U.S. Department of Health and Human Services
Office of Minority Health

Identifying a Uniform Data Set Of Information/Data to Assess The Impacts of Activities Funded By the Office of Minority Health

Final Report

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1. Introduction

This report details the results of contract #213–99–0011 between Development Services Group, Inc.(DSG), and the Office of Minority Health (OMH) within the Department of Health and Human Services, for the development of a uniform data set, signed on Sept. 29, 1999. In addition, chapter 8, Grantee Technology Survey, is the result of a contract modification dated Sept. 28, 2001.

Goals of the Uniform Data Set Initiative

Increasingly, community-based health and social service programs must compete for funding—whether from the public or private sector—under the same evaluation standards with which larger, more formalized organizations have become familiar. In a word, those standards revolve around *data*—measures of performance, indicators of success, "risk factors," process data, data demonstrating the need for funding, and so on. For many community-based organizations (CBOs), this has been problematic because there is often a *disconnect* between the kinds of data and program designs typically required and the nature of the work they do, which is, in part, a result of the human and social complexities of the communities they serve. Community-based work is synthetic, organic, and interactional in nature, not fragmented and analytic. It is also contingent upon the exigencies of the moment and on a multitude of factors beyond the control of any given program or CBO. How then can such programs find a balance between the need to operate and succeed within a data-driven support structure and attempting to carry out their program work in a community setting?

This report describes one attempt to straddle both worlds, in which qualitative and quantitative methods were employed to develop a standard or uniform evaluation data set that could be used across all grant and cooperative agreement projects funded by OMH. DSG was contracted to develop this data set, known as the Uniform Data Set (UDS), for a range of programs from which extensive standardized data had not been required up to that point.[%] Projects funded through these programs had previously collected or currently collect data, but the data have typically been uniquely tailored to each project, to its evaluation design, and to its specific social/cultural setting.

OMH Mandate. The Office of Minority Health is mandated by the U.S. Congress to coordinate Federal agency efforts to improve racial/ethnic minority health status and eliminate disparities in health, healthcare for African-American, Hispanic/Latino, American Indian/Alaska Native, Asian, and Native Hawaiian/Pacific Islander populations (under the *Healthy People 2010* goals). Most OMH-funded programs are directed to racial/ethnic

*A pilot effort to collect some initial standard data, however, had been implemented through the OMH Division of Program Operations.

minority CBOs, and most of these programs involve a mixture of health promotion, screening, access to services and treatment, training and education, materials development, case management, capacity-building, development of community linkages, and other such activities. At the time this project began, the programs included a) minority health coalitions, b) bilingual/bicultural access to care grants, c) managed care-related grants, d) HIV/AIDS technical assistance grants, e) coalition and State-level grants, and f) cooperative agreements with hospitals and universities related to health promotion, screening, and family/community violence prevention.

Specific UDS Goals. First, data from the UDS were intended to serve as the basis for evaluating program effectiveness and impact, and in doing so improve the evaluation and quality of OMH programs. Second, the data collected would contribute to agency reporting efforts under the Government Performance and Results Act (GPRA) of 1993. Third, and very important, the UDS was conceived as an attempt to develop a data collection system that would be meaningful for OMH-funded CBOs and the racial/ethnic minority populations they serve. Implementation of the UDS has applications to the general issues of evaluating community-based health programs, and in identifying or assessing the nature of progress with respect to racial/ethnic minority health, beyond its direct application to OMH projects (Wells and Conviser, 1998). OMH and the UDS development team felt strongly that it was important to recognize the enterprising and ground level work these community programs carry out to improve the health status of diverse racial/ethnic minority populations. A great deal of their work is unique and often not adequately accounted for by traditional performance indicators (e.g., process counts, health outcome measures). Not surprisingly, guides to evaluating community-based programs (Kellogg Foundation, 1998; United Way, 1996) often argue against evaluating such programs using uniform measures, because of the variety and uniqueness of situations they face and the commensurate differences in program goals and appropriate data needs. However, as already noted, the current program environment requires systematic data reporting for continued program support; thus such measures become necessary. Therefore, a further goal of the OMH UDS was to capture at least some of these unique program factors in a standardized system.

Moreover, this effort builds on the work previously completed by DSG, under an OMH contract, Implementation Study of the Bilingual/Bicultural Service Demonstration Grant Program (fiscal years 1993–95). That study involved the empaneling of an expert, multicultural Advisory Committee; reviewing all grantee records; developing and administering a mail survey to FY 1993–94 grantees (including a telephone follow-up interview); and conducting site visits to OMH grantees. The resulting report included 12 recommendations, one of which was to develop the Uniform Data Set.

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Areas of Inquiry

Questions to be answered under the OMH UDS effort included at least the following:

1. What are the uniform information/data set needs that must be met by OMH to monitor and assess the public's return on investment in the short- and long-term?

2. What are the common types of information and data elements that should be collected, despite type of approach, intervention, or disease condition?

3. What unique information/data elements are needed based on the type of funding arrangement, type of approach or intervention, or type of disease condition?

4. What information should be collected to enable successful completion of process, impact, and outcome evaluations?

5. Are OMH-funded activities able to conduct assessments themselves or will it be necessary to obtain data from other sources (i.e., State and local health departments)?

6. What means can be employed by OMH to assist funded activities in accessing and collecting necessary information/data?

7. What other grant-funded activities have uniform information/data sets? What is contained in these data sets?

8. Are there key points in time during which specific data elements should be collected, to make all data collection meaningful? When are they and what information should be collected?

9. Can OMH-funded activities determine who is served by their programs related to the stated goals and objectives of the funded effort?

10. (From the Contract Modification) What is the technical feasibility of implementing the UDS across all OMH-funded grant and standard cooperative agreement programs?

The developed UDS must be useful and relevant across all OMH grant programs and standard cooperative agreements (to be abbreviated as "grantees/SCAs"). These programs involve different types of organizations with different capabilities, a variety of program modalities and target health conditions, and other variations. Thus, the UDS must be structured so that it is flexible enough to apply to this broad range of programs. As will be discussed throughout, the formative research process led to the development of a UDS based on standardized categories of *project activities* (categories that cut across all OMH-funded programs), supported by a *core database* of general project information (e.g.,

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organization type, funding, staff, location of activities, collaborating partners).

OMH Grant and Cooperative Agreement Programs

OMH funds a variety of grant and standard cooperative agreement programs under its mandate to contribute to the elimination of disparities in health for minorities. During development of the UDS, these programs included the following:

Grant Programs

BILINGUAL/BICULTURAL SERVICE DEMONSTRATION GRANT PROGRAM
This includes both managed care and nonmanaged care years. This program operates through grants to racial/ethnic minority community organizations or minority CBOs linked to healthcare providers. The primary health issues vary widely, including cancer, HIV/AIDS, dental health, diabetes, cardiovascular disease, tobacco, and others. Primary activities include: education and outreach; community and health provider training; capacity building; development of culturally appropriate prevention or health information materials; and mediating services such as interpretation; transportation, case management, and screening. In FY 1999, there were 12 Bilingual/Bicultural grants awarded; in 1998, 15 managed care Bilingual/Bicultural grants were awarded.

MINORITY COMMUNITY HEALTH COALITION DEMONSTRATION PROGRAM
This program operates through grants made to minority coalitions that include racial/ethnic minority CBOs and at least one healthcare facility. Primary health issues vary but center on the "7+4" issues identified by OMH: cancer, cardiovascular disease and stroke, chemical dependency, diabetes, homicide, suicide and unintentional injuries, infant mortality, and HIV/AIDS, *plus* access to healthcare, health professions personnel development, improved data collection/analysis, and cultural competency. Primary activities include the development and operation of the coalitions themselves, and activities conducted by the coalitions that are similar to those conducted by the Bilingual/Bicultural projects. Coalition projects tend to have more emphasis on behavioral health assessments, counseling, case management/referral, wellness education, and screenings—because the focus is on risk reduction. In FY 1998, there were 23 Coalition grants awarded.

HIV/AIDS PROGRAMS
These grants operate through three program mechanisms—the HIV/AIDS Coalition Demonstration Program, the Technical Assistance and Capacity Development Demonstration Program for HIV/AIDS–Related Services, and the State and Territorial Minority HIV/AIDS Demonstration Program. The Coalition Demonstration program funds CBO-based projects that conduct education/outreach, develop an integrated community response, and address sociocultural, linguistic and other barriers in accessing HIV/AIDS related services. Project goals include increasing awareness, increasing testing, and improving access to prevention and treatment services. The Technical Assistance and

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Capacity Development program provides technical assistance to organizations (e.g., CBOs, healthcare facilities) in high-impact HIV/AIDS sites to help improve services available to racial/ethnic minority populations. The State and Territorial grants are designed to support State and Territorial Offices of Minority Health in coordinating statewide responses to HIV/AIDS to maximize impact and make the best use of available resources. In FY 1999, 11 HIV/AIDS Coalition grants, 4 HIV/AIDS Technical Assistance grants, and 15 State/Territorial HIV/AIDS grants were awarded.

Cooperative Agreements

There are essentially two types of cooperative agreements funded by OMH: *standard* and *umbrella* cooperative agreements. Both cooperative agreement types are noncompetitive, sole-source arrangements that stem from legislative directions:

- *Standard Cooperative Agreements:* These agreements are usually negotiated to provide support to health providers (e.g., Children's Hospital of Philadelphia, Albert Einstein Medical Center) and national racial/ethnic minority organizations (e.g., Association of Asian and Pacific Community Health Organizations, National Medical Association). The funding is generally designed to support: expansion of health education/promotion activities, health-related services, efforts to increase the number of racial/ethnic minority health professionals, efforts to address social/educational needs that impinge on health, and efforts to conduct health-related research. There are currently six standard cooperative agreements (including the Family and Community Violence Prevention Program).

- *Umbrella Cooperative Agreements:* These are sole-source agreements with racial/ethnic minority organizations, including large national organizations such as the National Medical Association or the National Council of La Raza. There are many complicating factors with respect to including these agreements in the UDS. They are, for example, primarily funded through interagency agreements, and their goals/purposes come from the interagency agreements. To separate the OMH role from that of other agencies is difficult. Moreover, the applicant organization may not be the entity doing the work. They also do not operate under standard budget periods, and the funding level for a given agreement may be anywhere from $20,000 to $4 million. Finally, activities are often specified after the agreement has been made. Currently, there are 28 umbrella cooperative agreements. *Because of the unique nature of these agreements, it was determined that the UDS would not apply to umbrella cooperative agreements.*

In addition, we can mention separately the Family and Community Violence Prevention Program (FCVP), because it is somewhat unique among standard cooperative agreements. The agreement is with Central State University, which, in turn, funds 25 Family Life Centers. Twenty of the centers are located at Historically Black Colleges and Universities. The remaining five are at other minority organizations and educational

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institutions, including tribal-related and traditionally Hispanic organizations. The primary health issue is youth violence. Thus, these Centers provide: academic support and career preparation; violence prevention; mentoring; family-based counseling, training and education; substance abuse prevention; support groups; case management; cultural and recreational activities; parental skills development; and other prevention activities.

Issues for Consideration in Development Of the Uniform Data Set

There were many issues to consider in the development of the OMH UDS, including the variety of data currently collected across projects, the unique nature of OMH-funded projects, the racial/ethnic minority health issues of primary concern, and the nature of interventions directed at those health issues undertaken by OMH programs. Several of these issues are discussed below:

1. Current OMH Measurement Efforts

During the development of the UDS, there were also two existing OMH efforts to collect cross-program and cross-project data. As much as possible, the UDS development process drew on these efforts.

CROSS-PROJECT DATA COLLECTION

The Division of Program Operations at OMH recently began collecting data from grantees/SCA via a set of forms completed as part of the continuing application process (see **appendix 1A**). The data reported supplement the data already collected as part of regular project activities. Four forms have been used:

- Part 1—Number of Persons Receiving Service: This is a table in which to record numbers of people served *by coded health issue area*, and within that, by race/ethnicity, gender, and age group. The available health issue areas comprise a partial list. Grantees/SCA are requested to provide total counts across all issue areas, as well as unduplicated counts. (This may cause some confusion, because the instructions for unduplicated counts ask grantees/SCA to count each individual only once, even if served under more than one issue area. Thus, both the total and unduplicated numbers of persons served by health issue are likely to be undercounts, skewed by the first health issue column where the most comprehensive total likely will be placed.)

- Part 2—Screening Data: This form asks for number of screenings, screening results, referrals, and follow-ups, by health issue area. A separate form must be filled out for each health area addressed by the project. Again the screening data columns are also broken out by race/ethnicity, gender, and age.

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- Part 3—Service Providers and Ancillary Persons Trained: This form is applicable when the providers inolved in the project are participants in various types of training. The form asks for counts of providers/ancillary persons receiving cultural competency, academic development, personal development, or career development training, broken out by race/ethnicity, gender and age.

- Part 4—Major Activities Conducted: As with part 2, grantees/SCA must fill out a separate Part IV form for each health issue area they address. This form has two parts: the first part includes columns for a limited set of activities (case management, patient contacts-facility, patient contacts-home, and medical interpretations provided), followed by a column for an unduplicated count of persons. As for the others forms, all is broken out by race/ethnicity, gender and age. The second part is for "group" activities, including outreach (such as workshops, health fairs, etc.), media exposure, and information dissemination. Here the form just asks for the number of times the activity was conducted and number of participants, or in case of materials, the total number distributed.

There is no system yet in place to store and analyze the data collected via these forms.

EVALUATION OF THE FAMILY AND COMMUNITY VIOLENCE PREVENTION PROGRAM

An evaluation of the FCVP program was conducted over the 1998–99 academic year. That evaluation entailed pre and post-test administration of instruments, across projects, to a sample of youth aged 4–18 who were selected based on risk factor criteria. Evaluating the 19 Family Life Centers (FLCs) was no easy task, in part because program requirements allow for a variation in program elements. While all FLCs must have prevention activities in academic development, personal development, family bonding, cultural/recreational enrichment, and career development, each FLC is free to develop its own programs under these broad categories. Therefore, the evaluation (conducted by Laxley W. Rodney, Ph.D., and William D. Kennedy, Psy.D.) could not focus on any set program methodology, but had to assess cumulative impact by measuring intermediate outcomes (proximal) and longer term (distal) affects. The instruments used were the following:

Proximal	
1.	Wide Range Achievement Test (Third Edition, WRAT–3)
2.	School Bonding Index (Revised, SBI–R)
3.	Youth Self-Report Inventory (YSR)
4.	Multigroup Ethnic Identity Measure (MEIM)
5.	Career Maturity Inventory (CMI)

Distal	
1.	Violence Risk Assessment Inventory (VRAI)—developed specifically by the Evaluators for this study
2.	Delinquency and Aggressive Behavior subscales of the Youth Self-Report Inventory (YSR)

Youth under 12 were administered only the WRAT–3 and SBI–R, because the other tests were not appropriate for younger age groups. Dosage levels were recorded for each child under the major program component areas listed above. Results were based on a total of 792 pretests and 545 post-tests.

While this report is not meant to discuss evaluation results, brief mention of results is pertinent because of the difficulties encountered using the instruments and measures across projects—a fact worth noting in consideration of such measures/data items in a UDS. For *proximal* results, significant improvement in spelling and arithmetic were reported, though no statistically significant changes in school bonding occurred. Some significant increase in YSR score occurred, suggesting an increase in violence and risk-related behaviors, counter to expectations. No statistically significant changes in racial/ethnic identity or career maturity occurred, Evaluators noted, however, that youth involved in the program were already interested in or positive about their racial/ethnic identity at the outset (pre-test scores were already high), possibly skewing the likelihood of significant change in this area. For *distal* results, there were decreases in fighting and attitudes related to fighting (e.g., anger management), and significant decreases in delinquent behavior. The Evaluators are examining results that showed no change or counter intuitive change, and they have already refined the results by linking them with *dosages*, where higher dosage levels were often correlated with better results, and vice versa. Issues were also raised as to the appropriateness of the instruments used.

The evaluation was an important step in attempting to find a method for assessing performance with respect to this diverse and dispersed program. It also represented a caveat that any cross-project attempt to identify results for OMH grantees/SCAs on the level attempted by the FCVP program is likely to be inconsistent and difficult to interpret conclusively.

2. Program Characteristics

OMH programs also have several characteristics that were taken into account in developing the UDS.

FOCUS ON SPECIFIC POPULATIONS

OMH programs, unlike many more generalized interventions, focus on specific racial/ethnic minority population groups, some native born/English speaking and others that are not. With respect to the UDS, several issues become salient. One is simply that outcome and other health data often are not available by specific racial/ethnic minority population groups, either at the national level or at local levels in particular. A second issue concerns demographic categories. Since community grantees/SCAs often focus on a few specific populations (e.g., Cambodians, or African-American youth), what demographic categories will be used to collect and report data on project participants? Standard Census categories? Or more detailed subpopulation categories?

IMPACT INTERTWINED WITH OTHER AGENCY PROGRAMS

OMH is one of several Federal agencies that have a mandate to improve minority health status and reduce disparities in health status, healthcare, and access to healthcare for racial/ethnic minority populations. For OMH, this is the basic agency mandate—for other Federal agencies, it is included as part of their overall respective mandates. Because of

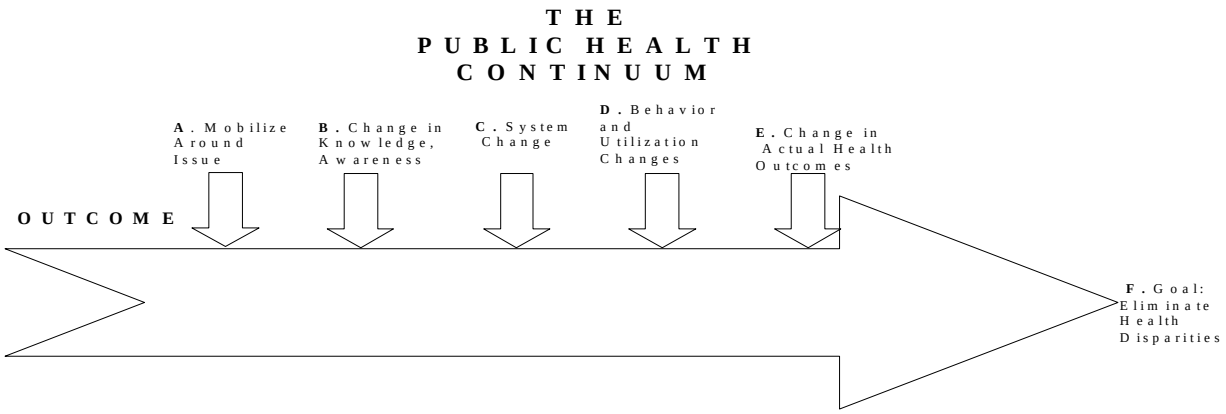
this, no logic model for OMH programs can posit longer term outcomes (improvements in health status, or even in most cases increases in healthcare utilization) that are solely the result of the OMH program. As we will discuss below, measurable program outcomes will be those more closely tied, at an intermediate level, to program activities.

MULTI-ACTIVITY PROJECTS

Almost all OMH grant and cooperative agreement programs fund projects that are not single-activity modalities. Across programs, OMH projects tend to include a mix of activities such as education/outreach, training, prevention programming, interpretation, case management/referral, capacity building and system change, counseling/prevention, and others. Thus, for evaluation purposes, it is difficult, even inappropriate, to treat such projects as tightly drawn, theory-based efforts. They are instead highly diverse.

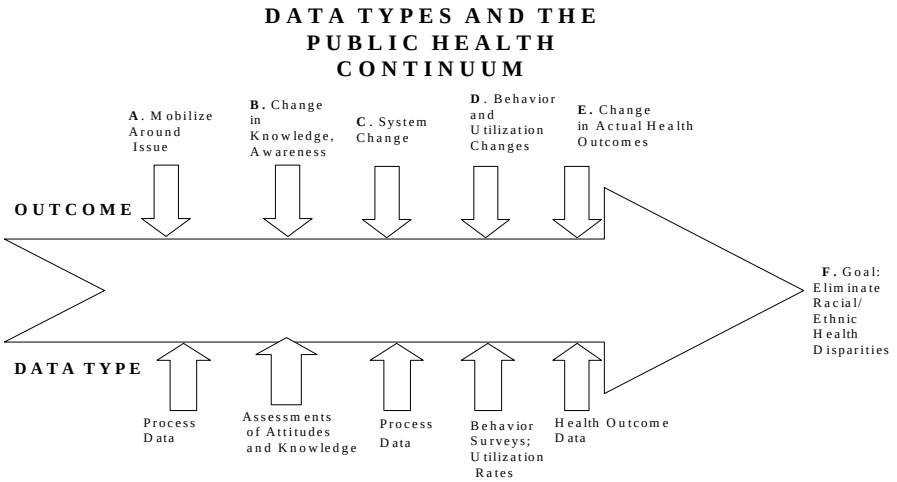
EMPHASIS ON PROCESS AND INTERMEDIATE OBJECTIVES: THE PUBLIC HEALTH INTERVENTION CONTINUUM

Moreover, except for the few services (e.g., counseling) provided via the Family Violence program, OMH programs *do not provide direct medical services*. Therefore, it is useful to situate OMH programs within a public health continuum (Figure 1, below) where the end point E represents achievement of the overall goal of eliminating racial/ethnic minority health disparities:



Because of the range of barriers to healthcare for racial/ethnic minority populations (e.g., language, cultural differences, socioeconomic status), programs intervening at points A (mobilization), B (knowledge change) and C (system change) may be necessary to produce intermediate outcomes that lay the groundwork for interventions and outcomes at points D (behavior and utilization change) and E (health outcome change). OMH programs primarily target points A, B, C—and sometimes D—on the continuum.

For each intervention point on the continuum shown above, program impact can then be measured by a different type of data, as follows:



Because OMH programs intervene primarily at points A , B, C, (and sometimes D), they should be measurable by their commensurate data types:

- *Point A—Mobilization:* Primarily *process* measures such as the formation of coalitions, coalition activities and membership, training of community and health provider staff, as well as implementation of awareness activities.

- *Point B—Changes in Knowledge and Awareness:* Primarily determined through *short term assessments of changes in attitude and knowledge*, among project clients, health providers who receive training, community members who participate in outreach/education activities or who receive informational messages/materials. In addition, *counts* of materials developed/disseminated, training and educational activities held and attendance at those activities, and process records of activities conducted.

- *Point C—System Changes:* Primarily assessed through *process* measures, identifying actual changes in specific health systems, policies developed, committees formed, etc.

- *Point D—Behavior and Utilization Changes:* Primarily determined through *surveys*

or questionnaires concerning self-reported behavior change, and potentially through *counts* of screenings conducted, referrals made or services used by the target population—where such data are available.

3. Minority Health Issues of Focus

HEALTH ISSUES

Healthy People 2010, and the minority health initiative within the Department of Health and Human Services identified a number of key areas in which there are significant disparities in health with respect to minorities. OMH programs focus on a set known as the "7+4" issues:

- Cancer, cardiovascular disease and stroke, chemical dependency, diabetes, homicide, suicide and unintentional injuries, infant mortality, and HIV/AIDS; along with

- Access to healthcare, health professions personnel development, improved data collection/analysis, and cultural competency.

EVALUATING MINORITY COMMUNITY HEALTH PROGRAMS

Apart from GPRA and other imperatives, developing the OMH UDS represents a way for racial/ethnic minority community programs to "tell their story"—whether good or bad, to *learn what works and what does not, and build on best practices developed through the feedback cycle of program development, implementation, and evaluation.* In short, building the evaluation capacity spurs progress in alleviating the health/social conditions targeted by the programs.

However, a major challenge facing this project and others that focus on community-based programs lies in the basic question: *What kinds of measures and what kind of data can* ***adequately*** *capture the impact and effectiveness of community programs*? Communities, and what goes on within them, are organic entities of a sort, and that progress toward the alleviation of health problems is not a one-dimensional phenomenon. Accountability imperatives tend to push evaluations toward simplistic definitions of success that can easily be expressed in numbers or other discrete, measurable analytic units. Yet progress and change are in reality much harder to define. In one situation, it may be that subtle changes in attitude among a key community group "ripples" to other community constituencies. Eventually, this could lead to change in the prevailing attitude toward diet, or toward the use of preventive healthcare services. In another situation, the mere fact of having language interpreters available to accompany a non-English speaking minority individual to a health facility may be enough to generate confidence in that individual (and then others), allowing the (once-intimidating) medical system to be mastered. *Indeed, these kinds of subtle, hard-to-define impacts were some of the most important impacts encountered in conducting the Implementation Study.* Yet such impacts were not, and could not be, reflected in basic statistics on the number of persons served, kinds and

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numbers of materials developed, and the like. Of course, such statistics are a vital part of the story, and it is important to resolve problems in obtaining these data (e.g., duplication, lack of uniformity across projects in defining what, for example, counts as having "completed training"). To summarize, some of the basic issues and needs that had to be addressed in developing the UDS included the following:

- *The wide variety of target populations* for programs, in terms of culture and subculture, and in terms of occupation/background. Some programs target health professionals, some target the community, and so on. Different performance measures may be needed for these different target populations.

- *Programs of varying modality*, or that may include several modalities within one program. For example, programs that address training, development of materials, or media campaigns; those offering health screenings and other direct care services; and case management, coalition-building, and other types of modalities. Such different modalities can be measured best by different performance measures.

- *The variety of health conditions to be addressed*, which may require different modalities and approaches. For example, HIV/AIDS prevention programs often entail substantial community outreach work. Other health conditions may be best addressed through modalities such as health screenings and provider training.

- *The variety in capabilities to handle data collection*. Available equipment and staff are critical elements. Some programs may be centered in a large minority health organization, or at a college/university, where access to computer equipment is relatively good and familiarity with data is high. Other programs may be small CBOs with very little capability in this regard as well as a small staff. Often, however, a consistent factor is that much staff time is devoted to project clients (whether they are target population members, health professionals, or community leaders), the total number of staff is small, and evaluation/data collection activities must be structured so that they do not impose an excess burden.

- *The variety in understanding of, and attitudes toward collection of data*. This is a very sensitive issue. In part, it touches on the issue mentioned earlier where the kinds of impacts program staff may see are not necessarily the kinds they are asked to report. Such disassociation can produce anxiety over program continuity because funds may depend on evaluated impact. It also can lead to an overcompensating allocation of staff, to make sure "the numbers are good," at the expense of other activities. Potentially, this issue could diminish the collaborative relationship with the funding organization.

- *Mistrust.* Mistrust, especially that associated with health/medical research in any form, is a major issue with some populations. For example:

- ✓ Among many American Indian groups, there is a reluctance to report data on tribal health issues to outside agencies or to the public, because of a concern that the data may be publicized or used in a negative way. This sentiment is not uncommon among programs serving other racial/ethnic minority groups as well.
- ✓ Among programs serving refugee and migrant populations, there may be a reluctance to report data because of historical experiences with government repression, or because of concerns over potential immigration issues.

The range of program types funded by OMH, from demonstration grants, to coalition grants, to cooperative agreements, which may have different aims and thus different standards for performance.

Multiple funding streams within projects and the potentially confusing mix of data collection requirements from each funding source. A complex situation also exists in terms of disentangling the OMH-related impact of activities that may be supported by various funding sources. This argues strongly for an OMH system cognizant of, and designed to work with other Federal agency data sets.

The balance between process, impact, and outcome and the focus for outcome data. As explained in the Public Health Continuum diagram earlier, a program may be very successful in catalyzing a change in community behavior, but the actual health impact, in terms of change in health status, may not appear for a significant period of time. This has to be assessed against the length of the grant.

The need for clarity in the data to be collected. Among the potential problems resulting from the variety of program modalities is the need to establish common categories and definitions for the modalities themselves, and what counts as a "completion," a "full cycle," or "dose" of the modality. For example: How many training sessions must be attended for a person to be counted as having completed a training? Another problem arises from modalities in which a complete count of participants may be difficult to obtain, or may result in duplication—attendees at health fairs, for example, present this kind of situation. In addition, what are the most important kinds of demographic and background information to be collected from clients (to understand who is served), and how this is to be collected.

The need to find data indicators, formats and protocols that can capture some of the real impacts of community projects that also cannot be reported easily using strict quantitative form. As noted previously, some of the most important project impacts for CBOs serving racial/ethnic minorities are not captured easily. Building trust, feeling more confident and knowledgeable with respect to the health care system, increased rapport between patients and doctors, understanding that a particular health condition is preventable, and other such impacts may require narrative or other nonquantitative formats for adequate reporting.

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- *The need to develop measures that can be integrated realistically and meaningfully throughout, based on a project's goals/objectives, through its activities, or through evaluation.* Projects assessed in the Implementation Study often included far more objectives than were possible to achieve, and far more than could be adequately measured.

- The range of *regulations and requirements* that must be met to collect data across projects, particularly the potential necessity of obtaining Office of Management and Budget (OMB) clearance.

- Finally, the need for a data set that will *allow for useful cross-program and cross-project analyses.*

4. Limitations With Respect to Current Databases And Performance Measurement Efforts

Performance measurement in population-based health services is typically based on two factors: 1) accountable entities, and 2) routinely collected public health status data (outcomes) consistent with the geographic boundaries of those entities. There are several Federal data sets that address a variety of heath status, disease, and access to care factors. Most of these data sets provide national-level data only, though a few provide State-level estimates.*

Moreover, even at the State level, not all of these surveys provide extensive racial, ethnic, or socioeconomic level data at the level of detail necessary for OMH programs. As regularly collected data, these surveys will not be useful as already existing databases. There are, however, two uses for these data:

- As a national or statewide baseline for comparing local outcomes with ascertain changes.

- Drawing from the data collection process—model instruments for questions used in specific, original, or local-level surveys where administrative data are not available.

The calculation of basic rates—whether for public health outcomes or for service utilization—requires both a numerator and a denominator. The numerator would be the number served, or the number with a particular condition in a specified geographic area served by a program. The denominator would be the overall population either in total or at risk for a specific condition. Unfortunately, even if a program can calculate unduplicated

*The National Immunization Survey is unique in that it also provides estimates for 27 urban areas, as well as at the State and Federal levels.

numbers of individuals served, the denominator is usually unavailable below the State level (except some urban communities) beyond the decennial Census.

Thus readily available information concerning impact on national health outcomes is limited for racial/ethnic minority communities. The Indian Health Service (IHS), for example, notes several limitations for estimating Indian health data. First, the Census Bureau, the most authoritative source for Indian population counts, produces "reliable Indian census data at the county level" only once every 10 years (IHS 2001 Performance Plan, 84). Second, vital statistics, which are based on official State records, do not include tribal identity. And third, the IHS has found that "several studies have shown considerable miscoding of Indian race on State death certificates" (IHS 2001 Performance Plan; 84). In recognition of this, *Healthy People 2010* Public Infrastructure Objective 14–7 is to "Increase to 100 percent the proportion of *Healthy People 2010* objectives that can be tracked for select populations."

For some specific health issues in discrete racial/ethnic minority communities, the disease incidence may be rare enough with respect to the larger population that such data are only irregularly collected in public health indicators. Another methodological issue reflects specific health issues that may be targeted by CBOs for which data are difficult to obtain because they are a rare event. As such, it may be rare enough for the larger population to be collected irregularly in public health indicators. This would be true for genetic diseases or rare diseases specific to some groups. Other problems arise with domestic violence, for which adequate local data are almost always unavailable because of the confidentiality and anonymity of some programs, and the challenge of collecting data cross-system.

Outline of the Uniform Data Set Report

In the report that follows, the step-by-step development of the UDS will be described. These steps followed a careful, grounded approach that sought to develop a data set with grantee/SCA input, and that reflected, as much as possible, grantee/SCA circumstances and needs—together with advice from agencies and organizations that had experience in undertaking similar efforts.

- **Chapter 2** discusses the role of the Project Advisory Group (PAG), composed of representatives from public and private agencies/organizations that have undertaken uniform data efforts.

- **Chapter 3** presents the results of an extensive literature review that assessed current literature on performance monitoring and uniform data sets, together with public and private agency documentation of standard data set efforts.

- **Chapter 4** presents the preliminary *logic models* that were developed for OMH grant and cooperative agreement programs to aid in conceptualizing data needs.

Chapter 5 summarizes the results of a focus group and telephone interviews that were held with a sample of OMH grantees/SCAs, to collect input on current data collection practices as well as needs.

Chapter 6 summarizes the results of site visits conducted with eight OMH grantees/SCAs across the country, representing different grant types, program modalities, and target populations. These site visits were instrumental in finalizing the descriptive typology of activities that became the *activity modules* in the final UDS. They were also vital toward an understanding of how grantee data collection functioned.

Chapter 7 presents the results of a pilot test, in which a sample of nine grantees/SCAs used the draft UDS for one reporting period.

Chapter 8 presents the results of an additional task (by contract modification)—the conduct of a telephone survey of a sample of OMH grantees/SCAs to assess technology needs with respect to implementing the UDS, and the development of a demonstration Web-based UDS system.

Chapter 9 represents the culmination of the formative research process, and outlines the final UDS.

Finally, the report includes numerous **appendices** that document the process used in the various stages of UDS development.

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2. Project Advisory Group

To guide development of the UDS and provide experienced insight, a Project Advisory Group (PAG) was formed, consisting of representatives from Federal and private agencies/organizations that had undertaken or supported uniform data efforts. The role of the PAG was to provide insight from lessons learned on their own efforts, to help guide the literature review, and to provide, periodically throughout the project, review and input as the UDS was developed.

The following agencies/organizations were represented on the PAG:

- Health Resources and Services Administration (Maternal and Child Health Bureau, Bureau of HIV/AIDS, and Bureau of Primary Health Care), Centers for Disease Control and Prevention (Office of Program Planning and Evaluation, Office of Minority Health)
- Center for Substance Abuse Prevention/SAMHSA
- Office of Population Affairs
- National Association of City and County Health Officials
- Kaiser Family Foundation
- National Association of Community Health Centers
- Commonwealth Fund
- Association of State and Territorial Health Officials
- Three OMH grantee representatives (first meeting only)

The PAG met near the beginning of the project and just before the pilot test, and then PAG members were contacted by telephone or e-mail for specific feedback and comments.

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3. Literature/Agency Review

This chapter* summarizes the first step in development of the UDS, a review of several categories of information relevant to the development of the OMH UDS:

- Current literature concerning data sets and performance measures—to glean any approaches, issues or trends that pertain to the OMH effort. Gaps in that literature are noted, particularly insofar as the OMH UDS may contribute to their resolution.

- A sample of current and recent UDS/performance measure efforts at other Federal agencies and in the private sector (associations, foundations). These efforts are reviewed to: build on best practices, ensure that the OMH effort does not "reinvent the wheel," find UDS elements—such as standard data categories and definitions—that can be replicated in the OMH UDS, enable cross-agency comparisons, and, generally to look for common elements and experiences across the efforts reviewed. The agency/private sector review is confined to data sets and program types that are relevant to OMH programs.

- Finally, we drew from the material reviewed to outline an initial model of a UDS. This model formed the basis for the final, pilot-tested version discussed later in this report.

Relevant Literature

A great deal of the literature relevant to the development of a Uniform Data Set tends to fall under the *evaluation* or *performance measurement* categories. Some, but not all, of this literature has useful implications for the UDS.

General Issues

First, it is important to note that some of the literature on data sets/performance measures is associated with the 1993 Government Results and Performance Act (GPRA), which required Federal agencies to develop/improve their performance monitoring systems. Performance measurement had been traditionally associated with cost factors and efficiency, e.g., the cost or number of hours per unit of output (Hatry, 1989). However, the "reinventing government" movement stressed the application of this approach to nonfinancial sectors of public management (Osborne and Gaebler, 1993). National associations (e.g., the Government Standards Accounting Board, the National Academy of Public Administration, and the American Society for Public Administration) have passed resolutions supporting public sector use of performance measurement and reporting

*This chapter is a revised version of the document previously submitted as the *Current Issues and Practices Report*.

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systems, and Federal agencies have large projects which seek to create goals and standards (e.g., the U.S. Department of Labor has Workforce 2000, the U.S. Department of Labor has Goals 2000, and the U.S. Department of Health and Human Services has Healthy People 2010).

