



Elimination of health disparities in racial/ethnic minority communities: developing data indicators to assess the progress of community-based efforts

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Abstract

This paper describes the development of a pilot uniform data set (UDS) intended to serve as the primary data collection mechanism for all grants and standard cooperative agreements funded by the US Office of Minority Health (OMH), within the US Department of Health and Human Services. OMH is mandated by Congress to coordinate Federal agency efforts to improve racial/ethnic minority health status and eliminate disparities in health, health care, and access to care for these populations. The majority of OMH programs are directed to racial/ethnic minority community-based organizations (CBOs), and 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 in support of *Healthy People 2010* goals concerning the elimination of health disparities. A range of OMH-awarded grants and cooperative agreements fund these projects. A key issue has been the need for uniform data across these programs, and the UDS was developed in response to this need. The modular format and content of the UDS was the product of a formative research process involving an advisory panel, focus groups, interviews, site visits and a pilot test aimed at identifying and defining appropriate data elements as well as an overall structure that made sense in terms of providing some form of standardized data across widely disparate projects. The UDS as developed is not only an important accountability and performance monitoring effort for OMH, but also a significant attempt to develop a data collection system that is meaningful for CBOs and the racial/ethnic minority populations they serve. Knowledge gained from the implementation of this system can be applied to general issues of evaluating community-based health programs, and to identifying/assessing the nature of progress with respect to racial/ethnic minority health, beyond its direct application to OMH projects.

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The purpose of this article is to describe a pilot uniform data set (UDS) that has been developed for the US Office of Minority Health (OMH), within the Department of Health and Human Services, to assess and monitor a range of process and intermediate outcome indicators that are important steps towards the elimination of racial/ethnic minority health disparities as articulated in *Healthy People 2010* (US Department of Health and Human Services). The UDS is intended as the basis for evaluating OMH program implementation, effectiveness and impact. In addition, this flexible data set can easily be adapted or tailored to fit the needs of local or community organizations. There are four major sections to this article: (1) a brief background to this effort; (2) a review of major conceptual and methodological

issues in the design of such a data set; (3) a description of methodologies used to create the set, and; (4) a description of data set elements and general implications of the UDS.

1. The need for a uniform data set across office of minority health programs

OMH is mandated by Congress to coordinate Federal agency efforts to improve racial/ethnic minority health status and eliminate disparities in health, health care, and access to health care for African-American, Hispanic/Latino, American Indian/Alaska Native, Asian, and native Hawaiian/Pacific Islander populations. The majority of OMH-funded programs are directed to racial/ethnic minority community-based organizations

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(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 the UDS was developed, 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.

There are several key purposes for the UDS effort: First is that the UDS will serve as the basis for evaluating program implementation and impact, and in doing so improve the evaluation and quality of OMH programs. In addition, the data collected will contribute to reporting requirements under the Government Performance and Results Act (GPRA). Second, and very important, the UDS represents a significant attempt to develop a data collection system that is 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/assessing the nature of progress with respect to racial/ethnic minority health, beyond its direct application to OMH projects (cf. Wells & Conviser, 1998). It is important to recognize the enterprising and ground level work these 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 via traditional performance indicators. 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, given the current program environment in which systematic data reporting is important for continued program support, such measures become necessary. Therefore, a further goal of the OMH UDS is the attempt to capture at least some of these unique program factors within a standardized data system.

2. Conceptual and methodological framework

2.1. Key issues in developing a uniform data collection system for racial/ethnic minority-based projects

There are clearly many issues involved in developing an adequate system for collecting meaningful data from these community projects. In this paper, we would like to focus on just a few of those issues.

Structural issues (limited data and multiple funding). First, there is simply a limited amount of data available for

many racial/ethnic minority populations and sub-groups (e.g. Hispanics from Central America, or Southeast Asian subgroups). OMH programs, unlike many more generalized interventions, often target specific racial/ethnic minority population groups (some native born/English speaking and others that are not). Outcome and other health data are rarely available by specific racial/ethnic minority population group, either at the national level or at local levels in particular, so there is no way to use such data as a benchmark for progress.

Secondly, recipients of OMH funding often receive funds from multiple sources. Because of this, no logic model for OMH programs can posit long-term outcomes (improvements in health status, or even in most cases increases in health care utilization) that are *solely* the result of the OMH program. The attribution of outcomes or impacts to OMH-funded activities may have 'blurred edges' because the direct connection with OMH is not always discrete. Measurable program outcomes will thus be those more closely tied to intermediate, not final outcomes with respect to health. This is even more true when one considers that OMH programs provide only short-term funding.

The integration of health and social conditions. By this we refer to the complexity inherent in the task of 'health intervention' that is so common for grantees that are racial/ethnic minority CBOs. The complexity exists because the specific health issues targeted by a given project are so often embedded in a web of related social conditions. At one (OMH-funded) diabetes and alcoholism intervention on an American Indian reservation, for example, the intervention activities were multiple, flexible, even ad hoc at times—but cognizant (in an informal way) of the linked relationship between diabetes, diet, poverty and social depression—the latter related to both poverty and larger issues impacting American Indian peoples. In such a case, what data can meaningfully capture project accomplishments? There are specific project activities as set out in goals and objectives, but these become more of an anchor point than the sum total of all the activities that take place. In reality, *any* intervention or activity that impacts on the specific health problem or its associated social conditions is an important piece. Yet many of these activities are unplanned and few are likely to be picked up in whatever data are routinely gathered. As described later in this paper, this is one of the many circumstances the OMH UDS is designed to address—in this case, the modular, activity-based structure of the UDS allows activities not listed under a project's original goals and objectives to be included in the reporting process by using any applicable data category to record their occurrence. Moreover, each data category includes descriptions of the kinds of data that are needed (for that category), serving as a guide of sorts to help systematize reporting.

