your being able to access care?
- What are your suggestions for improving care or access to care for persons living with HIV/AIDS, especially members of your special population?

b. How to Conduct Client Focus Groups

See pages 95 - 98 for information.

3. Public Forums

See pages 102 - 103 for information.

B. From Providers/Key Informant

Surveys, interviews and workshops/committees are most often used for provider input.

1. Provider Surveys

Provider surveys can usually be performed by including additional question sets in the resource inventory questionnaire.

Type of questions that can be used for provider input and the data needed to answer those questions are indicated below. Questions may include but are not limited to the following:

<u>Subject</u>	<u>Type of Question</u>
Barriers to Access	Opinion
Gaps in Service/Services Needed	Opinion
Priorities of Need	Opinion

2. Provider/Key Informant Workshop or Committee
See page 100 - 101 for information.

3. Provider/Key Informant Interview
See pages 93 and 98 - 99 for information.

C. From Case Managers

Surveys, interviews and workshops/committees are most often used for case manager input. Particular attention should be paid to questions about barriers to accessing services, gaps in service, unmet needs and priorities of need.

Ongoing routine information gathering helps to provide faster and better responses to developing needs and should be a goal of all needs assessments. Ongoing surveys can be completed by case managers during routine ongoing case visits.

See earlier sections for information on survey, interview and workshop/committee methods.

VIII.How to Analyze the Data and Write the Report

A. General Comments

Analysis of the data collected during the needs assessment process is performed to answer the following questions:

- What services are available in the community? What are the capacities of those services?
- What services do clients and their caregivers need? This question should be answered for all individuals who need services, whether they are currently receiving them or not.
- What available services are clients using? Are they satisfied with the services or are there significant problems with them?
- Do clients (potential clients) have needs that are not currently being met? What are the gaps in service in the community?
- What are the reasons for gaps in service? Are there significant access barriers to service for some or all individuals? Are people needing services aware of the services that are provided?
- Will community services be adequate to handle the needs in the community over the next year? How are needs changing?

- What does the community need to do to fill in the gaps?
What strategies can be devised to come up with ways to address the problems?

Each part of the data gathering process provides part of the answer to these questions. Each question can be answered in a general way or, if the group has been able to gather more complete data, a more thorough understanding of community needs and more complete answers can be found.

B. From the Resource Inventory

The resource inventory should result in a listing of all services provided by whatever group is performing the assessment (e.g., if a CBO, all services provided by the CBO; if an HSDA, all services provided within the HSDA). If basic services have been defined, the list for an HSDA should be reviewed to see if all basic services are offered.

If complete information has been compiled within a CBO or HSDA, then the listings can include how much of each of that service is available and the capacity that is used. Average wait for services and average frequency services are used can be compared between providers of similar services. Answers about eligibility policies of providers can be reviewed to find out if policies pose significant barriers to access.

C. From Client Data

1. Survey

Survey results should be analyzed to give the numbers and percentages of clients who

- need services that are provided
- use each of the services (and average number of times a service is used by a client)
- are satisfied with each of the services used
- need services that are not provided
- know about the services available in the community

If the additional questions were included in the surveys, these answers can also be gathered for

- different groups (i.e., analyzed separately for different ages, sexes, racial or cultural groups, stages of disease or number of T cells)

Separate analysis for different sub-populations can be very important. Different groups have very different needs and different levels of need.

Surveys can also be examined to compile information about average waiting time for services, barriers to accessing care or other problems. A list should be made of responses and analyzed for possible trends or repeat answers.

2. Focus Groups

A summary analysis of responses should be prepared for each type of focus group (e.g., Hispanics, women, etc.). (See page 98.)

The summary analysis should provide information about recurring themes, consensus positions, important

discoveries about met and unmet needs, service gaps and barriers to access.

3. Public Forum

A summary analysis of responses should be prepared.

(See page 103.)

The summary analysis should provide information about the demographics of those who attended and those who spoke, recurring themes, consensus positions, met and unmet needs, service gaps and barriers to access.

D. From Provider/Key Informant Data

1. Survey

A report that summarized findings of provider opinion by type of provider (e.g., home health agency, social service agency) should be prepared. Reports should include services needed, priorities expressed by providers, opinions about barriers to access, and what to do to fill gaps in services.