Second, the performance measurement literature makes a distinction between output and outcome, where *output* is a measure of the volume of something actually produced (or how many people served, etc.) and *outcome* is a measure of the impact or quality. Osborne and Gaebler (1993) point out that performance measurement provides extremely useful information that revolutionizes public management, citing the following aphorisms:

1. What gets measured gets done.
2. If you don't measure results, you can't tell success from failure.
3. If you can't see success, you can't reward it.
4. If you can't reward success, you're probably rewarding failure.
5. If you can't see success, you can't learn from it.
6. If you can't recognize failure, you can't correct it.
7. If you can demonstrate results, you can win public support.

Generally, public sector performance measurement seeks accountability for results from "*accountable entities*," with two types of outcomes (results): program outcomes, and policy outcomes. Program outcomes measure the effectiveness of specific programs in achieving desired outcomes. Policy outcomes measure the effectiveness of broader policies in achieving fundamental goals.

According to Hatry (1999) and others, potential outcomes are determined first through a vision and mission-defining process. Federal agencies have often found that this has been a multiyear process requiring cross-agency collaboration, expert consultation, and ongoing interagency workgroups. For example, *Healthy People 2010* represents the state-of-the-art in performance goals around which a consensus has been built. As we will describe below, *Healthy People 2010* has been used to develop performance indicators for DHHS and OPHS.

PERFORMANCE MEASUREMENT SYSTEMS

Public sector performance measures/data sets are intended as part of an integrated system of measurement that is mission or goal-defined. As such, they should be linked directly to the overall mission of the organization or the accountable entity (or government), OR a program logic model which seeks to describe the goals of the program. Typically, public performance measures are said to have three key characteristics:

- They target end outcomes.

- They are population-based.

- They are drawn from routinely collected data.

However, are measures of this description relevant to OMH grant programs? First, the emphasis on population-based measures virtually precludes OMH grantees/SCAs, who, as noted previously, are not operating at that level. Second, and also noted in chapter 1, many OMH programs target intermediate outcomes. Thus we see the first indication of a pattern that exists in the literature and with many of the other Federal agency efforts: the fact that *most UDS or performance measure efforts are not fully relevant to the kind of projects typically funded by OMH*. To wit:

- *Targeting End-Outcomes.* Performance measurement is distinct from traditional evaluation, which requires in-depth measure of causal factors to assess impact (i.e., did the program cause the change in status?). Rather than seeking to test causal factors or effectiveness of an intervention, performance monitoring is tailored to the program, requiring careful specification of indicators "so that they truly measure the performance of accountable entities rather than other changes in a community's health" (Stoto, 1997, 361). This means that a results-based focus depends on either an agency's authorized mission or the program logic model defined into discrete steps (inputs {including program components}; outputs, initial outcomes; intermediate outcomes, and end outcomes).

- *Population-Based Measures.* These are not directly relevant for OMH grantees/SCAs because OMH programs do not focus on comprehensive coverage of a geographic accountable entity for which population measures are regularly collected. These measures, however, may provide a benchmark for comparison purposes if local data can be generated.

- *Easily or Routinely Obtained Data.* Since the purpose of UDS/performance measurement systems have often centered on accountable entities, the data to assess performance should be readily available from public sources. Of course, for most OMH projects, it is not.

PERFORMANCE MONITORING AND PLANNING

Performance-based systems are designed to do more than collect data. As one expert put it, "Just measuring something does not improve it. Performance measurement is a planning tool. The next step is benchmarking, which is an improvement (i.e., management) tool" (Fisher, 1994,11).

The data developed in performance-based systems produce indicators of effectiveness and can be used in many ways. Benchmarking means comparing your results to track change or improvement over time. One way to do this is to compare to numbers or figures

from average or national success or incidence rates. This information helps track progress toward goals. Another is to compare your practices to those of others who are doing similar programs—the "best practices." This information becomes a planning tool which will allow you analyze what is different about your process, and reengineer your process accordingly. Thus, through benchmarking, a performance measurement system can be both a planning and a management tool.

Is this relevant for OMH? Not at this point. No relevant benchmarking data are available, and probably won't be until OMH generates (through the UDS) its own comparative data.

RELATING PROGRAM GOALS/OUTCOMES TO DATA

Data to be collected in a performance or monitoring system are determined by linking program goals and outcomes through a logic model. The program logic model is an action theory which describes the chain of events that lead from the program resources and inputs, to program outputs (activities), intermediate outcomes, and end-outcomes—usually, but not always, tied to a theory of causation. The "results chain" specifies linkages from goals to measures, based on the causal theory. Initial outcomes will be impacted most directly by the program, while end outcomes will be affected by many factors external to the program.

The W.K. Kellogg Foundation (1998) has outlined three primary types of models that are based on different ways to construct the causal program theory. (These are discussed in more depth in chapter 4.) Logic models may be primarily of one type, or they may be hybrids.

- *Theory Logic Models* reflects the causal processes that impact behavioral change. This is most similar to theory construction in scholarly works.

- *Outcome Logic Models* focus on program outcomes or results. This type of model is what is most commonly assumed in performance measurement.

- *Activities Logic Models* places more emphasis on the sequence of events, outlining in great detail how one activity leads to another. This model is more common to community-based programs which may be complex in structure.

The key point is that these logic models should be based on specific programs, their missions and strategic goals. Further, activities or processes in one program may lead to different outcomes depending on implementation.

A key measurement issue for OMH and community initiatives is that the program goals focus on capacity-building, health promotion, system change, access to care, and other prevention-related outcomes. For example, most community initiatives have as their primary goal increasing access to health care for vulnerable and special populations. DHHS has recognized this in selecting, as part of its strategic plan, the goal of increasing access to health care. *Access-related measures have not been well-defined thus far in the*

performance measurement field. In fact, most handbooks (e.g., Hatry, 1999) treat such indicators as either a process or near-outcome or intermediate-outcome measure, rather than as an outcome itself. For the general population, public health measures already in place can be expected to have sufficient coverage that health outcome measures can be measured. *But, because access in relation to special populations remains a serious issue, the penetration of public health programs into vulnerable communities is not adequate enough to even look at health outcomes, nor is the public data available for many racial/ethnic minority populations.*

DATA MEASUREMENT AND RACIAL/ETHNIC MINORITY POPULATIONS

With respect to the development of data sets concerning racial/ethnic minority populations, there are several critical issues:

Cultural Issues. Data measures must be based on a culturally competent framework, particularly when racial/ethnic minority populations are surveyed. Specific terms (even for example, the term "counseling session") may neither translate into precise equivalents, nor have the same meaning across cultural groups. Certain assumptions about health behavior may also not pertain across different cultural groups and traditions. And, in the case of the OMH UDS, *it will be important to ensure that the types of activities for which we collect data are culturally inclusive.*

Population-Based Measurement. Generally, a key sampling issue is the ability to define and target measures to a specific racial/ethnic minority population (e.g., Vietnamese community, rather than all Asian and Pacific Islanders). CBOs tend to focus on such specific, geographically bounded populations. While it is relatively easy to conduct a type of customer survey among users of a service, assessing whether a program is meeting certain performance outcome measures *by population* means being able to quantify the proportion of the targeted population at risk or at need. This requires relatively accurate estimates that are usually unavailable below the State level. For example, estimates of the size specific population groups for the county level are usually only available in the decennial Census, i.e., once every 10 years). Owing to rapid change in some groups, this is inadequate for developing local population-based estimates.

Limited Reach of Federal Data Sets. The Federal government regularly collects statistics on health outcomes for use by State and local government partners, researchers, and grantees. Relevant issues for OMH grantees/SCAs include the timeliness and the ethnic and racial classifications of these data. CBOs will often target more narrow ethnic and racial groups than those usually aggregated in census categories such as Asian/Pacific Islander or Latino. Many Federal databases are only collected annually. Usually, they aggregate specific language or ancestry groups into large categories that are meaningless in terms of groups targeted by CBOs, and are limited in terms of their ability to provide local-level estimates. CBOs, without access to sophisticated research skills and the resources to identify and calculate their own estimates of incidence and prevalence of the health statuses targeted by their programs for the targeted group will be limited to available, public data that are usually not timely, or distributed on a case-level basis, or

aggregated according to the appropriate demographic target group.

COLLECTING THE DATA IN COMMUNITY-BASED ORGANIZATIONS—ISSUES OF CAPACITY

Performance measurement systems, while relatively established at the Federal level, are new to many CBOs, who have participated in this process only peripherally through partnership with Federal agencies and departments. For this reason, defining outcomes for CBOs remains at the frontier of performance measurement. As performance measurement expands to State and local governments and to CBOs, the nature of outcomes may need to be adjusted to included multiple stakeholder perspectives. *This means that not only GPRA-related purposes are important, but also community-based goals—in keeping with the tenets of participatory evaluation.* Moreover, while performance measurement stresses outcomes, OMH programs focus on underserved communities, and include such goals as capacity-building among community-based grantees/SCAs (HHS Strategic Goal 3).

Thus, OMH strategies include building partnerships and coalitions, which increases measurement complexity. According to Kubisch and others (1994), community-based collaborations are difficult to evaluate. The factors include both horizontal and vertical complexity, the nature of the interventions, the broad range of outcomes, and difficulties of providing comparisons across distinct communities.

- *Horizontal Complexity*—delivery of services across multiple service systems
- *Vertical Complexity*—designed to create change at multiple levels
- *Broad Range of Outcomes*—multidimensional outcomes crossing multiple disciplines
- *Flexible and Evolving Interventions*—each site will differ, change process will be unique, and "final" intervention will differ from original design
- *Contextual Issues*—community context means many factors beyond control of the intervention
- *Absence of a Comparison Community or Control Group*—cannot answer the "compared with what" question

For these reasons, it is usually unlikely that local programs, particularly those that are new and growing, will have internal expertise and established standards and practices that support rigorous data collection, maintenance, and analysis. Thus, the trend in some Federal agencies (e.g., SAMHSA) is to hire an outside cross-site evaluator, and provide funding for program grantees to hire a local evaluator. Another approach is to have a data collection center to provide support to the local programs and agencies.

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Uniform Data Sets and Health-Related Programs

TRADITIONAL EVALUATION DATA AND COMMUNITY HEALTH INITIATIVES

Evaluation tools and analysis techniques have lagged behind program development because community-level interventions are not provided to an isolated set of individuals that could be studied as a scientific sample. Thus evaluation approaches employing random assignment and/or comparison communities as means to control for confounding variables are difficult to implement (Holder et al., 1997).

Community-based initiatives are often complex, while traditional evaluation methodologies are designed around assessing single, stand-alone interventions or "treatments." According to the Annie E. Casey Foundation (1997), there is a gap between assessing outcomes and the real work that is going on in communities because "policymakers who rely on evaluation data have relied on standardized, centralized, isolated, and uniform 'treatments' while conventional evaluation design does not adequately address the complexity of comprehensive services that go beyond limited interventions . . . and [lack measures of] the process of change stimulated by comprehensive programs." Similarly, the California Wellness Foundation (1999) states that "The work we are funding is being carried out in high-noise environments, where many interventions are simultaneously taking place. Random assignment to 'treatments' is not an option. As a result, attribution of specific outcomes to our funding is, at best, problematic . . . [and] we have shifted our goals for evaluation to focus on capacity building and continuous feedback for program improvement."

Finally, it is acknowledged that, in general, performance measurement is difficult for certain types of programs and activities, including prevention programs; basic research; long-range planning activities; programs with anonymous customers; programs whose outputs vary in impact; programs whose coverage is not jurisdiction wide; and internal support services (Hatry, 1999). *The work of OMH, and that of the community-based programs often falls into these categories*.

PERFORMANCE DATA FOR POPULATION-BASED HEALTH PROGRAMS

Performance measurement in population-based health services is based on two factors: 1) accountable entities; and 2) routinely collected public health status data consistent with the geographic boundaries of those entities. There are a large number of Federal data sets that address a wide variety of heath status, disease, and access to care factors. However, most of these data sets provide national-level data only. A few of these data sets provide estimates at the State level. The National Immunization Survey is unique in that it also provides estimates for 27 urban areas, as well as at the State and Federal levels.

Another aspect of measurement relates to the level of detail provided for specific population groups within those geographic areas. Even at the State level, not all of these surveys provide extensive racial, ethnic, or socioeconomic level data at the level of detail appropriate for OMH programs. As regularly collected data, these surveys will not be useful as already existing databases. There are, however, two set of uses for these data:

1. As a national or statewide baseline for comparing local outcomes to ascertain changes

2. As model instruments for questions used in specific, original, or local-level surveys where administrative data are not available

Outcome or impact conclusions for a population have to be based on the number affected by the intervention (or the outcomes of these individuals) set against the total population of that target group. Unfortunately, even if a program can calculate unduplicated numbers of individuals served, for example, there is no way to assess impact in the target population as a whole since such data are usually unavailable below the State level (with the exception of some urban communities).

Federal Database Limitations. Readily available information concerning impact on national health outcomes will be limited for racial/ethnic minority communities. For example, the Indian Health Service notes several limitations for estimating Indian health data. First, the Census Bureau, which is the authoritative source for Indian population counts, produces "reliable Indian census data at the county level" only once every 10 years (the Decennial Census) (IHS 2001 Performance Plan, 84). Second, the Vital Statistics System, which is based on official State records, does not include tribal identity. And third, the IHS has found that "several studies have shown considerable miscoding of Indian race on State death certificates" (IHS 2001 Performance Plan, 84). Recognizing such limitations, *Healthy People 2010* Public Infrastructure Objective 14–7 is to "Increase to 100 percent the proportion of *Healthy People 2010* objectives that can be tracked for select populations."

Moreover, some health data (e.g., where the condition is rare or limited to specific small populations) are not regularly collected. Other problems arise with domestic violence, for which adequate local data are almost always unavailable owing to confidentiality and anonymity of some programs, as well as the challenge of collecting data cross-system. In general, local level data or estimates are hard to come by.

Databases are limited in their ability to provide annual or more frequent data. For example, the Vital Statistics System, while collected on an ongoing basis, provide only annual data. In fact, one of the goals for *Healthy People 2010* is to increase the frequency with which *Healthy People 2010* objectives are tracked (Public Health Infrastructure 14–8). Because many of the ongoing Federal databases lack specificity for local-level data, and are limited in their ability to offer frequent baseline measures, they may be unreliable for estimating performance outcomes for a specific set of programs, such as OMH's demonstration grants or cooperative agreements, that target communities concentrated in reasonably geographically defined areas. Yet national data for populations that tend to live in selected geographic areas is still distributed across all 50 States. National figures will thus combine those not targeted by programs with those who are targeted. Thus, impact and outcome data even for successful programs may be suppressed by continued poor health status of those who are not in targeted communities.

PERFORMANCE MEASUREMENT IN PROGRAM-SPECIFIC HEALTH PROGRAMS

Performance measurement can be applied to program-specific health programs or objectives. Evaluation instruments and uniform data measures have been developed for statewide programs that have a specific focus. For example, the American Academy of Pediatrics has developed an *Evaluation Tool* (1998) for the *State Children's Health Insurance Program (SCHIP). SCHIP* was created as part of the Balanced Budget Act of 1997, and extended health insurance to millions of uninsured children in the United States. States are given considerable flexibility in designing their programs, which must be evaluated to assess the degree to which their programs reduce the number of uninsured low-income children and to assure their access to quality health services. The *SCHIP Evaluation Tool* includes measures of access, process, and outcomes based on 1) measurability, 2) demonstrated effectiveness, 3) availability of data, and 4) attention to special populations.

Other access measures have typically been defined on a population-basis. For example, *Healthy People 2010* includes a new "Access to Quality Health Services" (chapter 10). This new chapter relies on the Institute of Medicine (IOM) definition of access as "the timely use of personal health services to achieve the best possible outcome" (Millman, 1993). This includes both the use of services, and their quality. *Healthy People 2010* objectives which focus on access and are of particular concern as a racial/ethnic minority health issue include the following: those who lack healthcare coverage (A.1), those who have coverage for clinical preventive services as part of their health insurance (A.2); those who lack a medical "home" (B.1.); those in who report they have not obtained all the health care they needed (B.2); and those in poor health who have had no primary care during the previous year (B3). Recommended data sources are the National Health Interview Survey (NHIS) and the Medical Expenditure Panel Survey (MEPS), both of which only provide national-level estimates.

PROCESS MEASURES RELATED TO HEALTH OUTCOMES

With respect to health outcomes, the term "process measures" is often used to measure two very distinct phenomena:

1. *Measures of whether or not patients/clients receive appropriate and needed care.* This would focus on the content and quality of health services provided to patients.

2. *Measures of how well a program is implemented,* and the fidelity to the program components.

The first type of measure focuses on standards of care. The second reflects more traditional performance measurement of program implementation. From an outcomes perspective, traditional performance measurement treats these measures as less important than real outcomes because different programs may have differential efficacy on outcomes. Foundation evaluation programs, as well as other approaches to assessing impact seek to treat process measurement as critical when these process measures have

been shown in other research as strongly linked to health outcomes.

CAPACITY-BUILDING MEASURES FOR ORGANIZATIONAL GROWTH AND CHANGE

Measuring capacity can occur at two levels: 1) the overall public health system (which is the focus of *Healthy People 2010*); and at the organizational or community level (which is where OMH places its focus).

Developing measures of capacity and capacity-building is an uncharted area in performance measurement. Healthy People and Healthy People 2000 were both drafted prior to GPRA, and focused primarily on health statuses, rather than capacity to address health outcomes. However, as a result of *Healthy People 2010*, the need for capacity-building measures is expanding among a wider group of Federal agencies. *Healthy People 2010* incorporates a number of new capacity-building measures for which indicators and appropriate data sets have not yet been defined, and which span a number of Federal agencies. As a result, its measures are considered "developmental," which means that "sources of data for measuring achievement will need to be developed" (HP2010, 14–5).

Because national data are lacking even on basic measures of capacity to address racial/ethnic minority and underserved populations, it is clear that OMH's programs are the frontline of increasing capacity. However, OMH's focus on measures of CBO capacity represent a different scale of measurement.

***Organizational Growth and Change*.** One of the more sophisticated efforts at defining organizational growth and change was recently completed by the Institute of Medicine (IOM). In a study sponsored by the Center for Substance Abuse Treatment and the National Institute on Drug Abuse, the IOM Committee on Community-Based Drug Treatment produced a report entitled *Bridging the Gap Between Practice and Research* (1998). Because most drug treatment is community-based, the models identified and developed provide considerable insight into the state of the art of capacity-building in CBOs. The study encompassed 19 states, and a variety of roundtable and workshop discussions with providers, experts, researchers and policymakers, as well as site visits with diverse CBOs. Yet, even this study provides only a nascent level of conceptual identification for service delivery by CBOs.

The IOM Committee identified two basic types of models of organizational growth and change:

1. *Technology Transfer Models.* These models are based on distinctions between "hard" (e.g., equipment) and "soft" (practices) technologies; "high" and "low" capital or resource-based technologies; embodied (e.g., a drug) and "disembodied" technologies (e.g., a new procedure); and basic "information dissemination" versus "knowledge utilization" efforts to turn the knowledge into practice.

2. *Organizational Change Models.* These models are impacted by organizational characteristics, culture (e.g., relying on experience and "faith" versus using science

and established practice), and stages of development (ranging from rudimentary, to stable, to highly differentiated).

Beyond identifying these basic elements of the two models, the IOM Committee did not go on to identify basic parameters of these models.

Data on Community-Based Collaborations. There are a number of ways to evaluate and assess community-based collaborations and partnerships. The Lewin Group (2000) recently completed a *Research Synthesis* for the Assistant Planning and Evaluation for HHS. The *Research Synthesis* was designed to provide guidance for assessing a planned series of demonstration projects on the intersection of domestic violence and child abuse, which involved public and private sector collaboration that spans multiple systems. The Lewin Group identified the following evaluative frameworks:

1. **Stages of Collaboration** (Gray, 1985)—*Ranging from individual organizations being aware of one another's existence (Coexistence) to working informally through a network or a roundtable (Communication), to discovering shared interests and working together through a consortium or coalition (Cooperation), to more formalized interactions based on matching and coordination of needs through a task force or council (Coordination), to development of shared vision and interdependent systems (Collaboration).*

2. **Seven Keys to Successful Collaboration** (National Assembly of National Voluntary Health and Social Welfare Organizations, 1997)—*Shared vision, skilled leadership, process orientation toward including people, diversity and appreciation of differences, membership-driven agenda, engagement of multiple sectors, and accountability.*

3. **Together We Can Checklist** (U.S. Dept. of Education and the U.S. Department of Health and Human Services)—*Five stages of development include: 1) Getting Together, 2) Building Trust and Ownership, 3) Developing a Strategic Plan, 4) Taking Action, and 5) Going to Scale. Each stage includes specific indicators and sequential steps to be taken. For example, some indicators for Going to Scale include: adapting and expanding the prototype model to additional sites, developing a pool of collaboration leaders, managers, and service delivery personnel, devising a long-range financing strategy, and building a formal governance structure*.

4. **Communities Working Collaboratively for a Change** (Himmelman, 1996)—*This framework views collaboration as a developmental continuum of change strategies, ranging from networking to coordinating to cooperating and collaborating. Collaboration is multi sector, and ranges from social service to social justice and includes both collaborative betterment (organized by institutional entities) and collaborative empowerment (organized by a community power base).*

5. **Collaboration as a Means, Not an End** (Golden, 1991)—*Successful collaboration*

for service delivery is based on the following elements: redefined and overlapping missions, ongoing conflict resolution to address turf issues and other conflicts, commitment of managerial time, personal relationships are cultivated, exchange of relationships among agencies, and families and a broad spectrum of the community are involved.

6. **Collaboration: What Makes it Work** (Mattessich and Monsey, 1992).
   This approach is less a framework than it is a compilation of factors influencing the success of collaboration: Environment (e.g., history of prior collaboration; perceptions of collaborative group as a leader; political and social climate); Membership (e.g., trust, cross-section, self-interest, ability to compromise), Process/structure (e.g., stake in outcome; multiple layers of decisionmaking, flexibility, clear roles and policy guidelines, adaptability); Communication (e.g., open and frequent, established formal and informal communication links); Purpose (e.g., concrete, attainable goals and objectives, shared vision, unique purpose); and Resources (e.g., sufficient funds, skilled convener).

The usefulness of any of these frameworks for OMH depends on the way that specific OMH programs are designed and their logic model. As a way to measure partnerships *between* established institutions and community-based groups, this Collaborative Framework proposed by the Lewin Group provides a useful way to measure capacity-building that would not be excessively burdensome to OMH grantee. While the Lewin Group did not specify that progressive improvement was always expected, this framework could be quantified so that different programs could be ranked on their progress in developing regular ongoing partnerships between racial/ethnic minority organizations and existing healthcare providers.

However, to the extent that several OMH programs focus on capacity-building *within* racial/ethnic minority communities, the other frameworks reviewed by the Lewin Group as well as the IOM focus on organizational learning and technology transfer change models may be more relevant.

Conclusions

This is but a brief review of a selection of methodological literature on performance measurement, outcome and evaluation paradigms for assessing health outcomes in racial/ethnic minority communities, as well as measures of access, process and capacity-building. Because Federal performance measurement is focused on accountable entities (i.e., governmental agencies with exclusive responsibility for a specific, concrete geographic and population-defined area), *most Federal data sources lack direct relevance to OMH grantees/SCAs*. Most Federal data collection efforts lack information below the State level. However, these databases will provide assistance in defining data elements and questions for use in surveys of clients and use of administrative records for tracking. *There are also critical issues in that Federal databases in terms of their ability to target*

specific ethnic or racial minority groups beyond the Office of Management Budget classifications.

Measures of access, process and capacity-building have been reviewed as well. As evidenced, for example, in the SCHIP Evaluation Tool, there are models of how access is measured. However, these models focus on accountable entities (the States), the collection of original evaluative data by the States, and depend on the ability to use population-based measures.

Process measures include two types of measures: whether or not patients receive appropriate and needed care related to health outcomes, and how well a program is implemented that seeks to provide an intervention or appropriate prevention activities. These measures are distinct. Because OMH grantees/SCAs do not provide direct patient services, it will be difficult to obtain access to administrative/health records necessary to ascertain whether or not patients receive appropriate and needed care compared to some baseline prior to the OMH grantee program. Process measures of program implementation can be developed; however, lacking funding for local evaluators embedded in OMH grants, this will need to be generic to obtain measures across OMH programs.

There is no general agreement on which capacity-building measures should be used, and many of these, while used in some instances, have not been validated as a successful indicator or instrument for collection across sites. There are a number of capacity-building measures whose relevance to OMH depends on the specific program model being used. For example, while OMH depends on building community partnerships as a strategy, this may not be the program logic model of a specific OMH grantee. It may be that OMH will seek to collect information about partnerships as part of the uniform data set as a way to measure overall effectiveness in partnership and collaboration as an OMH strategy, rather than the effectiveness of specific OMH funding streams and programs.

Federal and Private Efforts Relevant to Development Of the Office of Minority Health's Uniform Data Set

Under the GPRA imperative, or because of historical agency data collection functions (e.g., in the case of CDC), most health-related Federal agencies have developed or are developing some form of UDS or performance measures system. In addition, private foundations and associations have undertaken many such efforts as well. Many of these efforts focus on performance measurement as a management tool; some focus on performance measurement in a very broad sense where larger social goals are addressed (e.g., Robert Wood Johnson Foundation); others derive from efforts to develop uniform data standards for information sharing across systems; and yet others originate in more traditional program evaluation methodologies directed toward assessing impact in the field at the community level. This chapter reviews a selection of these efforts among Federal and private agencies.

As will be seen, there are several UDS/performance measure efforts that have some relevance to the OMH project. Yet in no case did the relevance extend to actual data collection systems that target the same or similar project types with a similar range of measurable outcomes. Thus, from this review it was clear that we would be developing much of our data set as a unique venture.

A. Federal Efforts

GPRA required each government agency to produce annual performance plans, annual performance reports, and to develop a strategic plan covering a period of at least 5 years. These strategic plans comprise the starting point for defining program goals and outlining strategies for achieving these goals. GPRA was phased in over several years, with the first strategic report submitted to the Office of Management and Budget (OMB) and Congress in September 1997. Annual performance plans that include performance measures were submitted first in 1998 for the 1999 fiscal year, and the first performance reports which use the data collected to compare actual performance against the program goals were issued in March 2000. Within each agency, individual programs and offices are assigned individual and joint responsibility for specific performance measures.

THE DEPARTMENT OF HEALTH AND HUMAN SERVICES—GENERAL

The Department of Health and Human Services (HHS) has 16 operating divisions and staff offices within the Office of the Secretary with responsibility for over 300 programs. DHHS has responded to GPRA by 1) developing a comprehensive strategic plan for DHHS as a whole and its centers/agencies based on performance measures; and 2) seeking to implement performance reporting for its grantees through the development of Program Performance Grants (PPG).

HHS Strategic Goals

- ➜ Reduce the major threats to the health and productivity of all Americans
- ➜ Improve the economic and social well-being of communities, families, and individuals in the United States
- ➜ Improve access to health services and assure the integrity of the Nation's health entitlement and safety net programs
- ➜ Improve the quality of health care and human services
- ➜ Improve public health systems
- ➜ Strengthen the Nation's health sciences research enterprise and enhance its productivity

During the period of this project, the HHS Strategic Plan included six departmentwide goals and objectives implemented through governmentwide and departmentwide initiatives, as well as more specific goals supported by individual agencies. These initiatives included Healthy People 2010 and the President's Initiative on Race.

The PPG concept required the application of performance measurement methods to a set of Federal block grant programs that provide funding to the States for public health, substance abuse, and mental health activities. Nonetheless, PPG does comprise the basis of some grant programs, like the Maternal and Child Health Block Grant (discussed below) and others such as the Indian Health Service, and the Preventive Health and Health Services Block Grant. Furthermore, in 1995, HHS contracted with the National Research

Council to convene an expert panel on performance measurement for PPG (discussed below).

Healthy People 2010 and Performance Measurement

Healthy People 2010 builds on initiatives pursued over the past two decades. In 1979, *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention* provided national goals for reducing premature deaths and preserving independence for older adults. In 1980, another report, *Promoting Health/Preventing Disease: Objectives for the Nation*, outlined 226 national targeted health objectives to achieve over the next 10 years. *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*, released in 1990, identified health improvement goals and objectives to be reached by 2000. It included three overarching goals: to increase years of healthy life, to reduce disparities in health among different population groups, and to achieve access to preventive health services organized into 22 priority areas, with 319 supporting objectives. The *Healthy People 2010* initiative continues in this tradition as an instrument to improve health for the first decade of the 21st century.

One use of *Healthy People 2010* is as a strategic management tool—for the Federal Government, States, communities, and many private sector partners. As of the date of this review, 47 States, the District of Columbia, and Guam had developed their own Healthy People plans. Most States have emulated national objectives, but nearly all have tailored them to their specific needs. A 1993 National Association of County and City Health Officials survey showed that 70 percent of local health departments use Healthy People 2000 objectives (as a guide to programs and evaluation). Within the Federal Government, *Healthy People* provides a framework for measuring performance under GPRA. Success is measured by positive changes in health status or reductions in risk factors, and improved provision of services. Progress reviews using Federal data on morbidity and mortality and Federal survey data are conducted periodically on each of the 22 priority areas and for crosscutting objectives for population groups, including women, adolescents, people with disabilities, and racial/ethnic groups.

With respect to the OMH mission, it is worth reiterating that *Healthy People 2010* goals reflected former President Clinton's Initiative on Race and the goal of eliminating disparities in six areas of health status experienced by racial and ethnic minority populations (Infant Mortality; Cancer Screening and Management; Cardiovascular Disease; Diabetes; HIV Infection/AIDS; and Immunizations). The intent of the Initiative was to identify and address the underlying causes of higher levels of disease and disability in racial and ethnic minority communities. These include poverty, lack of access to quality health services, environmental hazards in homes and neighborhoods, and the need for effective prevention programs tailored to specific community needs. The HHS Secretary established a senior-level steering committee in the Department, chaired by the Assistant Secretary for Planning and Evaluation and the Surgeon General to

1. Review the status of the six health disparity reduction goals for 2000 and ensure that the Department's research, health services, and prevention programs give

priority to them

2. Conduct a process of consultation with minority community representatives and with the scientific and health services communities to improve our understanding of how to achieve both the near-term disparity reduction goals and the 2010 disparity elimination goal
3. Examine the Department's research, data, service, and prevention programs
4. Recommend to the Secretary necessary changes in these programs to support the President's goal of eliminating health disparities in the next century

A key challenge is to improve collection and use of standardized data to identify all high-risk populations correctly and monitor the effectiveness of health interventions targeting these groups. As part of the research needed to focus on understanding the relationships between health status and different racial and ethnic minority backgrounds, in FY 1991, the Minority Health Statistics Grants Program was initiated. It was sponsored by the National Center for Health Statistics under the Centers for Disease Control.

Generally, HHS has worked to develop a "robust system for measuring the performance of HHS programs," but acknowledges that it is an "iterative process" complicated by the complexity of the "data issue" generated by the "range, complexity and diversity of (HHS) programs" (HHS Fiscal Year 2000 Performance Plan Summary, 1999, 18–19). These data issues (some of which parallel those we have discussed) include the following:

- A diversity of data sources that reflect different agendas for information collection and analysis
- The complexity of data systems that focus on counting service units, rather than the number of individuals served (thereby resulting in duplicated counts that are inappropriate for performance measurement)
- The need to obtain agreement by partners to data definitions and assuming the burden of data collection and reporting
- Data collection time points that are inconsistent with annual assessments
- A lack of agreement on program elements and activities that reflect different intervention strategies
- Variability in technical sophistication and ability to deal with data systems and needs
- Integration of data needs across the multiple agencies involved in service delivery, which requires sharing data across program streams
- Chronic lack of resources for data collection that is costly and requires a significant investment in staff resources

Work is proceeding on developing national baseline data for the Healthy People Initiative. In the most recent *Healthy People 2000 Review* (1998–99), the sixth in a series of profiles

tracking the year 2000 objectives, 35 objectives (11 percent) have baseline data but have no additional data with which to evaluate progress. Two new baselines were later obtained on health promotions programs for older adults and counties with health promotion programs for racial and ethnic groups. As of this review, baselines had yet to be attained for nine objectives (3 percent). In other areas, some 15 percent of the objectives have reached or surpassed 2000 targets (e.g., child and adolescent death rates), and progress has been made for another 44 percent of the objectives (e.g., prenatal care, child immunizations, and mammography screening). Some 18 percent of the objectives show movement away from the targets (e.g., overweight and diabetes prevalence). Data for 6 percent of the objectives show mixed results and 2 percent show no change from the baseline.

Relevance to the Office of Minority Health's Uniform Data Set: As an actual system, of course, it is clear that *Healthy People* is not applicable to the OMH effort because it is a "grand system" focusing on national population data, and on health outcome data—neither of which are possible for OMH projects. Yet OMH's overall goals, as outlined in the OPHS Performance Objectives, are drawn from *Healthy People*.

THE NRC PANEL ON PERFORMANCE MEASURES AND DATA FOR PUBLIC HEALTH PERFORMANCE PARTNERSHIPS GRANTS ASSESSMENT GUIDELINES

The National Research Council, at the request of the Assistant Secretary for Health of the U.S. Department of Health and Human Services (DHHS), convened an expert panel to consider and make recommendations on the developing program performance measures in ten substantive program areas. The resulting Panel on Performance Measures and Data for Public Health Performance Partnership Grants has produced two reports. The first report, *Assessment of Performance Measures for Public Health, Substance Abuse, and Mental Health* (1997), made specific recommendations on measures that can be used for program partnership grant (PPG) assessments. The second report, *Health Performance Measurement in the Public Sector* (1999), has as its focus developmental improvements in existing local, State, and Federal data systems that would support the collection of data for use with existing and proposed performance measures.

The Panel on Performance Measures and Data found that while performance measurement is not new, it is new as a widespread requirement in publicly funded programs. To support the use of performance measurement, the Panel recommended that Federal and State governments work collaboratively with the private sector to develop a broad national health information network. This network must take into account the following points (52–55):

- *Performance measurement should be linked to program goals,* rather than as an end in itself.
- *Use of a "market basket" approach* including both "core" and "optional" measures that would facilitate flexibility at the program level.

- *Recognition that performance measurement needs will differ* at the program and at the Federal or policy levels is key to developing both process and outcome measures.
- *Development of measures must take account of the feasibility of data collection and analysis,* and less desirable measures may be required if the existing data sources are inadequate.
- *Consequences of performance measurement must be considered* to reduce likelihood of manipulation or inadvertent adverse results.
- *Development of a performance measurement system is an ongoing, developmental activity,* which should be implemented in managed phases.

The panel concluded that developing plans for performance measurement, assessing data needs, and designing (and redesigning) of data systems "must be a top priority" (1999, 138). Only by collaborating, can the Federal and State governments ensure that information needs, at all levels, are met; that duplication of effort and incompatibility across programs are avoided; and that attention to essential functions, not specific to any one program, are ensured. Key goals are to involve a broad range of public agencies, build on existing information systems, work to develop the evidence base for capacity, process and risk status measures and implementation standards.

Relevance to the Office of Minority Health's Uniform Data Set: Clearly, at least three of the NRC recommendations directly support what this project is attempting to construct as a data set: the recommendation for flexibility, including core and optional measures; recognition that measures will differ for the program and Federal levels; and the fact that measures must take into account the feasibility of data collection.

THE INDIAN HEALTH SERVICE

The Indian Health Service (IHS) is responsible for delivering health services to federally recognized American Indians and Alaska Natives (AI/AN) through a system of IHS, tribal, and urban (I/T/U) operated facilities and programs based on treaties, judicial determinations, and Acts of Congress.

IHS has developed a data set that encompasses several types of data—not just health outcomes. The IHS approach has been strongly collaborative, and involves stakeholders. This approach was critical because of the diversity of I/T/Us, and the fact that tribal programs participate in GPRA at their discretion. In 1995, a group of stakeholders was charged by the Indian Health Service Director with reorganizing the IHS. As a result, strategic objectives included improving health status, providing health services, assuring partnerships and consultation with I/T/Us, and performing core functions and advocacy. In August 1997, the IHS Program Statistics Office sponsored a Data Policy Roundtable to explore "the future of Indian Health Information Systems."

