AN ASSESSMENT OF DATA COLLECTION FOR ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH SERVICES

OFFICE OF INSPECTOR GENERAL

OFFICE OF ANALYSIS AND INSPECTIONS

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PURPOSE

The purpose of this inspection was to assess the nature and extent of available data relating to State alcohol, drug abuse, and mental health programs and to ascertain any difficulties in obtaining meaningful data.

BACKGROUND

This inspection was requested by the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA). It was prompted by their concern, shared by the Administration and Congress, that comparable data are not available across States to effectively answer questions about alcohol, drug abuse, and mental health programs nationally.

Funding for these programs has always been primarily by the State governments with a percentage provided by the Federal Government. Prior to 1981, the Federal share took the form of categorical grants with federally mandated State reporting requirements. In 1981, these categorical grants were consolidated into the ADMS (Alcohol, Drug Abuse, and Mental Health Services) block grant which allowed the States to more fully determine their own program needs and establish their own data collection systems within certain limitations.

The block grant legislation required applications from the States and annual reports with no specified format. As a result, the type of information submitted by the States could, and eventually did, vary. However, the 1984 ADMS amendments required the Department of Health and Human Services (HHS) to develop model data collection criteria and forms, in consultation with appropriate national interest groups.

In 1986, the Anti-Drug Abuse Act created a new Alcohol and Drug Abuse Treatment and Rehabilitation (ADTR) block grant which provided additional funds to the State substance abuse programs.

The ADAMHA continues to collect a range of provider and epidemiological data on the incidence and prevalence of alcohol, drug abuse, and mental health disorders on both an annual and periodic basis. These are in the form of surveys or inventories rather than ongoing data collection on client characteristics and the delivery of services. A number of earlier Federal data systems which collected detailed treatment, patient, staffing, and related data prior to the block grant program have been phased out. One that was phased out but continues to be collected by some States is the Client Oriented Data Acquisition Process (CODAP) which provided client characteristics and treatment information on all clients in federally funded drug abuse treatment programs.

ISSUES AND METHODOLOGY

The following issues were addressed: what data are actually being collected by the States and professional associations; what are the problems and concerns of individuals who have a need for and/or collect information about these programs; and how receptive are involved individuals to the establishment and use of a uniform national data set?

The inspection was conducted in three phases. During phase one, on-site visits were made to the State drug, alcohol and mental health programs and 26 local providers in nine States, representing a cross section of the country, to gain insights on the kinds of data essential to collect and their uses. In phase two, telephone discussions were held with representatives of the remaining 41 State programs to obtain their perceptions regarding present and future data collection. In phase three, the copies of the data sets, data element definitions, and data reporting procedures received from 45 State mental health programs and 48 State substance abuse programs were collected and analyzed.

FINDINGS

Present Data Collection

Most States have extensive data collection systems, though most believe they lack key data. Although similar elements are collected by many States, the breakdowns and definitions vary widely from State to State.

Virtually all State programs collect individual client data and can give aggregate reports whenever needed. Some of the most commonly collected data elements in the substance abuse data sets from each State include basic demographic elements such as age and sex (collected 98 percent of the time), primary drug of abuse (68 percent), and admission type (67 percent). Five of these States continue to collect CODAP in its entirety, and many States continue to collect some of the CODAP data elements in their exact format.

Similarly, the most common mental health data elements collected include age (94 percent), sex (91 percent), race (85 percent), history of treatment (71 percent), and diagnosis (69 percent).

More than two-thirds of the States believe that the collection of waiting list data would be useful. However, less than one-third are presently collecting such data.

Almost all (92 percent) of the State substance abuse programs and most (75 percent) of the State mental health programs say they can identify the specific provider recipients of block grant funds. The State substance abuse programs can trace the block grant funds to the treatment environment in 90 percent of the States, and 86 percent can trace it to the treatment modality. Mental health programs are less likely to have these capacities: 49 percent of the

State mental health programs can identify both the treatment modality and environment receiving block grant funds.

Data Problems And Concerns

The problem most frequently mentioned concerning lack of data was the difficulty in answering questions from legislatures or other external sources at both the State and Federal levels. Other problems were related to information needed by program administrators to manage and evaluate their programs. This included the inability to identify the number of individuals served and to provide information on specific areas such as intravenous drug use, relapse, homeless persons, funding sources and private sector programs.

Several problems in data collection were mentioned. The absence of uniform definitions of data elements was cited repeatedly.

Respondents also cited difficulties in getting a statewide unduplicated count (i.e., a count that does not show duplicative services to the same client). Support was expressed for use of a unique client identifier to help provide data on relapse and to assure effective coordination of service delivery among providers and monitoring of service outcomes. However, many cited concerns for the client's confidentiality as an obstacle to an unduplicated count.

Receptivity To A National Data Set

Most States see value in having a uniform national data set. (85 percent of the State substance abuse programs and 77 percent of the State mental health programs).

Over half the States feel the collection of minimum national data should be mandatory. Almost all say they do not like to have anything mandated. However, they also state that the only way this could work is if all States participate in a uniform fashion.

Key uses of uniform national data, according to respondents, include comparisons among States and information for outside sources such as legislatures. One State said, "We need nationally comparable data to answer questions for Government, legislature and the press." Other uses include allocation of funds, program management, reporting, research, and program planning. Others felt the data would be useful to evaluate the effectiveness of programs. Virtually all States want the Federal Government to pay for the collection of data; half would be willing to pay a share of the costs.