2. Workshop/Committee

A report that summarizes the findings of the workshop(s) or committee(s) should be prepared. (See page 101.) The report should present information on group consensus about gaps in service, service needs and priorities, barriers to access, and problems with service provision.

3. Interview

Interviewers should prepare summary findings from key informant interviews about gaps in service, service needs and priorities, barriers to access, and problems with service provision.

E. From Case Manager Data

Summary report should be prepared from case manager survey, interviews, and/or workshop/committee reports. Summary report should address consensus opinions about gaps in service, service needs and priorities, barriers to access, and problems with service provision.

F. How to Combine and Analyze all the Data

The Advisory Committee or a designated subcommittee should meet to review all summary reports and findings. It is unlikely that all data sources will give the same results about service needs and priorities, and the Committee must weigh all findings and arrive at final decisions.

The Committee should study the capacity and quality of (satisfaction with) services provided. Are services used to capacity? Is expansion of services needed? Are services available, but are clients unaware of them or ineligible for them? What can be done about these problems? Are services needed that are unavailable? What are the priorities for expanding current services and adding services?

Very importantly, what populations are underserved? What can be done to address the unmet needs of special populations?

Are the services provided in the community adequate to meet the needs of the individuals that epidemiologic data indicates are in the community now or will be present over the next year? How do services actually provided compare with the best available TDH data on number of cases? Are few (or more) clients served than are living in the area?

What strategies can the committee devise to solve the problems that have been identified? The committee should consider all available federal, state and local resources as well as both traditional and non-traditional solutions.

G. How to Write and Present the Report

A final report should be written that summarizes answers to the questions and issues considered by the (sub)committee. The critical questions that must be answered are, "What are the needs of the community and what priorities are established to meet those needs?" Special consideration must be given to gaps in service, access barriers and the needs of special populations.

A draft of the report should be distributed for comment to members of the Advisory Committee before the report is finalized.

Large needs assessment projects that plan for community needs over several years may consider providing for public comment in order to foster a sense of ownership in the process. In such situations, the final report should be formally presented to the public with expressions of support

for its findings by various public and private community leaders. Announcement of release of the report at a public dinner with a presentation by an individual prominent in AIDS or health care issues may help to draw attention and support for HIV/AIDS issues and planning in the community.

APPENDIX 1: DEFINITIONS OF SERVICES

The definitions of the Texas Health and Human Services Dictionary of Terms have been used when available.

ACTIVITIES OF DAILY LIVING	Activities that are essential to daily self care; including bathing, eating, dressing, grooming, toileting, housekeeping, shopping, meal preparation, transferring/ambulation, transportation, writing, mobility and others.
ACUTE CARE	Care for an illness considered to be of limited duration (as opposed to chronic and ongoing).
ADULT DAY CARE	An array of services provided in a congregate, nonresidential setting to individuals who need supervision but do not need institutionalization. These services may include any combination of social/recreational activities, health maintenance, transportation, therapeutic activities, training that is essential for sustaining the activities of daily living, meals and other supportive services.
AMBULATORY CARE	Health care services provided to individuals on an out-patient rather than in-patient (hospitalized) basis.
ATTENDANT SERVICES (Personal Assistance Services)	Assistance in accomplishing the activities of daily living.
BENEFITS ADVOCACY	Assistance to individuals in claiming the various kinds of benefits to which they may be entitled. Activities may include legal or other assistance.
CASE MANAGEMENT (Service Management)	An ongoing process which includes assessment, service

plan development, arranging of comprehensive and unified services, follow-up, ongoing monitoring of an individual's and family's status and the services delivered, and periodic review, with any necessary revision of the service plan.

COUNSELING

Services that offer personal or group consultation in which the counselor helps individuals resolve their mental, emotional, social, or medical/health problems.

DENTAL CARE

Services to promote oral health which include prevention, treatment and/or improved access to care.

EMPLOYMENT ASSISTANCE

The planning and provision of services to prepare an individual for work, to assist in obtaining suitable employment, and/or to assist in maintaining employment. May also include the provision of needed transportation and child care to support employment service activities.

FINANCIAL ASSISTANCE

Cash or vouchers provided to eligible individuals and families to meet program-defined needs.

FOOD DISTRIBUTION/BANK

Services provided in which donated foods are distributed to individuals and families in need.