The IHS follows a public health approach that includes external factors (such as poverty),

as well as program inputs and activities ("process") in the consideration of reductions in health risk factors. The IHS logic model assumes that outcomes measured in changes in morbidity or mortality are long-term results of programs over years and even decades. As such, *outcomes (that is, end outcomes), while important in setting long-term strategic GPRA goals, are viewed as inappropriate for yearly performance plans, and inadequate for assessing program effectiveness.* The IHS has also chosen to concentrate on "sentinel indicators" specifically focused on 1) "the most significant health problems facing AIs/ANs" and/or 2) the essential services addressing them. These include indicators that refer to primary prevention functions (e.g., immunization) and secondary prevention (e.g., to reduce morbidity/mortality after the disease has occurred, for example, through access to dental care or breast cancer screening).

Kinds of Data Elements: The IHS uses both non-IHS (including Bureau of the Census, and the Centers for Disease Control and Prevention) and IHS data sources. The types of data are based on a logic model that links resources to activities or "process" (including both support and direct health services that reduce risk factors for diseases and conditions). *Process Indicators* assess the quantity or quality of activities that are essential to "running an effective healthcare program, but do not in and of themselves result in improved health outcomes" (IHS 2001 Performance Plan). Examples of process indicators are construction of clinics, identifying the prevalence of a disease, conducting consumer satisfaction surveys, the conduct of needs assessments and the formation of coalitions. A number of these process indicators have considerable relevance for OMH projects. *Impact Indicators* are "interim indicators" that "assess the quantity or quality of activities that have a scientific, evidenced-based link to improved health outcomes." Examples of impact indicators are immunizations, dental sealants, assuring safe drinking water, and cancer screenings. *Outcome Indicators* assess "changes in mortality and morbidity relative to a disease or condition." Examples of outcome indicators include reducing the prevalence of obesity, diabetic complications, or unintentional injury and mortality rates. As is clear, these latter outcome indicators are not the kind of indicators that can be employed usefully with respect to OMH grants; though, as noted, the process and impact indicators may well be.

Another aspect of IHS programs has been the decision to aggregate its 24 budget categories into four functional areas: Treatment; Prevention; Capital Programming and Infrastructure; and Consultation, Partnerships, Core Functions and Advocacy. Different criteria for performance measurement are used for each functional area.

Technologies Used for Collecting Data: The IHS has its own automated data collection software system, known as the Resource and Patient Management System (RPMS). Patient-specific data are collected at each facility through the Patient Care Component (PCC) of the RPMS, and transmitted to the IHS central database. These data make up the bulk of IHS's GPRA measures. For example, information concerning diabetes outcomes are maintained through a diabetes registry. Each year, IHS conducts a systematic random sample from each facility's registry, using a sample size adequate to produce a plus or minus confidence interval at the 90 percent level of confidence. Some of the proposed measures require new software development, including sampling routines from facility-level

databases. Other required data are not included in the PCC and will have to be obtained through standard local survey questionnaires and procedures.

Relevance to the Office of Minority Health's Uniform Data Set: Even though the bulk of data collected are clinical data, the IHS system has some applicability to the OMH data set because it does define and collect process and impact (intermediate) indicators, viewing these as connected in a logic model to eventual changes in health outcome—much as we have outlined the public health continuum in chapter 1. These process and impact indicators are the kinds of data that OMH projects can collect. It also employs customer satisfaction surveys—one of the ways in which qualitative data might be collected for the OMH UDS.

CENTER FOR SUBSTANCE ABUSE PREVENTION

The Center for Substance Abuse Prevention (CSAP) has as its mission to decrease substance use and abuse and related problems among the American public by bridging the gap between research and practice. CSAP has a Minimum Data Set (MDS) which measures the numbers and types of services, as well as the numbers and types of populations served, which has been in place for some time. As part of the MDS, CSAP conducted an initiative called the Core Measures Initiative (CMI) which sought to measure effectiveness of projects and programs.

1. Core Measures Initiative

In October 1998, CSAP initiated a Core Measures Initiative (CSAP–CMI) to respond to GPRA requirements, to promote more consistent use of proven program measures in the field, and to improve accessibility of common data to cross-site evaluations.

The Process of Developing the Data Set: The CSAP–CMI project was developed and implemented through successive phases that included collaboration with grantees, consultation with experts, tailoring of established measures for use in specific populations, and development of grantee support through a CD–ROM and CSAP Program Coordinating Centers (PCCs) and a Data Coordinating Center (DCC).

Initial phase 1 work began in the Spring of 1998 with CSAP staff

Phases for Core Measures Initiative
Center for Substance Abuse Prevention

Phase 1: **(partially completed)**

- Development of Core Measures Catalogues (completed)
- Establishment and Implementation of Task Forces (completed)
- Field Testing in State Incentive Grant States (in progress)

Phase 2: **(projected)**

- Expansion to Additional Variables (including appropriateness for particular populations)

Phase 3: **(projected)**

- Use of CSAP Program Data Collection Center for Analysis and Reporting

conducting an internal review of core programmatic measures cross-site. The goal was to develop a core compendium of evaluation measures within five behavioral and risk factor domains: Alcohol, Tobacco, and Other Drug (ATOD) Use, Individual/Peer Factors, Family Factors, School Factors, and Community Factors. Next, CSAP began compiling the program variables for process, intermediate, and longer term outcome measurement that all projects were using. The initial review included Project officers and staff from the Data Coordinating Center (contracted) who considered current inventories and identified priority constructs based on research literature and their experience in the field. CSAP found in this review that they often had competing instruments that measured the same thing for the same population.

Following this, CSAP held a meeting with external researchers and State representatives and established Task Forces in each of the five domains. The task forces were charged with reviewing basic constructs within key domains of family, community, school, peer and use, the indicators used to define constructs, and then the instruments used to measure indicators. These experts reviewed literature in the field to identify which they thought were the best measures for the particular constructs in those domains. Each task force used the same criteria for selecting their recommended core measures (popularity, prior use, availability, scoring, length, reading level, developmental appropriateness, internal reliability, test–retest stability, face or content validity, sensitivity to change, cultural appropriateness, recognition, generalizability, ease of administration). However, each task force weighted these criteria a little differently. A high level of reliability was sought, with a Cronbach's alpha coefficient of reproducibility of over 70 percent, but less than 90 percent (to ensure that the items were not all measuring the same thing). The experts recommended measures for most, but not all, of the core variables. For some core variables they recommended three or four good measures, from which CSAP then selected one.

Kinds of Data Elements: The CMI instruments are drawn primarily from sample surveys, and include quantitative attitudinal and self-report data. National surveys instruments are drawn from the Monitoring the Future Survey, the National Household Survey of Drug Use, the Student Survey of Risk and Protective Factors, and the National Youth Survey. Other sources include Rosenberg's Self-Esteem Scale, the Family Relations Scale, Sense of Community Index, and the Tanglewood Research Evaluation. The CMI does not seek to address capacity-building.

Development and Implementation: CSAP found that allowing sufficient development time was a key issue. It took CSAP 6 months for initial development, followed by piloting the proposed measures, and another year to refine the measures through the Task Forces. In phase 1, the CSAP–CMI instruments are now being tested through State Incentive Grants (SIGs). SIG States have to give 85 percent of their funds to communities, and must fund a minimum of three science based programs with rigorous evaluations, one in each domain. Local SIG funded programs are not expected to use all of the core measures. Instead, CSAP recommends selected core measures to measure constructs that programs are measuring or addressing already. Once the results of the SIG pilot are in, CSAP will

continue phase 1 by modifying and finalizing the report, and filling gaps for construct measurement, age and gender groups and respondent categories.

CSAP developed a draft Guidance Document for Grantees, and identified a number of crosscutting methodological issues for the implementation stage. These concerns include: selection of appropriate variables at the program level; appropriateness for special populations; developmental issues; mode of administration; sampling; missing information (e.g., reliability and validity data); problems arising from customizing the instruments that may compromise the psychometric properties of the scale; operational definitions that may vary; the fact that grantees may select a longer or a shorter version of the instrument; public versus private domain constructs; and potential copyright and cost issues.

Cross-Cultural Measures Component: Phase 2 of the CSAP–CMI project focused on special populations. CSAP empaneled task forces for each major ethic/racial group, composed of experts on instrumentation with special populations. They reviewed the literature and looking at instruments recommended in the first phase. The task forces then submitted reports containing their recommendations.

Office of Management and Budget Clearance: CSAP is in the process of preparing an OMB clearance package that will be an "umbrella" package for all grantees. CSAP does not intend to ask grantees to collect information on constructs they are not already planning to collect. However, where appropriate, CSAP will ask them to use their measures if they were already going to collect the information Respondent burden for OMB includes the time grantees need to extract the data from whatever system they are using and send them in.

Technologies for Collecting the Data: The CSAP–CMI builds on CSAP program data coordinating centers (PCCs) implemented several years ago, which ensured that there are common data elements across sites, and eases the burden of data collection for CSAP grantees. Projects do have an amount set-aside for evaluation. This amount set aside for evaluation varies by project, with a high average set-aside amount of 10 percent of the overall budget. CSAP does not require the core measures data at the present time. Initially, the CMI included plans for an electronic system (a CD–ROM with software for projects to use in reporting data). This no longer exists because it has grown to include more than the core measures, and has become its own initiative—the Decision Support System (DSS). As now anticipated, program information will be disseminated via CSAP's Decision Support System, an electronic Web-based system that is available to the public.

2. The Minimum Data Set Project

The CSAP Minimum Data Set (MDS) is a software program that enables providers, State, and other entities to collect uniform prevention services data. As clearly stated in MDS training materials, the MDS is not an outcome assessment, but a tracking, planning and reporting tool—though it does have performance outcome functions.

Basically, the MDS is intended to help States better manage their block grant

prevention/treatment programs for substance abuse, establish appropriate services, track programs and populations, and, more specifically, to

- Distinguish between single, one-time services and multiple, recurring services
- Provide an unduplicated count of prevention services delivered
- Collect age, gender, and race/ethnicity data on populations receiving prevention services
- Track the number of sessions provided in recurring prevention programs
- Analyze whether or not program goals/objectives are being met
- Analyze staff activities
- Ensure that CSAP strategies are being followed
- Track and measure performance outcomes
- Analyze who receives which types of prevention services

The MDS is designed to track 52 individual program activities, and 29 service populations. Service populations include, for example, college students, health professionals, parents/families, high school students, elementary school students, people using substances, and the general population. It distinguishes between single, one-time services and recurring, multiple services (including the number of sessions), and collects the age, gender, and race/ethnicity data on the populations that receive the services.

Relevance of CSAP Efforts to the Office of Minority Health's Uniform Data Set: For the most part, the CSAP Core Measures effort cannot be applied directly to the OMH data set, because all measures/indicators relate to identified changes in risk factors and outcomes specifically connected to substance abuse. However, these measures/indicators do apply to activities funded under the OMH Family and Community Violence Prevention program. In addition, the process (expert consensus) that CSAP followed is of interest as well, though for OMH projects the need is not for academic-based measures. In a sense, the OMH Project Advisory Group serves as an expert group on a more applied level. On the other hand, the MDS effort does offer an example for how certain kinds of data can be collected and defined that are more relevant to OMH.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

HRSA's Bureau of Primary Health Care

The Bureau of Primary Health Care (BPHC) effort began in 1992, when the Bureau decided to review all the different ways it was collecting data. BPHC concluded that different grant programs were using different data definitions, even for very basic items, and that standardization was necessary. Generally, goals for the data set were to provide a reliable and scientific basis for documenting BPHC program effectiveness and improved health outcomes, and to move from qualitative case studies to quantifiable results. The current iteration of that process is described in the BPHC *Uniform Data System Manual,*

1999 Revision. The grantees collecting data are funded at a range between $200,000 and $4 million, with an average size of $500,000 to $1 million—significantly larger than most OMH grantees, other than some cooperative agreements.

Process of Developing the Data Set: BPHC has had a reporting system in place since the 1970s. However, this reporting system was not structured to be common across projects. Consequently, the Bureau called all senior staff together for a retreat to discuss and decide what the most important questions should be in terms of developing a UDS, and what data would be responsive to those questions. These discussions resulted in three different types of information: user characteristics, center characteristics, and outcomes/intermediate outcomes (Are users receiving appropriate services, etc.?).

Generally, BPHC collects different levels of data from three source types:

1. ***Routinely reported data***, reported annually—these are the data that correspond to a uniform data system.
2. ***Sample surveys*** focused specifically on the users of the service; BPHC took the national surveys and adapted them for use in our populations. These can say a lot about individual center users.
3. ***Special studies*** that look in depth at special topics and answer specific questions about access and outcomes.

Routinely reported data (UDS) are used to provide a national overview and overall program management. UDS data are developed from annual grantee reports. The data are aggregate, not patient-specific information, and are collected via existing administrative systems at funded primary care centers. The Bureau assumes costs for tabulations. The UDS combines five different reporting systems using the same definitions and age categories, and provides unduplicated counts, demographics, and added information on diagnosis, language barriers, types of sites and specific enabling services.

The first year was most difficult in terms of implementing the new system. Obtaining unduplicated counts, for example, was problematic. Or, there were problems with the amount of effort required: for example, one table on the data collection form calls for data from the billing system, which proved difficult to collect because of the amount of computer time required. At the same time, grantees had contracts with vendors who were required to make changes free of charge if they were required by the Federal government, so there was no additional cost burden. There was also a concerted attempt to include as many "reality checks" along the way as possible, and BPHC conducted extensive regional, and in some cases, State-based trainings (from 1 to 1½ days per training). This was considered very important to implementation.

Technologies Used for Collecting Data: Data under the new reporting system were first collected in 1996. After questions were developed, BPHC worked closely with groups of

grantees to understand if the data being requested were within their capabilities to collect—particularly since the level of sophistication among grantees varied drastically. The goal was to find a "technological middle ground" among grantees, and not to design the system for those who had the highest capabilities. Currently, the information is submitted on paper. However, BPHC is planning to go to a stand-alone data entry package, to see if it is possible to move toward electronic reporting.

Types of Data Collected: All grantees report on a calendar year. Because the system covers five programs, there is a core of information slated for a universal report, combined with other reports depending on the individual grant module.[%] In the universal (UDS) report, data are collected under the following domains: center/grantee profile; user (client) profile; staffing and utilization; and financial information. Clear definitions are provided in the manual with respect to patient–provider encounters, who providers are, users, sites of delivery, kinds of services, and many other terms. However, because the data are collected from primary care facilities, the focus is on diagnoses and health services provided. Demographics and socioeconomic information is collected on patients. There are some tables for which data are collected on *enabling services* (e.g., outreach, case management, education), but the information concerns either staff utilization for those services, or cost.

Office of Management and Budget Clearance: To collect the data, BPHC was required to obtain OMB clearance. For any change in the data items, it will be necessary to gain OMB approval as well.

Relevance to the Office of Minority Health's Uniform Data Set: As a model for presenting instructions, definitions, and data tables, the BPHC manual/data set is very clear and well laid-out, though perhaps on the complicated side with respect to CBO use. There are definitions of enabling services which can be used or adapted for the OMH effort. However, none of the data actually collected, except for client demographics, are the kind of data that will likely be the focus of the OMH UDS.

HRSA's HIV/AIDS Bureau

The HIV/AIDS Bureau (HAB) was formed in August 1997 to consolidate within HRSA all the programs of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. HAB and the CARE Act programs benefit low-income, uninsured and underinsured individuals and families affected by HIV/AIDS. Some of these funds are given out on a formula basis: through the HIV emergency relief grant program for eligible metropolitan areas (EMAs) (Title I), or HIV care grants to States and eligible U.S. territories (Title II). The remaining funds are given out on a discretionary basis: for HIV early intervention services and planning grants (Title III), and coordinated HIV services and access to research for children, youth, women, and families (Title IV).

Data collection in the past has been affected by type of funding. Administratively, HAB now

*This follows the "core and module" type of approach that is being proposed in this document for OMH.

oversees all the Titles that were once separately administered and funded. Each Title has historically had its own data collection tool, increasing grantee burden particularly for grantees who have multiple streams of funding with multiple data collection requirements, including three or four related just to Ryan White funding (frequently, data questions are similar but are worded differently and may result in slightly different numbers). The 1996 Care Act includes some specific evaluation requirements for Title I and Title II. Title I planning councils, and Title II consortia are required to evaluate the cost and outcome effectiveness of interventions and mechanisms to deliver primary care. State grantees may spend up to 10 percent of their funds on planning and evaluation. To assist grantees, HAB has developed several guidance manuals, and is in the process of developing a cross-project and cross-title instrument. This instrument is in draft form. It will be placed on the HAB Web site in May for grantee comment, and is not expected to be piloted until 2002.

Goals of the Data Set: HAB uses six evaluation questions to guide all the research and data collection activities. These are "big picture" questions critical to the successful delivery of HIV care:

- Are CARE Act programs enrolling underserved and vulnerable populations in primary care?
- Are the programs providing CARE Act clients with care of the same quality as received by other persons living with HIV, including continuity of primary care?
- Are the programs providing services that remove barriers to primary care access, so as to ensure equitable access for historically underserved minority populations?
- Are the programs reducing morbidity, as indicated by reductions in opportunistic infections, increases or slowed rates of decline in CD4 counts that show compromised immune system functioning, and declines in perinatal transmission of HIV disease?
- Are the programs reducing HIV-related mortality?
- How are the programs adapting to changes in the care and service environment?

Process of Developing the Data Set: There are several manuals available to assist grantees. In 1998, HAB published *Using Data to Assess HIV/AIDS Service Needs: A Guide for Ryan White CARE Act Planning Groups*. This guide provides basic definitions of terms, discusses what Federal data are available for comparison purposes, describes how to conduct a needs and epidemiological assessment, and how to collect, analyze, and present outcome data. In 1999, HAB published *Primary Medical Care Outcomes, an Outcomes Evaluation Technical Assistance Guide*. This guide reviews techniques and approaches for collecting and analyzing outcome data based on a logic model developed by the United Way and popular among many HAB grantees. Previously, according to HAB staff, the Bureaus were giving out conflicting guidance for evaluation. HAB completed a

draft document that was distributed to grantees and advocacy organizations as well as Federal colleagues. HAB's goal is to have the primary care instrument in place by 2001. As part of the process, HAB held its first cross-title meeting, including a session on the tool as well as with respect to preliminary feedback.

Kinds of Data Elements: HAB collects several kinds of data. There is a set of assessment tools designed for primary care facilities (The *Primary Care Assessment Tool*), with modules on Administration, Clinical, Fiscal, and Support Services. Most of these modules contain questions on staff, policies, services provided and other areas, but in a YES/NO format: For example "Does the grantee have a linkage with the State ADAP program?" is followed by a space to check YES or NO, and a small space for comments. Occasionally questions will ask for a specific number or percentage. The form is set up to be filled out by a reviewer.

The biggest challenge in collecting these data is duplication, which is more difficult in some areas than others. Each provider has its own statistics. And since individual clients may visit a number of providers, this can result in considerable duplication—more so than for other Ryan White programs. It is hoped that the cross-title effort will help eliminate some of the duplication. Ultimately, HAB is seeking client-level data.

The cross-title data—most relevant to the OMH UDS effort—are, as mentioned, in draft form. They are collected via two forms: "Client Level Cross-Title Data Elements" and the "Cross-Title Aggregate Report Form" (both are forms revised as of April 4, 2000). For each client, the data form records: demographics, services or screenings received (including HIV testing/counseling), and diagnoses. The aggregate form records data on grantee/provider type, target populations, staff and cost information, services provided, clients served and client demographics, HIV rates (aggregate), and some basic information on education/outreach provided. Again, however, only some of these data are analogous to the data to be collected by OMH.

Implementation: HAB recognizes that there are many challenges in developing good outcome measures because they are "dependent on appropriate systems and procedures for the consistent collection, aggregation, and reporting of the required data" (HAB, 1999, 7). These include the following problems:

- Primary care services which are not provided by CARE Act funds; thus medical records necessary for client-level outcomes are not maintained by CARE Act–funded providers.
- Client-level data systems may lack unique client identifiers.
- Lack of a computerized system to report aggregate clinical data.
- Some grantees work with a large number of primary care providers with different record-keeping systems and types of medical records.
- Primary care providers may serve a small number of CARE Act clients and receive

limited CARE Act funds.

Technologies Used for Collecting Data: HAB is able to collect clinical data using online reporting, from patient data systems. Some HAB Title II grantees have been able to submit data online through the Web site, and this feature seems to be well-received. (*This is one of the recommended modalities for the proposed OMH UDS.)*

Relevance to the Office of Minority Health's Uniform Data Set: As noted, the HIV/AIDS Bureau data system is relevant to the OMH effort only in a limited sense. The data, for the most part, are not comparable. The development process—and extended involvement of grantees—is instructive. On the aggregate data form, there is a question concerning outreach and education which may be adaptable for use by OMH, because it specifies number of sessions *by type of outreach setting*.

HRSA's Bureau of Maternal and Child Health

The Maternal and Child Health Services Title V Block Grant to States Program, originally authorized in 1935 by Title V of the Social Security Act, supports four broad categories of services:

1. Direct healthcare services (e.g., prenatal care)
2. Enabling services (e.g., case management, transportation, outreach, respite care, health education, family support services, purchase of health insurance, coordination with Medicaid; Women, Infants, and Children; and education)
3. Population-based services (e.g., newborn screening, immunizations, lead screening, sudden infant death syndrome, counseling, oral health, injury prevention, nutrition and outreach/public education)
4. Infrastructure building services that promote comprehensive systems of services (e.g., needs assessments, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, systems of care, information systems)

Beginning in 1989, State accountability for Title V funds has been linked to reporting on key child and maternal health indicators, as well as budget and expenditure data. Spurred by GPRA, the Bureau of Maternal and Child Health (MCHB) added a performance measurement component for FY 1998 reporting. Each State is required to report on 6 health outcome measures (perinatal mortality, infant mortality, neonatal and postneonatal mortality, child death rates, and a measure of the disparity between black and white infant mortality rates), 18 "national" performance measures used by all the States, and an additional 7–10 performance measures developed by the State and negotiated with MCHB. The "negotiated" performance measures are expected to include at least one for each level of the pyramid, and at least one for each of the three population groups (i.e., women, infants and children). Each of these are further divided into three types: capacity, process, or risk factor. Finally, States may have differing strategies and roles in implementing these

performance measures: to monitor, advocate, provide, supplement, or assure their delivery. In reporting, States are asked to identify program activities for each level of the pyramid.

Maternal Child Health Bureau Block Grant National Performance Measures

Direct Health Care—*Capacity*

1. The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State Children with Special Health Care Needs (CSHCN) Program.
2. The degree to which the State Children with Special Health Care Needs (CSHCN) Program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable to its clients.

Enabling Services—*Capacity*

3. The percent of Children with Special Health Care Needs (CSHCN) in the State who have a "medical/health home."

Population Based Services—*Risk Factor*

4. Percent of newborns in the State with at least one screening for each of PKU, hypothyroidism, galactosemia, hemoglobinopathies (e.g., the sickle cell diseases).
5. Percent of children through age 2 who have completed immunizations for Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, Hepatitis B.
6. The birth rate (per 1,000) for teenagers aged 15 through 17 years.
7. Percent of third grade children who have received protective sealants on at least one permanent molar tooth.
8. The rate of deaths to children aged 1–14 caused by motor vehicle crashes per 100,000 children.
9. Percentage of mothers who breast-feed their infants at hospital discharge.
10. Percentage of newborns who have been screened for hearing impairment before hospital discharge.

Infrastructure Building—*Capacity*

11. Percent of Children with Special Health Care Needs (CSHCN) in the State CSHCN program with a source of insurance for primary and specialty care.
12. Percent of children without health insurance.

Infrastructure Building—*Process*

13. Percent of potentially Medicaid eligible children who have received a service paid by the Medicaid program
14. The degree to which the State ensures family participation in program and policy activities in the State CSHCN program.

Infrastructure Building—*Risk Factor*

15. The rate (per 100,000) of suicide deaths among youths 15–19.
16. Percent of very low birth weight live births
17. Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates
18. Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester

Relevance to the Office of Minority Health's Uniform Data Set: Once again, while the MCHD data set conceptually acknowledges the role of enabling and access services, the actual data are State level, not project-level data. OMH projects will not be working with statewide geographic entities.

THE CENTERS FOR DISEASE CONTROL AND PREVENTION

The Centers for Disease Control and Prevention (CDC) is organized into ten major program components and nine staff offices. Initially focused on the traditional public health approach of infectious disease control, CDC now encompasses a broader role in addressing the complex social and behavioral risk factors for disease, injury and disability.

CDC's Office of Program Planning and Evaluation

The CDC Office of Program Planning and Evaluation (OPPE) has responsibility for developing performance measures. CDC has approached this through a developmental process involving close collaboration with partners at the program level and with grantees to identify meaningful expectations about program intent, outcomes, and management challenges. In addition, program-level representatives worked with grantees. CDC then developed a refinement of its performance plans with a standardized format for all of HHS, including a goal-by-goal presentation of the program which includes performance measure, goal and results.

Goals of the Data Set: Generally, the goal is accountability but also improved program description.

Process of Developing the Data Set: CDC sought to have outcome measures whenever possible and used a variety of measurement tools. CDC has traditionally relied on major surveillance systems as part of disease reduction efforts, but also employs grant program reporting requirements, and quarterly reports or other standardized reporting. This is based on a decentralized approach that flows upward through the organization, and also involves coordination with other agencies. CDC has developed a "crosswalk" that compared CDC goals and measures with those of other HHS agencies.

In developing the data set, CDC considered the following factors:

- Program maturity and the relative need for capacity-building in certain areas
- Availability of annual data to measure performance
- Latency period associated with particular disease-specific programs
- Input from CDC partners

The HIV Prevention Program, however, has struggled with data collection. In 1995 they started considering indicators, beginning with management indicators. They brought together grantees and individuals from all levels of the organization, in a collaborative effort that identified measures for the management of these programs. These measures were appended to future

RFPs so that grantees would know what they were to report on. This activity was extended to the development of community indicators as well. Starting in 1996 the program launched a project to develop community-level indicators for HIV/AIDS, and struggled with definitions. A multistep process was used in the development. An expert group was asked to generate a list of potential indicators (over 2,400 indicators were identified), after which a subgroup of 10 individuals met to narrow the list down to 200. These were arrayed under the categories men/men; intravenous (IV) drug users; and women. The final step was bringing in end-users, CBO staff, academic researchers, and government scientists. While the intent was to develop a concrete set of indicators, it proved more difficult than developing a set of management indicators.

Kinds of Data Elements: While grantees collect the data, most CDC data are reported at only the State level. Moreover, it is not actually a uniform data system. Data collection methods vary widely by program funding, the maturity of the program, and other factors. Data tables in the CDC performance plan cite data sources, describe how data are verified, and list collaborators with CDC in collecting the data. Because CDC is "data rich," there are many sources from which to draw, though these are, again, not at the project level.

The CDC Preventive Health and Health Services Block Grant*

Process of Developing the Data Set: Language in the 1994 Preventive Health and Health Services (PHHS) Block Grant, required the Centers for Disease Control (CDC) to develop standard uniform data sets to track progress on health problems and outcomes associated with *Healthy People 2000*. While many performance measures are centered around GPRA, this block grant is intended to further the *Healthy People* objectives. The data sets developed in 1994 were revised in 1998, and the CDC PHHS program is now in the process of developing comprehensive indicators associated with *Healthy People 2010*. The new *Healthy People* includes eight additional chapters and more areas of concern, such as infrastructure and capacity building, expanding beyond the public health focus of the previous one. The process included State health departments, Federal staff and experts to develop a consensus around activities that the States are engaging in, and measures that capture these activities and the expected outcomes. This process is used to develop and define the measures, which are then sent out for review and comment to the State health departments, and local PHHS block recipients. This comment period allows for another level of review before the final measures are developed.

One set of measures are outcomes, and the others track risk factors. The latter measures were developed by looking for outcomes, and then analyzing the process from a backward direction: for example, asking why women get breast cancer, and then seeking appropriate interventions that would reduce morbidity and mortality. In this case, one answer was a lack of appropriate use of mammograms as a screening tool. When the reasons for this intermediate step were sought, explanations were found in education and income accessibility. Thus, risk factor

*This information came from a telephone interview with Robin Forbes, the Public Health Adviser for the PHHS block grant on March 28, 2000. Ms. Forbes shepherded the process through the third cycle, and worked in the first two cycles of development. Gary Hogelin, CDC Division Director of Adult Chronic Disease and Community Health, headed the process during the first two cycles.

measures assess interventions designed to affect how women become knowledgeable and seek mammograms by measuring the proportion who are screened. *This is one way to look at a rationale or logic for the kinds of intermediate services/capacity building that OMH provides.*

Kinds of Data Elements: Because the States have choices in the ways that they spend the PHHS block grant, the goal was to develop multiple uniform data sets to cover all possible program measures. There are three types of measures: outcomes, activity measures, and risk factor measures. The uniform data sets include data in five broad categories, some of which are relevant to the UDS:

1. **Clinical services** (screenings, physical testing, test readings, examinations, referrals, follow-ups, medications, patient monitoring, health risk appraisals [including those provided at health fairs]);
2. **Other client services** (e.g., number of participants in classes, cessations programs, group counseling, individual patient counseling, health fairs [except clinical services/health risk appraisals], health assessments, number of people affected by new environmental/policy initiatives implements, curricula adopted, school-based initiatives, worksite wellness programs);
3. **Technical Assistance to Individuals** (e.g., training, telephone calls for technical consultation, requests for information from policymakers, health professionals and the public, requests for assistance in the interpretation and use of data, requests for information from scientific-based literature, providing guidelines, grants information, participants in sponsored conferences, requests of clearinghouses, and telephone calls to program hotlines);
4. **Technical Assistance to Organizations** (includes similar activities provided to individuals as well as the design of programs, collection of data for setting priorities, surveys, professional presentations, sponsored conferences, program initiatives, development of guidelines, community planning/community service partnerships, developing coalitions, programming planning, and evaluation); and
5. **Comprehensive School Health Education** programs (e.g., health services, education curriculum, health environment, integrated school and community health promotion efforts, physical education, food service, counseling, and schoolsite health promotion program for faculty and staff).

The Federal data elements are drawn primarily from regularly collected data sets by the CDC, (e.g., the YRBS and the BRFSS), as well data collected from the Department of Transportation (DOT) (e.g., blood–alcohol levels in accidents), Vital Statistics, and other sources. *These sources are generally reporting types of data not collected by OMH projects.*

One data item for each chapter of *Healthy People 2000* is mandated. CDC has made this a Federal data item, and collects the mandated data for all the States. When the Federal data are collected, the reporting forms are sent to the States with the Federal data already printed in the form. The States have only to complete their State level data.

The measures are essentially State level case rates per 100,000 population, divided by age. No breakdowns by population group other than age strata are currently provided. The States

still present a problem in the collection of unduplicated data. Moreover, at the local level, county health departments still use a hands-on paper system focused on activities, rather than individuals. While the Federal government works with a computerized database, at the county level, the programs and services are not focused on head counts. Only for some diseases—such as cancer—with a well-developed and a well-funded health system, have registries been developed.

Another issue is the difficulty in coming up with meaningful data that address accountability. Many States contract out funds, and the PHHS funds go through several "pass throughs." When funds are divided into as many as 20–30 local health departments, the amounts may be so small that it is difficult to turn, for example, a proportion of an FTE into an activity function. In addition, the medical data are sometimes cumbersome and do not specifically address what the PHHS block grant is accomplishing. For example, if the PHHS is funding only 10 percent of a diabetes program, what does that 10 percent accomplish in itself? In many cases, the result is a "guesstimate" of the impact because there is no clean way to capture activities.*

Development of new measures will be necessary for *Healthy People 2010* because of the chapter on infrastructure and capacity-building. The PHHS data sets currently include no capacity-building measures. These will be developed during this third cycle.

Collecting the Data: The data set includes different measures, about 60 percent of which are Federal data that are collected by the CDC, and calculated for the State level, and 40 percent of which are State measures that are collected and calculated by the States.

Office of Management and Budget Clearance: OMB Clearance must be obtained every 4 years. This is a cumbersome process, which requires a 60-day notice in the Federal Register, and allows up to 6 months for the OMB to review the proposed clearance package. The current clearance will expire in November 2000. CDC has asked for a 1 year continuation of the current clearance package prior to developing the new measures with the State PHHS stakeholders for *Healthy People 2010*. The Federal Register notice was placed in January, and CDC expects to submit the continuation clearance request to OMB in April.

CDC's Office of Minority Health

The CDC–OMH found that the UDS elements were very narrowly focused on one issue. However, they are looking for applications: In Project REACH, grantees have to consider six specific areas. Applicants can address only one of these areas. There were 35 community coalition grants in fiscal year 1999. Grantees spend the first year planning and looking at disparities, then will reapply in the second year. This will be evaluated. Working groups were formed around each of the six areas to define best practices that could help underpin each of these efforts and to provide advice to grantees. A blue ribbon panel is being developed. Experts from culturally diverse backgrounds are guiding this evaluation effort.

*We note that OMH, of course, faces this same dilemma in a number of its programs.

Other relevant activities at CDC include a task force developing a guide to community prevention services. One document is based on risk factor areas—these are best practices based on current literature and research. With respect to the public health integration surveillance system: CDC is now responding to grantee concerns regarding the need to integrate required reporting. CDC–OMH is creating standards for a uniform data collection process across surveillance systems and will require any new surveillance to comport with these standards. With respect to behavioral risk factors surveillance systems: This is a core data set provided to States, developed through a random digit dialing (RDD) sample throughout the State. States participate because they can use the data to measure health status.

THE OFFICE OF POPULATION AFFAIRS

OPA administers two programs: a teen pregnancy program and a larger Title X family planning program that has existed for 40 years. Services delivery programs (contraception) have a UDS that is similar to the system developed by the HRSA Bureau of Primary Care. The data collected on service grantees were collected through Bureau of Common Data Reporting. In 1992 OPA created its own data system collecting information on such things as number of clients served, services provided, clinic characteristics. With respect to the other three areas—training, general training for personnel within service grants; information and education activities—OPA does not have common data collection activities. There is a very small research program focusing on service delivery improvement research. OPA has traditionally focused most data collection around service delivery. But it is undertaking new types of programs and is seeing a need to collect information in these new areas. In addition, OPA would like to have more than just input information on regular grantees.

Process of Developing the Data Set: OPA held workshops for regional program consultants and grantee representatives from each of the 10 public health regions, plus academics. OPA tried to make discussions diverse in breakout groups, and made sure grantees were dispersed throughout the groups. A second workshop on indicators for international programming was to be held in February 2000. OPA hopes to create a set of five subgroups of indicator sets, and is looking at validity, reliability, and other issues. There will be a third meeting in the spring inviting other Federal agencies. In the second year OPA hopes to institutionalize this process and set up a working group of 25 to 30 experts to come up with a workable set of 25–30 indicators. The OPA report would be modified to include these new indicators. Pilot testing and training will also be undertaken.

Technologies Used for Collecting Data: At the time of this review, the primary method was still pen and paper. Some grantees use an electronic system. OPA tabulates the data and will produce an annual report including definitions.

Office of Management and Budget Clearance: OPA will have to go back to OMB with this new effort; their current package comes up again in 2001.