CONCLUSIONS

Data collected by the States, although extensive, is not comparable and currently cannot be aggregated into reliable national statistics. This has proved a problem for the States, and they are receptive to the idea of a truly *minimum* national data set.

The following key issues in data collection need to be resolved before a decision could be made to proceed with a national minimum data set. Those issues include: the worth of a national minimum data set to the Federal Government, how and to what extent such a data collection should be federally funded, whether it should be voluntary or mandatory, how consensus on data elements and definitions should be reached, and how best to utilize the data once it is collected.

COMMENTS ON THE DRAFT REPORT

The report was shared with the Assistant Secretary for Health and the Alcohol, Drug Abuse, and Mental Health Administration, which includes the National Institute on Alcohol Abuse and Alcoholism, the National Institute of Drug Abuse, and the National Institute of Mental Health. The report was favorably received by these entities and no changes were recommended.

PURPOSE

The purpose of this inspection was to assess the nature and extent of available data relating to State alcohol, drug abuse, and mental health programs and to ascertain any difficulties in obtaining meaningful data.

BACKGROUND

Origin of Study

This inspection was requested by the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA). It was prompted by their concern, shared by the Administration and Congress, that comparable data are not available across States to be able to effectively answer questions about the alcohol, drug abuse, and mental health programs nationally.

Legislative History

To understand these concerns, it is helpful to review the legislative background of the alcohol, drug abuse, and mental health programs. Funding for these programs has always been primarily by the State governments with a percentage provided by the Federal Government. Prior to 1981, the Federal share took the form of categorical grants with the primary administrative responsibilities located at the Federal level and with federally mandated State reporting requirements. In 1981, these categorical grants were consolidated into the Alcohol, Drug Abuse, and Mental Health Services (ADMS) block grant with primary administrative responsibility being shifted to the States. This change allowed States to more fully determine their own program needs, set priorities, allocate funds, and establish their own data collection systems within certain limitations.

The block grant legislation required applications from the States containing descriptions of intended uses for the funds. It also required annual reports, with no specified format. As a result, the type of information that each State would submit could and eventually did vary. The legislation also required compliance reviews to be performed by the Federal Government in several States each year.

States were also required to establish criteria to evaluate the effective performance of local providers receiving ADMS block grant funds. The results were to be used by the State to guide internal management of block grant activities. However, there was no requirement to provide these evaluations to the Federal Government. The Federal agencies were nevertheless required to provide reports to the Congress on block grants.

The 1984 ADMS amendments required the Department of Health and Human Services (HHS) to develop model data collection criteria and forms, in consultation with appropriate national interest groups. The goal was to obtain national-level data on services provided, the number and types of clients served, and total funding (information on how ADAMHA has implemented this is on page 3-4 of this report).

In 1986, the Anti-Drug Abuse Act created a new Alcohol and Drug Abuse Treatment and Rehabilitation (ADTR) block grant which provided additional funds to the States as an emergency enhancement to their substance abuse programs. It also allowed the Federal Government to conduct data collection activities and specified that up to 1 percent of the total amount appropriated could be used to evaluate alcohol and drug abuse treatment programs.

However, this data collection authority was tempered by the Paperwork Reduction Act. The act precluded the Secretary from imposing burdensome requirements and from prescribing the manner of compliance for application or description of the uses of funds.

Another block grant was established in 1987 to provide services to homeless individuals who are chronically mentally ill.

Funding

The ADMS block grant funds for Fiscal Year (FY) 1985 amounted to $490,000,000 and were reduced to $468,930,000 in FY 1986. The FY 1987 ADMS grant was $508,860,000; an additional $162,855,000 was added by the ADTR block grant for a total of $671,715,000. The average block grant share of the total State FY 1987 funds was 18 percent, with a high of 68 percent and a low of 1.6 percent.

HHS Data Collection Policy

The Department's policy on evaluating block grants provides for the collection of descriptive information necessary for Federal policy development. However, any information to be collected must be readily available or be easily collected or compiled by the States.

Types of Data

There are several important types of data collected relating to alcohol, drug abuse, and mental health programs. Among the most important types of data collected are the following:

Client Data is information maintained on an individual who receives services from a provider. This information is used to determine the amount of service rendered to individuals, and to classify these individuals by such categories as sex, age, type of problem and type of treatment. This, in turn, assists decision-makers, managers and researchers in answering questions about patient populations, showing differential use of services among patient groups, and furnishing descriptive information about providers.

Provider data is collected from providers to identify the location, scope, characteristics, and activities of providers of alcohol, drug abuse, and mental health services. This is used to gain a picture of the kinds of services available within a particular geographic area. Some of this data is derived by aggregating individual client data for each provider.

Financial data determines the cost of services provided.

Event data shows who receives what, from whom, at what cost, and with what effect.

Human resources data is maintained on all individuals who provide services to clients or support the administrative structure of the organization. This can give numbers employed, distribution, demographics, training, and employment characteristics of staff to address issues such as recruitment, standards compliance, discrimination in employment, and shortage areas.

Epidemiological data is used to determine the incidence and prevalence of alcohol, drug abuse, and mental health disorders in a given population.

ADAMHA Data Collection Activities

The ADAMHA collects a range of provider and epidemiological data on both an annual and periodic basis. These are in the form of surveys or inventories rather than ongoing data collection on client characteristics and the delivery of services.