FOSTER CARE

Alternative family living arrangements in supervised private family homes for individuals who need care for a temporary or extended period of time during which the normal family environment is either non-existent or dysfunctional due to social, physical or

emotional problems or the age of some family member.

HOME HEALTH CARE

The provision of a health service for pay or other consideration in an individual's residence by home health agency.

HOME DELIVERED MEAL

Preparation and delivery of regular meals to individuals who are unable to shop for and/or prepare food for themselves or to travel to a site where a meal is being served.

HOMEMAKER ASSISTANCE (in-home assistance)

A service provided by trained and supervised homemakers involving the performance of housekeeping/home management, meal preparation, and/or escort tasks, provided to individuals who need assistance with these activities in their place of residence. The objective is to help the individual to sustain independent living in a safe and healthful home environment. May or may not include attendant care.

HOSPICE SERVICES

An array of services provided either in the home or in a residential setting to individuals with terminal illnesses. Services include medical care under the supervision of a physician, counseling for the individual and family members, and other supportive services.

HOUSING

An array of shelter provided to individuals who cannot provide for their own housing. May include:

Emergency

Housing available for a limited number of nights, typically offering a bed and a meal (e.g., homeless shelters).

Temporary	Housing available for more long term stays than emergency shelters.
Independent Living	Unsupervised single person/family dwelling available at subsidized rates.
Assisted Living	Supervised group residential facilities with staff support.
IN-PATIENT SERVICES	Services which require an individual to be admitted to stay overnight in a hospital or psychiatric facility.
INTERMEDIATE NURSING CARE FACILITIES	An institution licensed to provide health-related services and care on a regular basis to individuals who do not require the complexity of care which a hospital or skilled nursing facility provides.
LEGAL SERVICES	Legal advice, counseling and representation by an attorney or nonlawyer where permitted by law.
LONG TERM CARE	Services to individuals who are frail or have chronic illnesses or disabilities, who are unable to take care of their own daily living needs independently, and who require one, or a combination of ongoing, in- or out-of-home supports which may be provided in an approved nursing or medically oriented facility, or in the home, or through community-based services.
MEAL SERVICES	Meals prepared for individuals unable to shop for and/or prepare food for themselves. May be delivered to an individual's home or served at a central location.
MENTAL HEALTH COUNSELING	Preventative, diagnostic and treatment services provided in

a variety of community and hospital-based settings to help individuals achieve, maintain and enhance a state of emotional well-being, person empowerment, and the skills to cope with everyday demands without excessive stress. Included are programs that offer individual, group, family, conjoint counseling, peer counseling, helpline counseling or mutual support groups or which provide self-help materials which are intended to be used in lieu of in-person counseling or other forms of treatment.

MENTAL HEALTH SERVICES

Services provided to individuals who have mental illnesses, or emotional and social disabilities and require support and treatment.

NURSING FACILITY SERVICES

In-patient nursing and personal care given over an extended period (usually more than 30 days) to individuals who require convalescent care at a level less than that provided in an acute care facility (e.g., hospital) to individuals with chronic illnesses or those who are disabled.

NUTRITION CONSULTATION SERVICES

Assistance given to individuals regarding the planning, purchasing, preparation, and/or delivery of food. May include nutrition education.

NUTRITION EDUCATION

The educational process by which beliefs, attitudes and environmental influences about food are taught to encourage practices that are scientifically sound, practical and consistent with individual needs and available food resources.

OUTPATIENT SERVICES

Services provided on an ambulatory, out-patient (non-hospitalized) basis. Services may be provided in a hospital, clinic, community organization or physician's office.

REHABILITATION

A goal of many health and human services which improve, enhance, maintain or prevent deterioration in an individual's functioning.

RESPITE CARE

Any support options provided on a short-term basis for the purpose of relief to the primary caregiver in providing care to individuals.

SKILLED NURSING CARE

The most medically intensive level of care for long term care patients.

SUBSTANCE ABUSE SERVICES (Chemical Dependency and Abuse Services)

Services designed to prevent or treat substance abuse or chemical dependency. May include out-patient or residential treatment programs.

SUPPORT GROUPS

Groups of individuals who share a common problem or concern who meet for mutual support. Included are professional facilitated groups and groups that have no professional participation and/or no specifically structured format.