B. Private Efforts

Apart from the Federal efforts discussed above, there are several relevant data

set/performance measure efforts occurring in the private sector. The leading healthcare accrediting organizations—the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), National Committee for Quality Assurance (NCQA), and the American Medical Accreditation Program (AMAP), for example—have established a joint effort (Skolnick, 1998). Each organization defines performance measurements at different levels of the healthcare system—ranging from acute care, ambulatory care, behavioral health care, home care, clinical laboratory services, long-term care, and managed care (JCAHO) to managed health care (NCQA) to physicians (AMA). There is also a range of data collection, measurement, and evaluation activities undertaken by private foundations—all of which cannot be detailed here. A selection of these efforts is summarized below:

THE NATIONAL COMMITTEE FOR QUALITY ASSURANCE

The National Committee for Quality Assurance (NCQA) is responsible for a key performance measurement tool in health care: the Health Plan Employer Data and Information Set (HEDIS). HEDIS is a set of standardized measures for comparing the quality of care provided by participating health maintenance organizations. While originally developed to assist employers in selecting health services plans for their employees, HEDIS now includes consumer information as well and covers Medicare and Medicaid populations in addition to commercially insured populations. The performance measures in HEDIS address many significant public health issues such as cancer, heart disease, smoking, asthma and diabetes. Outcome and process measures focus on quality of care, utilization, finance, health plan management, and activities. HEDIS also includes a standardized survey of consumers' experiences that evaluates plan performance in areas such as customer service, access to care, assessments of the quality of care and claims processing. The value of HEDIS is the availability of precisely defined and well validated model instruments. *Moreover, it may be useful to draw from the customer experience survey for OMH data purposes.*

THE FOUNDATION FOR ACCOUNTABILITY

The Foundation for Accountability (FACCT) was created in 1995 to address concerns by consumer groups and purchasers of healthcare services to develop assessments of healthcare quality following the failure of national health reform in 1994. Sponsored by the Jackson Hole Group* which initially proposed the core of what became the Clinton healthcare proposal, meetings of large healthcare purchasers culminated in FACCT after meeting participants agreed to form an organization to focus on preserving and improving high-quality care as the

*The Jackson Hole Group takes it name from Jackson Hole, Wyo., the home of Paul Ellwood, a former Minnesota physician who was instrumental in persuading President Nixon to support the Health Maintenance Organization Act. In the late 1980's, Ellwood began to host meetings of a small group of well connected men at his new home in Jackson Hole to formulate a healthcare reform proposal relying on HMOs' rather than government price controls. Ellwood's guests, who took to calling themselves the Jackson Hole Group, included representatives of the insurance industry (the Health Insurance Association of America, Aetna Life & Casualty, Kaiser Foundation Health Plan, Blue Cross and Blue Shield–Colorado, Prudential, Metropolitan Life Insurance, Cigna Corporation, Main Line Health, Harvard Community Health Plan, New York Life Insurance, U.S. Healthcare, Blue Cross and Blue Shield Association, and Travelers), corporations (PepsiCo, General Electric, Washington Business Group on Health, Syntex Corporation, Carlson Holdings, Mobile Technology, Pharmaceutical Manufacturers Association, and Medtronic, Inc.), provider associations (American Hospital Association, American Medical .Association, American Group Practice Association, American Academy of Pediatrics), foundation executives (Pew, Hartford, Mayo) and a number of academic and other participants (e.g., Alain Enthoven of Stanford, Paul Elwood of InterStudy, and Lynn Etheredge). In 1991 the Jackson Hole Group announced its support for managed competition, which was instrumental in then-candidate Bill Clinton announcing his support for the concept in October 1992.

health system underwent a massive, market-based restructuring. The purpose was to develop appropriate ways to communicate their shared vision to the health industry: providers, plans, and suppliers. FACCT produced *The Prototype Guidebook for Performance Measurement* in 1995 that discussed the need for a more accountable healthcare system and a new way of assessing quality focused on the experiences of patients. FACCT published its first five quality measurement sets in June 1996. It began publishing the Accountability Resource Series in October 1996. FACCT's work in measures development and consumer information is ongoing. In June 1996, FACCT published breast cancer, diabetes, major depressive disorder, health risks-smoking and consumer satisfaction measurement sets. Health system competencies are drawn from research with consumers to identify what is important to people living with chronic disease. These competency areas are the following:

- Patient education and knowledge (have patients been educated about their condition and treatments?)
- Getting essential treatments
- Access to good care
- Involvement in care decisions
- Communication with providers
- Patient self-management behaviors
- Coping
- Symptom control
- Maintaining regular activities
- Functional status (patient's)

As for NCQA, OMH may be able to draw on the FACCT consumer satisfaction instrument for purposes of the UDS.

THE JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) evaluates and accredits nearly 20,000 healthcare organizations and programs in the United States. An independent, not-for-profit organization, JCAHO has developed professionally based standards and evaluated the compliance of hospitals, healthcare networks and plans, home care organizations and services, nursing homes and other long term care facilities, behavioral healthcare organizations, ambulatory and outpatient care providers, and clinical laboratories against these benchmarks. Organizations are accredited every 3 years, and laboratories every 2 years.

draft

In February 1997, the Joint Commission launched *ORYX: The Next Evolution In Accreditation,* to integrate the use of outcomes and other performance measures into the accreditation process. Performance measurement requirements have already been established for hospitals, long term care organizations, healthcare networks, managed behavioral healthcare organizations, home care organizations, behavioral healthcare providers and laboratories. Requirements for ambulatory care organizations and long term care pharmacies under ORYX have not yet been established.

THE ANNIE E. CASEY FOUNDATION

Before continuing with brief descriptions of data collection efforts as conducted by several of the major foundations that fund community projects, we caution that these efforts, by and large have *not* moved toward development of uniform data sets. Private foundations are, of course, not subject to GPRA requirements. The fact that, without such requirements, many foundations have expressly chosen not to develop uniform data sets may, if nothing else, reinforce the message that community-based programs pose unique challenges to data collection as envisioned under GPRA or performance measure systems in general. Therefore, we will describe the data collection activities of several foundations, with a view toward outlining what they do and do not collect and the rationales for these choices.

The Annie E. Casey Foundation limits its grant-making to initiatives that have significant potential to demonstrate innovative policy, service delivery, and community supports for children and families. Since the early 1990s, the Casey Foundation has altered its approach from emphasizing comprehensive and radical reform of traditional service systems to focusing on comprehensive community-based reform involving multiple systems simultaneously. In its evolution from understanding traditional systems as "fragmented, categorical, and inaccessible" to one viewing children and families as affected by multiple systems, the Casey Foundation has also developed a broader understanding of evaluation/data collection.

In 1997, the Casey Foundation sponsored a conference on evaluating comprehensive community change that brought together researchers and Evaluators in an effort to develop better strategies for evaluation. Cross-cutting themes of the conference included the following:

1. Evaluation is an evolving process, not a static, one-time action with a clear beginning and end.
2. Useful evaluations of comprehensive community initiatives use a variety of approaches.
3. Effective evaluations do more than collect and analyze data.
4. Opportunities for learning about comprehensive community initiatives can be improved by strengthening collaboration and building relationships between researchers and community stakeholders.
5. Critical design issues must be addressed and resolved.
6. Evaluators must reconcile the competing expectations of various Comprehensive Community Initiative (CCI) stakeholders without letting them dilute or excessively complicate evaluations.
7. Evaluations must balance the compelling stories of unique, local experiences with a broader discussion of universal principles. (Casey, 1997, iii)

Draft

Overall, the Casey Foundation views evaluation as a process in which the research goals and methods change in response to refinements of the CCI, and one which is sensitive to the views and needs of the community stakeholders, as well as incorporating knowledge from a variety of research fields. Included in recommended research approaches is ethnography—the combination of unstructured/structured interviews and observation over a period of months, aimed at providing contextual information. By moving toward CCI, the Casey Foundation is stressing the importance of determining expected outcomes during the planning stage. As Sharon Kagan put it, individually oriented interventions where one examines differences in outcomes, "community-based interventions—given the breadth of their purview and the diversity of the interventions—must specify outcomes at the outset" (1995, 5). Yet, design issues (controlling for complex variables, developing reliable and appropriate indicators of change in policies and practices of public systems, assessing and measuring change, embedding evaluation within reform efforts and comprehensive strategies, and building the capacity of community stakeholders to participate in evaluation) remain unresolved. Thus the Casey Foundation has not developed a set of uniform data for assessing community changes.

THE W.K. KELLOGG FOUNDATION

Like the Casey Foundation, the W.K. Kellogg Foundation has moved toward a model of evaluation data that is "supportive and responsive to projects, rather than becoming an end in itself" (1998, 1). In this sense, it has also taken a position against the development of a uniform database. The Kellogg Foundation, in fact, does not provide uniform data definitions or recommendations. Kellogg Foundation has three levels of evaluation: project, cluster, and programming and policymaking evaluation. For *project level evaluation,* the goal is to strengthen and improve Kellogg-funded projects, and focuses on outcomes related to the project stakeholders. The Foundation has published an *Evaluation Handbook* (1998) for Project Directors to assist project evaluation, which is structured around questions that should be addressed in developing an evaluation of use to the project and the community it serves. *Cluster evaluation,* conducted by the Foundation to "enhance the effectiveness of grant-making, clarify the strategies of major programming initiatives, and inform public policy debates" (chapter 3, 3), is designed to evaluate entire programs, not individual projects. *Program and policymaking evaluation,* also conducted by the Foundation, operates at a macro level, and addresses crosscutting programming and policy questions.

At the project level, Kellogg encourages an evaluation framework includes the following elements:

1. Evaluation should *strengthen projects* by providing ongoing, systematic information.
2. *Evaluation should be community-based,* and *contextual*—that is, "based on local circumstances and issues."
3. Evaluation should include *multiple perspectives* and be *participatory.*
4. Evaluation should be *flexible* because funded projects are not discrete programs, but are instead, "complex, comprehensive efforts" designed to produced "systemic

community change."

5. Evaluation should build *capacity* by "looking beyond specific outcomes to expanding the skills, knowledge, and perspectives acquired by the individuals who are involved in the project."

Thus, the emphasis on evaluation is not just the traditional *ex post facto* approach where Evaluators assess projects with objectivity and distance to prove that the project intervention works, but rather, to improve the way the project works in process. Projects are encouraged to evaluate throughout the project—at early (formative) stages, as well as at the of the project (summative) stage. There are three types of evaluations that Project Directors can conduct: context, implementation, or outcome. The Kellogg Foundation encourages grantees to chart progress toward interim and long-term outcomes through the development of a program logic model. There are three different types of program logic models offered: the outcomes model, the activities model, and the theory model. The Outcomes Model is designed to focus on the interrelationships between goals and objectives. The Activities Model identifies various activities so that the process of program implementation is mapped. The Theory Model links theoretical constructs to explain the causal dynamics.

KELLOGG FOUNDATION
TYPES OF EVALUATIONS

Context Evaluation assesses the unique aspects of the community and project that help and hinder the achievement of project goals. It includes community and organizational needs assessments, as well as contextual factors (e.g., environmental, organizational, human, etc.) which are often critical to replicating the program

Implementation Evaluation stresses the improvement of current activities by monitoring strengths and barriers, perceptions of the project, assessing the quality of services, documenting systemic change, etc. to provide documentation about how the project developed.

Outcome Evaluation measures the impact, and includes individual, client-focused outcomes as well as program, and system-level outcomes, and broader family and community outcomes

The Kellogg Foundation strongly encourages the use of both qualitative and quantitative data collection methods—using a multiple method approach. These include observation, interviews, written questionnaires, tests and assessments, and document review. Project managers are asked to determine their data collection approach based on resources (with no more than a maximum of 15 percent of the project budget devoted to evaluation); sensitivity to the respondents/participants in the project; credibility, and the importance of the information. *As this brief overview suggestions, the Kellogg Foundation does not recommend a uniform or specific set of data indicators to their grantees.*

THE ROBERT WOOD JOHNSON FOUNDATION

The Robert Wood Johnson (RWJ) Foundation assesses the performance of foundation programs as if they were business operations, in terms of how they help/do not help achieve

long term strategic goals. RWJ also has a large research and evaluation unit that is involved in the performance assessment. At this point, RWJ is developing a performance assessment system, but primarily focusing on factors identified as associated with the larger social goals of the RWJ Foundation.

In addition to its work on evaluating RWJ grantees and projects, in 1994–97, RWJ jointly funded a project with DHHS to examine performance monitoring at the community level. This project included an 18-member Committee convened by the Institute of Medicine, and a report, *Improving Health in the Community: A Role for Performance Monitoring* (National Academy Press). This report outlines a performance monitoring process and provides sample indicator sets for nine specific public health concerns at the community level based on an evolving, collaborative community health improvement process known as CHIP (not referring to the Federal health insurance effort by the same acronym).

Goals of the System: The goals of the model are to increase accountability for the social changes resulting from RWJ programs; to improve the performance of grant making process; and to help achieve RWJ's potential as an information producing organization.

Development Process: This approach is a part of a larger set of changes at RWJ. The foundation was reorganized into the healthcare group and the health group to better emphasize commitment to general health. There are eleven program management teams, each responsible for a particular health goal. The eleven teams are working to develop more specific objectives for their activities.

RWJ has been through a labor intensive process to identify specific goals and strategic objectives and to look at logic models for achieving the kind of social change they are trying to attain. RWJ, according to consultants working with this effort, has given up the notion of dealing with ultimate causality in terms of measures and logic-linkages, and are seeking to establish the linkage between the objectives of the projects and the outcomes by focusing on critical success factors that must be in place for the outcome to be produced. For this, RWJ employs Kurt Lewin's Change Theory, in which change is seen as a balance of *driving* and *restraining* forces that act on the situation. Thus teams are identifying lists of forces that are either helping or hindering achievement of the goal.

The key is to identify the critical success factors. What kind of leverage could RWJ have over these sets of forces? The field is narrowed to those factors that RWJ can affect. For example, concerning end of life care critical factors: consumer dissatisfaction, unsupportive public policies, shortage of knowledgeable providers.

Data Collection: RWJ does not collect this information from grantees. The primary strategy is to use the tracking data normally obtained from funded sources. Most of this is

collected/analyzed by academics, but as a result RWJ feels that they cannot produce information as quickly as needed to provide feed back to teams. While for academics, the first interest is in publication and pure data; RWJ is interested in usable data that can be used as indicators at a national level.

Technology Used for Collecting Data: RWJ uses the Internet fairly extensively, especially in the area of chronic disease. RWJ in fact has access to people on the Internet who have chronic disease, and contracts to "mine" that database to track trends and look for program progress in these areas.

Principles Guiding Current Indicator Development Activities (at RWJ):

- The primary focus is assessing progress toward changing critical success factors; not so much in counting people/activities.
- The data need to be useful to program management teams for making midcourse correction decisions. Intermediate outcomes must be identified that indicate the need to change course. RWJ is establishing national baselines to measure progress against them.
- No more than three or four indicators are reported on a regular basis. Even so, RWJ staff acknowledge that there is a significant amount of uncharted area here, particularly in identifying indicators.

Again, RWJ is looking at whether the overall strategy is working, not whether or not any one grant is achieving their particular objectives. It may also be necessary to look at "wholesaler" grantees who give other grants. They need to be involved in a similar program for assessing their success.

Most RWJ milestones are called "activity packages." There is an effort to increase the "maxout" strategy, and increase enrollment in programs. For example, the number of people reaching an 800 number and then enrolling in a program—that is a milestone.

Local grantees may be doing evaluations of their own activities. RWJ doesn't have a well developed grant monitoring process.

Commonalities in Public–Private UDS Efforts

Perhaps the clearest message, amplifying what has been stated in the previous chapter, is that there is not a surfeit of practical examples for evaluating CBO-level programs from which the OMH effort can draw. To briefly summarize what has been reviewed, we can say the following about Federal and private efforts as they apply to the OMH UDS:

- The bulk of data types collected for existing performance measures/data sets are not of the same category as that which needs to be collected for OMH projects: they are health outcome data, broader social indicator data, risk factor data, and other kinds of data not available for specific community projects that focus on health promotion and capacity building. Where relevant data are collected, they are generally process data.

- The bulk of data collected for existing performance measure efforts are not collected at the project or even local level, but at larger units, such as the State. Data that are collected at the project level, or even at the individual level, are often inappropriate for the outcomes to be expected from OMH. There are some exceptions here: some of the CSAP risk measures may be appropriate for the Family Violence program; some data definitions for outreach and education from HRSA can be used for OMH.

- Most of the data collection efforts retain paper-and-pencil forms as at least the basic option, even if they are experimenting with/using other technologies such as the provision of software on disk or the Internet.

- Most UDS/performance measurement efforts among Federal agencies have involved a long development process, with substantial involvement from grantees. The CSAP effort is an exception, because the primary input came from academics.

- Because the Indian Health Service data set is directed to a specific minority population, it may have more relevance for OMH than other data sets overall—even though it is geared toward evaluating clinical services. This is because it specifically includes indicators for access issues such as number of health screenings and case management, as well as consumer satisfaction with respect to access. The other efforts most relevant are those undertaken by HRSA's Bureau of Primary Care and HIV/AIDS Bureaus, again because access factors are included as data items.

- Many organizations—especially the private foundations—recommend qualitative data collection as well as quantitative data. However, there are few models for conducting this research included with such recommendations. We note here that DSG has experimented, on its VDET project, with simple and focused models of community qualitative data collection, which may be adaptable to the OMH UDS. However, to implement such methods requires training so that the qualitative data can be collected with at least a minimal degree of standardization.

A Proposed Initial Uniform Data Set

In the Introduction (chapter 1), we discussed general goals and requirements for an OMH Uniform Data Set and presented a brief description of where OMH programs fit on a "public

health continuum" leading from mobilization around a health issue to actual changes in health outcome, for defined racial/ethnic minority populations. In this chapter, numerous data set/performance measure efforts have been discussed, along with current literature on performance measure efforts in general. From this discussion, it is clear that a significant gap exists in terms of data elements and measures implemented to address the kinds of outcomes—*intermediate* outcomes—most likely resulting from community projects of the type commonly funded by OMH. Gaps also exists in attempts to develop performance measures and data sets for programs which operate in a "messy" data environment in which the lines between OMH-funded and other-funded activities are not always clear, and where there are many potentially confounding factors in the fluid and complex social environment of a given community. Moreover, OMH projects, as noted, typically include multiple activities, not necessarily organized by theoretical construct or logic model. Yet there are some commonalities in these activities across programs, which argues for a data set that includes standardized methods for collecting cross-program data *by activity type*. Therefore, the initial proposed model of a UDS described in this section will be structured as a *modular* system to include both *core data* and *data by activity type*, along with other elements to be described, as well as indicators appropriate for measuring performance for each element. The model will also include implementation guidance (e.g., data collection intervals, system to be used). This type of core-and-module approach draws from that used by HRSA's Bureau of Primary Health Care in their UDS system, as noted earlier, as well as from the initial data forms piloted by OMH's Division of Program Operations. It also draws from the Indian Health Service's data set that is organized into general activity categories.

Generally, a uniform data set for OMH should be able to

- Report *basic information on numbers and characteristics of people served* (to determine program reach), in a way that makes sense for the different categories of projects, and enables assessments of program reach by type of project or type of project activity.

- Report on *intensity and availability of project modalities*—how many times outreach was conducted, or case management was available, or education sessions conducted, and how long/how comprehensive each session or unit of these modalities was, *by type of activity*. This is necessary for a consideration of *dosage—how much of the program intervention was received by participants, and what is the relationship between impact and dosage?* Developing data indicators to capture this information can be a sensitive and difficult task. For example, some programs (e.g., Ryan White) have attempted to use "service units" to measure how much of a particular modality was delivered. But in the case of support group coordination, or volunteer coordination—to name but a few—service units are not adequate, because the real impact from those activities often comes from the extended involvement of the coordinator in "shepherding" people through their personal circumstances, an effort that is often continuous and that extends

beyond specific coordinator duties. Or consider the example of outreach: How is dosage to be measured? By number of outreach contacts? By time spent per contact? Again, innovative methods must be found, because outreach, as an activity, is complex, interpersonal, and tied in to the fabric of the community (especially since outreach workers are typically from the community, and their work involves bridging between the community and the healthcare system). In addition, this task of course necessitates the development of standard definitions of service types/modalities.

Where applicable, report on *type and number of products produced and distributed*, such as manuals, directories, guides, translated pamphlets, public service announcements.

Report on *changes in factors related to health outcomes.* We say "factors related to health outcomes" because actual change in health outcome is not a realistic measure for small, often short-term community projects. Target population health outcomes may change, but most likely not during the course of a project—unless the health outcome is being measured specifically for project participants only. Factors related to health outcomes include individual knowledge/attitudes/practices (by practices, we refer to behaviors such as using a condom, changing diet), access to health services, utilization of health services, and referrals to other medical/health services (the latter being data that would not be collected from just the project itself, but from other health services)—to name a few.

In *limited situations*, report on *health outcomes*, but with project participants only. An example would be projects that enlist participants in wellness or exercise classes to reduce blood pressure. Pre–post tests of the actual health indicator (blood pressure) would be possible.

Report on *qualitative impacts* to a limited degree. These are actually very important, but difficult to pick up via standardized data collection. Such data include, for example, increased trust and/or willingness to use the medical system, better rapport between doctors and non-English speaking minorities, and other such factors. In a UDS, these impacts will have to be assessed in a limited fashion, perhaps with customer satisfaction instruments, a limited question set, or special studies.

Report *system changes*, including the formation of committees, institution of cultural competency standards at health providers, development of coalitions and linkages, or the institution of new services to meet the needs of racial/ethnic minority patients.

Report on *innovative program approaches*, modalities and impacts that may not be reported via other more standard data indicators, and may not have been described in

original grant proposals. *In the Implementation Study, numerous innovative approaches and impacts were discovered that were not adequately described or even noted in the project data that were collected.* For example:

- ✓ One California grantee developed an innovative "marketing approach" to increase health provider interest in, and attendance at, training workshops concerning the use of interpreters for limited English-speaking minorities. This approach included newsletters and bulletins sent out to an extensive mailing list of providers, in which health practice (and even legal) issues concerning language/interpretation issues were featured, and in which past training participants were prominently featured. This marketing effort was developed in response to barriers encountered, and was not in the project's initial description, goals, objectives, or performance measures.
- ✓ A Spanish language training was developed by one grantee in part through "mock visits" by training developers to clinics so that the roleplays and situations included in the training would be highly applicable to real-world experiences, and thus more likely to be incorporated by trainees. One impact reported by training participants was an increased willingness and capability to use Spanish with clients, leading in many situations to better client rapport and ability to handle emergencies—again, an impact not reported in the project data.
- ✓ Health educators and interpreters at several projects became, in effect, health advocates for their clients—one impact of which was to increase confidence among clients in their ability to negotiate the health system, an important precursor to increased utilization. This impact was rarely measured in the project data collected, but was significant.

Provide *data that can be tied to specific program components* so they can be used as evidence in support of best practices (and ineffective practices).

Report on all the above factors *by category of project, type of project activity (e.g., training, education, health screening), target population, and type of organization.* It is very important that the data set be structured to do this—otherwise, comparisons will be invalid. Like programs and modalities need to be assessed based on their particular characteristics, and, as noted, different target populations have different needs, backgrounds, understandings, and issues with respect to health.

Finally, *satisfy GPRA requirements for performance measures and accountability*. And, where possible, be structured so that data from different agency systems can be aggregated, compared, and analyzed with reasonable validity and reliability.

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Most of these data must be generated from the project itself. However, in our experience, there may be some data from outside sources that could be fruitful; for example, data on community impacts may come from local health providers or organizations. Or, data on healthcare utilization (or referrals) by the targeted racial/ethnic minority community may be useful and would also come from local health providers.

The data set must also be culturally appropriate across a number of populations. As noted elsewhere, grantees encompass a wide range of racial/ethnic minority (including immigrant) populations, with differing cultural issues concerning health. This means that the data set must combine uniformity with flexibility to accommodate these differences. As an example, for some older Asian American immigrants (particularly women), an issue to be addressed might be *how patients perceive their role vis a vis the doctor—in other words, if doctors have a traditional authority status that precludes patient questions, the achievement may simply be to help patients understand that questions are acceptable, and that learning about their own condition and possible treatments is acceptable.* Given that issues of this sort are not uncommon among a range of racial/ethnic minority populations, we may find that this is a culturally relevant *data category* requiring indicators or measures. Thus, based on the review, we concluded that the proposed UDS should include development of *culturally competent data indicators*, in support of overall OMH efforts related to cultural competence.

An initial list of proposed UDS "core and module" data elements, based on the literature/agency review and past DSG experience, can be found in **appendix 3A.** This initial list of data elements served as a working draft that was modified through the successive stages of UDS development as described in this report.

Data Issues

DATA COLLECTION—PROCESS AND FORMAT

Again, based on the agency/literature review and past DSG experience, we concluded that there were several ways to format a data set so that the data collection process is flexible and maximally useful for both OMH and grantees/SCA. For example:

- Provide data collection forms on paper with the required data elements, so that projects can just fill them out and send them in regularly to OMH or a data coordinating center, thereby skirting concerns about potential computer/technology barriers or lack of resources. *Most Federal agencies contacted for this review, including those on the Project Advisory Group, used this as the basic method*.

- Provide the forms on disk or CD–ROM, so that they can easily be filled out on computer, after which the project can e-mail the file or transmit it in some other way to OMH or a data coordinating center. This is the planned method for the CSAP Core Measures

Initiative.

- Set up an Internet-based system, with a home page for the data collection center or OMH office, through which the data forms can be filled out on line and thus be transmitted instantly to the data center. The advantage of this approach—should the technology and Internet connections be widely enough available to grantees/SCA—is that it also allows for a considerable amount of interactive capability, where grantees/SCA could report problems with certain data elements, or suggest new ones, or discuss other matters related to the Uniform Data Set. This method is used by the HRSA HIV/AIDS Bureau.

With regard to format, we know that a balance must be struck between a data set/system that is optimal for research and evaluation goals, and one that is practical for users. After all, if the data collection component of an OMH project becomes too burdensome, fewer grantees/SCA may apply, and fewer of those that do will be the CBOs that are such a vital link to the community.

Therefore, we propose (and this will be amended based on focus group results) that **two formats be made available to projects for collection and reporting of their data:**

1. Paper forms, as described.
2. Internet/online reporting to an OMH Web site or Web site operated by a data collection center.

Paper forms can be used at any technological level, and if a project is reasonably equipped in terms of computers, it is a small step from there—at the project level—to use the Internet, and much simpler than using and transporting disks. However, at the *agency* level, this will require a database for storage and processing of the data.

DATA COLLECTION CENTER

We understand that, currently, OMH does not have the facilities or resources to process, store and analyze existing data that are collected. Our review of current agency efforts suggests that, if possible, the collection and maintenance of UDS data for OMH would be best accomplished if a data coordinating center were established either within the agency, in partnership with other DHHS agencies, or by contract to an outside organization. Such a dedicated unit could provide at least four functions which may not be possible within the current system:

- Storing and analyzing the data from all grantees/SCA

- Technical assistance to grantees/SCA in collecting/reporting the data

- Troubleshooting
- Preparing summary reports for use by OMH

Thus both GPRA and internal programmatic functions would be centralized within one unit. Moreover, the unit could work in collaboration with evaluations or special studies conducted by OMH.

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4. Logic Models

To facilitate development of data items in the Uniform Data Set, DSG developed draft logic models for all OMH grant programs as well as for the Family Violence Prevention standard cooperative agreement. These logic models are presented below.

Based on the general description of the proposed UDS, and the activity-type definitions set out in chapter 3, we will use a logic model form adapted from United Way* and posit "logic chains," with associated data types, for each of these programs. The logic chains for each program are based on *activity type*. (Please note that these logic models were developed as preliminary guidelines to help in defining outcomes by activity type. They are not yet complete in closely connecting activities, outcomes, and measures. They are subject to continued modification as activities and measures become more clearly defined.)

Several assumptions were key in formulating the logic models:

Assumption 1: The Office of Minority Health is one of several Federal agencies that have a mandate to improve racial/ethnic minority health status and reduce disparities in health status, health care, and access to health care for minority populations. For OMH, this is the basic agency mandate—for other Federal agencies, it is included as part of their overall respective mandates. Because of this, no logic model for OMH programs can posit longer term outcomes (improvements in health status, or even in most cases increases in healthcare utilization) that are solely the result of the OMH program. Measurable program outcomes will be those more closely tied, at an intermediate level, to program activities (as delineated earlier in the Public Health Continuum).

Assumption 2: OMH pursues its mandate by funding grants and cooperative agreements to racial/ethnic minority health organizations, community organizations, healthcare providers, universities, and other entities. These grants and cooperative agreements undertake activities primarily in the following categories:

- Capacity-building—racial/ethnic minority CBOs and other organizations
- Capacity-building—healthcare providers
- Mediating services (e.g., interpretation, case management, transportation, screening

*This is documented in a United Way publication entitled *Measuring Program Outcomes: A Practical Approach*. This approach to logic models is specifically geared toward community-based programs.

and referral)

- Education/awareness targeting racial/ethnic minority population (e.g., outreach, presentations, health fairs, materials development and dissemination)

- Cultural and linguistic competency training for health providers

- Coalition-building, linkage development, systems change

- Counseling and direct prevention services (Family Violence program only)

Assumption 3: OMH funding is provided to projects (whether grant or standard cooperative agreement) targeting specific racial/ethnic minority populations in a particular geographic area. Health outcome data, however, are not likely to be available for those specific populations, especially on a local level. Therefore, such outcome data are not viable as a means of assessing program impact. Reinforcing Assumption 1, measurable program outcomes will thus need to be at the intermediate level, closely tied to program activities.

Assumption 4: Except for the few services (e.g., counseling) provided via the Family Violence program, OMH programs *do not provide direct medical services*. Therefore, seen as part of a public health continuum (see chapter 1 of this report) where the end-point F represents achievement of the overall goal of eliminating minority health disparities, OMH health interventions/programs contribute to that goal largely via community mobilization, knowledge/awareness change, and systems change. As noted previously, these changes may be necessary antecedents to outcomes at points D (behavior and utilization change) and E (health outcome change).

Assumption 5: For each intervention point on the Public Health continuum (chapter 1), program impact is measurable by different types of data—for example, mobilization is measured with process data, such as knowledge change through pre- and post-tests.

We have noted earlier that a UDS will likely be broken out by program and activity type because of the fact that a given program and its funded projects engage in multiple activities. Generally, each program funds interventions (grants or cooperative agreements) that target mobilization, knowledge/awareness, systems change, and sometimes utilization or behavior change in specific ways, some of which are overlapping. The activities that are typical for OMH-funded grants and standard cooperative agreements include the following:

- *Bilingual/Bicultural Service Demonstration Grant Program (including both managed care and non–managed care years):* This program operates through grants to racial/ethnic minority community organizations or racial/ethnic minority CBOs linked to healthcare

providers. Primary activities include: education and outreach; community and health provider training/capacity building; materials development (e.g., culturally appropriate prevention or health information materials); and mediating services such as interpretation; transportation, case management, and screening.

Minority Community Health Coalition Demonstration Program: This program operates through grants made to minority coalitions that include minority CBOs and at least one healthcare facility. Primary activities include the development/operation of the coalition itself, and activities conducted by the coalition that are similar to those conducted by the Bilingual/Bicultural projects—though these projects tend to have more emphasis on behavioral health assessments, counseling, case management/referral, wellness education, and screenings—because the focus is on risk reduction.

Family and Community Violence Prevention Program (FCVP): The FCVP program operates through a cooperative agreement with Central States University and funds 19 Family Life Centers at Historically Black Colleges and Universities as well as at other schools/institutions. These Centers provide: academic support and career preparation; violence prevention; mentoring; family-based counseling, training and education; substance abuse prevention; support groups; case management; cultural and recreational activities; parental skills development; and other prevention activities.

Cooperative Agreements: There is a wide range of cooperative agreements other than the FCVP program described above. Cooperative agreements have been made primarily with health providers (e.g., Children's Hospital of Philadelphia, Albert Einstein Medical Center) and national racial/ethnic minority organizations (e.g., Association of Asian and Pacific Community Health Organizations, National Medical Association). The funding is generally designed to support: expansion of health education/promotion activities, health-related services, efforts to increase the number of racial/ethnic minority health professionals, efforts to address social/educational needs that impinge on health, and efforts to conduct health-related research.

HIV/AIDS Programs: These new grants operate through three program mechanisms—the HIV/AIDS Coalition Demonstration Program, the Technical Assistance and Capacity Development Demonstration Program for HIV/AIDS-Related Services, and the State and Territorial Minority HIV/AIDS Demonstration Program. The Coalition Demonstration program funds CBO-based projects that conduct education/outreach, develop an integrated community response, and address sociocultural, linguistic and other barriers in accessing HIV/AIDS related services—with the goals of increasing awareness, increasing testing, and improving access to prevention and treatment services. The Technical Assistance and Capacity Development program provides technical assistance to organizations (e.g., CBOs,

healthcare facilities) in high-impact HIV/AIDS sites to help improve services available to racial/ethnic minority populations. The State and Territorial grants are designed to support State and Territorial Offices of Minority Health in coordinating statewide responses to HIV/AIDS in order to maximize impact and make the best use of available resources.

Using the logic model form adapted from the United Way*, "logic chains," with associated data types, for each of these programs have been developed. Note that the logic chains for each program are based on *activity type*. Therefore, the Bilingual/Bicultural program may include activities that are also conducted under the Coalition program—where this occurs, for each activity the activity definition, output and outcome will be the same, as will the types of data used to measure performance.

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*This is documented in a United Way publication titled *Measuring Program Outcomes: A Practical Approach*. This approach to logic models is specifically geared toward community-based programs.

Bilingual/Bicultural Service Demonstration Grant Program

Program Goals

Reduce cultural and linguistic barriers between health providers and minority communities; improve access to good healthcare

Project Activity Types

- Train healthcare providers (includes curriculum development)
- Interpretation
- Target population education and outreach
- Develop education materials for minority population
- Screenings and Referrals
- CBO capacity-building

Outputs

- Trainings and curricula
- Interpretation sessions
- Presentations, public events, outreach encounters
- Brochures, posters, flyers, directories
- Screenings, referrals
- Bilingual staff, hired/ trained; linkages formed

Outcomes

- Increased cultural and linguistic competency of health providers
- Improved patient/client interaction, improved understanding of treatment, reduction of miscommunication, better decisionmaking
- Increased awareness about health condition, prevention, treatment and services
- Increased use of healthcare services by LEP minority populations
- Increased role of CBO's / healthcare facilities as community resource

Minority Community Health Coalition Demonstration Program

Program Goals

Promote development of community coalitions to plan and coordinate health promotion and disease/risk reduction programs that reduce barriers to care; and to strengthen indigenous leadership and organizations

Project Activity Types	Outputs	Outcomes
• Community linkage-building	• Linkage relationships formalized; collaborative roles defined and operationalized; culturally sensitive interventions developed	• Coordinated and expanded services; improved access to care; culturally sensitive interventions
• Screening and referral	• Screenings, referrals	• Increased utilization of healthcare services
• Case Management	• Individualized treatment plans; monitoring of plans	
• Target population, education and outreach (awareness)	• Presentations, public events, outreach encounters	• Increased awareness about health conditions, prevention, treatment and services
• Target population education (treatment)	• Presentations, workshops	• Increased knowledge about treatment protocols; better compliance
• Wellness and exercise activities	• Exercise and nutrition classes	• Lower blood pressure; improved nutrition
• Health provider trainings	• Trainings and curricula	• Increased cultural and linguistic competency of healthcare providers

HIV/AIDS Minority Community Health Coalition Demonstration Program

Program Goals

To demonstrate the effectiveness of community-based coalitions (with nontraditional partners) in
a) addressing barriers related to accessing testing and treatment;
b) developing an integrated community response; and
c) developing and conducting HIV/AIDS education and outreach to hardly-reached groups.

Project Activity Type	Outputs	Outcomes
• Coalition-building	• Coalition relationships formalized; collaborative roles defined and operationalized	• Coordinated and expanded services; improved access; culturally and linguistically appropriate education activities
• Implementing a replicable model of an integrated community-based response to HIV/AIDS crisis	• Program components implemented	• **Increased awareness about HIV/AIDS, prevention, treatment and services**
• Target population education and outreach (awareness)	• Presentations, public events, outreach encounters	• **Increased numbers tested; increased number** of persons served

State and Territorial Minority HIV/AIDS Demonstration Grant Program

Program Goals

To demonstrate that the involvement of State and Territorial Offices of Minority Health in coordinating a statewide response to the HIV/AIDS crisis in minority communities can have a greater impact (on community understanding and services provided) than agencies working independently.