The National Drug and Alcohol Treatment Utilization Survey (NDATUS), originally conducted in 1974 by NIDA, has been conducted periodically. This is provider data collected to identify the location, scope, and characteristics of drug abuse and alcoholism treatment and prevention units and activities throughout the nation in both public and private sector providers.

A number of systems which collected detailed data on treatment, patients, staffing, and related matters prior to the block grant program have been phased out. These include the National Alcoholism Profile Information System (NAPIS), the State Alcoholism Profile Information System (SAPIS), and the Client Oriented Data Acquisition Process (CODAP). Prior to the block grants, CODAP--a client data collection instrument--was required of all treatment clinics receiving Federal funds. It provided client characteristics and treatment information on all clients admitted to and discharged from federally funded drug abuse treatment programs.

The ADAMHA and the Institutes -- the National Institute of Mental Health (NIMH), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the National Institute of Drug Abuse (NIDA) -- have taken the following actions in response to the 1984 amendments which required HHS to cooperate with special interest groups to develop data collection criteria and forms:

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- The Mental Health Statistics Improvement Program (MHSIP), a cooperative Federal/State program designed to upgrade mental health data collection activities, has been active for over 12 years as a joint effort in the development of suggested client, event, and human resources data elements. However, its system has not been implemented in any formal way.

- Under a contract from the NIMH, the National Association of State Mental Health Program Directors (NASMHPD) have developed a methodology for compiling comparable data on State mental health agency allocations and expenditure of funds as well as sources of revenue for mental health operations. Originally supported by NIMH, it is now conducted by NASMHPD without Federal support.

- The NIMH, in collaboration with NASMHPD, is proposing to implement a State mental health data profile system in FY 1989. It will contain information on the organization, funding, operation, and services provided through State mental health agencies. A feasibility study was completed in 1987.

- Both NIAAA and NIDA have established a cooperative relationship with and provided funds to the National Association of State Alcohol and Drug Abuse Directors (NASADAD) for the collection and analysis of data voluntarily submitted by the States on alcohol and drug abuse funding and services. Existing sources of information are utilized for this reporting which is known as the State Alcohol and Drug Abuse Profile (SADAP). The data are not verified by either HHS or NASADAD, and States are not required to collect them in any uniform way.

Key Data Collection Issues

When contemplating data collection, a number of issues arise which must be considered. Data can be collected on individual activities on a regular basis (monthly, quarterly, or annually) or in the form of special studies or surveys done either periodically or one time only using sampling techniques. Individual data (which is data collected on each individual client in the facility) can be aggregated or combined in reports to provide specific information. In other cases only aggregate data can be collected.

When collecting individual client data two important issues arise. The first involves the difficulty of achieving an unduplicated count. Clients may be counted more than once if they are discharged and readmitted either to that or another facility. If an unduplicated count cannot be assured, the data collected can exaggerate the size of the treatment need in a given area and/or the number of people in treatment.

A second important issue in the collection of individual client data is the importance of confidentiality. Many clients are reluctant to provide information on their mental health and sub-

stance abuse treatment. In addition, many States have laws prohibiting the release of any information about these clients. Although this data is of crucial planning importance for those who run treatment programs, it is also important to those providing the data that no data be traceable to an individual client.

INSPECTION ISSUES

- What data are actually being collected by the States and professional associations?

- What are the problems and concerns of individuals who have a need for and/or collect information about these programs?

- How receptive are involved individuals to the establishment and use of a uniform national data set?

METHODOLOGY

This inspection was conducted in three phases. Initially, on-site visits were made to the State drug, alcohol, and mental health programs in nine States representing a cross section of the country. Discussions were held to determine the kinds of data presently being collected and their uses. Insights were also obtained regarding the kinds of data considered essential to collect.

Additionally, visits were made in each of the nine States to three local-level providers: one each for alcohol, drug, and community mental health programs. They included six social detoxification, three medical detoxification, four methadone maintenance, and three drug-free programs in the substance abuse area. The mental health program visits included four suburban, five urban, and one rural community mental health centers. The facilities ranged in patient load from 14 to 20,000 clients. Discussions with providers gave grass roots perceptions as to the strengths and weaknesses of the States' data collection systems as well as insights into the providers' data collection needs and practices.

The second phase consisted of telephone discussions with representatives of the alcohol, drug abuse, and mental health programs of the remaining 41 States and the District of Columbia to obtain perceptions regarding their present data collection procedures and their ideas about a national data collection system.

The third phase consisted of collecting copies of the data sets, data element definitions and data reporting procedures presently in use by each of the 50 States and the District of Columbia. This information was analyzed for both variations and commonalities in the elements, definitions, and reporting procedures.

PRESENT DATA COLLECTION

The data analysis in this first section and all graphs and charts derived from it are based on the client data sets received from 45 State mental health programs and 48 State substance abuse programs. We chose to analyze the client data sets because client data is the most generally collected data type and because client data is used by State program administrators and providers to generate reports which will provide information on patients, providers and services.