TRANSPORTATION

Services that provide for the basic transport of individuals and goods, and special arrangements for individuals who have no personal transportation and who cannot utilize public transportation.

VOLUNTEER SERVICES

Services that recruit, place and train individuals who are willing to volunteer their time for little or no wages.

APPENDIX 2: WHERE TO FIND MORE INFORMATION ABOUT NEEDS ASSESSMENT

More information about all of the needs assessment methods discussed in the model can be found in the following references available from your library or bookstore. Copies may also be obtained directly from the publisher.

Needs Assessment: The State of the Art (A Guide for Planners, Managers, and Funders of Health and Human Services)

- by the Planning and Allocation Division of the United Way Institute, 1982.
- Published by United Way, United Way Plaza, 701 North Fairfax Street, Alexandria, Virginia, (703) 836-7100.

Needs Analysis: Tools for the Human Services and Education

- by Jack McKillip.
- Published by Sage Publications, 2111 West Hillcrest Drive, Newbury Park, California, 91320.

Research Methods for Needs Assessment

- by John M. Nickens, Adelbert J. Purga III and Penny P. Noriega, 1980.
- Published by University Press of America, Post Office Box 19101, Washington, D.C.

Focus Groups as Qualitative Research

- by David L. Morgan, 1989.
- Published by Sage Publications, 2111 West Hillcrest Drive, Newbury Park, California, 91320.

APPENDICES AND BIBLIOGRAPHY

APPENDIX A: LISTING OF HRSA FUNDED PROJECTS

<u>State</u>	<u>Study Area</u>	<u>Grantee</u>	<u>Principal Investigator</u>
AL	Birmingham SMSA	AIDS Task Force of Alabama	Linda Potts
AZ	Tucson SMSA (Pima County)	Pima County Health Dept.	Bruce Porter
CA	San Jose SMSA (Santa Clara Co.)	Santa Clara Co. Health Dept.	Su-Lin Lenker
CA	Four County Region of Northern California	Center for AIDS Research Education and Services	Susan Rooney
CT	New Haven SMSA	City of New Haven	Sher Horosko
FL	Five County Area of NE Florida	AIDS Action Council of NE Florida	Donnelly Rembert
IN	State	State Board of Health	Howard Hess
LA	State	Louisiana State University Medical Center	Ted Wisniewski
MA	State	Department of Public Health	Anne Dievler
MN	State	Department of Health	Aggie Leithheiser
MS	State	Department of Health	Donna Antoine Perkins
NM	State	University of New Mexico Hospital	Thom Sloan
NC	Charlotte SMSA (Seven counties)	Regional AIDS Consortium	Donna Arrington
OH	Cincinnati	University of Cincinnati Medical Center	Tina Roberts

<u>State</u>	<u>Study Area</u>	<u>Grantee</u>	<u>Principal Investigator</u>
OH	Columbus (Franklin Co.)	Regional AIDS Planning Project	Linda Crawford Cloud
OR	State	Oregon Health Division	Robert McAlister
RI	State	Rhode Island Project AIDS	Marilyn Fenner
SC	State	Department of Health	Robert Ball
TX	117 County Region in West and Southern Texas	Texas Tech University School of Medicine	Bob Cattoi
UT	State	Salt Lake City Health Dept.	Hank Welch
WA	State (without King County)	Department of Health	Marne Perry
WI	Milwaukee SMSA	Milwaukee AIDS Project	Tamara Stark

APPENDIX B: GLOSSARY OF SCIENTIFIC TERMS

AIDS	Acquired Immunodeficiency Syndrome, a profound defect of the immune system caused by the HIV virus.
CDC	Centers for Disease Control, the federal centers for disease research.
HIV	Human immunodeficiency virus which is associated with AIDS.
HRSA	Health Resources and Services Administration, a division of the Public Health Service, Department of Health and Human Services.
RYAN WHITE	The 1990 federal legislation that provides federal funding for AIDS services.
SERONEGATIVE	Lacking antibodies to the HIV virus.
SEROPOSITIVE	Having antibodies to the HIV virus.
SEROPREVALENCE	The incidence of seropositivity in a population.
TITLE I	A section of the Ryan White Act that provides federal funds for AIDS services to hard hit metropolitan areas.
TITLE II	A section of the Ryan White Act that provides federal funds for AIDS services to states.

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