Project Activity Types

- Needs Assessment
- Facilitate linkages with other State/ local recipients of Federal HIV/AIDS funds
- Coordinate Federal resources

Outputs

- Research conducted; data assessed
- HIV/AIDS recipients identified; linkages established
- Programs identified; access facilitated to technical assistance

Outcomes

- Service gaps identified
- Greater resource capacity and interventions in the areas of need
- Increase in programs and assistance to minority high-risk communities

HIV/AIDS Technical Assistance and Capacity Development Grant Program

Program Goal

To stimulate and foster the development of effective and durable service delivery capacity for HIV prevention/treatment among organizations targeting highly-affected minority populations

Project Activity Types

- Needs assessment
- Administrative and organizational capacity-building
- Identifying and linking programmatic technical assistance
- Providing technical assistance
- Developing linkages with other service providers

Outputs

- Research conducted; data assessed
- Technical assistance provided; mentoring relationships established
- Appropriate DHHS technical assistance identified; linkages established
- Expert technical assistance provided
- Linkage relationships formalized

Outcomes

- High-risk minority communities and service gaps identified
- Improved organizational and fiscal systems implemented
- Increased staff skills; better grantsmanship abilities
- Continuum of prevention and treatment services established for target minority population

Family and Community Violence Prevention Program

Program Goals

To reduce the incidence of violence and abusive behavior in low-income, at-risk communities

Project Activity Types	Outputs	Outcomes
• Academic support and career preparation	• Tutoring, classes, workshops, field trips	• Improved academic performance and future expectations; increased bonding to school
• Violence and substance abuse prevention	• Workshops, education, sessions	• Improved resistance skills; conflict resolution skills; reduced involvement in violence, substance use
• Mentoring	• Establishment and maintenance of mentoring relationships	• Increased bonding to adults
• Parent skills training	• Workshops, classes	• Reduction in family conflict; improved family management
• Family counseling and education	• Workshops, classes, counseling sessions	
• Case management	• Individualized treatment plans; plan monitoring	• Increased utilization of healthcare services
• Self-esteem building	• Workshops, activities	• Increased self-esteem
• Cultural activities	• Workshops, field trips	• Increased knowledge of and bonding to cultural identity
• Recreational activities	• Sports, outdoor activities	• Healthier lifestyle; reduced involvement in violence and substance use

Cooperative Agreements

Program Goal

To provide additional support to existing organizations or health providers for expanding capacity and services

Project Activity Types

- Support expansion of health education and promotion activities
- Support expansion of health-related services
- Support expanded efforts to enhance educational status
- Support efforts to increase number of minority health professionals
- Support efforts to conduct health services research

Outputs

- Funding
- Technical and administrative assistance and oversight
- Collaboration in workshops and information exchange activities
- Technical assistance for program assessment

Outcomes

- Continuation or expansion of specified health education/promotion services, research, and target population capacity-building activities

5. Focus Group and Telephone Interviews

As a second and critical developmental step, a focus group and telephone interviews with samples of grantees/SCA were conducted to learn more about the kinds of data collected, grantee capacity, kinds of data needed, and barriers that would have to be overcome in collecting/reporting data in a Uniform Data Set (UDS).

Focus Group

As called for under contract Subtask 2, a focus group representing a diverse sample of eight OMH grantees and one additional standard cooperative agreement representative (nine total; see **appendix 5A,** Participant List) was held at DSG's Bethesda office on May 1, 2000, from 12:00 p.m. to 4:30 p.m. The purpose of the focus group was to obtain feedback on a range of issues related to data collection and reporting for the development of a pilot UDS. The focus group sample was selected, as much as possible, using the following criteria:

- Diversity of grant program type (e.g., coalition, bilingual/bicultural, managed care)
- Diversity of populations served
- Diversity of geographic area—region, rural/urban
- Diversity of grantee size/organizational type
- Budget—cost of transportation/lodging; transportation access (e.g., near airport city?)

Questions for discussion concerned the following general issues (for full protocol, see **appendix 5B**):

- Current data collected/reported, data collection/reporting processes, and staff/resource allocations for data-related purposes
- Technology used, and technological capabilities
- Barriers to collection of evaluation data
- Any innovations or best practices for collecting data

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- Types of data that are possible and desirable to collect, as well as types of data that would be useful to projects

- Other information helpful in development of the UDS

A questionnaire was distributed to focus group participants covering the same issues to capture information not discussed or that participants think about at a later point (see **appendix 5C** for copy of this questionnaire). Seven completed questionnaires were returned, and this information will be included in the summary below.

Mark Edberg, Project Director, served as focus group moderator.

The following is a brief thematic summary of the discussion, organized by content category.

1. Data Currently Collected

Grantee/SCA response on this issue showed considerable diversity—not only because of differences in grant type, but also to unique efforts undertaken by individual grantees/SCAs.

DEMOGRAPHIC DATA

All participants collected demographic data of varying types. This included standard items such as gender, age/birth-date, race/ethnicity, and address/contact, along with more program-specific data. Several projects asked clients whether they had health insurance, and at least one asked for marital status. Projects working with immigrants and non-English speaking populations also collected language spoken, country of birth, and length of time in the U.S. One project serving an A/PI population in California (we will abbreviate it as API–CA)—to which we will refer a number of times in this summary because of the unique database it has developed—collected many of those items plus such information as number of bedrooms. This was collected because it was viewed as indicative of living conditions and socioeconomic status, and therefore related to health. Some of the refugee/immigrant families who are clients of A/PI–CA have large families, packed into one-bedroom apartments.

The Project Director for this API–CA project developed, in Microsoft Access, a set of data tables for recording a host of data, described below in Section (2) of this focus group summary.

Projects focusing on HIV/AIDS used expanded gender definitions in their demographic data collection, including transgendered individuals as a category. However, in such cases, participants noted that it is not always easy to collect those data, and the categories are sometimes inferred by CBO staff if not known directly.

For technical assistance (TA) projects or State/territorial grantees, collecting such data presents

a serious problem: if for example, a TA grantee provides assistance to 15 CBOs and other organizations, how is that grantee to collect such information? The actual clients served are clients of the organizations receiving the TA, and it therefore becomes very difficult for the TA provider to have the "reach" needed to obtain such information.

IMPACT/OUTCOME DATA

Impact/outcome data are not typically collected, except in a few cases. The Family Violence Program requires its 25 Family Life Center grantees to undertake prevention activities in the areas of academic development, personal development, family bonding, cultural/recreational enrichment, and career development, but each Center is free to develop its own programs under these broad categories. So the cooperative agreement partner (Central State University) assesses cumulative impact by measuring intermediate outcomes (proximal) and longer term (distal) impacts, using a battery of instruments: *For proximal outcomes*—Wide Range Achievement Test (Third Edition, WRAT–3);School Bonding Index (Revised, SBI–R);Youth Self-Report Inventory (YSR); Multigroup Ethnic Identity Measure (MEIM); Career Maturity Inventory (CMI). *For distal outcomes*—Violence Risk Assessment Inventory (VRAI), developed specifically by the Evaluators for this study; and Delinquency and Aggressive Behavior subscales of the Youth Self-Report Inventory (YSR).

The technical assistance grantee attempted to determine if the collaborative technical assistance model resulted in improved client outcomes (e.g., increased utilization, more screenings, etc.).

A case management/outreach program determined some client outcomes through case management progress forms.

PROCESS DATA

Many different types of process data are collected. The A/PI helpline project (New York) plans to collect frequently asked questions, and languages used in phone requests. Data collected by projects providing interpretation included language of interpretation, location of interpretation, and length of interpretation. One interpretation project also collected data on how long patients (and their interpreters) had to wait to receive services, and the reason for the waiting time (e.g., crowded waiting room). Another interpretation project collected, for each interpretation, information about both the interpreter and the requestor of interpretation services: language, who provided the interpretation, nature of the medical service, who requested, and the length of the interpretation. For project management purposes, some information was also collected on the status of the interpretation—for example, whether there was a cancellation, no-show, conducted as planned. An American Indian project collected process data from school records concerning who received educational interventions. The same project attempted to collect different kinds of data from recipients of outreach activities, but concluded that target population members "did not like to answer personal questions," and

so the project collected only numbers (of encounters, materials). A Latino HIV/AIDSoutreach program collected data on number of condoms, literature, and bleach kits distributed, as well as number of referrals made, and also recorded referral data on their case management records.

The technical assistance grantee collected process data to help in assessing the model of technical assistance that they are providing: To what extent have general and culturally specific procedures been disseminated (among the CBOs/programs receiving technical assistance)? To what extent does collaboration exist?

The State and territorial grantee developed a data collection "toolkit" for HIV/AIDS programs in its jurisdiction, based on a CDC evaluation manual or booklet. The toolkit suggests a number of types of process data, including services provided versus objectives, numbers of individuals served versus objectives, and services accessed measured against need (unclear where the standard for need is derived).

CLIENT SERVICE DATA

An API project collects these data, and compares them with State data. It is not broken down by race/ethnicity, but by national origin. A project serving American Indians collects clinic data related to diabetes—it is not clear whether these are collected for all project participants.

EVALUATION DATA

Various projects collect a range of small-scale evaluation data. An interpretation project gives healthcare providers a form to fill out evaluating the quality of the interpretation—asks the provider to rate the evaluation and note whether or not they received an explanation about the purpose and techniques of interpretation to be used. Most projects that hold trainings have some post-training evaluation form that participants fill out. At least one project that conducted educational seminars used a pre–post test of knowledge gained. The API–CA project collected client satisfaction data.

As noted above, the "toolkit" developed by the State/territorial grantee is intended to help HIV/AIDS programs (primarily funded through Ryan White) evaluate progress in terms of their objectives. The toolkit includes the collection of service completion data.

2. The API–CA Database

A considerable amount of discussion occurred surrounding the database developed by what we have called the API–CA project. The API–CA Project Director created a database in Microsoft Access that records, among other things, the following:

- Client demographic data, including (as noted) the question of how many bedrooms, and

health background information.

- Unduplicated count of clients served. (Note that it is unclear how this is achieved).

- Interpretations: who conducted/who conducted for, location, and comments related to interpretation sessions.

- Transportation: How many clients are able to access services *without* transportation help from the grantee.

- Counseling: Descriptions of issues/topics discussed.

- Behavioral health codes: related to pre–post behavioral "contracts" made or signed by clients to change health risk behaviors and reach their specified goals. This system collects (by client) goals, barriers, and actions taken.

- For health education: topics discussed, whether session was individual or group, who conducted.

- Knowledge change: as part of health education, based on pre–post tests.

- Screenings: Numbers of screenings conducted at health fairs; numbers of "special screenings."

- Health fairs: collaborating partners (which other agencies?), number in attendance (it is unclear how this is derived), and evaluation results from forms given to the other participating agencies.

- Cultural competency trainings: how many conducted, location, professional background of attendees, and evaluation—from forms completed by participants.

- Pamphlets: number distributed and list of subscribers.

- A list of health providers with contact information.

- A list of volunteers with contact information.

- Survey data: These include data from a baseline survey of unduplicated clients from the first (project) year, which requests information on disease conditions, whether or not they see a specialist, symptoms, and other data. It also includes data from other surveys, on tobacco use, "hope for the future," socioeconomic issues, and health.

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- Refugee intake data: during the intake process, the API–CA project collects information on how many refugee camps an individual was in, for how many years, how many family members were lost, and responses to mental health questions.

3. Staffing/Who Collects Data

For a majority of projects represented in the focus group, data are collected by higher level staff—the Evaluator or Project Coordinator. For three of the nine projects represented, staff collected data. At the API–CA project, these staff were trained by the Project Evaluator. On another project, it was outreach staff who collected required data. Both staff and the Project Director collected data for the American Indian project.

4. Technologies Used for Data Collection/Reporting

All projects used paper forms to record data. Five input the data from the paper forms onto a computer database. Two did some data reporting via the Internet—one of these projects appeared to work with an outside contractor for data reporting. Technology levels differed, however: In the District of Columbia, the government does not yet have e-mail. On the American Indian project, there was only one computer.

5. Handling Data Collection for Multiple Funders

This in general is a difficult and burdensome issue for grantees/SCA.

When the services provided are distinct for different funders, data collection is burdensome but not as confusing; where there is overlap, it is more confusing. Some OMH HIV/AIDS projects, for example, also receive Ryan White funds. One project used the HRSA Uniform Data Form for Ryan White–funded services, and recorded OMH data separately. Another conducted interpretation related to both Ryan White and OMH activities. To handle this, clients coming in under Ryan White services had a Title I identification number, allowing a distinction to be made in the data. One project handled the differentiation by staff assignment—where a staff member was hired under the OMH grant, his/her data was viewed as OMH-related.

Not necessarily related to Ryan White, another project reported data to multiple funders simply by dividing up the total data collected proportionate to the amount of funding received from different sources.

6. Privacy and Confidentiality

Privacy and confidentiality of collected data were handled in the following ways:

- Both the large cooperative agreement and American Indian coalition grantee had Institutional Review Boards (IRBs)—which review and approve human subjects data collection protocols and processes.

- One grantee said they operated on "trust agreements" with their clients.

- Several grantees/SCA used release forms.

- An interpretation project required interpreters to sign a confidentiality form.

- The technical assistance grantee had no "clients"—it collected only aggregate data from the projects to which it provided assistance.

- Several projects used barcodes for client data, where each client was assigned a barcode to enter/retrieve data.

- An A/PI project identified data only by birth date; and all access to data was restricted to case managers.

7. Burdens/Problems in Collecting Data

Several data collection difficulties were discussed; however, out of seven focus group participants responding to the question, two found their current data collection task "very difficult"; four said it was "moderately difficult"; and one said it was "no problem." On the questionnaire (n=7), there was a 1–7 scale concerning the level of burden with respect to current data collection, with 7 being "extremely burdensome." Two projects selected 7 (highest burden); one 5; one 4; two 3, and one selected 2. Thus for most projects, there is at least a moderate burden.

The following categories of data collection burden were most common in the discussion:

COLLECTING DEMOGRAPHIC DATA

Focus group members mentioned a number of problems in collecting demographic data. First, the current data collection form now being included by OMH calls for demographic and other data *by health issue area*. This was viewed as problematic by projects concerned with more than one area, because it is often not possible to separate out clients—and their participation in various activities—by health issue. Second, if a project conducts several types of activities, for example, case management and education sessions, it will be able to collect demographics on the intake form for case management, but will not be able to collect such information on

individuals who are attending an educational session. That, said most grantees/SCA, would be impossible—to do so it would be necessary to distribute a self-report form to every person who attended at every such session. What often happens in this case is that project staff just make a visual "guesstimate" of the demographics.

DATA ENTRY/RECORDING PROBLEMS

Data entry/recording was specifically mentioned as problematic and very time consuming. Data are typically collected on paper, then entered or recorded by staff. These staff may be college interns, or may not be highly trained, and there are often accuracy problems that require the Evaluator or Project Director to review and correct. Cleaning and editing data is time consuming.

RELEVANCE

There was a common sentiment that required data are often not relevant. One relevance issue, as mentioned above, concerned the OMH data collection form and its division into health issue areas. A second and larger issue centered on the view that much of what is accomplished is not collected or captured in numbers. There is, said one participant, "no space for telling the stories of how people are helped" (by the OMH project). Moreover, projects often rephrase what they are doing to fit the particular data reporting needs of a given funder.

UNDERSTAFFING AND LACK OF RESOURCES

Not surprisingly, this was a common problem. Staff are overburdened with multiple data collection activities, taking time away from the services they are supposed to provide. According to one participant, "everyone needs at least a part-time tech support person" to handle computer and equipment problems that get in the way of efficient operation. There is not enough money in project budgets for data and technology support.

OUTCOME DATA

For the technical assistance project, any outcome will take much longer than the project period—because they are providing assistance to other projects who then implement specific activities or approaches. Generally, participants felt that it was unrealistic to expect outcome data from their OMH-funded projects. The question was asked: How can impact be demonstrated? While not required by OMH, it would be very difficult, for example, to find a comparison group from which credible data could be obtained.

8. Recommendations and Comments

The following are comments and recommendations from focus group participants regarding data and a uniform data set:

- On the issue of unduplicated data: When there are multiple project modalities, it is

difficult to track individuals and prevent unduplicated data.

- The OMH form should not ask for data by health issue area.

- Since it is difficult to obtain demographic data across all project modalities, *different modalities should have different (demographic) data requirements.*

- For immigrant populations, certain demographic information is important—nation of birth, and length of time in the U.S.

- The data set should be modular and should allow projects to choose from a number of measures.

- Impact data on access could be collected if, for example, project clients responded to a pre–post question related to their interaction with the project: "Before coming to Project XX, did you have a) An HIV test? b) A regular physician? c) screening for [name of disease]?" Impact data on behavior change are often known by staff members, but may have to be reported as case-history examples, unless a pre–post behavior questionnaire could be administered.

- Generally, it was said that a large amount of operations information is uncollected, but exists as *informal knowledge* possessed by staff members. This could include informal knowledge about impact—for example, how many clients now have health plans or coverage of some kind (after participating in the project).

- A possible method for collecting qualitative data: In the data software for required reports, include a brief set of narrative questions. These could ask for 1) case examples of individual change/individual impact; or 2) case examples of how culturally competent assistance resulted in a service being provided, or provided in a better way.*

Telephone Interviews

As per Subtask 2, telephone interviews were collected during the week of May 7–12, 2000 with the Project Directors/Clinic Directors of four standard cooperative agreement sites, using the same interview protocol as used for the focus groups (see **appendix 5B**). The sample for telephone interviewing was selected based on diversity of 1) health issue, and 2) racial/ethnic minority populations served.

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*If all projects reported such narrative information, common patterns could be extracted through theme/content analysis and be included as part of a report to Congress.

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As will be evident, data issues for standard cooperative agreements were often different than for other grantees—primarily because the cooperative agreements (except for the Family and Community Violence Prevention program, which was represented in the focus group) were typically large hospitals together with other organizations and providers.

Mark Edberg, Project Director, conducted all interviews.

The following is a brief thematic summary of the discussion, organized by content category.

1. Data Currently Collected

DEMOGRAPHIC DATA

Most programs collected the demographic data requested on the OMH form. Most collected additional data, including such items as address, level of education, work, and insurance status. As will be noted below, data collection was facilitated because most cooperative agreements are hospitals, and intake data are a major source for OMH program data—though not necessarily in cases of outreach and education.

IMPACT/OUTCOME DATA

Very little impact or outcome data are collected. One program providing cancer education and screening gives a pre–post test of knowledge change to education session participants. Outcomes of screenings are tracked (e.g., whether or not the screening was normal/abnormal, whether there was a subsequent referral and follow-up), but this is not necessarily impact/outcome of the program itself. The asthma intervention program, however, is conducting a randomized control study of outcomes between patients who receive an environmental (i.e., changing their home environment) intervention versus those who do not, but it is unclear whether or not this is part of OMH-funded activities. Another project collects intermediate outcomes that include, but are not limited to, the success of pregnancies, breastfeeding, and the number of people referred and receiving services.

PROCESS DATA/CLIENT SERVICE DATA

A cancer screening and education program collects process data on outreach, education, and screening. For outreach—an estimate of individuals reached, along with number of encounters, and location of encounters is collected. For education sessions, number in attendance is collected. For screenings, data collection includes the number of screenings, types of screenings, and results. One cooperative agreement ran a hotline, and tabulated number of calls, repeat calls from the same individual, and number of successful referrals. Data were also collected regarding the number completing a mammography and PAP test, as well as the number who completed a follow-up test 1 year later. (It is unclear how the follow-up and repeat data were collected, but note that intake data collected from patients as part of hospital records include address/contact information.) A third cooperative agreement project counted numbers

of people receiving (asthma) education as well as sites receiving the educational intervention. A project serving primarily a Chinese population collected data on numbers of screenings, number of people served overall, number receiving case management, and number of individuals linked (by referral) to primary care. This project also included a telephone "health line," and for this line number of calls and reasons for use were collected. For clients using translation or benefits counseling, number of persons using the service(s) was counted, along with the number who obtained benefits.

Note that tracking this kind of (process) data is easier for cooperative agreements than it is for regular grantees, because grantees are large hospitals or healthcare providers and have more state-of-the-art technological resources. Also many program participants are therefore also hospital patients—for example, if the OMH-funded program involves referrals to screening, the screening is done at the same hospital, allowing for successful referrals and screening outcomes to be tracked because one organization is performing all services. For this reason, it is also easier for these programs to develop a count of unduplicated clients—though one project serving a Chinese population had some difficulties with this because clients changed names, and provided false names when they were undocumented. The asthma project had some problems with unduplicated counts because some, but not all, of their study patients also attended health education sessions (where detailed data are not collected).

EVALUATION DATA

The cancer screening program uses evaluation forms at its health education sessions (for participants to rate the sessions). As mentioned above, the asthma program was conducting a study assessing the impact of the environmental intervention on asthma symptoms, emergency visits, and other factors.

3. Staffing/Who Collects Data

For projects that had an outreach component, the outreach staff collected data. On one project, a parent educator collected data about health education sessions. Just as for grant programs, volunteers, interns, or staff entered the data—which, as will be reiterated below, were viewed as problematic. On the asthma study project, data were collected by home visitors.

4. Technologies Used for Data Collection

All cooperative agreements responding to the telephone interviews used paper forms to collect data, which were then entered into a computer database. As large hospitals, there is usually sufficient computer technology available. The key is finding staff who are knowledgeable. These programs, like the smaller grants, experienced a lack of computer-proficient staff.

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5. Privacy and Confidentiality

The primary method mentioned for handling confidentiality was ID numbers, used in the database.

6. Burdens/Problems in Collecting Data

DATA COLLECTION IN GENERAL

While hospitals have more in the way of technology resources, data collection was still reported as a problem. Several respondents said that not enough funds are budgeted to collect the data that are needed. At one hospital, the project was lucky to have a data manager and training provided free by the hospital's Educational Research and Special Projects Department. Otherwise, there would have been no budget funds for that.

No project mentioned collecting qualitative data.

DEMOGRAPHIC DATA

One project mentioned that "Asian (clients) don't like to identify by nationality even though OMH asks for that." Also, respondents said that demographic data for outreach and education are done by estimate.

DATA ENTRY/RECORDING PROBLEMS

Several cooperative agreement respondents mentioned that they used volunteers or even work-study students to input data. This was a problem, because much time was spent in going back to fix errors. But it was viewed as necessary so regular staff could focus on delivering care.

7. Additional Recommendations/Comments

One respondent noted that access and use are affected by a number of factors, about which data are not collected. Welfare-to-work has resulted in parents being at home less, and parents who "work crazy hours," affecting their ability to follow treatment protocols with their children. Outcomes are also affected by insurance—what is and is not covered.

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6. Site Visits

The third key developmental step (still under contract Subtask 2) entailed eight site visits to a sample of OMH grantees/SCA. These site visits were a key part of the process of identifying issues, barriers, and best practices with respect to collecting performance data across OMH grants and cooperative agreements. The site visits were also intended to provide input from the field to complement the earlier development stages discussed thus far in chapters 3 and 5. The site visit results, combined with the focus group, telephone interviews, and agency/literature review provided the basis for development of a pilot Uniform Data Set form.

Methodology

Site visits were conducted to a total of eight grantees/SCAs. Sites were selected to ensure a diversity of grant types, geographic location, and populations served. The sites were also selected based on cost; thus, sites were set up (as much as possible) in "clusters" so that often more than one site visit was made per trip to minimize travel expenses. Once the initial sample was selected, a letter was sent to each site to determine availability. Based on their responses, a schedule was set up or alternate sites were selected if a site visit was not possible during the scheduled timeframe. The final list of sites, with contact information, is shown in **appendix 6A.** The site visits were conducted in the following order, during summer and fall 2000:

- Community Resource Exchange, New York City (HIV/AIDS Technical Assistance). July 25–26.
- Concilio Latino de Salud, Inc., Phoenix, Ariz. (Bilingual/Bicultural). Aug. 14–15.
- Little Singer Community School, Winslow, Ariz. (Minority Health Coalition). Aug. 17–18.
- The Cambodian Family, Santa Ana, Calif. (Bilingual/Bicultural). Aug. 21–22.
- Vietnamese Community of Orange County, Santa Ana, Calif. (Managed Care). Aug. 23–24.
- Tug River Health Association, Gary, W.Va. (Minority Health Coalition). Aug. 29–30.
- Tennessee Department of Health, Nashville, Tenn. (HIV/AIDS State and Territorial Demonstration). Sept. 6–7.
- Albert Einstein Medical Center, Philadelphia, Pa. (Standard Cooperative Agreement).

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Sept. 20–21.

A ninth site, Congress Heights Training Center in Baltimore, Md., was not visited because of scheduling conflicts.

Most site visits covered 2 days. Primarily, four categories of information were sought in the site visits:

1. *Current data collection*—what kind of data are currently being collected, how it is collected, who collects it, what technologies are used, and what problems or solutions exist/have been developed.

2. *Project activity types*—what are the project activities being conducted, do they fall under the initial typology presented in the Current Practices document, how are data collected (or not collected) for each of these activities, and what kinds of data could or would be useful to collect for each of these activities.

3. *Customer/client data*—(where applicable) how clients/customers define project impacts, and how they could (or would they be willing to) report these impacts so that such information could be collected regularly.

4. *Data and technical assistance needs*—what kinds of technical assistance would be useful for implementing a UDS, and what kinds of data should be collected, using what technologies, and in what format.

Draft site visit instruments were developed and submitted to OMH for review and approval, after which they were finalized. The four instruments developed were the *Project Director Interview, Project Staff Interview, Evaluator Interview, and Client Focus Group Protocol* (see **appendix 6B**). The first three instruments were intended to collect information from project staff about the kinds of data currently collected, technologies/systems used to collect the data, data collected by project activity type (using the initial set of "activity categories" posited in chapter 4 of the *Current Practices* document), barriers and issues concerning data collection, and whether or not the data collected were adequate to "tell the story" of what the project accomplished. The latter question (regarding the reporting of project accomplishments) is important if the UDS seeks to represent an improvement in the way data about (racial/ethnic minority) community health projects affect their respective target populations. The *Client Focus Group Protocol* was primarily intended to collect information on exactly this issue—how clients define the impact of the project based on their experience and degree of participation.

Site visits were conducted by DSG staff and consultants. Project Director Mark Edberg, Ph.D. participated in all site visits except for the Tug River Health Association in West Virginia, which

was conducted by Deputy Project Director Katherine Williams, Ph.D. Participating consultants included Joao Ferreira–Pinto, Ph.D. and Frank Wong, Ph.D. Owing to scheduling conflicts, not all site visits were conducted with consultants.

Site Summaries

The following are brief summaries of the information gathered during the eight site visits. All data collected were gathered using the four site visit instruments, and notes of observations were recorded.

1. Community Resource Exchange/Capacity Project

Community Resource Exchange (CRE), a nonprofit organization in New York City, has been conducting the Capacity Project under an OMH HIV/AIDS technical assistance grant. The Capacity Project is a partnership of several organizations seeking to provide technical assistance to racial/ethnic minority CBOs in New York City that will increase their capacity to develop and sustain HIV/AIDS services to high-impact communities. The Project also seeks to increase the number of CBOs providing these services, to increase linkages between these CBOs and appropriate healthcare services, and to increase their capacity for evaluation. Members of the partnership, in addition to CRE, include: the Asian American Federation of New York (AAFNY); the Federation of Protestant Welfare Agencies (FPWA); and the Hispanic Federation (HF). Because this is a *technical assistance* project, which does not provide direct prevention services to racial/ethnic minority clients, the data collection issues with respect to the OMH Uniform Data Set are somewhat unique. Project participants/clients are organizations, not individuals.

The site visit to CRE spanned 2 days and included: an interview with the Project Director; interviews with Project Evaluators; a group interview with technical assistance providers from the four collaborative partners in the project; and visits and interviews with two of the organizations for which CRE provides technical assistance— the Jacob Riis Neighborhood Settlement (Long Island City) and Roza Productions (Staten Island).

DESCRIPTION OF ACTIVITIES

As outlined by the CRE Project Director, the Capacity Project engages in the following specific activities:

- *Organizational development*—includes assisting with financial management and systems, strategic planning, fund-raising, board development, and program development/targeting.

Development fellows—training in program development and fund-raising for key individuals from minority CBOs.

Program development—train CBOs in "HIV/AIDS 101," conduct workshops and presentations, use community (peer) consultants to provide program development assistance.

Fund-raising—development of a fund-raising database that can be accessed on the Internet.

STAFFING

The CRE project staff includes a Project Director (80 percent), one (80 percent) CRE Evaluator (along with three part-time Evaluators from the partner organizations), and a Program Assistant (80 percent). Staff used from the partner organizations are not counted in this tally. The Evaluators play a significant role in this project, developing the evaluation methodology, designing instruments, training staff, analyzing data, and producing reports. Evaluators also "coach" TA providers when necessary on data collection issues.

DATA COLLECTED

Again, it is important to remember that the project's clients are CBOs and CBO staff, not the "end user" clients of CBOs themselves. Thus, data collected will reflect that distinction. CRE developed (and pilot-tested) an extensive set of data collection forms in an effort to document the process, and at minimum, any short-term outcome of their technical assistance (TA) efforts. The forms track each step of the process. Because the process is so extensive, it will be summarized briefly here before specific data elements are discussed. The forms are used chronologically as part of a routinized TA process, as follows:

A. When a CRE TA provider either receives a TA request (from a CBO) or solicits one, he/she interviews the Executive Director or appropriate contact person at the CBO using a Client CBO Intake Form. This form asks for detailed information on the CBOs structure, budget, service area, target population (demographics), services provided, HIV/AIDS services provided, barriers and challenges, and priority TA needs.

B. The TA provider then uses an *HIV/AIDS Prevention Assessment Instrument* to assess in detail the HIV/AIDS activities provided by the CBO and where gaps or needs may exist. If TA is also needed for organizational or programmatic capacity building (e.g., board development, evaluation), the instrument requests information on these needs as well.

C. The TA provider completes a TA Workplan, which lists goals and objectives and projected TA activities. This Workplan is the basis for process and outcome

assessment.

D. During the administration of TA, activities are recorded on several detailed forms. The TA provider Timesheet records all calls, contacts, activities, and problems and CBO Attendance Logs document attendance at trainings, workshops, etc. All this process information is extensively documented by quarter in a Quarterly TA Activities and Services Summary. Midcourse changes are also documented in the Quarterly Report.

E. Finally, when the TA Workplan has been carried out, an Evaluator conducts an extensive exit interview using the *CBO Survey* instrument, to document outcomes as well as barriers/accomplishments. The exit interview is summarized (with commentary) in a Closeout Letter.

Using these forms and other records, the following data are collected:

Demographic data. Extensive demographic data are collected on the TA providers themselves (using a *Technical Assistance Provider Profile* instrument), on the target population for CBOs served, and on every attendee at a training or workshop. The latter data are collected on a form distributed to attendees (the *Ethnicity/Race/Gender Log*), which asks for race, ethnicity and gender. (On the form, the category "transgender" is included, and Census categories are used for race/ethnicity.)

Numbers served. This is collected via Client Intake Forms, Attendance Logs (for trainings and presentations), and the detailed timesheet form which has spaces to record telephone contacts (with client CBOs), time spent by client, and other contacts/activities by client. Obtaining an overall unduplicated count, however, is difficult. For example, when providing trainings, trainers will ask the following: "If you have filled out an attendance form for this training already, you don't need to fill it out again." Despite the effort, this question may or may not be an adequate check. Yet project staff report that they are happy just to get the forms filled out at all and that, with respect to the funding database, use will be tracked through user ID numbers.

Process data. Number of trainings/presentations and all other client contacts are extensively documented using the attendance logs and timesheet forms, all of which are then summarized in detail on the quarterly report form. Collaborative meetings with partner organizations and CBOs are documented in meeting minutes, which are retained in a file. (Some of the partner organizations do not use the timesheet form but collect process data in personal logs.)

Short-term outcome data. This project developed a unique and extensive system for recording short-term outcomes—defined in terms of organizational change and program

changes (at the client CBO) resulting from the technical assistance. This is clearly documented in a "process chain" beginning with the TA Workplan through the Exit Interview (on the Quarterly Reports, it is documented in the "Noteworthy Accomplishments" section). For the funding database, some short-term outcome information may be gathered through an on-screen form. Materials developed as a result of the TA are also kept in client files.

Long-term outcome data. Not collected.

System change data. Some information is collected on changes in staff composition (adding minority staff) at CBOs that received TA, and on community member involvement in planning bodies. These data are collected through exit interviews.

DATA BY DRAFT UDS CATEGORY

The Capacity Project collects data in the following UDS categories:

Target population health education and outreach (#3). Under this category are the workshops and presentations on HIV/AIDS provided to CBO staff who will then incorporate the information into their own educational activities. Data are collected in attendance logs, workshop evaluations, and exit interviews. Demographics are collected on the form described above (Ethnicity/Race/Gender Log). Outcomes are collected in the exit interview and through satisfaction surveys/evaluation forms to a sample of client CBOs. (Note that this form also asks if the TA received was enough or if they need more to meet their goals.)

Academic support/career preparation (#8). Under this category, Capacity Project staff have included the Development Fellows program, which provides a 9-month training for promising CBO staff in fund-raising and development. In this sense, it could be viewed as career preparation.* Data are collected through surveys of Fellows, supervisor reports, and an exit survey conducted by Evaluators. The most important data collected are outcome data—such as funding the CBO has received attributable to the new skills of the Fellowship recipient (i.e., if they submitted a proposal or raised funds).

Linkage building/community coordination (#15). As part of TA activities, CRE and its partners sometimes help CBOs establish linkages to health providers, relevant organizations, and other CBOs (for peer assistance). Data on these activities would be based on the workplan, and collected via the timesheet forms/quarterly report, and the exit interview (including the closeout letter).

*We may need to define this category a little more clearly so that it does not include activities that are more like organizational/staff capacity building, as opposed to academic support primarily for youth or at-risk youth.

- *Organizational capacity building (#16)*. This is an important TA component which includes strategic planning, financial management, board development, staff training, etc. Data on these activities would be collected in a chain beginning with the workplan, the timesheet forms and quarterly report, and exit interview.

- *Resource coordination (#17)*. This category would include CREs funding database which, at the time of the site visit, was not yet completed. Data on numbers served will be collected by tracking user IDs and log-on information—that is, each user will have an ID, and it will be possible to track the number of "hits." Short-term outcomes will be tracked via an on-screen evaluation form.

- *Identifying and providing technical assistance (#18)*. This category includes the above activities, and data collection occurs as described.

WHO COLLECTS/ANALYZES THE DATA

TA providers collect some process data. Evaluators collect exit interview outcome information. Evaluators input the data into the system, analyze them, and produce reports.

TECHNOLOGY USED

Information is first recorded on paper forms, then entered in the project database, which was created in SPSS. Narrative information is entered/developed using word processing software. Computers are all networked, so staff can share the inputting of forms on the computer.

DATA COLLECTION BARRIERS/ISSUES

With an elaborate system such as this, an initial barrier was to "win over" staff so that it would be used as planned. There was resistance at first—staff did not like the idea of putting the "flow" of work they do into a set framework. They also found the forms time consuming. Moreover, staff reported that client CBO personnel did not like filling out the race/ethnicity log. Partner organizations found using the forms to be "strange" because they already knew many of the organizations for which they provided TA, and formalizing their contact with these organizations "after the fact" was not comfortable.

DEFINING CLIENT IMPACT

According to staff, "our story is the client's story." Success of client CBOs in surviving or growing as organizations that provide HIV/AIDS–related activities to underserved populations is the impact of the TA. For example, a Haitian CBO was on the verge of going out of business until it received TA from the Capacity Project. Now this CBO is functioning and can provide services to its constituents. A small CBO serving refugees from war-torn Sierra Leone had little of the infrastructure or board development necessary to sustain itself, even while the organization's director was dedicated to community youth and experienced at running youth

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programs in Sierra Leone itself. The Capacity Project helped develop these organizational necessities, and also provided assistance in developing an HIV/AIDS educational component for youth.

Other staff said that "we are the Advil of the CBOs," in the sense that TA providers help the CBOs to overcome barriers and alleviate frustrations. A very useful way to understand TA of this type is to think of TA providers as *the resource partner and link between the CBO and the other "worlds" with which they have to interact*. TA can also prevent the need for further TA by identifying underlying problems, not just symptoms.

DESIRED DATA (WHAT WOULD BEST TELL THE STORY?)

The extensive data collection system does tell the story to some degree. It would help to have case examples and less emphasis on breakdowns of the types of TA provided. The focus of data should be on client results. In addition, staff felt that it is *very important* to find some way to describe impact (by client) based on where the client began (baseline). There is no absolute standard for what constitutes successful TA—it must be relative. Project Evaluators expressed willingness to conduct qualitative interviews to obtain these kinds of data. Qualitative data would also help pick up unplanned impacts. Some qualitative data could be collected in an exit interview format with the addition of just one question: "Can you summarize how the TA has helped your organization?"

TECHNICAL ASSISTANCE NEEDS TO IMPLEMENT A UNIFORM DATA SET

This is most likely integration of what they already collect into the eventual UDS format.

2) Concilio Latino de Salud, Inc.