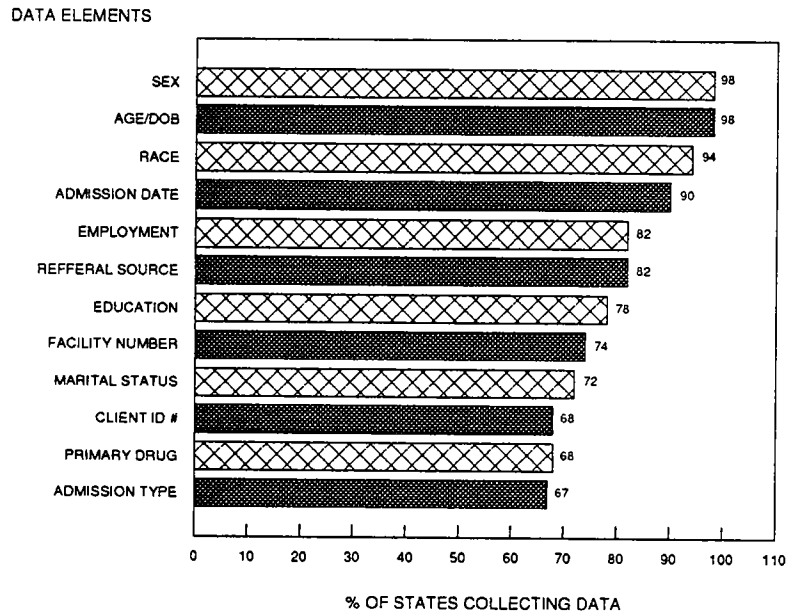*State Data Sets Usually Include Individual Client Data*

Most States have extensive data collection systems, but most believe that they lack key data. Although similar elements are collected by many States, the breakdowns and definitions vary widely from State to State.

Virtually all State programs collect individual client data from providers, though they collect it in different ways. It is usually on a State-prepared form which is submitted on a monthly basis, and produce aggregate reports upon request. Funding does sometimes limit the number of reports which can be generated. Four State mental health programs and four State substance abuse programs collect only aggregate data. Additionally, some mental health programs collect individual data only at the institutional level and collect aggregate data from their other programs. Two of the eight programs that collect aggregate data only are in large States with populations of about 10 million; the other six are in medium to small States with populations ranging from 750,000 to 5 million. At least two State programs do not have a data collection instrument for use at the State level. These States provide the county or area offices with a list of key data elements that must be available upon request. The offices can then use any data collection instruments they choose and can collect any desired additional data.

In addition to this regular data collection, most States produce special reports or surveys on topics of particular interest. Some examples of these include a report of the estimated number of problem drinkers, a sex offender report, a statistical prospective on drug abuse treatment, and a report on re-arrest following residential treatment for repeat offender drunken drivers.
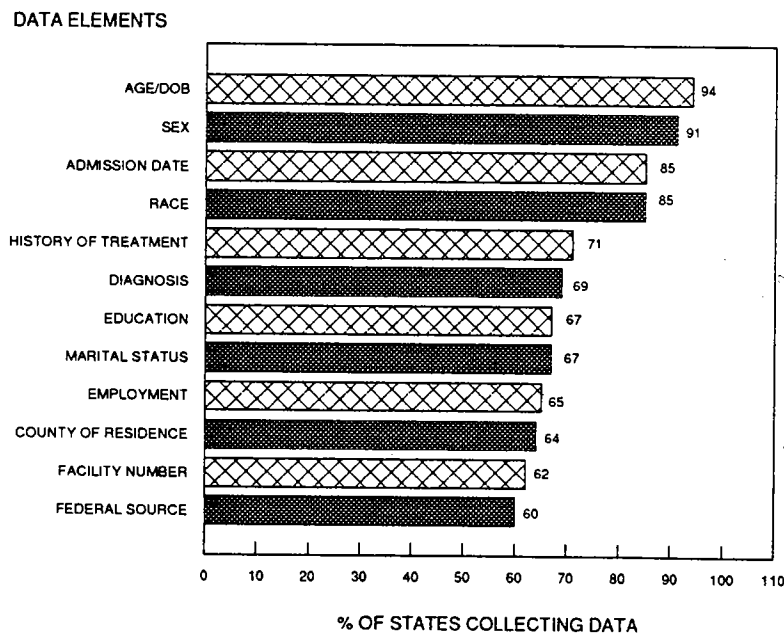
Figure I contains the most commonly collected individual client data elements found in the substance abuse data sets from each State. As can be seen below, the elements range from basic demographic information such as age and sex (collected 98 percent of the time) to the primary drug of abuse (68 percent) and admission type (67 percent).

FIGURE I
MOST COMMON SUBSTANCE ABUSE ELEMENTS COLLECTED

DATA ELEMENTS

Data Element	%
SEX	98
AGE/DOB	98
RACE	94
ADMISSION DATE	90
EMPLOYMENT	82
REFFERAL SOURCE	82
EDUCATION	78
FACILITY NUMBER	74
MARITAL STATUS	72
CLIENT ID #	68
PRIMARY DRUG	68
ADMISSION TYPE	67

% OF STATES COLLECTING DATA

Similarly, the most common mental health data elements collected are shown in figure II below. They include basic demographic elements such as age (94 percent), sex (91 percent), and race (85 percent). Also included are history of treatment (71 percent) and diagnosis (69 percent).
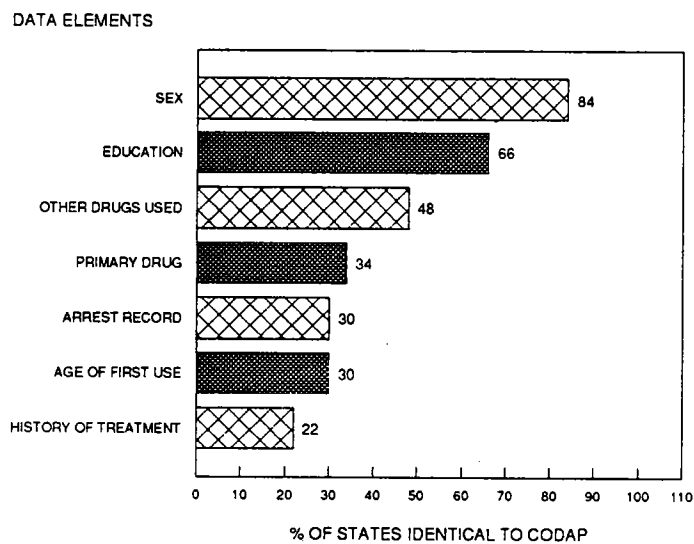
FIGURE II
MOST COMMON MENTAL HEALTH ELEMENTS COLLECTED

DATA ELEMENTS

Data Element	%
AGE/DOB	94
SEX	91
ADMISSION DATE	85
RACE	85
HISTORY OF TREATMENT	71
DIAGNOSIS	69
EDUCATION	67
MARITAL STATUS	67
EMPLOYMENT	65
COUNTY OF RESIDENCE	64
FACILITY NUMBER	62
FEDERAL SOURCE	60

% OF STATES COLLECTING DATA

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Further analysis of figures I and II reveals that substance abuse programs are more frequently collecting uniform data elements than mental health programs. The average percentage of States which report collecting these common data elements is 81 for substance abuse programs and 73 for mental health programs.

Although the national collection of CODAP was discontinued in 1981, five States continue to collect it. Many States continue to collect some of the CODAP data elements in the exact CODAP format. These include sex (84 percent of all States), education (66 percent), and information on other drugs (48 percent).

FIGURE III
SUBSTANCE ABUSE DATA ELEMENTS COLLECTED IDENTICAL TO CODAP

DATA ELEMENTS

Data Element	% of States Identical to CODAP
SEX	84
EDUCATION	66
OTHER DRUGS USED	48
PRIMARY DRUG	34
ARREST RECORD	30
AGE OF FIRST USE	30
HISTORY OF TREATMENT	22

% OF STATES IDENTICAL TO CODAP

### State Data Elements and Definitions Vary

Although most States collect basic demographic information, the breakdowns and definitions vary widely from State to State. For example, race is broken down in at least 10 different ways. Some States have five categories, others six categories, etc. Even States that define the elements in the same *number* of categories do not necessarily delineate them into identical categories. For example, while one State breaks down race into "white, black, American Indian, other," another uses "black, white, Asian, other" (see figure IV).

FIGURE IV
SUBSTANCE ABUSE DATA:
VARIATIONS OF STATE PROGRAMS IN REPORTING RACE

OF CATEGORIES OF RACE USED
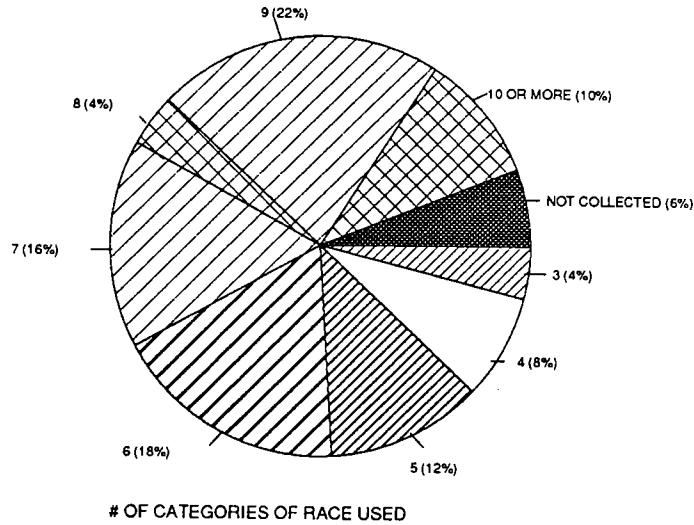
Employment status is defined in at least nine different ways. Some States have four categories, others have six categories, etc. A number of States do not collect employment status. As with race and other types of data, the States that define the elements in the same number of categories do not necessarily define them identically. For example, while one State breaks employment status into "full time, part time, armed forces, homemaker, retired, inmate of an institution, other," another uses "works 35 hours or more in competitive job market, works 35 hours or less in competitive job market, works 35 hours or more in a noncompetitive job market (such as sheltered workshop or protective environment), works 35 hours or less in an noncompetitive job market, unemployed, not in labor force, unknown" (see figure V).