Concilio Latino de Salud, Inc., is a nonprofit CBO focusing on health issues affecting the Hispanic/Latino communities in Maricopa County, Ariz. (Phoenix area). It is located in a small, church-related building in which a number of other activities are housed. The OMH-funded, Bilingual/Bicultural Demonstration grant to Concilio supports a program called *Conocimiento* that 1) provides training to health providers in cultural issues related to disease/disease management, and 2) provides education to the target Hispanic/Latino community concerning chronic diseases such as cardiovascular disease, diabetes and asthma. The 2-day site visit included interviews with the Project Director, Project Coordinator, and one of the training staff, as well as attendance at a cross-cultural training for health providers conducted at Maricopa Medical Center. A brief focus group was conducted with attendees of the training regarding their perceptions of impact of the TA.

Concilio Latino de Salud, Inc. is an example of a small CBO with only a few staff, that is highly oriented to community work and for whom extensive data collection would likely be a burden.

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DESCRIPTION OF ACTIVITIES

According to the Project Director, the Conocimiento project includes:

- *Health provider training*—training in both intercultural communication and in cultural competency with respect to the three health conditions of concern: diabetes, cardiovascular disease, and asthma.

- *Development of materials*—the primary materials developed in this project are *rotofolios,* which are, essentially, desk-size folios in which the pages can be "flipped" and which provide information, in cartoon and pictorial form, about the three health conditions.

- *Rotofolio training*—training of healthcare providers in the use of the rotofolios with Hispanic/Latino audiences.

- *Health education*—on various occasions, Concilio staff themselves use the rotofolios for health education at health fairs and parent meetings.

STAFFING

The Conocimiento project has a part-time Project Director, full-time Project Coordinator, and two other part-time staff members. Different Evaluators have been used to conduct a needs assessment, focus groups, and for process evaluation, but these Evaluators are only retained on an occasional basis.

DATA COLLECTED

The following are the data collected according the represented categories.

- *Demographic data.* Basic demographic data are collected on attendees at trainings, but these are largely a visual determination of race/ethnicity and gender (they are, however, reported using the OMH categories of gender and race/ethnicity). Trainers record the information in their own informal activity logs. On the training evaluation form, information is also collected on participant educational background, profession, and work setting.

- *Numbers served.* This is collected via sign-in sheets at trainings. While there is no method for obtaining an unduplicated count, each training is a single 4-hour event. There are different attendees each time. At health fairs/parent meetings, the count of people served is based on a visual estimate, recorded in personal logs.

- *Process data.* Number of trainings/presentations are determined by counting sign-in sheets. The number of pamphlets distributed is a rough calculation based on the number taken to a health fair less the number brought back.

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- *Short-term outcome data.* The only short-term outcome data collected are on the training evaluation form, which includes both evaluation questions and some questions on projected utility of the training (e.g., how much difference will the training make to you in delivering culturally competent care? Will you be able to use the information learned at the training?).

- *Long-term outcome data*. None collected. This was viewed as a problem, since project staff never have any long-term knowledge of impact. A staff member called this a "disconnect."

DATA BY DRAFT UDS CATEGORY

The Conocimiento project would respond to the following draft UDS categories:

- *Training healthcare providers (#1)*. This includes the cultural competency, intercultural communication, and rotofolio training. Data are collected by sign-in sheets and estimates as noted earlier.

- *Target population health education and outreach (#3)*. This includes participation in health fairs (e.g., setting up a table or booth) and distributing literature. Data for this activity are informal counts/estimates of people that come up to the table or booth and counts of materials distributed. There are no official data collection forms for this category. A completed activity is a contact or conversation.

- *Target population health educational materials development/dissemination (#4)*. This refers to the rotofolios. No data are collected other than recording the health fairs/meetings at which they were used.

WHO COLLECTS/ANALYZES THE DATA

The Technical Assistant to the Project Coordinator usually collects the data. Either the Assistant or the Project Coordinator inputs the data and prepares reports.

TECHNOLOGY USED

The technology used is simple paper forms and personal logs, input into a computer file using word processing software. Computers are used by most staff, and the project is connected to the Internet, which is primarily used for e-mail and other basic tasks.

OPTIMUM TECHNOLOGY

Staff felt that a data collection system via the Internet would be welcome and "great."

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DATA COLLECTION BARRIERS/ISSUES

Because a minimum amount of data are collected, there are no great difficulties in collecting/reporting them. Data are somewhat useful to the project, even as reference points for how well they are doing. However, one staff member noted that "the numbers don't say anything."

Additionally, another staff member did note that having preset categories of data—even as required in the new OMH form—is helpful because it provides a clear guide to what OMH wants to see.

DEFINING CLIENT IMPACT

According to the Project Director, the Conocimiento project has two basic impacts: 1) helping Latino people better understand the three diseases and how cultural issues are related to them; and 2) serving as a "bridge" to the Hispanic/Latino community by helping providers to better understand and communicate with the target population. The Project Coordinator said that "there are so many situations where Latinos can't get services. They feel lost. No one can help. Many of the materials out there are not appropriate." This project makes an impact by providing health providers with cultural knowledge and communication skills. "It's like a light when they understand. . . . A seed is planted—it's not something that happens overnight."

Clients who attended an Intercultural Communication Training during the site visit defined the probable impact of the trainings largely in terms of increased awareness about the ways in which culture influences action, about multicultural issues in general, and about increased awareness about the need for clear communication. (Many of the exercises and content in the training emphasized intercultural communication issues, errors in assumptions about what other people should know, etc.)

DESIRED DATA (WHAT WOULD BEST TELL THE STORY?)

Staff felt that data currently collected *do not* tell the story of what the project accomplishes. "Although we are a bridge," said the Project Director, "the two components (providers and clients) are separate, so we don't see what happens." To gauge impact, they would like at least some data on provider behavior change (possibly using cultural competence scales) and changes in client awareness, or even giving health providers (attending the trainings) questions to think about as they leave the training—questions about how things may be different. Staff also felt that some pre–post evaluation of provider communication skills, cultural competence and "comfort level" across cultures would be useful. Another possible solution might be provider and customer surveys.

Anecdotal data, if their collection were possible, would also help tell the story. Anecdotal data "empower and legitimize" what the CBOs do.

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TECHNICAL ASSISTANCE NEEDS TO IMPLEMENT A UNIFORM DATA SET

Both training and some form of ongoing technical assistance would make it easier to implement a new UDS data form/system.

OTHER COMMENTS

N/A**.**

3. Little Singer Community School

GENERAL DESCRIPTION AND CONTEXT

Little Singer Community School is a Minority Health Coalition located on the Navajo reservation approximately 30 miles north of Winslow, Ariz. Coalition members include the Indian Health Service (Winslow Unit) and the Northern Arizona University Department of Nursing, together with the school. Before describing data that are or are not collected by the Little Singer project, it is important to understand the nature of this type of program and the consequent implications for data collection in general. The Little Singer school is located off a dirt road that begins on Navajo Highway 15, which traverses the southern part of the Navajo reservation. The nearest town is Leupp, a small reservation town some 15–20 miles away. Birdsprings and Tolani Lake are small communities nearby, with the former community closest to and most involved in the Little Singer school. This part of the reservation is expansive, with many miles of wide open, sparse territory. Residences are scattered, often at great distances from each other. Some residences are traditional hogans, with no electrical power or running water; some are trailers; some are standard houses. The poverty and unemployment rate is high. While a number of Navajo work off the reservation in Winslow, there are not, it would seem, many available jobs there and those that exist do not likely pay well. As a result, the primary employers in Winslow are the railroad, a nearby prison, and a few hotels/motels.

The health conditions addressed by the Little Singer project are diabetes (rates are high on this and other American Indian reservations), domestic violence and substance abuse[%]. These are all lifestyle-related conditions where the social and health situations intersect. Adult onset diabetes, for instance, can be brought on by poor diet and alcohol. Domestic violence and substance abuse are also known to be related. All of these are related by poverty, thus creating a nexus of influence such that *any intervention in the lifestyle or socioeconomic situation* is a potential intervention with respect to diabetes, domestic violence and substance abuse. Almost everything is integrated. This presents what might be described (to use the classic Durkheimian term) as a kind of *anomie*. A project such as this must then adapt to and address the general situation as it presents itself, all toward the general goal of alleviating the specific health problems for which it is funded. How then, can the impact of a specific program be tracked via data collection? Or via strict adherence to a specific intervention protocol?

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*These were the top priorities identified in a survey of community health concerns.

Program activities take place at the school, which is a small group of buildings centered around the "dome," a dome-shaped structure inside of which there is a gym/exercise area, offices, classrooms and a learning center. The four entrance doors to the dome correspond to the (Navajo) Four Directions. Out in front of the school is a community hogan, built by community members and used for a number of learning and integrative activities. Taped to the inside wall of the hogan are the terms of the original treaty establishing the reservation.

The 2-day site visit included: interviews with the Project Director, Project Coordinator (and family nurse practitioner), and a health educator; a tour of the site and activities; an offsite meeting with project staff; and a review of data collection systems/practices.

PROJECT ACTIVITIES

The Little Singer project was slated to engage in a number of activities, all centered at the school (which, again, acts as both a community center and a school). These activities include:

- *Clinical preventive and referral services*—for all three health conditions. This could include screenings, counseling, and referral to other health services.

- *Education and information dissemination*—This includes a wide variety of activities in which these health conditions, and lifestyles associated with them, are discussed. One focus is on educating children, which is done through the school (in the classroom) as well as through other kinds of traditional activities, including participation in the growing of healthy and native foods, sweat lodges, and games or cultural activities in the hogan. Classroom curricula use Navajo themes, such as the Medicine Wheel. There is also outreach education for adults, because one significant problem (especially for older adults) is isolation, owing to great distances and lack of transportation. In addition, educational activities include workshops, "family fun nights," and the use of traditional healers and counselors.

- *Healthy physical activities*—As part of the general health and wellness focus, the program conducts activities such as morning runs and exercises, aerobics, and tai chi.

Like many community projects, there are many disparate activities which are supported by multiple funding (in the case of Little Singer, this includes State tobacco funds). It is not always easy to separate out which activity at a given time is being supported by OMH funds.

STAFFING

The Little Singer project has a part-time Project Director and part-time Project Coordinator, as well as two full-time counselor/educators and one full-time traditional counselor (currently no one in this position). There is an Evaluator from Northern Arizona University, but this is not an ongoing position, and there are no regular meetings with the Evaluator. He has been retained

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to conduct periodic, participatory evaluations, one of which had been completed at the time of the site visit.

DATA COLLECTED

Generally speaking, the Little Singer project collects minimal data, and none at all on many of the activities they engage in which were not necessarily outlined in the project application, but which are part of what they do as a matter of necessity. The data that are collected are collected in staff logs and notes. There are few official forms—except for one contact form and the charts maintained at the clinic.

- *Demographic data*. Demographic data on age and gender are collected informally (in staff logs and notes) for education sessions, workshops, and events. All attendees are Navajo. Specific age is not typically recorded; only adult versus youth, or older adult status. Reported age data are just estimates. However, for the education modules done at the school, specific age can be recorded because it is done by grade.

- *Numbers served*. This is collected primarily in staff logs and notes, though there are attendance sheets for some events, such as family nights. There is no method for obtaining unduplicated counts, though where attendance sheets are used, unduplicated counts could, to some extent, be measured. For classrooms, the number served is known simply because it is the number of children in each class. For counseling, counselors record the number of people counseled in their own client files. However, the Family Harmony counselor was at Little Singer for the first 2 years, apparently leaving after that time period with any records that were kept. At this time, clients needing counseling are referred to regular counselors, and it is unclear whether records are available.

- *Process data*. Number of sessions, activities, outreach activities, and so on are recorded in staff logs and calendars. Counseling session records were kept in client files, but last year the domestic violence counselor left and those records are viewed as confidential. The confidentiality of records is a very sensitive issue in a small, close-knit community such as this where gossip and hearsay are potentially damaging. One staff member stated that they just began using contact sheets for home visits.

- *Short-term outcome data*. Other than the counseling records, the only other short-term outcome data are collected through pre- and post-tests (sometimes) given to children during the classroom health education sessions. However, staff mentioned many anecdotes, particularly with respect to youth, concerning changes in diet in their homes, paying more attention to labels and nutrition in stores, and family members wanting healthy recipes.

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- *Long-term outcome data*. None collected.

- *System change data*. While no such data are collected, staff did mention that their workshops and events have been attended by people from other communities. This is an important issue on the reservation since the different small communities often act as separate bodies, a pattern that can create rivalries, political differences, and blockages in communication. These data could be collected with sign-in sheets.

- *Other data*. Two recent documentary films have been made about the Little Singer project. In addition, some diabetes testing has been done on children because the incidence is rising.

DATA BY DRAFT UDS CATEGORY

Going through the draft activity categories, it became clear that there were many categories in which the Little Singer project *ended up creating or conducting activities*, even if it was not laid out in the original plan. This may be typical of projects like this where the specific health conditions to be addressed are so integrated with overall wellness and life situations. By category, Little Singer project activities (and data collected for the activities) funded by OMH were as follows:

- *Interpretation (#2).* Again, not part of the project plan. Yet for presentations and home outreach as needed, interpretation in the Navajo language is provided, especially for older adults. No data are collected.

- *Target population health education and outreach (#3).* This is a primary project activity which uses many approaches and methods (e.g., curricula, outreach presentations, community events). Data are collected in staff logs and journals regarding number of sessions or events conducted, number in attendance, demographics, and the like. This data, however, are by staff estimates, not via any sort of self-report form. As one staff member said, "we know." For classroom presentations, pre- and post-tests are sometimes given. They are also just starting to use home outreach contact forms.

- *Target population health educational materials development/dissemination (#4).* This is not listed as a planned activity, but the project has developed health education materials and brochures, healthy recipe guides, flyers, and brochures. They are planning a newsletter as well. No records are kept concerning these materials.

- *Screening and referral (#5).* Diabetes screenings are conducted, as well as informal domestic violence screening. The latter screening is done to facilitate referrals to services. Data are collected for screenings, via informal staff notes/records. The information is also kept on client charts at the clinic.

Wellness and exercise activities (#7). This constitutes a major part of what they do and includes daily morning exercise for kids, pow-wow dancing, martial arts (chi-kung, tai chi), American Indian athlete visits, the "100-mile club" (walking, running), sweat lodges, and cooking/diet classes or other wellness activities at weekly family fun nights. No specific data are collected except for the 100-mile club, which does have a sign-up sheet. Estimates are made of attendance at other events (e.g., about 8 persons per sweat lodge, 15–20 per family fun night). As for short-term outcome, staff keep informal note (not recorded) of observed weight loss among program participants. They may try to institute fitness exams as a way of assessing progress.

Violence/substance abuse/delinquency prevention (#9). The activities under this category focus on domestic violence, and include: one-on-one counseling (at the school and in the community); a support group for women (about 12 women every week); a sweat lodge for men; and classroom curricula. Records of class presentations are kept, counseling records are kept (formerly by the Family Harmony counselor), and there are sign-in sheets for adult support groups conducted at family fun nights. No other data are collected on attendance at these activities. Most age and demographic numbers reported are estimates made by staff. Attempts to collect attendance data by sign-in sheet would be difficult and misleading since many will not sign their names because they don't want it known that they attended.

Mentoring (#10). What they do in this category may or may not be considered an official "activity," yet they nonetheless train and mentor people from the community to help in the activities of the project, and try to hire from the community as a way of building community capacity. No data are collected. This activity may also fit under *#16, organizational capacity building*. Also note that this activity occurs with "blended funding."

Parent skills training/family counseling (#11). This is part of the planned activities, and includes family fun nights, the women's support group, and parent advisory committee. As noted previously, minimal data are collected on number of sessions/number of activities, and estimates on numbers of participants—collected in staff logs and calendars.

Self-esteem building (#12). Part of the health and wellness curriculum in the classroom and with children at the school involves self-esteem building. A specific curriculum (RISTRA) is used, with additions made by staff, in areas such as "liking yourself," "pride in self," "protecting yourself," and so on. This is also an element of the family fun night activities. Data are collected for students because records are kept on class presentations made. These are kept in staff logs/calendars.

- *Cultural activities (#13).* Games and "integrative activities" in the ceremonial hogan, sweat lodges, storytelling, and the use of a traditional counselor (a position which, at the time of the site visit, was not filled) fall under this category. In addition, the class curriculum itself and most wellness activities are framed within Navajo values and knowledge. Again, these are not set out in the application or goals/objectives as "cultural activities," but that is what they are. Some of the activities are recorded (informally) in staff logs.

- *Recreation/sports (#14).* This is an integral part of the school itself. Other recreation/sports activities include the morning walks/runs and games at family fun nights. No specific data are kept on this, other than the 100-mile club list and sign-up sheets at some events.

- *Linkage building/community coordination (#15).* Because it is a coalition, there is a linkage-building effort that is documented with memorandums of understanding (MOUs). The linkage with the Indian Health Service (IHS) unit involves referrals to the IHS clinic (data kept in clinic charts). In addition, staff make presentations about health and the Little Singer program at other communities, increasing the interaction of these communities. There are sign-in sheets for these presentations to record attendance.

- *Organizational capacity building (#16)*. This includes in-service training on diabetes for teachers. Only informal records are kept.

WHO COLLECTS/ANALYZES THE DATA

Data recording is informally done by counselors/educators, and compiled by the administrative assistant or Project Coordinator.

TECHNOLOGY USED

The technology used is personal logs, records, and calendars, later copied into the regular quarterly OMH reports (on computer, using word processing). While there are computers used by some staff, the project was only recently connected to the Internet (one computer only). Moreover, the Internet connection is by microwave, not telephone line. This may have an effect on data transmission.

OPTIMUM TECHNOLOGY

Even though the Internet connection is recent and uncertain, staff felt that an Internet data form would be "great."

DATA COLLECTION BARRIERS/ISSUES

One barrier, mentioned above, is confidentiality. As noted above, collecting personal

information is not always well-received. A second barrier or issue, as stated by one staff member, is that "the most intensive things we do are not recorded." This comment goes to the heart of a major data collection problem for projects like this—many activities are impromptu, done out of the necessity of the moment. Such activities, which may be very important in many ways, are rarely ever recorded. They are just "known." Examples:

- In the first year of the project, staff going out for home visits/outreach found a man whose heart had stopped. They had to perform resuscitation and crisis intervention thus saving the man's life. While out of the scope of work, their actions helped the reputation of the project in the community, indirectly benefitting other project aims.

- At one home visited by staff, there was a girl who had leukemia. She wanted to be able to go to school. One of the project staff arranged for a teacher to provide home teaching. Eventually, the girl began to come in to the school for classes, even for a full day. Again, this is "out of scope," but part of an overall wellness approach that is likely to have benefits for a number of health conditions of concern in the community.

This may argue for a new data category to be added, called *crisis management*.

A third barrier: project staff felt that data on numbers served are misleading with respect to impact, because for each person served, there are *families* involved. Finally, sign in sheets don't always work well because there are a number of participants who don't read.

DEFINING CLIENT IMPACT

According to the Project Director, the major health problems are based on lifestyle issues. To have an impact on this, the project must deal with children and their families. "We have to respond to what families tell us their concerns are...it means we have a shifting target." The impact should be viewed as emanating from the model of a school-based clinic and wellness center combination, where the wellness activities have more impact than the clinic because they address lifestyles. The clinic is not set up to deal with lifestyles. "The OMH program allows us to take the strengths of the culture and the school's role in the community and expand our role in the community."

Other staff define the impact as focusing on youth: "Teaching kids about health at a young age is important, and that diabetes is a problem for their people." Staff see impact when kids ask about fruit, or show an increased consciousness about buying food, for example.* They also see impact when family members began to use the clinic, or attend wellness activities regularly.

*The sale of soft drinks and candy is not allowed at the school, and teachers try to increase water consumption.

Desired Data (What Would Best Tell the Story?)

The data collected now capture only a limited amount of what is accomplished. As noted above, the Project Director felt that a video, pictures or more narrative means would be better at capturing the full story. He also noted that having a data collection form with activity categories would be a help: "We don't need people to tell us what to do. We do want people who can make it easier to document what we do."

The best data, say other staff, are stories about what we do.

Technical Assistance Needs to Implement a Uniform Data Set

Both training and some form of ongoing technical assistance would make it easier to implement a new UDS data form/system.

Other Comments

N/A**.**

4. The Cambodian Family

General Description and Context

The Cambodian Family is a Bilingual/Bicultural grantee located in Santa Ana, Calif., adjacent to an area known as the Minnie Street neighborhood, which has predominantly low-income Cambodian and Southeast Asian residents. Like the Little Singer project, this project is a good example of how OMH-funded CBOs often confront the interplay of social conditions and health and, as a result, have to improvise or otherwise adjust to carry out their health-related activities. The health conditions addressed by the project are gastrointestinal problems, cardiovascular problems and stroke, and extreme emotional stress. However, it is a high-poverty neighborhood in which apartments are often crowded, few adults speak English, many adults have some form of trauma-related distress, and there are gang problems with youth (it is also an area close to Hispanic/Latino gang turf). In some ways, according to project staff, the Minnie Street neighborhood is not unlike a refugee camp. Not only that, but many adults still have reactions based on their experiences under the Pol Pot regime in Cambodia. Therefore, project outreach staff, in the process of conducting educational activities, also help with other problems that exist, including housing problems, mediation of disputes, and finding access to services in general.

For example, one woman contacted during a neighborhood tour and outreach observation was a single mother of seven children, the oldest of whom were 18 and 20, high school dropouts, and gang members who had been in trouble a number of times. Her husband had died of cancer several years before, and she spoke no English. She was distressed because the night before, Latino gang members had come over to assault her son while he was sitting on the front step (a "repayment," apparently). With all her children, she faced the difficulty of handling

school, court, and other issues when only her children spoke English. In addition, on the day of our conversation she had received an official form letter of some sort and assumed the worst, when in fact the letter was only a notice about other (low income) housing options. Finally, she had an alcohol problem—however, it was clear that her alcohol use was at least in part an attempt to cope with a very difficult situation. The project staff were trying to convince her to come in for stress management and other assistance.

These kinds of examples support the need for an activity category in the UDS that accounts for "crisis intervention."

An additional note of interest: In one of the neighborhood apartment complexes, residents were almost all (Cambodian) Muslim—a Cambodian subgroup known as the Cham. One apartment in the complex was used as a mosque. Project staff felt that conditions were somewhat better in this apartment complex because of the social and religious unity of residents.

The 2-day site visit included interviews with the Project Director and health education/outreach staff; a review of the data collection/reporting system developed by the Project Director (identified previously as a potential model in the focus group); a tour of the neighborhood together with observation of outreach activities; conversations with some clients; and watching a film about Cambodian issues.

PROJECT ACTIVITIES

The Cambodian Family conducts a range of activities, including:

- *Access assistance:* This includes providing transportation (of clients) to health facilities and help in making appointments.

- *Translation and interpretation:* This is provided for clients at medical appointments.

- *Health education:* Provided as group sessions/workshops or on an individual basis via outreach.

- *Development of low-literacy materials:* Materials will be pictorial along with simple text in Khmer.

- *Health provider cultural competency training:* These are designed to cover cultural traditions, history of trauma, and healthcare needs of Cambodians suffering from Gastrointestinal stress, or heart disease/stroke problems.

- *Health fairs:* To provide screenings and education regarding the health conditions of concern, and to better acquaint health professionals with Cambodian health issues.

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Wellness activities: Includes stress management and exercise.

STAFFING

Project staff include the Project Director (full-time), one full-time health educator, and one part-time health educator. An outside Evaluator was brought in to conduct a first year evaluation, but there is no budget to retain the Evaluator again.

DATA COLLECTED

The Cambodian Family collects a significant amount of data for a project of its type, because of the data collection system developed by the Project Director. This system, primarily in Microsoft Access, maintains a file for each client which includes data collected through intake, health information, and health behavior goal forms. This information serves as baseline data. The system also includes computer files by type of activity (counseling, classes/education sessions, etc.), which track each activity, including date, location, topic (if applicable), number of organizations or number of participants, staff or volunteers present, what happened, and comments. The information is first collected on paper forms by Outreach staff, then passed on to the Project Director who does all the inputting.

Demographic data. A substantial amount of demographic data are collected on the Intake Form: age, gender, ethnicity/race (though this is a problem when conducting large education sessions), marital status, number of children, level of English competency, income, primary language, country of birth, number of rooms and residents in the house (because of its health implications), refugee experience (e.g., years in camps), location of family members. Income information is not exact; it is simply a self-designation as low income, supported by questions about welfare and food sufficiency. Staff don't always ask this question; they sometimes just "know." This is also true with information about number of people or rooms in the household.

Numbers served. These data are collected using the Intake Form, attendance sheets at presentations and provider trainings, and with Client Follow-Up Logs. There is a specific method for determining unduplicated counts for individual project participants. First, on the Intake Form there is a space at the top to indicate if the client is a new client. Then, since many clients continue their relationship with the project, there is a space for New/Year 2 (or New, Year 3) to track clients who are *continuing* in those years. Second, the forms are *color coded* for each year; thus it is possible to determine who the new clients are for each year. Numbers served at group outreach/education presentations are sometimes staff estimates and are tracked through attendance sheets or the Community Activities form.

Process data. From the point of intake and collection of intake data, an individual client's

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participation is tracked with a Client Follow-Up Log, filled out by outreach/education staff. This information is then input and displayed on an activity table for each (individual) client. At health fairs, cultural competency trainings, screenings and target population education are conducted. For each of these, the appropriate attendance sheet is used, tracking both numbers served and how many of what type of activity was conducted. For screenings, a Screening Form is used. For outreach and community activities (e.g., home visits), a Community Activities form is used, on which date, location, staff, activity, and number of participants is recorded.

Short-term outcome data. Short-term outcomes include verified access to medical care and knowledge change. These outcomes are tracked through client referral forms (documenting referrals and health services actually provided), and through pre–post tests of knowledge administered at health provider trainings. At target population health education classes, informal oral pre–posts are used, but these are not recorded as formal data, but they are noted in the trainer's log.

Long-term outcome data. Some longer term outcomes for individual clients are documented in the health behavior contracts. Outreach/educator staff observe or ask clients if they are meeting their behavioral goals by the proposed deadline, and if they are, the deadline is marked with a check.

System change data. No data are collected in this area; however, staff believe that their participation in task forces[%] and the conduct of health provider trainings do have a system impact. This could potentially be documented through a follow-up survey.

Other data. Data on health background and experience are collected on the Intake Form and on a set of Health Information Forms. The Intake Form asks whether or not the client has health insurance, if they have a regular doctor or HMO, and their experience with that doctor. The Health Information Forms ask about trauma experience, cardiovascular health, diet, and gastrointestinal health. Finally, a Healthy Behavior Goal Form records the client's target behavior goal for the program. Staff said that they also record notable changes or specific circumstances on individual clients' Client Follow-Up Form.

DATA BY DRAFT UDS CATEGORY

Going through the draft UDS categories, the Cambodian Family conducted activities and collected data in the areas described below.

*For example, the Orange County Health Department/Department of Behavioral Care Multi-Ethnic Task Force. The Project Director was also chair of the Subcommittee on Access.

Training healthcare providers (#1). A designated contract activity, the trainings were cultural competency trainings intended to familiarize health professionals with Cambodian cultural issues and their healthcare implications. Data on numbers served and workshops given were collected using attendance sheets, which are then put into the database and summarized on a table attached to the Quarterly Report. Short-term outcome data were collected through pre–post tests.

Interpretation (#2). Interpretation is provided in person or by telephone. Interpretation sessions and demographics of the client being served are tracked using the Intake Form and Follow-Up Logs filled out by all staff, as well as calendars used by staff. The medical service(s) received by the client—with the help of the interpretation—are tracked as short-term outcome on client follow-up logs.

Target population health education and outreach (#3). Conducted both as individual outreach and group presentations. The latter are conducted at the project office, in homes, at doctor's offices, and at other locations. Group presentations and attendance are tracked using attendance sheets; short-term outcome is assessed using pre–post tests. Individual counseling/education is documented in client follow-up logs, which also contain demographic information on these clients. Thus for *individual clients*, the system can track how many education sessions a client has had, and on what topics.

Target population health educational materials development/dissemination (#4). At the Cambodian Family, this included the development and dissemination of low-literacy informational materials. No data are collected on this activity.

Screening and referral (#5). Screenings are conducted at health fairs, and sometimes at health provider appointments. These are tracked using Lung and Heart, Neurological, and Vision Screening forms for each person screened. However, the Access database records only individual screenings for clients who are already entered into the database. Referrals for individual clients are tracked using the Client Follow-Up Log.

Case management (#6). For this project, case management takes the form of individual client counseling. Eighty percent of clients are repeat clients. This is tracked in the Client Follow-Up Log, and the information is input into a (client) counseling file on the computer. It is possible to query the file and determine how many sessions a given client has attended. The follow-up log documents referrals made and health/medical services received as a result of the referrals.

Wellness and exercise activities (#7). These activities include stress management/relaxation classes, and exercises—such as breathing and stress release exercises. Each class that is conducted is recorded in a health class computer file.

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Number of participants is recorded by "head count." Some outcome data can be determined from the Healthy Behavioral Goal contract.

Parent skills training/family counseling (#11). Under this activity, the Cambodian Family conducts family counseling (on child abuse, family violence, crisis intervention). These counseling sessions are tracked on Client Follow-Up Logs (demographics are collected on the initial Intake Form), and recorded under a "counseling folder" on the database. Therefore, it is possible to determine how often a given client or family has attended counseling sessions.

Linkage building/community coordination (#15). The Cambodian Family participates on a number of task forces and committees, and has formed linkages with various organizations as well as lawyers. No regular data are collected on these linkages other than a summary in the quarterly report under the "Linkages and Issues" section.

Organizational capacity building (#16). Activities in this regard include staff training on health issues. No data are collected.

WHO COLLECTS/ANALYZES THE DATA

Data collection is done by the Outreach Specialists/Health Educators, as well as the Project Director, using the forms described above. Data are input, compiled, and analyzed by the Project Director.

TECHNOLOGY USED

Paper forms which were entered into the computer are used. The database has been developed by the Project Director using Microsoft Access.

OPTIMUM TECHNOLOGY

N/A.

DATA COLLECTION BARRIERS/ISSUES

In general, data collection is viewed as a very important part of project activities. It was not viewed as excessively burdensome, though it took training and time for staff to become accustomed to use of the forms. Other than the Project Director, none of the staff are computer or Internet literate, though one computer is connected. At the moment, the Internet connection is on a nondedicated telephone line, so that the telephone and Internet cannot be used simultaneously.

DEFINING CLIENT IMPACT

The Project Director noted that, before the project began, only a small number of Cambodian residents had medical insurance, and very few saw a doctor on any regular basis. The project

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has made a big change in this pattern. Other project staff talk about different impacts: "The project," said one outreach/health educator, "seeks to educate the community, to build self-sufficiency." There are many issues of community change involved. "When they first came, Cambodians felt that the U.S. had bombed them and done bad things, and that they were being paid back with welfare." And, "in Cambodia, the man was the head of the family. Here there are many single-woman households." Many in the Cambodian community "used to work on farms, and had a low level of education. The idea of competition and working to survive is new. They don't understand the situation here." The language problem and resulting needs (for interpretation) are also great. "There is a big problem with language in families, because the children mostly speak English, and can't translate."

A key goal, according to this staff member, is to train community members to learn about health, because the program itself may or may not continue. "Those who learn may go on, get an education, and leave, but that is good. At least there is a cadre of residents who have a knowledge base."

DESIRED DATA (WHAT WOULD BEST TELL THE STORY?)

The impact as described by the Project Director *is* captured in the extensive data collection system used at the Cambodian Family. (This is clearly a unique situation, where the Project Director developed a data system specifically to capture that impact.) Other project staff, however, talk about the difficulty in capturing the "flow," the role of cultural and social bridge that outreach staff often play. Data have to be written to fit the data collection program. Funders don't always understand that health is a holistic concept, and the connection with community is so important before it is possible to enlist people in a specific program activity. Related to this is the need for trust-building, which, according to another outreach staff member, is crucial for a refugee population. So, while many aspects of gaining that connection are not spelled out in the grant, they are important.

TECHNICAL ASSISTANCE NEEDS TO IMPLEMENT A UNIFORM DATA SET

In many ways, a UDS would duplicate the system already in place, so technical assistance needs are unclear.

OTHER COMMENTS

N/A.

5. The Vietnamese Community of Orange County, Inc.

GENERAL DESCRIPTION AND CONTEXT

During Aug. 23–24, a site visit was conducted to the Vietnamese Community of Orange County, Inc. (VNCOC), a Managed Care grantee. This project, called Project Harmony, was conducted out of the VNCOC Asian Health Center, a clinic operated by the Vietnamese

Community with funding from multiple sources. Its focus is on education/training of both healthcare providers and limited English proficient (LEP) Vietnamese—the former training focused on providing culturally appropriate care, the latter on negotiating managed care. Media and other educational activities are also included under their grant. The Asian Health Center and VNCOC are located in a community known as "Little Saigon" because of its substantial Vietnamese population. In contrast to the low-income Cambodian neighborhood served by the Cambodian Family, the Little Saigon area appeared to include a broad cross-section of the Vietnamese community, with many shops, stores, restaurants, and professional offices.

The site visit consisted of interviews with the Project Coordinator, health education staff, and VNCOC Executive Director, a tour of the clinic facility, and examination of the data collection system and process.

In a side note, project outreach/education staff said that alcohol and smoking are big problems with Vietnamese men, but that denial is high. Domestic violence is also prevalent, primarily because of frictions relating to the role change from a largely patriarchal Vietnamese society. Teen pregnancy and sexual activity are also more prevalent, though denied. Finally, staff have received many personal telephone calls about HIV/AIDS, which is brought in to the community (in the opinion of project staff) from people who travel.

PROJECT ACTIVITIES

These activities include

- *Health provider trainings:* These are cultural competency trainings for health providers designed to improve their ability to provide culturally competent care. Trainings are also to be provided to medical students and other students in the health professions.

- *LEP population workshops:* Workshops on managed care for LEP Vietnamese, designed to increase knowledge about how to choose and obtain health services under managed care.

- *Resource books:* The project is producing a guidebook for health professionals to accompany the cultural competency trainings, and a guidebook for LEP Vietnamese to accompany the managed care workshops.

- *Public education:* To include a talk show on managed care-related issues, articles in the local Vietnamese newspaper, and brochures and flyers.

STAFFING

Project Harmony has two full time Health Educators, a part-time Project Coordinator, a part-time Outreach staff, and part-time administrative support. There is no Evaluator.

DATA COLLECTED

In general, data concerning the trainings and workshops are collected from attendance forms and pre–post tests/evaluation forms. The attendance sheets record age, gender, race/ethnicity, home city, and profession. In addition, the pre–post forms ask participants if they have health insurance of any type and if they have a PCP. Once entered in the computer, this information is all tabulated by participant, along with their pre–post scores. The system is very simple, but very effective, and *perhaps a model*.

- *Demographic data*. Age, gender, and race/ethnicity data are collected on training/workshop participants. As noted, these data are collected via attendance sheets.

- *Numbers served*. Determined from attendance sheets. Because names are recorded in the database, duplicates can be determined. Numbers served with respect to the resource books is, at a minimum, the same as attendance at workshops/trainings. However, informal tallies are also kept of mail requests for materials.

- *Process data*. Number of workshops/trainings can be determined from the attendance sheet records. For broadcast and print media announcements, the total number reached is based on an estimated audience from the media source, and the number of announcements placed (with dates recorded in the Project Coordinator's log).

- *Short-term outcome data*. The only short-term outcome data come from pre–post tests that are administered at almost all trainings and workshops.

- *Long-term outcome data*. None collected.

- *System change data.* None collected.

- *Other data*. None.

DATA BY DRAFT UDS CATEGORY

- *Training healthcare providers (#1)*. As mentioned, this is a primary project activity—cultural competence trainings for doctors, nurses, medical students, and paraprofessionals. Demographic and numbers data are collected using attendance sheets and the pre–post tests, and are then entered into the data tables. Because data are recorded by participant, it is possible to determine how many sessions a given client has attended, and to check for duplicate counts. Short-term data (knowledge change) are collected from the pre–post tests.

- *Target population health education and outreach (#3)*. The workshops on managed care

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for LEP Vietnamese are categorized under this category. In terms of collecting data, these are handled exactly the same as health provider trainings (data from attendance sheets and the pre–post tests).