FIGURE V
MENTAL HEALTH DATA:
VARIATIONS OF STATE PROGRAMS IN REPORTING EMPLOYMENT STATUS

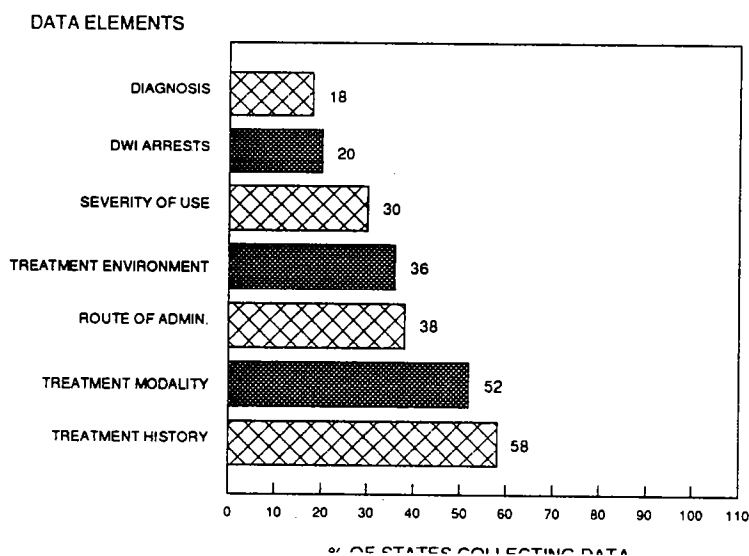# OF CATEGORIES OF
EMPLOYMENT STATUS USED

9
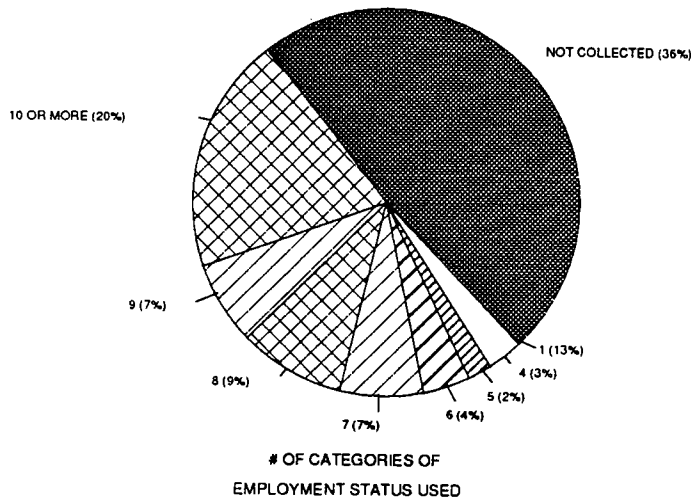
Data elements which we analyzed from the State individual client data sets were often collected in varied ways among States. Even sex and age were collected in different ways.

Because the States collect information in different formats, the State data cannot be accurately aggregated into national data. Thus, although almost all States may be collecting the same data elements (such as those discussed above) their data collection efforts cannot be used to make reliable national projections or enable States to compare their programs with those of other States.

Data Sets Often Lack Elements Considered Important

Some data elements considered to be important by State substance abuse and mental health professionals are collected by less than half of the States. Figures VI and VII show some data elements considered to be important by State substance abuse and mental health professionals which are not collected by many States.

FIGURE VI
SUBSTANCE ABUSE ELEMENTS NOT CONSISTENTLY COLLECTED
ALTHOUGH CONSIDERED IMPORTANT

DATA ELEMENTS

Data Element	% of States Collecting Data
DIAGNOSIS	18
DWI ARRESTS	20
SEVERITY OF USE	30
TREATMENT ENVIRONMENT	36
ROUTE OF ADMIN.	38
TREATMENT MODALITY	52
TREATMENT HISTORY	58

% OF STATES COLLECTING DATA

Only 38 percent of States collect route of administration (how the drug is taken). Professionals consider this crucial data needed to properly deal with the growing AIDS crisis. The collection of accurate data about the route of administration of the drugs used by those in treatment helps to provide trend information on IV drug users. Only 30 percent of the States collect data on the severity of use, while 36 percent collect treatment environment (see figure VI above).

FIGURE VII
MENTAL HEALTH ELEMENTS NOT CONSISTENTLY COLLECTED
ALTHOUGH CONSIDERED IMPORTANT

DATA ELEMENTS

% OF STATES COLLECTING DATA
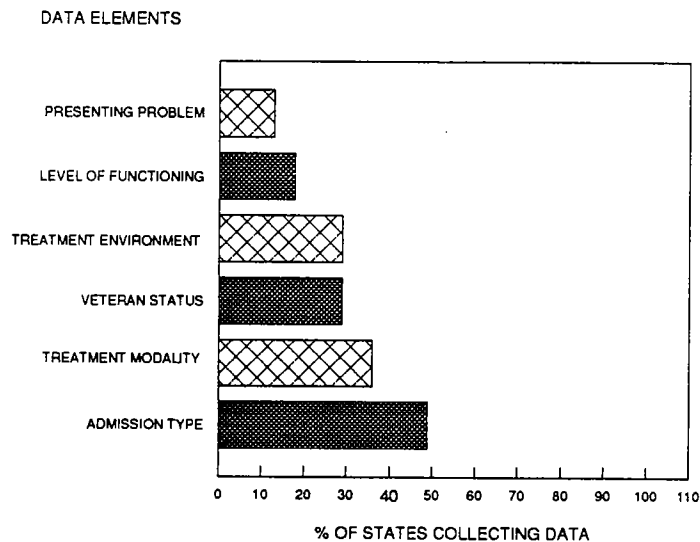
Some elements considered to be important by State mental health professionals are presently collected by less than one-third of the States. Only 13 percent of the States collect data on the presenting problem at the client's time of admission (the reason the client comes to the facility). The client's level of functioning at admission is collected by 18 percent of the States. Twenty-nine percent of the States keep information on the treatment environment for each client (see figure VII above).

The most common reasons given by State program administrators for not collecting these data were lack of funds and lag time between identifying data needs and data collection form updates.

Most States Believe the Collection of Waiting List Data Would Be Useful

More than two-thirds of the States believe that the collection of waiting list data would be useful, though less than one-third are presently collecting such data. Most States consider it important that all providers define a waiting list uniformly. One provider said its waiting list started after the patient completed the intake process, was deemed appropriate, and given an appointment. Others had waiting lists comprised of anyone who called. One methadone maintenance center kept the names of everyone who called, but expected the person to periodically call back, since this showed real interest. One State program administrator said, "the problem is no generally accepted definition of a waiting list."

Sixty-one percent of the providers visited maintain waiting lists for at least some of their services. For some services mandated by the courts a waiting list is essential because the client must prove he/she is on a waiting list for treatment in order to avoid incarceration.

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The most frequently mentioned uses of a waiting list are to document the need for services and to make funding decisions. One State representative said, "It is definitely a valuable tool at the State level to help justify additional appropriations and identify unmet needs."

Others not in favor of waiting lists said these individuals might request services at one moment and, if they are put off, not be interested when the services are available. They considered it important to treat the patients or refer them elsewhere.

Almost All States are Able to Identify Providers Receiving Block Grant Funds.

Almost all (92 percent) of the State substance abuse programs and most (75 percent) of the State mental health programs say they can identify the specific provider recipients of block grant funds. The State substance abuse programs can trace the block grant funds to the treatment environment in 90 percent of the States, and 86 percent can trace it to the treatment modality. Thirty-nine percent can identify the clients receiving the funds. Mental health programs are less likely to have these capacities: 49 percent of the State mental health programs can identify both the treatment modality and environment receiving block grant funds. Only 16 percent can identify the actual clients.

Forty-two percent of the providers visited can separate data by funding source. Of these providers, 40 percent can identify ADMS clients and 30 percent can identify ADTR clients.

DATA PROBLEMS AND CONCERNS

State Program Administrators and Providers Experience a Variety of Problems Due to Lack of Data

The problem most frequently mentioned was the difficulty in answering questions from legislatures or other external sources at both the State and Federal levels. Many State program administrators also mentioned their inability to compare their State activities with those of other similar States or those States seen as leaders in the field.

Other problems were related to information which was not available to help program administrators design, manage, and evaluate programs. These include the inability to identify the number of individuals served and to provide information in specific areas such as IV drug use, relapse rates, homeless persons, funding sources, and private sector programs.

Beyond the problems at the State level, almost one-half of the local providers visited reported problems due to lack of data; 54 percent said there were additional data they would like to have. One provider said, "It would be interesting to know where similar agencies are, we have nothing to compare ourselves to."

State Program Administrators and Providers also Experience a Variety of Problems in Data Collection

Some States officials felt that the collection of data on private sector programs was important, but difficult to collect. They felt that the collection of this data should be part of the State licensing or certification process so that this gap is filled.

Another problem is the difficulty in getting uniform definitions of elements. One person said, "It's difficult to get uniform definitions from provider to provider throughout the State, how could we expect uniform national definitions?" In spite of this, most agreed that the standardization of definitions is essential.

Respondents also discussed the problem with the automation of data collection. While almost all States have partially or fully automated data collection, many providers are not automated. In most States, providers and State agencies lack compatible systems; data are usually submitted on hard copy to be entered at the State level.

Lastly, a few States raised the issue of quality and felt not enough is being done in this area. This is particularly important because only through adequate quality control can accurate data be assured.

State Program Administrators Report that Unique Client Identifiers are Needed to Assure an Unduplicated Count

Confidentiality concerns about client identification make it difficult to get an unduplicated count, thus making it impossible to track a patient throughout State programs. However, 60 percent of the States indicated they can obtain unduplicated counts. In most of these States a client identifier is assigned to each client when he/she is admitted to a facility. Thus, an unduplicated count can be achieved as long as the client continues to be treated at a particular facility. Admission to a new facility, however, would give the client a new identifying number.

Several States, however, did discuss their use of a unique State client identifier. This identification number is made up of coded numbers and letters derived from certain unchanging characteristics of a client such as the first letter of the first name or the date of birth and mother's maiden name. A client does not need to memorize this number. In some States each facility in the State knows the code for constructing this number and can recreate the number based on the client's unchanging characteristics. In other States the State itself constructs the numbers upon collection of the individual client data. This ensures an unduplicated count for all facilities within a State.

Most respondents mentioned the importance of the unique client identifier for effective coordination of service delivery among agencies and monitoring of service outcomes. Further, out-

come data, which some respondents said is frequently unavailable, is difficult to obtain without a unique statewide identifier.

Providers Do Not Always Receive Reports Based on the Data They Submit

Although some providers feel that State and national data collection is helpful and 73 percent get reports back from the States on the information they submit, only 19 percent said they get national reports. Others feel that although they collect data for the State separate from their internal data collection, they never get anything useful back from the State and certainly not from the Federal Government.

States Fund Data Collection at Low Levels

States fund data collection at low levels, despite encountering problems due to the lack of data. Most respondents estimated that one percent or less of their total expenditures are spent on data collection. Almost two-thirds of the State program administrators thought this was not enough. Many had difficulty coming up with their estimates.