- *Target population health educational materials development/dissemination* (#4). The resource books for health professionals and the LEP Vietnamese participants, as well as the print and broadcast material are categorized under this category. Dissemination records for resource manuals is straightforward—each training or workshop participant receives one, plus there are mail requests for the manuals. With respect to print and broadcast material, the only data kept are dates that the material was printed or broadcast.

- *Linkage building/community coordination (#15)*. As a result of the cultural competency trainings, Project Harmony has developed informal linkages (for participant recruitment) with nursing colleges and student placements. No data are currently kept on these linkages, though project staff said that they planned to collect some via student pre–post tests (perhaps a question on what school or organization a student is from).

- *Organizational capacity building (#16)*. Project staff attend various health trainings. Only informal notes are kept (by the Project Coordinator) as to trainings attended by staff.

WHO COLLECTS/ANALYZES THE DATA

Data are collected and input by health educators. Compilation and analysis is done by the Project Coordinator.

TECHNOLOGY USED

Paper forms are entered into tables maintained in a computer word processing program (Microsoft Word).

OPTIMUM TECHNOLOGY

Even if some training is necessary, Project Harmony staff would prefer a data system that is computer (or even Internet) based.

DATA COLLECTION BARRIERS/ISSUES

The activities at the VNCOC project are relatively straightforward, as is the data collection system. No staff reported any undue burden with respect to data collection. The only issue mentioned was an issue (see the section on Concilio Latino above) common to programs that focus on trainings and workshops: they were not able to see much of the impact from their work because, once the training is completed, there is no further connection with the trainees.

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Defining Client Impact

Because they bring information to "both sides" (health providers and potential patients), project staff feel that they promote better communication between provider and patient, and that they increase the knowledge of LEP Vietnamese clients and their confidence in accessing health care. With respect to the information for health providers, "understanding the people (we) serve is more than just understanding the ailments they have." For LEP clients: "The English level is low in the community. Presentations help them understand managed care better and increase the likelihood of early treatment."

Desired Data (What Would Best Tell the Story?)

Project staff feel that the basics of what they do are captured in the data they collect. But they have no data on how the workshops actually affect behavior. They would like to get that kind of data if possible, for example, using follow-up interviews or focus groups with providers and LEP clients.

Technical Assistance Needs to Implement a Uniform Data Set

Their system is relatively well developed, so it is likely that the TA would be necessary primarily to train staff in the new system, but not so much to build basic staff capability. However, they would like assistance in developing follow-up protocols to collect longer term data.

Other Comments

N/A.

6. Tug River Health Association, Inc.

General Description and Context

The Tug River Health Association, Inc., is a public, nonprofit CBO that operates two community healthcare facilities in rural McDowell County, W.Va. The largest center is located in Gary, W.Va., and there is a smaller, satellite center in Northfork, W.Va. These are full service centers that provide a full range of medical and dental services. The Association also receives funding from the State Office of Rural Health, Federal Black Lung Program funding, Medicare, Medicaid, and a small amount of fee-for-service funds.

McDowell County has the greatest composition of minorities of West Virginia's 55 counties. African Americans are the largest racial/ethnic minority group by far, comprising 14 percent of the county's population. The county is also one of West Virginia's more economically depressed areas—particularly since the early 1980's when the coal mining industry suffered a severe decline. Tug River staff indicated that the poor economy and high unemployment rates show no sign of improvement. It is a designated Empowerment Zone and Enterprise Community. Historically, the African American population was drawn to the area to work in the coal mines. When the mining companies left the area, a large portion of the African American

population remained behind, especially the older residents.

PROJECT ACTIVITIES

As with many projects operated by community based organizations, the staff of the Minority Health Coalition Project provide many more services than are formally listed in project documentation. Specific health concerns include cancer, cardiovascular disease and maternal and infant health. According to the project proposals and official documentation, the project conducts the following types of activities:

- *Community awareness:* OMH project staff take part in activities that are designed to raise the awareness of minority health concerns in their community especially in the three health areas listed above. Specific activities include such things as publishing a project newsletter, placing articles in local publications and information spots on local radio stations, developing a calendar, and taking part in health "fairs" and other activities that are sponsored by the Clinic.

- *Outreach/case-finding:* Outreach activities involve identifying and contacting members of the local community in an effort to provide prevention, screening, and direct care intervention. The case managers use any opportunity that presents itself to reach out to potential clients including such things as community screening and other events sponsored by the Clinic, casual contacts, and door-to-door canvassing in minority neighborhoods.

- *Case management:* The case management activities of the staff on the OMH project focus primarily on coordinating basic care services, assisting in dealing with social services agencies for other needs, and providing ongoing direct patient education services. Transportation is a major component of the program as many of the older clients do not have means of transportation to doctor and dental appointments and social service agencies. Case managers also facilitate access to basic household needs such as food and clothing and provide health education and make regular visits to the homes of program clients.

- *Health education:* The case managers provide education activities designed to address health issues of particular importance to the minority community. Community and church based health education programs concerning cardiovascular disease and cancer in minority populations are provided. Education sessions on pregnancy and substance abuse are provided to minority students in public school, grades 7 through 12.

STAFFING

Organizationally, the Minority Health Coalition Project comes under the supervision of the Special Programs Coordinator of the Tug River Health Association who reports to the Executive

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Director of the Association. Grant funds provide for three full-time staff positions, two case managers and a secretary/statistician. A social worker who works for the Association also helps with some project activities. The project does not have an Evaluator, nor do they use volunteers. The remote location of the Association's facilities and the economic depression of the area have made it extremely difficult to contract with professional Evaluators. This may change in the future, however, since the current director is working to build formal liaisons with the medical school in Charleston which may make these types of resources more available. The severe economic conditions of the area also make it difficult to recruit volunteers.

DATA COLLECTED

Project staff use both paper forms and a computerized Microsoft Access database to collect data about project activities. For outreach/case-finding activities and case management, the data collection begins with the initial profile sheet. This screening form is completed during an initial home visit with a client who has been identified through the projects outreach activities. It contains basic information about the primary client and limited information about all others in the household. The remaining assessment questions are framed in terms of the family (e.g. Does the family have any other expressed medical needs? Does the family have any expressed social service needs?). Healthcare and social service needs are described in narrative forms and the automated data collection process does not link specific needs with specific household members. The chart also contains a narrative treatment plan and a patient contact sheet which allows the case managers to chart the date, time and nature of contact with the family. The Case Management database has three tables. Table 1 is the most complex and includes information about the primary contact and the family's health needs from the initial screening instrument. Table 2 identifies the primary family contact and includes fields for the date the family was enrolled, the name of the contact, case manager assignment, and comments. Table 3 is used to record contacts with the family; fields include contact date, client name, person initiating the contact, service provided and case manager providing the service.

The Meetings Database is used to capture information on education and other community group activities. It has fields for the name of the meeting (which does not necessarily reflect anything about the meeting content), the date, the total number of people attending, and where the event was held. Attendance is not tracked by individual thus the project cannot provide an unduplicated count of people attending these events.

A monthly paper report summary is completed by each case manager. This report lists the number of outreach contacts, initial client profiles, treatment plans, referrals, rejections, transports, and other services provided for the month for the worker's caseload. These figures are not a part of the computerized database. This form provides the basis for the monthly report that each case manager provides to the Project Coordinator for her monthly report to the Association's Board of Directors. The Coordinator finds the information useful for project management purposes to ensure that "they're doing what they're supposed to be doing."

Database information is also used for the semi annual reports to OMH.

The Access databases used by the project were developed by one of the Clinic's staff. OMH project staff were trained by the person who designed the database and have a rudimentary understanding of the software. The database is very simple although adequate to provide descriptive statistics about the primary project activities and to provide the case managers with the information they need to track services provided to individual clients. Information is updated daily. The databases in their present form were developed to provide the information required in the suggested format data form found in the proposals for years 2 and 3.

- *Demographic data:* Age and sex of the primary contact in the household is collected for those families receiving case management services. Information on race is not collected, although, as a practical matter, all of the clients served by this program are African-American. Race could easily be added to their data collection forms and database. Family income as a percentage of the poverty level is also collected The project data collection system could also provide the number of people living in the house. It would not be possible, however, to determine which household members needed or received specific services.

- *Numbers served:* The project's data collection system can provide an unduplicated count of primary case management clients. Project reports also include and the number of events and the people attending by event but this is not an unduplicated count.

- *Process data*: The number and type of community outreach and education activities can be determined from the monthly report summaries completed by the case managers. The number and type of case management services provided to program clients can also be provided.

- *Short-term outcome data*: No short-term outcome data are collected.

- *Long-term outcome data*: No long-term outcome data are collected.

- *System change data*: Project activities do not focus on system change and no such data are collected.

- *Other data*: The Clinic routinely collects customer satisfaction data that can be sorted for OMH project clients if they are also patients at the clinic.

DATA BY DRAFT UDS CATEGORY

Because of the way in which the case managers do much of their work, the data that are collected cut across many of these categories. Many of the activities in which the case

managers and program clients participate are clinicwide and involve more than just the OMH project staff and clients. This collaboration is by design and helps all of the clinic's programs to provide services as broadly and efficiently as possible. As a practical matter, it would be almost impossible to isolate many of the activities of the OMH project staff from overall clinic activities.

In addition, case managers see themselves as providing many of the services outlined in the UDS categories, but they are not a central focus of activities and are not counted as separate and distinct. For example, they may talk about substance abuse when they hold the teen pregnancy workshops in the schools, but they don't do systematic substance abuse prevention. Similarly, some racial/ethnic minority program participants receive parent skills training, but these activities are provided by the Clinics Maternal and Infant Health Program. It would be very difficult to tease out these types of services and they are certainly not exclusively provided by the OMH funded project. Only the main category services are included below.

- *Target population health education and outreach (#3)*. The number of education events outreach contacts are collected and reported monthly. The Meetings database provides information on the number of meetings/sessions and how many people attended. The case managers could reconstruct the topics of the sessions, but the database does not categorize health education sessions by type of information provided. Outreach activities to families is provided by the case management database. Cases could be characterized by size of family, age of family members, and household income. Case managers also participate in health fairs and special projects organized by the Clinic and use these events as opportunities to provide outreach to minority attendees.

- *Target population health educational materials development/dissemination (#4)*. Project staff have started a project newsletter and developed a calendar that was distributed to the community. This type of information is reported in narrative format in the monthly report compiled by the Program Coordinator. Project staff could report the number of newsletters and calendars that have been distributed in the community.

- *Screening and referral (#5)*. These are major activities for this project. The initial family assessment provides information on service needs at that time. In addition, the case managers participate in community health screening events. Information is collected on the number of referrals that case managers make each month and where the referral was made. It would be cumbersome, but the staff could track and group the number of referrals by client family. There is no information about the outcome of the referrals.

- *Case management (#6)*. The major database for this project collects information on case management activities. Information is included on how many families are enrolled in the case management program, how many contacts are made, and what services were

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provided in broad, general categories.

WHO COLLECTS/ANALYZES THE DATA

Data about program participants and activities are generated by the case managers. Data used in reporting are collected from the charts of program participants by the secretary/statistician and entered into the projects computerized database. Most of the information entered into the database comes from the intake screening instrument used by case managers in their initial home visits and from their case management notes as well as their case contact notes. Case managers have primary responsibility for collecting data. Case file management, database data entry, and querying the database is the responsibility of the secretary/statistician. Data analysis is primarily simple counts of people and activities and is also provided by the secretary/statistician.

TECHNOLOGY USED

All of the staff are familiar with computers and able to use them for word processing, data entry, and Internet searching. The secretary/statistician usually runs statistical queries and reports from the projects database. The Coordinator feels that both paper forms and computer databases are necessary, however. She noted that using laptop computers to collect data in the initial in-home family assessments would be intimidating and case managers would be reluctant to collect the information in this way. Although all of the staff use the Internet, the Coordinator is the only staff member with a computer that has Internet access. The Internet is used as a source of educational information, especially on minority populations and for locating funding sources.

DATA COLLECTION BARRIERS/ISSUES

The project staff did not perceive any major barriers to collecting the project information that they currently collect, although the Project Coordinator did say that the OMH reporting requirements were the most stringent. The secretary/statistician mentioned that calculating the unduplicated count of case management clients was time consuming. The Clinic does have to collect similar data for other funding agencies (both State and Federal) that support other clinic programs. There are differences among agencies in what is required to be reported and the reporting frequency. Current data reporting requirements are seen as burdensome, but manageable.

DEFINING CLIENT IMPACT

At this time, the project does not collect either long-term or short-term outcome information although they are aware that this would be important information to have. The project proposals provide a systematic set of quantifiable goals and objectives related to the health conditions of concern to the project. Outcome objectives are stated in terms of communitywide reduction rather than changes in health status for program participants. For example, this case management will result in an overall reduction in the number of deaths attributed to this disease

(heart disease). The overall reduction is projected at 12 percent over the 3-year period. The hope is to increase this rate to at least 90 percent for the number of minority infants receiving immunizations according to schedule by age 2. This would represent an increase of 21 percent over the current level.

At the time of the site visit, the project had not measured these goals and it is unlikely that a program of such short duration would be able to bring about the changes of this magnitude within the population. A better approach would have been to track changes in health attitudes, behavior and outcomes in the population they serve on a regular basis. These types of outcome measures are not being measured at the current time.

DESIRED DATA (WHAT WOULD BEST TELL THE STORY?)

The Coordinator and the staff felt that the story of the project was not being captured by the data that are currently collected. They feel that the project is having a positive impact on the racial/ethnic minority community, especially among the adolescents who participate in program activities. They felt that there needed to be a way to capture the short-term outcome of the project. Several suggestions were made including:

- Revising the initial screening instrument to use as a follow-up data gathering tool
- Checking the Clinics demographic profile to see if the percent of the caseload made up of minority patients had increased since the beginning of the OMH project
- Designing a follow-up survey to determine changes in behavior and health status as a result of project activity
- Checking patient records for before and after health status

The staff would be willing and able to collect observational and/or interview data. However, they would need technical assistance on instrument development and interviewing skills. They would also need additional funds to defray the cost of the survey and staff time.

TECHNICAL ASSISTANCE NEEDS TO IMPLEMENT A UNIFORM DATA SET

The staff on this project are computer literate and are committed to collecting the information that is on their reporting forms and in the project database. However, their current database is very simple and they would probably need technical assistance to design one that would capture the complexity of the work they do. Similarly, it would be beneficial if they had some training on how to better use the information they already collect.

OTHER COMMENTS

The Project Coordinator reinforced the observation that it would be somewhat difficult to pull

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apart services provided by the different programs provided by the Clinic. Programs work together on special projects and refer clients back and forth as the need arises. Staff could sort out which of their clients had services from other programs as a process measure, but it would be much more difficult to sort out the outcome issues.

7. The Tennessee Department of Health

General Description and Context

This project is a State and territorial minority HIV/AIDS demonstration grant, in a State where concern about HIV/AIDS is relatively recent, and where the affected minority populations (African-American and, increasingly, Hispanic/Latino) are in both urban and rural areas. The project is operated out of the Office of Minority Health within the State government, an office with only four staff members. At the outset, the grantee intended to develop a minority community coalition in the form of the Minority Health HIV/AIDS Community Care/Prevention Advisory Committee (CACC) which was to identify organizations and groups within the State that were providing (or could provide) HIV/AIDS prevention and assistance services, identify their support needs, and recommend resources to fill those needs through technical assistance, capacity building, and other support. The needs and plan for addressing them were to be compiled in a Minority Collaborative HIV/AIDS Plan for the State. The CACC also aimed to identify and coordinate Federal resources coming in to the State which were available for racial/ethnic minority HIV/AIDS prevention and treatment. The CACC would also be working with the six already-existing Regional Minority Health Coalitions to increase linkages and coordinate activities. In addition, the State Health Department/Office of Minority Health planned to conduct public awareness activities to increase awareness in the minority community about HIV/AIDS.

In practice, the project has encountered obstacles that might not be atypical with respect to grant funds disbursed to States. The primary obstacle is politics. Following award of the grant, there was some apparent maneuvering which resulted in the original Project Director not being given control of the project. Instead, control of the project was shifted around among several individuals/offices until the current Project Director was selected. At the time of the site visit, the current Director had been in position for only a few weeks. Therefore, while some activities have begun, there has been no data collection, and no development of instruments as originally planned. Moreover, the current Project Director—who comes from a health educator background and is quite committed—is responsible for almost everything. It also appears that he has, at most, one other staff person to help the efforts.

The site visit included attendance at a CACC meeting, interviews with some CACC members, an interview with the Project Director, an interview with a Health Department staff who has been involved with the project, and a review of records.

Project Activities

Specifically, these activities include:

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- *Convening the Advisory Committee (CACC):* The CACC is composed of a broad range of members: healthcare providers, Meharry Medical College, clergy, treatment providers, community based organizations, persons with AIDS (PWAs), at least one representative from a Regional Minority Health Coalition, and others.

- *Conducting a needs and assets assessment:* This was to be conducted by the CACC, in partnership with the Regional Coalitions. Findings will be summarized in a report.

- *Identifying and providing technical assistance:* Based on the identified need, identifying and coordinating the provision of technical assistance to organizations serving high-risk racial/ethnic minority populations. This assistance could cover programmatic, fund-raising, and capacity-building needs.

- *Facilitating linkages:* Increase participation of racial/ethnic minority HIV/AIDS organizations in statewide planning groups and knowledge-exchange meetings, and develop linkages between these organizations and Federal or other funding sources.

- *Identifying and coordinating resources:* Identifying Federal and other resources that could be channeled to the target organizations, and assisting the organizations in applying for those resources.

- *Public education:* This is not a clearly laid-out activity, but the linkages and proposed racial/ethnic minority health conference are intended to increase awareness as well as facilitate linkages. In addition, the Health Department has funded a subcontractor to develop a racial/ethnic minority resource guide (to resources, organizations, etc., that have some relevance to HIV/AIDS services.

Other activities, such as using Geographic Information Systems (GIS) in the needs assessment and compiling epidemiologic data, do not appear likely to be conducted.

STAFFING

The Tennessee Project has one full-time Project Director and one 25 percent assistant. There is no Project Evaluator.

DATA COLLECTED

Currently, virtually no data are being collected except for CACC meeting minutes, and there is currently no system for collecting data. Originally, a follow-up survey was planned to determine what kinds of impacts the project had with respect to racial/ethnic minority HIV/AIDS organizations/providers (e.g., increased knowledge, resources or linkages made, etc.). For this type of grant, however, data items are less clearly defined because the project is primarily about process—of facilitating linkages, convening meetings, identifying needs and filling them, and the like. (It is important to note that the CRE technical assistance data collection forms may be of great use here.)

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- *Demographic data*. None collected
- *Numbers served*. None collected.
- *Process data*. CACC meeting minutes only.
- *Short-term outcome data*. None collected.
- *Long-term outcome data*. None collected.
- *System change data.* None collected.
- *Other data*. None.

DATA BY DRAFT UDS CATEGORY

As noted, the Tennessee Health Department project collects almost no data. However, if they did, the following UDS categories would be responsive to their needs.*

- *Target population health education and outreach (#3)*. This category would include the conference(s) and other modalities designed to increase awareness.
- *Target population health educational materials development/dissemination (#4).* The minority health resource guide.
- *Linkage building/community coordination (#15)*. Fostering involvement of minority CBOs in HIV/AIDS planning and other meetings; linking the CBOs with resource-providing organizations and agencies.
- *Organizational capacity building (#16)*. Coordinating or providing training to minority HIV/AIDS CBOs.
- *Resource coordination (#17)*. Identifying available Federal or other resources, and facilitating the channeling of those resources to minority HIV/AIDS CBOs.
- *Identifying/providing technical assistance (#18)* The CACC has the task of identifying technical assistance needs among minority CBOs, and coordinating assistance to meet those needs.

WHO COLLECTS/ANALYZES THE DATA

At this point, the Project Director collects any data that are collected.

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*While there is no current category for "conducting needs assessments," perhaps this category should be added, since one of the first tasks of the Tennessee project is to conduct a needs assessment with respect to minority HIV/AIDS organizations and services and compile the findings into a report.

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TECHNOLOGY USED
N/A.

OPTIMUM TECHNOLOGY
This project first needs to put in place any data collection system. In this respect, the preset data categories of the proposed UDS would be very helpful to the Tennessee project, because they would provide some framework for creating a system.

DATA COLLECTION BARRIERS/ISSUES:
There are three main barriers at this time: 1) there is little staff support; 2) agency politics have delayed project activities such that no data collection system was ever put in place; and 3) the nature of the activities will require a substantial amount of process data.

DEFINING CLIENT IMPACT
Defining "clients" is somewhat difficult for a project like this—racial/ethnic minority CBOs are the most applicable target or client population. According to the (new) Project Director, the impact of the project will include: an increase in the number of minority CBOs involved in HIV/AIDS prevention and treatment; a better HIV/AIDS infrastructure in the African-American and Latino communities; better HIV/AIDS services for minorities; decrease in the rate of HIV infection; an increase in the number of health providers serving the racial/ethnic minority population; minority PWAs living longer; and the conduct of a statewide conference. Expected impacts voiced by CACC members included: technical assistance; better collaboration ("bringing people to the table that need to be there") and networking; dissemination of effective prevention strategies and models; increased funding for minority CBOs; and increased Latino participation in statewide HIV/AIDS prevention and treatment planning.

DESIRED DATA (WHAT WOULD BEST TELL THE STORY?)
Clearly, the lack of current data means that no story is being told at all. The rapid implementation of some data collection activities would be a start. The original plan for a survey of CBOs, State agencies, and others to determine the extent to which racial/ethnic minority-focused HIV/AIDS activities have expanded. It is an ambitious effort, but would provide useful data, particularly if the survey instrument included questions that would show whether recipients had been directly assisted by the Tennessee project. In this type of situation, even a small number of interviews or focus groups might provide some useful data.

TECHNICAL ASSISTANCE NEEDS TO IMPLEMENT A UNIFORM DATA SET
This project needs an Evaluator or other individual to help them develop a data collection system from the ground up. If the proposed UDS is implemented, there should be at least an option to provide *onsite technical assistance* to high-need OMH projects such as this one (in addition to the regional TA meetings that will likely be recommended).

OTHER COMMENTS
N/A.

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8. Albert Einstein Medical Center

GENERAL DESCRIPTION AND CONTEXT

The Albert Einstein Medical Center Cancer Awareness Project is a standard cooperative agreement. The Center is located in North Philadelphia, and for this project works in collaboration with the LaSalle Neighborhood Nursing Center (part of the LaSalle University Nursing School) and the American Cancer Society. The zip-code areas served by the project are generally low income, with target populations from several groups, particularly African-American and Asian/Southeast Asian, who have high rates of certain types of cancers and low rates of early detection. The types of cancer of most concern are cervical, breast, prostate, colorectal, oral and liver. This project is different in significant ways from the other grantees visited, primarily because the funded entity is a hospital, and as such there are many more data-related resources available than there would be for a CBO (for example, screening clients are processed through the hospital data system, so intake and client charts are maintained with detailed information). However, the activities themselves share many similarities with those performed by CBO grantees: the Cancer Awareness Project aims to conduct education/outreach, screenings, case management, and linkage building.

The site visit included interviews with the Project Director, Project Coordinator, several health education staff, observation of a prostate cancer screening and education, a tour of community linkage sites, and review of the database and data collection system.

PROJECT ACTIVITIES

Generally, project activities include:

- *Outreach:* This involves a continuous effort at building linkages to minority community organizations, individuals and schools by presenting the program and trying to organize activities (such as education sessions or screenings) in collaboration with that organization.
- *Education:* Educational presentations on cancer prevention, screening, and treatment are sometimes conducted at Albert Einstein Medical Center, but most often in the community. Both LaSalle and American Cancer Society staff conduct these presentations. Some informal education/training is given to medical residents and nurses as well.

- *Screening:* Screenings for all the cancer types noted above, with specific screenings depending on the particular target population segment being addressed. Screening results are processed by the Medical Center.

- *Case management/follow-up:* Where an abnormal screen occurs, Einstein/LaSalle staff follow up and contact the person to refer them for further testing or a medical intervention.

- *Public awareness:* Public Service Announcements (PSAs) for health screenings in

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newspapers, on radio, and on the public access cable channel. Education workshops are also presented on the public access channel.

STAFFING

The Cancer Awareness Project (CAP) has one full-time, seven part-time, and two in-kind staff members. The project also uses volunteers from the American Cancer Society, AmeriCorps, medical residents, and community doctors/nurse practitioners. There is no Project Evaluator.

DATA COLLECTED

A significant amount of data are collected in this project. However, at this time there are two sets of data—one at the Albert Einstein Center (for screenings and case management), one at the LaSalle Nursing Center for outreach and education. The project's Administrative Assistant is currently in the process of integrating the two systems.

- *Demographic data.* This is collected differently by activity. For outreach and education, age, gender and race/ethnicity are estimated by the outreach educators and recorded in informal notes, later entered into the database. For screening, there is a screening intake form which also asks about smoking, menstrual history, family and personal medical history.

- *Numbers served.* For screening, numbers served are determined by individual case records (beginning with intake). Thus, identifying duplicates is possible. For education sessions, attendance forms are used to compile numbers served. At some education sessions, satisfaction forms are also used. Numbers served through outreach are generally estimates of people attending presentations made to community groups about the CAP project. At health fairs, attendance sheets are often used when the activity is a presentation.

- *Process data.* For outreach, process data are just a record (on a community outreach form) of sites where outreach was conducted. For education, attendance records and field activity forms are used for tracking number of sessions. Number of screenings can be determined from screening attendance sheets and client charts. For media campaigns, clients who come in for screening and education are asked how they heard about the program. In addition, a fax list is kept of organizations/individuals to whom faxed notices of screenings or education sessions are sent. Home visits are tracked in charts or on client follow-up forms.

- *Short-term outcome data.* This is obtained primarily in connection to screening, and the only salient data are gathered if a client comes in for a follow-up or re-screening at a later point than his or her initial screening. Pre–post tests used to be conducted in education sessions, but attendees didn't like them so they were discontinued. Some short-term outcome data are available regarding linkage activities—this would consist of the increase in numbers of screenings conducted because of increased participation by other organizations.

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- *Long-term outcome data.* No systematic long-term data are collected; it is "too hard to track health behavior change." On occasion, however, a client with health problems is tracked over a period of time.

- *System change data.* Not collected.

- *Other data*. N/A.

DATA BY DRAFT UDS CATEGORY

- *Training healthcare providers (#1).* While this is not an official project task, medical residents and nurses nevertheless participate in screenings as a training exercise. No specific data are collected on their participation, though they are noted anecdotally in periodic reports.

- *Target population health education and outreach (#3).* Data are collected for education presentations using attendance sheets, and sometimes "head counts" (for numbers) or estimates (for demographics) by project staff. When presentations are conducted in a school or classroom, the class roll can be used to obtain number served. Process data on number of education sessions are captured on the Field Activity Form. Outreach contacts are recorded on Community Outreach forms; demographics are estimated. LaSalle staff also keep calendars and informal journals to record calls made and "everything else" that occurs in the conduct of outreach. Home visits are noted in client follow-up forms or put in patient charts.

- *Target population health educational materials development/dissemination (#4).* The project overall develops or translates a range of educational materials which are distributed at health education sessions. Training curricula are also developed. No formal data are collected on the development and dissemination of these materials, because they are often given out in informal contexts where they are hard to track. The American Cancer Society, however, does apparently track numbers of their materials disseminated.

- *Screening and referral (#5).* Numbers and demographics of screening clients are collected via Screening Forms filled out at the time of screening. Since names and addresses are also collected, unduplicated clients can be determined. Referrals are documented on a Client Follow-Up Form.

- *Case management (#6).* Case management and follow-up is provided for clients who have an abnormal screen result. Records of follow-up activities are recorded on a Client Follow-Up Form.

- *Linkage building/community coordination (#15).* This activity includes the maintenance

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of the project collaborative as well as the ongoing effort to "widen the net" by establishing linkages with community organizations and other medical professionals. Data on contacts made are kept on Community Outreach forms; data on presentations made at other organizations are kept on Field Activity Forms. Meeting records and minutes are also kept of meetings with the project collaborators (to which community groups are invited as well). Some short-term data, as mentioned above, can be gleaned from screening records that document an increase in the number of organizations at which screenings were provided.

Organizational capacity building (#16). This was conducted with project staff early in the project, but since the turnover rate has been low, these activities have tapered off. Capacity building has included staff training (e.g., from the American cancer Society), and the annual training of AmeriCorps volunteers. No formal data are kept, although these trainings are noted in the quarterly reports.

WHO COLLECTS/ANALYZES THE DATA

The outreach staff collect data and enter them into a Microsoft Excel database. Health educators collect data on education sessions. Screening data are collected by registrars at each screening. The database has been developed by the administrative assistant. Analysis is done by the Project Coordinator.

TECHNOLOGY USED

Paper forms are used to record the data, after which they are entered into databases in Microsoft Access (hospital) and Excel (nurse/outreach).

OPTIMUM TECHNOLOGY

Einstein staff would prefer either an Internet-based data system or a Microsoft database that is sent to projects on disk.

DATA COLLECTION BARRIERS/ISSUES

Generally, the data collection system is well-staffed and collects a substantial amount of data, especially in connection to screening. The few problems mentioned had to do with patients not filling out forms completely (so empty data items) and delays in getting medical information from other providers. Outreach staff also mentioned the classic data collection problem with respect to outreach: how to document the extensive unrecorded activities and after-hours work that take place in the face of so many barriers, including language, weather, and others.

DEFINING CLIENT IMPACT

According to the Project Director, the CAP project 1) increases awareness of cancer as a preventible disease; 2) increases access to screening; and has increased the move to treatment for underserved populations.

DESIRED DATA (WHAT WOULD BEST TELL THE STORY?)

Despite all the data that are collected, "it is hard to know if health behavior has changed. We

need follow-up." As one measure of increased awareness in the population, it would be possible to count those who got their first screening then returned for follow-up screenings since that information is in the client database. An argument for impact can be made just on the basis of the increased number of screenings conducted in populations that traditionally do not access care until late diagnosis. However, to show impact on mortality, "we would want to follow-up those who are screened versus a control group who are not. [But] it takes a long time to determine."

Technical Assistance Needs to Implement a Uniform Data Set

N/A.

Other Comments

N/A.

Commonalities and Conclusions

Several lessons from the site visits described above were viewed as important for UDS development. First is the clear integration of health and other social conditions. This refers to the encompassing nature of "health intervention" that is true for so many of the grantees/SCAs that are racial/ethnic minority CBOs, where the specific health issues they are targeting via their project are ensconced in a web of related social conditions. At Little Singer, for example, diabetes was clearly related to diet, which was clearly related to poverty and social depression—the latter of which is itself related to both poverty and the current social position of American Indians. In such a case, it is unclear what data can meaningfully capture project accomplishments. Specific project activities set out with goals and objectives become more of an anchor point than the sum total of all the activities that take place. *Any* intervention or activity that has an impact on the specific health problem or its associated social conditions is, in reality, and important piece to consider. However, many of these activities are unplanned and few are likely to be picked up in whatever data are gathered. The following is one of several ways in which a preset list of "activity categories" under which data are to be collected (such as we have proposed for the UDS) will be useful: for even if an activity was not listed under the goals and objectives, a data category may be available through which to record its occurrence, and that data category will include descriptions of the kinds of data that are needed, thus serving as a guide of sorts.

Related to the above issue is the *under-reporting tendency*—the fact that many activities, and the breadth of many activities, simply go unreported, either because data are not collected for that activity, or because the data that are collected cannot begin to cover what is involved. A perfect example of the latter is health education and outreach. The data may include counts of materials distributed, or persons attending a presentation, but they will not capture the extensive "off hours" work involved in building and maintaining the community relationships necessary to carry out the activity. For example, in the Cambodian Family project, outreach staff had to intervene to mediate disputes, provide emergency interpretation, and any number

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of other tasks which were not part of their listed tasks. But their involvement of this nature was important in gaining community trust and credibility for the program and laying the groundwork for community participation.

To capture at least some of this kind of impact, and non-numerical impact in general, we have determined that, for each activity category in the UDS, there will be at least one "semi-qualitative" question. The question(s) will not require any extensive grantee/SCA effort, but will encapsulate a type of information that many grantees/SCAs often include in their quarterly reports, though not in an organized fashion. An example of such a question is: *Please describe how your work in this activity category has impacted on three clients (either individuals or organizations)*. This would allow the grantee to select examples of client impact that show the broader range of what they do and what is involved. Moreover, narrowly focused qualitative questions such as this do not pose a great analytical burden for OMH. The analysis would simply involve, for each category, some coding or review of all response and identification of the major themes (e.g., "the three main ways in which activities under category X impact clients are a, b and c"—followed by anecdotal material).

Other data issues arising in the site visits include the blending of funds from multiple sources. On some projects, there are several funding sources that support overlapping activities. This does not mean there is an inefficiency, for those multiple funds allow for a greater flexibility to buttress staff capability from time to time as needed. What it does mean is that the attribution of outcomes or impacts to OMH funded activities can have "blurred edges" because the direct connection with OMH is not always discrete.

Finally, evaluating performance with respect to these kinds of projects must, of necessity, involve relative judgement. It must begin with an awareness of context and of where the target population is with respect to the health issue. A success for one project may simply mean that, over time, some segment of the target population begins to accept the idea that prevention of a particular health condition is even possible. The "numbers" may not tell the story.

Technology for a Uniform Data Set

Based on the site visits, we continued to believe that the UDS should be presented to grantees/SCAs in several forms. All awardees should receive paper versions of the UDS forms. At the same time, Internet accessibility, while still problematic for a few grantees/SCA,[%] will most certainly be increasingly salient and familiar by the time a UDS is implemented. A UDS on disk might be an option as well, but the option of entering data through a Web site (by project ID number) opens a wealth of possibilities in terms of ongoing and productive contact between OMH and its grantees/SCA, and in terms of data management.

*The Little Singer site, for example, was just connected to the Internet, and only by microwave.

7. Pilot Test

The final stage in UDS development was the conduct of a pilot test with a sample of nine grantees/SCAs. These pilot test sites were to use the UDS as their data reporting form for one sample 3-month reporting period, then fill out an evaluation form and participate in a conference call to discuss their pilot test experience.

With respect to sampling strategy, we determined that, for the pilot test, it would be best not to include any sites that had previously participated in the site visits. There were several reasons for this: 1) that pilot test conditions mimic as much as possible what would ultimately occur when the UDS is first sent out for use by OMH grantees/SCA; and 2) because some duplication would be involved, particularly since (during the site visits) we had already obtained sample instruments and data collection forms used by sites, some of which we adapted for use as general data collection tools for inclusion in the pilot test technical assistance package. Thus, some test sites might be piloting data collection instruments that they already had worked with, or even developed. With this understanding, we selected sites using criteria similar to the site visit sample—that is, to include a diversity of grant types, geographic location, and populations served. The nine OMH grantees/SCAs participating in the pilot test were:

- Chicago Women's AIDS Project, Chicago, Ill. (HIV/AIDS Minority Health Coalition)
- Porcupine Clinic Health Board, Porcupine, S.D. (Minority Health Coalition)
- Ke Ola Mamo Native Hawaiian Health Care System, Honolulu, Hawaii (Minority Health Coalition)
- La Clinica del Pueblo, Inc., Washington, DC (Bilingual/Bicultural Demonstration)
- Asian Pacific Development, Aurora, Colo. (Bilingual/Bicultural Demonstration)
- Union of Pan-Asian Communities, San Diego, Calif. (Bilingual/Bicultural Demonstration)
- Community-Based Organization Resource Network/CBORN, Miami, Fla. (HIV/AIDS Technical Assistance)
- Georgia Department of Community Health, Atlanta, Ga. (HIV/AIDS State and Territorial Demonstration)
- Children's Hospital of Philadelphia, Philadelphia, Pa. (Standard Cooperative Agreement)

Participation in the pilot test included a training on the use of the UDS. To help sites collect their data, DSG also developed a draft technical assistance "minipackage," together with

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sample data collection records/forms for use in regular collection of data from different activity types. Some of the sample forms were adapted from materials that had been successfully used at projects visited during the site visits. The technical assistance package is included as **appendix 7A.** The 1-day training was held on March 12, 2001, at DSG's Bethesda office. In addition to introducing the pilot test and the project to site representatives, and reviewing the UDS form and technical assistance material, the training included a working session during which we went through every Activity Category to see if the category and its questions corresponded to what trainees did (if they engaged in activities in that category). During this process, trainees brought up a range of questions and issues which required revisions in the UDS before sending it out. Questions and issues raised included the following:

A. How would different types of language interpretation (e.g., consecutive, group) be handled using the UDS?

B. Does "mentoring" include organizational mentoring?

C. Does the category "cultural activities" include ceremonies and rituals?

D. How does the form capture education/awareness materials that are adapted, but not originally developed by the grantee?

E. Faith-based organizations need to be added to the organizational categories.

F. The use of attendance logs and evaluation forms will work for smaller group education sessions, but not so well for large groups.

All sites were contacted to determine what software format would be most useful for a UDS on disk. Answers varied widely; some sites did not have or could not use Microsoft Access, some wanted the UDS in Microsoft Word. After these phone calls, it was determined that, for pilot test purposes, data would simply be reported on the paper form, and we would continue to develop a demonstration disk or Internet UDS format with the supplemental funds (as discussed with OMH), to be based on the technology survey of OMH grantees/SCA.

The pilot test of the UDS began (officially) on April 1. The nine pilot test sites were to collect their data for a 3-month period (through June 2001) so that they could be reported on the pilot UDS form. Follow-up calls were made during the test period to check on the progress of implementation. Three sites had continuing problems or delays in data collection and implementing the UDS: the Porcupine Clinic (South Dakota), Clinica del Pueblo (Washington DC) and Asian Pacific Development Center (Colorado). In one case, delays were the result of staffing changes. Staff from that site who attended the training no longer worked there, and it was necessary to resend the entire package (UDS and technical assistance materials) to the person identified as responsible for data. Delays in the other sites were either because they were preoccupied with other issues, or short staffed.

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After July 1, data reported on the UDS for the pilot test period were requested. There was some lag time in returning data, and DSG staff did not receive all data until August. As will be described below, the initial data submissions were incomplete, requiring some technical assistance interaction before being finalized.

Analysis of Pilot Test Response

Eight of the nine test sites submitted data using the pilot UDS forms. As completed data forms were sent in, DSG staff reviewed the forms for completeness and errors. **Appendix 7B** summarizes the data submitted in the UDS pilot test. The initial review of data showed that all returned UDS forms had at least some missing data or omissions. The lowest number of omissions was one and the highest was 23 (see **appendix 7C** for complete list of common errors and missing data). Pilot sites were contacted to correct these problems. After the technical assistance was provided, six sites were able to complete their data. The other two sites were unable to make the corrections, owing to staffing changes and grant termination. The ninth site (Porcupine) never submitted final data.

The most frequent data omissions were 1) complete demographic data and 2) and full qualitative impact responses. Five sites were unable to provide one or more demographic items (age, gender, race/ethnicity) in one or more modules. This occurred because sites often did not collect the detailed level of demographic data requested on the UDS. Six sites were also missing qualitative data in one or more modules. The qualitative data were sometimes not included because sites (as brought out in the conference call) did not always understand where they could obtain these data.

Note that the following modules were not tested because none of the sites conducted activities that would require them to complete these modules:

Module 8: Academic Support/Career Preparation

Module 9: Mentoring

Module 10: Parent Skills Training/Family Counseling

Module 11: Self-Esteem Building

Module 13: Recreational/Sports

Module 14: Crisis Intervention

Specific Problems in the Uniform Data Set

The following comments were made by pilot test grantees/SCA concerning problems and

ambiguities they encountered with specific activity modules.

Module 1: Training Health Care Providers—Clarification is needed as to whether section III (Short-term Outcomes) pertains to trainee evaluation of materials or trainee evaluation of the trainer, or both. *Note that the question is actually intended for reporting of data on trainee outcomes; that is, changes in awareness, knowledge or skills. This will have to be made clear.*

Module 2: Language Interpretation—In section II [Sessions Conducted and Short-term Outcomes], Question 1, the table lacks a column in which to supply the "percentage of clients that received a follow-up . . . ." The question asks for this information, however none of the sites completing this module (3) provided it. *This omission was clearly due to an error in the table, which in fact did not have a column in which to enter any follow-up data.*

It is also not clear whether Question 4 on translated materials is asking for the total number of materials or the number of types of material. *The table will have to be modified to include separate columns/rows in order to make the distinction clear.*

Module 3: Target Population Health Education and Outreach—Three of the 6 sites completing this module omitted or incorrectly reported information in table 3–2 [Number of Sessions Conducted]. In one case, the project representative entered information about individual sessions, whereas, in the previous section, information on group sessions had been entered. *These differences will need to be emphasized in training and training materials, and in general definitions.*

Module 4: Target Population Health Educational Materials Development/Dissemination—Two of the five sites completing this module did not appear to understand that the first table in Section I [Materials Developed for and Disseminated to Target Population], is for the total number of materials and the second table is for the types of materials. *While the two tables are clearly marked as calling for different kinds of data, it may be necessary to emphasize the difference in training and training/technical assistance materials.*

In addition, two of the 5 sites did not respond to Section II, Question 1 [on how the language and graphics of any materials are appropriate for the target audience]. *Again, this may be a training issue.*

Module 5: Screening and Referral—Neither of the two sites completing this module used CPT codes for types of referral and screening. *Because of their complexity, we are dropping CPT codes and substituting a simple screening code*

Module 18: Needs Assessment—Two of the three sites completing this module did not answer Question 6 ["Does your project address gaps identified in the needs assessment?"].

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Pilot Test Evaluation Response

An evaluation form was developed and sent or faxed to all sites seeking feedback on their use of the UDS. A copy of the form is included as **appendix 7D.** Six of the nine test sites returned their evaluation forms. The following is a summary of the responses on those six evaluation forms.

All of the test sites said that the UDS was, overall, easy to use and that the instructions were clear and easy to follow. In addition to this, all reported that they understood the core-module structure of the UDS.

Three sites said that to complete the UDS they had to collect new data. For one site, these were data on linkage-building, community coordination, and resource coordination. The remaining two said that to properly complete the forms they would have to begin to collect different demographic data. One of these did not collect race/ethnicity or age. The other did not collect gender information. Since most of their clients are Latino, they felt it might be possible to deduce this from the client's first name, but decided to add gender because "sometimes we run into clients we thought were females because of their first name who ended up being males… [and] because we serve other languages which client's first name does not necessarily tell us about the person's gender."

Most respondents reported that they were able to collect and report the necessary demographic data (ethnicity/race, gender, age). One site representative said that they do not collect data on ethnicity "because we ask for client's country of origin . . . [but] it is not difficult to provide an estimate of clients' ethnicity since our clients are overwhelmingly Latinos."

All six sites said that they were able to collect and report the necessary data for gender, however, two of the six respondents did not report these data on the UDS forms. Two respondents said that they were unable to report the necessary data on age because they are not something they ordinarily collect, and they were unaware that the data were needed.

Four sites said that they were able to provide information on the qualitative impacts of activities on their clients. The remaining two reported that they had trouble because they do not have a system in place for collecting client feedback or because they did not know where to get these data.

Four site representatives reported that they were able to use the UDS for their own organizational needs and to help them organize their own data collection. One site said that they would use it "to keep more accurate records for use in grant reports and proposals." Another said "the pilot exercise somehow helped us to rethink our data collection process... [and] review and update our forms."

Only two sites said that they had used any of the technical forms provided to help collect data. One said that they had used forms for the language interpretation module, and the other did

not elaborate. In conversations following the end of the pilot test, we learned that one site has adopted the technical forms for regular data collection use.

The overall response to the UDS was positive. When asked which features were liked best, project representatives said that “it helped our project become more organized,” it was “user friendly,” and a “simplistic” and “clear way to put data.”

When asked what was least liked about the UDS, one site said that they found the numbering system confusing. Other comments were that there are “too many categories” and “some questions seemed repetitive.” Finally, one site said that they would have liked the UDS better if it were on computer.

The only suggestion given for improving the UDS was to make it computer-based.

Summary of Conference Call With Pilot Test Sites (Sept. 28, 2001)

A conference call was held with Uniform Data Set pilot test sites to discuss their experience using the draft UDS instrument. The conference call was intended to augment information provided in the evaluation form, and cover implementation issues in more depth. Comments made in the conference call, as in the pilot test evaluation, were incorporated into the final UDS revisions.

Conference call participants included

- C–BORN project, Miami, Fla.
- Union of Pan-Asian Communities, San Diego, Calif.
- Chicago Women’s AIDS Project, Chicago, Ill.
- Clinica del Pueblo, Washington, DC
- Porcupine Health Clinic, Porcupine, S.D.
- Violet Woo, Project Officer, Office of Minority Health
- Mark Edberg, Project Director, DSG
- Alan Bekelman, President, DSG
- Frank Wong, Strategic Consultant, DSG

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Kristen Corey, Research Associate, DSG

A sixth pilot site had to cancel its scheduled participation. Three remaining pilot test sites could not participate because of scheduling conflicts or personnel changes.

The following is a summary of key points discussed during the call:

General Ease/Difficulty of Use

There were varied responses on the overall issue of ease or difficulty of using the UDS—two projects found the form generally difficult; others found it relatively easy. Those who found it most difficult felt that the data called for in the UDS differed from what they customarily collected, requiring new data or the adaptation of existing data. There was also some confusion between the UDS and the OMH data form in current use. One project found the qualitative data elements time consuming to complete. Another felt completion of the form would have been easier if there were ongoing data collection forms to help (NOTE: such technical assistance forms were provided with the training materials). The technical assistance project (C–BORN) said that the form did not have enough space to accommodate the large number of trainings conducted or the diversity of organizations served. At the same time, several projects found the UDS easy, and despite the difficulties referred to earlier, C–BORN was "excited" because the UDS gave them a data collection format they previously did not have. Finally, most projects felt that the process would be easier if it could be completed using a computer, with software or on the Internet.

General Structure

All participants understood the general core-module structure, and the purpose of the activity modules.

Specific Problems and Suggestions

Again, the C–BORN project encountered difficulties because that project provides technical assistance (TA) to a broad range of CBOs that are diverse not only in terms of language/culture but in terms of how far they have developed as organizations. Thus the impact of their TA varies greatly by (at least) these variables, and the impact information requested on the UDS does not capture this diversity. (One suggested solution was to include in Activity Module 16 a grid of organizations served by organizational "newness" and by the organization's target population.) The C–BORN representative also commented that there is no way to capture differences in outcomes between specific groups, for example, differences between native and non-native English speakers.

Clinica del Pueblo is an interpretation/translation project that conducts simultaneous interpretation, consecutive interpretation and translation (of documents). The Clinica representative felt that the types of data requested in Activity Module 2 (Language Interpretation) did not capture these three types. Nor is there space to note whether the client is insured/not insured, which is one of the criteria they use to determine client eligibility for the

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service. The UDS also requests demographic information about providers served by the interpretation service—data that Clinica does not collect. Finally, Clinica would like data on why clients miss appointments. (Such data, however, are beyond the scope of the UDS.)

At least two projects did not know where they could fit data on health fairs, cultural activities, or similar community events. (This information is supposed to be placed in Module 3, Target Population Health Education and Outreach. However, it must not be clear that Module 3 has places for entering health fair/meeting data.)

The Chicago project said that there was no module in which to include data on such modalities as performing arts or rallies (These probably fit under module 3, Health Education and Outreach).

Obtaining unduplicated numbers is a general difficulty for many projects, as is obtaining demographic information on client/provider populations. For instance, race/ethnicity data are not always available—sign-in sheets for community education meetings, for example, may not ask for this information, and it is not always possible to glean ethnicity from names themselves. In addition, the representative from Clinica pointed out that the standard 'male/female' gender categories do not fit Clinica's population, which often includes self-identified transgenders.

At least two projects found that the qualitative data sections were time consuming, because it was necessary to review records of focus groups, meetings, or program evaluations to pull them out.

It was also noted that some intervention modalities are linked together (through referrals, for example). These links are not clearly captured on the UDS.

OVERALL POSITIVES

Despite the specific problems mentioned, most projects welcomed the UDS as a much-needed step toward management of data. It was, said one participant, a "ray of hope." The UDS can also serve as a framework for data collection where no such framework exists.

TECHNOLOGY

Most projects said that they would like the UDS provided on disk (with software) or via the Internet. Only one participant said that project staff might not have enough Internet familiarity to use the UDS through that modality.

Implications

In developing a UDS with field input, there is often the need to assess comments against goals and requirements that may not be familiar to grantees/SCA or field projects. Thus, while some pilot test sites had difficulties, the overall response has been positive. The UDS clearly fulfills an important need and, for most participants, appears reasonably easy to use. Some of the

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reported problems will require modifications: for example, Module 16 (Technical Assistance) will need expanded grids to account for the variety of CBOs that may be receiving technical assistance; Module 3 (Health Education) will need to include performance arts, rallies, and other activities under the definition of health education; Module 3 will also have to be modified to more clearly capture health fairs; Module 2 (Interpretation) will need to include different types of interpretation. We may also want to include more detailed suggestions as to where/how sites can obtain their qualitative data.

Moreover, some of the problems that occurred in the pilot test were exactly the type of problems we hoped to uncover—instances where the form was incomplete, ambiguous, or in error. Awareness of these problems contributed to an improved final form.

There were some differences between conference call and pilot test responses. This, we believe, is due to the format—a telephone call in which a range of views could be aired, even if they strayed somewhat from the specific issues set out for comment. Some of the comments (e.g., the request to include a financial management system with the UDS) were clearly out of scope, and other comments resulted from situations particular to individual sites. The C–BORN representative was new, and had never been to the training or received any of the technical assistance calls/materials, and so she had questions that ordinarily would have been answered at an earlier stage. The same was true for the Porcupine Clinic representative—in that case, the person who attended the training left the project and a considerable amount of time elapsed before the UDS was given to the current representative. Finally, some of the comments seemed to stem from an optimism that the UDS would report project-specific information that grantees/SCAs feel is important for OMH to know when making funding decisions and in addressing gaps and unmet needs.

As indicated in the analysis of pilot test problems, there are a number of issues that needed to be clarified in any training and technical assistance provided for implementation of the UDS. These issues include

- How to obtain/record certain types of data, including demographic and qualitative data.
- Distinguishing the differences between *numbers* and *types* of materials, or between *individual* and *group* training/education sessions.
- In evaluating training *impact,* we generally mean impact on trainees, in terms of their knowledge, awareness, or skills.

Final UDS Data Elements

Following the pilot test, the UDS was further modified, resulting in its final form (**appendix 7E**). A full paper version of the final draft was sent out (by FedEx) to all Project Advisory Group members for comments by telephone or e-mail. No substantive changes were recommended.

8. Grantee Technology Survey

This chapter describes a telephone survey added on to the original contract tasks via contract 231–99–0011, modification 1. The purpose of this telephone survey was to assess the capacity of grantees/SCAs to collect and manage the data collection called for under the proposed UDS, and to determine the technological format (e.g., disk, Internet, paper) most favored by them. While we have made a concerted effort throughout the development process to create a data set that is user-appropriate and user-friendly, this survey provided additional data in support of our final recommendations as to the best format for implementing the UDS.

The brief telephone survey was conducted with a small sample of grantees/SCAs to gain a better sense of technical capacity. Four groups of nine current OMH grantees/SCAs were selected for participation. Three of these groups were those participating in the focus groups, site visits, and pilot test. The remaining group of sites were selected using criteria similar to the site visit and pilot test sample—that is, to include a diversity of grant types, geographic location, and populations served.

Of the 36 projects originally selected for the sample, six were duplicates. The 30 remaining unduplicated projects were contacted and asked to participate in the survey. There were some difficulties in enlisting participation, including: staffing changes and grant expiration (n=2), time constraints (n=1), and inability to reach contact person (n=5). The final list of 22 survey participants is included as **appendix 8A.**

The 22 participating projects were from CBOs (15), government agencies (5), and universities (2). Numbers of OMH-funded staff in these organizations ranged from 1–16, with five organizations having 10 or more staff and 16 having five or fewer. Twelve projects used volunteers in addition to regular staff, but the volunteers were excluded from the count.

Grant types represented in the survey were Bilingual/Bicultural Service Demonstration (5), Minority Health Coalition (5), HIV/AIDS Minority Health Coalition (4), HIV/AIDS State and Territorial (4), HIV/AIDS Technical Assistance (2), and Cooperative Agreement (2). The majority of surveyed projects (20) also received funding from other government agencies (Federal, State, local) and private foundations.

The target populations of surveyed projects include Asian and Pacific Islander (6), Latino (6), African American (4), and American Indian (2). Eight projects did not target one specific racial/ethnic group. Most (19) of the surveyed projects targeted one or more specific health conditions/issues, including HIV/AIDS, diabetes, chemical dependency, cancer, and cardiovascular disease/stroke.

Most (19) surveyed projects conducted two or more of the following activities (according to UDS categories): target population health education and outreach (12); technical assistance and

organizational capacity building (7); screening and referral (6); training healthcare providers (4); language interpretation (4); linkage building/community coordination (4); target population health educational materials development/dissemination (3); case management (3); resource coordination (3); wellness and exercise activities (2); and needs assessment (1).

The "Data Technology Needs Assessment" phone survey began in October 2001. The survey instrument was developed by DSG staff and approved for use by OMH. The instrument is included in **appendix 8B.** The instrument was used in a flexible manner to accommodate the wide range of grantee types, and to account for previous interactions (through the focus group, site visits, and pilot test) DSG had with a number of the respondents. The results of the survey are described in the following, and summarized in **appendix 8C.**

Findings

Data Collection, Management, and Reporting

Survey participants (n=22) were asked about the types of data they collect for their OMH project. The results are as follows:

Type of Data	Projects Collecting (#)
Race/ethnicity of clients	19
Number of clients served	21
Number of events, trainings, screenings, etc. conducted	20
Number of materials developed and/or disseminated	19
Evaluation data	17
Health outcome change data	6
Other types of data	13

Only one project reported not collecting any "hard" numerical or quantitative data. All other projects reported collecting some combination of the above items.

"Other" types of data included 1) demographic or other information on clients [i.e., country of origin, age, gender, risk behavior, household structure, SES/income, address, date of birth, name, insurance status]; 2) provider information; 3) location and length of event [i.e., interpretation, medical appointment, health screening, health education]; 4) reason client sought services/events [i.e., health condition, limited English proficiency, limited access to health care]; 5) information on coalitions/linkages; 6) funding sources for programs to address problems in community; 7) information on client follow-up; 8) community needs assessment; and 9) qualitative data or 'stories' on client experiences and outcomes.

Data were collected from a wide variety of sources, including event sign-in logs; meeting minutes; finance sheets and fiscal reports; progress notes and quarterly reports; participant, client, or provider evaluation/comment forms and surveys; and client charts. Data were most

commonly collected from the 'field' records of staff (i.e., interpreters, outreach staff, trainers/educators, counselors, case managers, healthcare providers] from events [outreach activities, interpretations, screenings, home visits, health fairs, workshops, phone infoline calls, case follow-ups).

Eighteen of the 20 projects receiving funding from other agencies said that they had to collect data for those agencies as well as for OMH. Most of these said that some of the data were similar, specifically the demographic and other quantitative data, although they were not necessarily helpful because different funding agencies often ask for the same data in a different format.

For most projects, data were collected using internally generated forms, however, at least one project site was using forms included in the UDS pilot test technical assistance package. In addition, four sites were collecting some of their data using computers. In one project site, data collected during calls to an information hotline were entered directly into the project's database.

For the most part, data were kept both in paper format and in a computer database. One project had only computer records of data because they did not use paper records. In this case, the Project Director was the only staff member and the data he collected were entered directly into the computer in the form of meeting and communication notes, periodic reports, and fiscal reports.

Two projects did not keep a computer database and had only paper records of data. In one case, the establishment of a computer database was pending. In the other case, a computer database was kept by the project's external Evaluator, but not used by project staff.

Of those projects using a computer database to record and store data (N=20), for more than half (11), the same staff members who collected the data were responsible for entering it into the database. In the other nine cases, the data were collected by staff who then delivered them to specific staff members responsible for data management.

Of those storing their data in a computer database, 16 used one or more of the following software types: word processing (4), spreadsheet (9), data analysis (2), and database (7). The remaining four project representatives did not know what software was used for the database, however, all of these projects had identified the MS Office package in an earlier part of the survey.

Only 10 of the 22 projects were doing any analysis other than basic totals and tabulations. For all of these projects, extended analyses were done for internal use. For half (5) of the projects conducting extended analysis, analysis was done by regular project staff, such as Project Directors, Data managers, and Project Coordinators; whereas for the other half, analysis was done by an internal (2) or external (3) Project Evaluator. Two of the 10 projects were not using software to do these analyses, whereas the others were using word processing (3), spreadsheet (1), database (1), or data analysis (2) software.

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Extended analyses consisted of more complex statistical analysis (i.e., crosstabs), qualitative analysis, process evaluation, and community needs assessment. In most cases, they were aimed at improving programming, revising curriculum, evaluating community needs, and/or preparing grant proposals. Many of the 22 surveyed projects commented that they would do more complex analysis if it weren't for a few key constraints: access to appropriate software, technical assistance and training to learn software and data analysis, time and money, and adequate staff to dedicate time to such activities.

All of the surveyed projects said that they reported the same data they collected to OMH. In 15 projects, reports were generated primarily by the Project Director. Reports were generated by internal (2) and external (2) Evaluators in 4 other cases. In the remaining 3 cases, reports were generated by regular project staff.

All projects generated reports for OMH by computer using a set of guidelines and submitted reports on paper. Nineteen used a computer to tabulate the data before reporting. One project representative did not know what software was used to do this and 18 said they used one or more word processing, spreadsheet, data analysis, and database packages. The remaining three sites did tabulations by hand on paper, to generate reports.

Project representatives were asked about the overall ease of use of the reporting systems they use. The majority of respondents (12) said that they were easy to use, and that the OMH format specifically was easy because it is "pretty broad," "simple and captures what is needed," and "allows for narrative accounts and gives suggestions for constructing tables."

Survey responses also highlighted a few key criticisms of current reporting systems. One of these is that the instructions on reporting forms are often vague, difficult to understand, and "not user-friendly." One project representative said that they were confused about what to do if the data asked for are not available or don't easily fit into OMH format. Another project added that it is difficult to create internal forms to collect appropriate data or to construct a database when the reporting format is unclear.

Other projects thought that the more important issues were utility and time rather than ease or difficulty of use. For example, a few projects said that entering data into different systems to generate different summaries and reports for different agencies was cumbersome and often not useful to project goals and activities. One project said that their data was "limited to serve the needs of the funding agency."

This was an issue particularly for projects collecting data for multiple funding agencies. Just under half of the surveyed projects found that organizing data collection, analysis, and reporting for multiple agencies was difficult, time consuming, and often confusing. Some projects said that it was "difficult to categorize data across all agencies" and they often found themselves "reformatting data a number of times for each system or funding agency." Others said that the different forms, requirements, and reporting formats caused them to waste time "retracing steps" or "running separate queries on the same data for separate reports at different times."

Respondents discussed some common problems with data collection, maintenance, and analysis. One of these was receiving incomplete or incorrect data because of difficulties reading handwritten forms, difficulties collecting data over the phone, cultural issues, or other reluctance to provide information. Another issue was that data are not always received in a timely fashion. An issue with regard to data recording and maintenance was that database maintenance often is time consuming and projects often lack the staff to check the accuracy of data in the database. Another concern was not having the staff or software to do data analysis.

Computer Use, Skills, and Resources

Computers were used extensively in data management, analysis, and reporting. All projects used a computer to generate reports. Twenty also used a computer to record data in a database and 19 to tabulate or analyze data. Only four projects used a computer in actual data collection.

Overall, the Microsoft Office software package was the most commonly used for all applications (word processing, spreadsheet, database, graphics). All of the surveyed projects were currently using one or more applications in this package (Word, Excel, PowerPoint, Access). In addition, some were using multiple software applications for the same purpose. For example, 5 projects using MS Word also had access to or used WordPerfect.

Word was given as the primary word processing software by 21 projects. The representative from the remaining project did not know what word processing software they used, but said that they use other applications in the MS Office package. The most commonly used spreadsheet software was MS Excel, used by 17 projects. The database software MS Access was also used by 17 projects. Graphics software was used by fewer projects but, of those using any, MS PowerPoint was the most common (14). Only seven projects used any software designed specifically for data analysis (six SPSS, one other).

While none of the project representatives rated themselves or their staff as “experts” in the use of these software applications, most said that they were at least functional and only one rated his staff “marginal.” Overall, most said that skill levels varied by staff member and software.

When asked about the overall familiarity of project staff with the use of computers for basic tasks, such as inputting data or producing reports, a majority (20) said that either “all” (13) or “most” (7) of their staff were that skilled. The remaining two projects said that only “a few” staff had this level of familiarity with computers. In both of these cases,

All 22 project sites said that they had an Internet connection. Most (16) did not know the speed of the connection. Of those who did know, five said they had a DSL connection and one a connection at 56K. Two rural sites added that, while they do have regular access to an Internet connection, it is not necessarily reliable because of their location.

When asked about the overall familiarity of project staff with the Internet and ability to use it to

find information or other necessary tasks, 20 project representatives said that either “all” (15) or “most” (5) of their staff were that familiar.

Despite an overall level of competence in the use of computers, the Internet, and software packages, many projects said that they did not feel they were able to take full advantage of their capabilities. While a few projects said that they either provide training to staff or require staff to have computer training and/or experience as a requisite for hiring, most agreed that it can often be difficult to get adequate training or to find experienced staff.

Optimum Data Technology

Projects were asked what they thought the best way to collect and record their data would be. Most said that what they were currently doing—for most, collecting data on paper and entering them into a computer database—was the best way. Most respondents argued that collecting data using a computer or the Internet was not feasible in the context of the work they do. A few projects commented that it would not be practical for field staff, such as outreach workers, to collect data in the field on computers because of financial constraints and the fact that clients may not be comfortable with that level of technology. Further, without adequate training, this manner of data collection might be too time consuming. The overall opinion was that computerized data collection would add to the work load of project staff: the data would still have to be collected on paper, regardless of where it ended up.

Almost half of the projects said that the Internet might be a good place to record and store data, provided that the system met a few basic requirements. There was consensus among these projects that the Internet-based system would need to be flexible enough to allow projects continuous access to their data and the ability to analyze or manipulate data online or easily transfer data to or from the Web site, data analysis software, or other reporting systems.

Despite their objections to changing data collection and recording systems, *most projects (20) thought that the best means of reporting data would be either via the Internet or e-mail. Most thought it would be faster and more efficient. Others though it could have the added benefit of allowing more contact with OMH and other funded projects to share ideas and project outcomes.*

Only one project said that it would be best for them to continue submitting reports on paper via regular mail and this was because of concerns about irregularities in Internet service. Another project said that they would do whatever was easiest for the granting agency, as long as they were supplied with training and necessary software.

A total of 15 projects said that they would prefer reporting data via the Internet. One of these argued that, although the Internet is preferable, it cannot be the only means of reporting for some rural sites who may not have reliable access to the Internet. Another concern was that the Internet-based system be flexible enough to be able to accommodate different kinds of

projects. For instance, some projects stressed the importance of being able to include comments or other non-numeric data in cases where project data are more qualitative than quantitative or where outcomes are difficult to represent numerically.

If particular software were required in the new reporting system most respondents had no preference as long as it was supplied or didn't add significantly to their costs. Many preferred software that could be used for multiple tasks, such as data recording and analysis, or software that they are already using or at least marginally familiar with.

Whatever the case, the majority of projects thought that some sort of training or technical assistance would be necessary for any new reporting system and should be provided because CBOs and projects staff often have varying technological skill levels. For some, this was minimally basic instruction on the new reporting system. Others thought that more involved training and the option for ongoing assistance would be preferable.

A Preliminary Internet Reporting System

Based on the technology survey and the Uniform Data Set development process, we have developed a preliminary, demonstration, Web-based data-reporting system, using three sample UDS modules.

The OMH UDSPT Web is the Beta version of a Web-based software application that streamlines the interagency information-sharing between OMH clients and DSG. It allows us to gather information from those clients instantaneously, in addition to giving the clients a dynamic storage facility for their evaluation reporting records. The application was developed to facilitate our client's ability to obtain quality evaluation reporting within a short timeframe. The application validates data and visually cues the user with regard to contradictory record information as well as the clarification of historically difficult questions. A JavaScript checks for accuracy and logical relationships between answers, while the historically difficult questions are clarified by a detailed description using Overlib. Because these descriptions are only displayed when the user moves his or her cursor over the questions, the application allows for the presentation of help and advice that would not fit on a hardcopy of the form. Greater detail regarding the nature of a question can be gained by e-mailing OMH project staff at DSG. The application is capable of storing thousands of records. Currently it can be accessed by up to 25 users per simultaneous logon.

OMH UDSPT's Web address is
http://www.dsgonline.com/Practice/OMH_UDSPT_BETA1.html.

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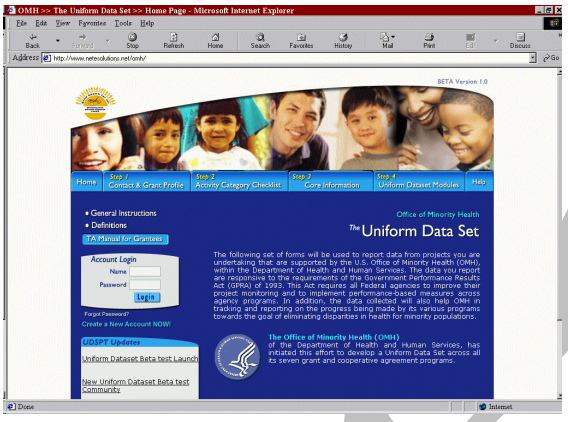

Initial Login Page (index.html)

The Initial Login Page describes the Web application and the data set forms. After detailing the purposes of the application, the initial page offers users the opportunity to either access a previously created account or create a new account. If the user chooses to start a new account, the user needs to select a user name and determine a password. Each organization should only use one account.

Upon creating an account, the user is invited to log into the system. Upon logging into the system, the software checks the record for previous visits by that user. If it is the first time the user has logged into the application, the user must complete the General Contact and Grant Information Form. This form records the current project reporting date and the contact information regarding the organization. The information will be used to contact the grant recipient if there are questions or issues regarding the Web application or data set.

Upon completing the General Contact and Grant Information Form, the user is transported to the main page of the Web application. This is the page that will be initially accessed by the user during all future logins. There are five tabs:

- Pilot Test—Instruction (a “help” function)

- General Contact and Grant Info

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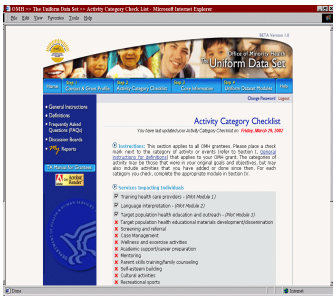
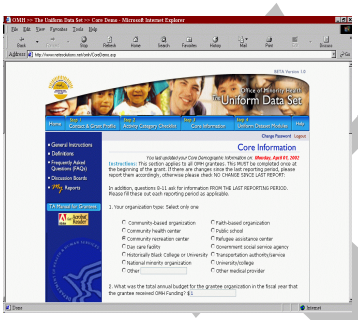
Activity Category Checklist

Core Demographic Information

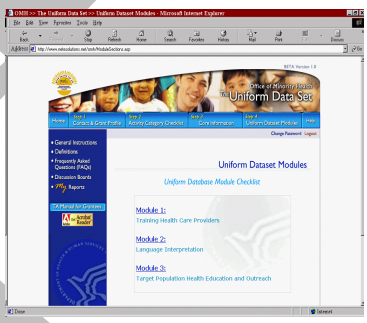
Uniform Dataset Modules



Activity Category



Core Demographic



Uniform Dataset

Each tab records key information regarding the Uniform Data Set.

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9. Summary and Final Uniform Data Set

As described in the preceding chapters, the project goal was to develop a Uniform Data Set (UDS) that would apply to all OMH grants and the standard cooperative agreements. The development process included input from a range of agencies and organizations mounting similar efforts and, crucially, from grantees/SCAs as well. The resulting UDS, attached in **appendix 7E,** is the culmination of those efforts. As noted previously, it is a core-and-module data set, with 18 activity categories that we believe are sufficient to encompass all the activities currently engaged in by OMH grantees/SCAs. Moreover, these activity categories have been developed inductively, by gaining a better understanding of what grantees and cooperative agreements do, then by creating a typology based on that understanding. The data to be collected and reported in each category represent a mix of OMH needs and grantee realities. Thus the *uniform* aspect of the UDS is category-based—all grantees/SCAs conducting a given activity will report uniform data, and comparisons can be made across grantees within any category.

While it is difficult to obtain substantial outcome data from OMH grantees/SCAs (because of the relatively short grant timeframes, blending of activities with those funded by other agencies, lack of available and relevant outside data at the local level, etc.), we were in some cases able to include at least short-term impact data. Many of the other data collected in the UDS are important intermediate and process data that indicate progress in building capacity, engaging the target community in health promotion, and providing better access to health care for racial/ethnic minority populations.

As we have stated, all our grantee input—and our own experience—points toward implementation of the UDS via the Internet (Web site). Doing so would address most of the issues that have come up during the development process. A few examples:

- Grantees/SCAs are often short staffed, and a Web-based system would include “help” functions as well as automatic checks that would assist them in providing good data.

- The Web site itself opens a significant channel of communication between OMH and its grantees/SCAs, providing online help and technical assistance, including data collection forms and other technical assistance materials.

- Both grantees/SCAs and OMH could use the Web site to create reports at any time to check progress.

Through the contract modification, we have developed a demonstration version of a Web-based UDS that features many of the most useful functions.

Finally, it is our recommendation that OMH would benefit the most by implementing the UDS

via an ongoing data coordinating center, either within OMH or through an external source. Many Federal agencies have taken this route. Having a data coordinating center (DCC) means that there is ongoing monitoring of the data collection function, staff available at any time to generate reports and address problems (as well as update the UDS itself as necessary), and, significantly, a technical assistance capacity—to provide training to grantees/SCAs in use of the UDS as well as ongoing assistance, helping to ensure that the OMH data collection process is useful and functioning well.

Development of this UDS also serves as a model for collecting evaluation data on community-based racial/ethnic minority health projects. It is at least a step toward documenting the important function such projects have in the overall effort to eliminate disparities in health.

Recommendations

The following recommendations summarize our conclusions from the development and testing of the Uniform Data Set:

Recommendation 1

OMH should implement the use of the UDS described in this report (final version in appendix 7E), a core-and-module data set in which the modules are based on a standard typology of grantee *activities*—the only comparative data possible given the variety of grantees/SCAs. The UDS as developed will provide a significant amount of process and intermediate outcome data for all OMH programs, and should contribute substantially to OMH's ability to assess multiple programs as well as provide information to Congress.

Recommendation 2

The UDS should be implemented using Internet/Web technology, as demonstrated in the pilot Web version included as a final product under this contract. We believe that this will maximize both OMH and grantee resources, because a Web-based data reporting system is not only user-friendly, but it also allows for the provision of technical assistance (online) and will increase contact between individual projects and OMH. Moreover, once in place, it can serve as the platform for other functions—generation of reports for grantee, as well as OMH use, the conduct of special studies, online training or courses, and many others. At the same time, a paper reporting form should be an option, and ongoing data collection forms/materials should be made available in paper form, which is most convenient for day-to-day grantee use (such forms can be downloadable from the Web site).

Recommendation 3

The UDS should be implemented and maintained via a *Data Coordinating Center*, either

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internally at OMH or via an external source. This is the model used by several other Federal agencies, and we believe it will be the most effective model for OMH. A Data Coordinating Center can provide the following key functions:

- Monitoring the Web and/or paper data reporting system—overseeing its implementation, ongoing maintenance, updates, and troubleshooting.

- Monitoring the data collection and analysis—ensuring quality data, generating reports, conducting special analyses.

- Providing technical assistance—serving as an ongoing source of technical assistance to grantees/SCAs (available online or by telephone), in terms of data reporting, and in terms of devising systems of ongoing data collection (day to day) that support quality data reporting.

- Providing grantee training—Every time new grants are awarded, the new grantees/SCAs will need to be trained in the data reporting system. OMH staff may also benefit from training in order to make maximum use of the system.

- Supporting special OMH data needs—if for example, a special study is needed, or in reporting to Congress or other entity, a Data Coordinating Center can provide ready expertise, freeing OMH staff to focus on program issues.

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