There were however, several State program administrators that said they spent a lot more than 1 percent and felt they were spending an appropriate amount. One State program administrator estimated spending seven percent, another estimated 13 percent. These State program administrators are satisfied with their own data collection systems and feel that their own instrument would be appropriate for a national data set.

RECEPTIVITY TO A NATIONAL DATA SET

Most States See Value in Having a Uniform National Data Set

Eighty-five percent of the State substance abuse program administrators and 77 percent of the State mental health program administrators see value in having a uniform national data set. In contrast, only half of the providers see such value.

Over half the States feel the collection of minimum national data should be mandatory. Almost all say they do not like to have anything mandated but the only way this could work is if everyone participates in a uniform fashion.

Virtually all States (86 percent) want the Federal Government to pay for the collection of the data; nevertheless, half the States would be willing to pay a share of the costs.

Key uses of uniform national data according to respondents include comparing one State to another and providing information to outside sources such as legislatures. One State said "We need nationally comparable data to answer questions for Government, legislature and the press." Other uses include allocation of funds, program management, reporting, research, and

program planning. Others felt the data would be useful to evaluate the effectiveness of programs.

Many States mentioned that there should be Federal leadership with a high participation by the States in developing standards and definitions. Some also said there should be sufficient lead time to implement the data collection system. Others mentioned the importance of technical assistance from the Federal Government, particularly for small States. Still others suggested a pilot program or test run before the new system gets underway. Additionally, several States stressed the importance of a *minimum* number when selecting elements for a national data set. One State said, "The key is minimum." Another said, "In any national system there should be core elements, but also enough flexibility and room for demonstration projects and optional reporting elements."

States would like timely reports from the Federal Government in a useful format. One said, "Clear, standardized definitions are probably the single most important item in developing a national data set, along with appropriate technical assistance. Rapid turnaround time is also very important." Another State said, "To be meaningful to States, the main thing is to make output more current and timely. It doesn't help to have 2-year-old data." These words were echoed by many.

Prior and Present Data Sets Viewed as Useful

Discussions with the States about prior and present data sets revealed that most State substance abuse respondents view CODAP as a useful form of national data collection. Sixty-four percent of the States have a positive recollection of the value of CODAP.

Twelve substance abuse programs recommended some form of CODAP as the minimum data elements to collect nationally. One said, "It was useful, well thought out, a significant minimum system." Another State mentioned, "Good for comparisons to other States, helped plan treatment and strategies." Still others thought it was good information but contained too much data and did not give feedback timely enough.

Forty percent of the States said that SADAP and NDATUS are useful. Four recommended SADAP as minimum data elements and four recommended NDATUS. Some said it is all they have to see what's going on nationally and to compare themselves with other States. However, some felt SADAP data is not too reliable since its categories are not the categories they use. One said, "It addresses a different structure than we have...I find myself filling out 'unknown' or 'not applicable' too much of the time." Another State mentioned a validity problem and said, "It is too general, hard to cross tab, hard to make decisions based on it."

Most State mental health respondents feel that MHSIP is a useful form of national data collection. Most States are familiar with MHSIP and are complimentary of the task force working on its development. However, other than a few basic demographic data elements, States are not collecting MHSIP data. One State commented, "We pay attention to it, but we don't use it." Another said, "It gives a good frame of reference."

It is important to note that MHSIP is a program to establish data standards for mental health decision support systems. It presently has data elements for client data, event data, and human resources data. It was the client data that people were most familiar with, although some thought event data was important to maintain. The MHSIP recommends minimum data elements with a specific structure, but at this time does not have a standard data collection document. Twenty-five mental health programs and three substance abuse programs recommend MHSIP as minimum data elements to collect nationally. One State said, "If we can get all 50 States to agree and use the same definitions, then it will be a very good system."

National Minimum Data Elements Recommended by State Program Administrators

Many State program administrators recommend, should a national minimum data set be constructed, the use of MHSIP data elements for mental health programs and CODAP or some variation for drug and alcohol programs.

The specific elements most often recommended by the State substance abuse program administrators include demographics, modality or services provided, type of substance, and route of administration. Those most often recommended by the mental health program administrators include demographics, services provided, clients served, and diagnosis.

CONCLUSIONS

This report was conducted to provide ADAMHA and other departmental decision-makers with information on the alcohol, drug abuse, and mental health data collection activities of the States and State receptivity to the idea of a national minimum data set. We can conclude from the findings of this report that the data collected by the States, although extensive, are not comparable and cannot currently be aggregated into reliable national statistics. We can also conclude that the States experience this as a problem and are receptive to the idea of a truly *minimum* national data set.

However, the following key issues in data collection need to be resolved before a decision could be made to proceed with a national minimum data set. Those issues include: the worth of a national minimum data set to the Federal Government, how and to what extent such a data collection should be federally funded, whether it should be voluntary or mandatory, how consensus on data elements and definitions should be reached, and how best to utilize the data once it is collected.

COMMENTS ON THE DRAFT REPORT

The report was shared with the Assistant Secretary for Health and the Alcohol, Drug Abuse, and Mental Health Administration, which includes the National Institute on Alcohol Abuse and Alcoholism, the National Institute of Drug Abuse, and the National Institute of Mental Health. The report was favorably received by these entities and no changes were recommended.