Under-reporting of staff effort. 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 typically collected may include counts of materials distributed, or number of persons attending a presentation, but it will not capture the extensive ‘off-hours’ work involved in building and maintaining the community relationships necessary to carry out the activity. At one OMH project working with low-income Cambodian refugees, for example, outreach staff often had to intervene to mediate disputes, provide emergency interpretation, and take on other responsibilities that were not part of their listed tasks. But their involvement of this nature was important in gaining community trust and credibility for the program, laying the groundwork for community participation and an improved program result.

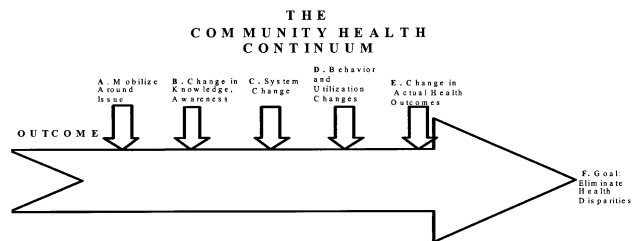
Success and relativity. Evaluating performance with respect to these kinds of projects must, of necessity, involve relative judgement. It must begin with awareness of context and of where the target population is with respect to the health issue. A success for one project may simply mean that, over time, some segment of the target population begins to accept the idea that prevention (of a particular health condition) is even possible. How can this be measured? Or, for projects providing technical assistance to CBOs, the assistance provided (and the outcomes expected) may vary significantly depending upon the capacity, experience and organizational development of the particular CBO.

The need to include some regular qualitative data. In order to capture at least some of the integrative, personal, and relative impact (non-numerical) discussed briefly thus far, 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 effort, but will encapsulate a type of information that many grantees 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 project staff to select examples of client impact that show the broader range of what they do and what is involved. Of course such examples are subjective choices and not statistically generalizable. Nevertheless, the examples serve primarily as a ‘vehicle’ for narratives about impact that are not otherwise recorded, yet often reveal important patterns. Moreover, narrowly focused qualitative questions such as this may not pose a great analytical burden. For each category, the analysis simply involves basic coding or a review of all responses 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). In later modifications of the instrument, some of the most common response themes, drawn from the qualitative data, may ultimately be presented as ‘check off’ responses, thus converting the qualitatively generated data into

a quantitative format. *This is just one example of how the UDS is flexible and can become more user-friendly over time.*

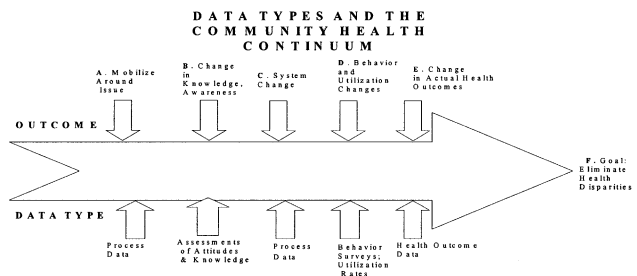
The importance of intermediate outcomes. All of this brings us to the importance of recognizing intermediate outcomes. While many health-related performance measures and data collection efforts focus on actual health outcomes, such outcomes are the result of a process, and a process that can take a significant amount of time. Furthermore, this process takes on added dimensions for many minority populations, because to reach some health outcome X, a whole host of other factors must be addressed, including poverty, language, access to care, historical patterns of use, awareness, disproportionate risk, and others.

Graphically we can represent this as an arrow, loosely called the Community Health Continuum, in which the elimination of minority health disparities is the goal.



Because of the range of barriers to health care for 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 in order 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. That is their primary role.

For each intervention point on the continuum shown above, program impact will be measurable by a particular type of data, as follows.



Because OMH programs intervene primarily at Points A, B, and C (and sometimes D), they are measurable by their commensurable data types:

- *Point A, Mobilization.* Primarily *process* measures such as the formation/growth 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, and 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 utilized by the target population—where such data are available.

2.2. Practical issues in constructing the uniform data set

In addition to the key issues mentioned above, there were a number of other practical issues that had to be considered:

- *The wide variety of target populations* for programs, in terms of culture and sub-culture, and in terms of occupation/background. Some programs target health professionals, some target community members, 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 require a range of performance and/or process 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 such as obesity or cancer may be best addressed through modalities such as health screenings and provider training.
- *The variety in capacity to handle data collection.* Some programs may be centered in a large racial/ethnic 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 less capability due to limited staff, funding, and available resources. 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) and evaluation/data collection activities must be structured so that they do not impose an excess burden.
- *The variety in understanding of, and attitudes towards 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 through their close and multiplex contacts with their clients and communities are not necessarily the kinds they are asked to report. Such disassociations 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 also 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 racial/ethnic minority groups, there is a reluctance to provide data on 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.
 - ✓ Among programs serving refugee and immigrant populations, there may be a reluctance to provide data because of historical experiences with government repression, or because of concerns over potential immigration issues.
- *The range of program types funded by OMH*, where programs have different aims and thus different standards for performance. A capacity-building, technical assistance program, for example, serves organizations, not individuals, and its performance is related to impact on client organizations’ functional capabilities as well as their ability to provide health promotion services. An interpretation program, by contrast, targets individuals and its performance is related to individual client utilization of health services, provider–patient communication, and the like.
- *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 in order 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 where duplicate clients cannot be counted. It is difficult, for example, to count the number of attendees at a health fair (much less obtain demographic data). And if some of the health fair attendees also attend education sessions or other program modalities, client duplication is very difficult to

identify. In addition, there are questions as to what are the most important kinds of demographic and background information to be collected from clients (in order to understand who is served), and how these data are to be collected.

- *The need to develop measures that can be integrated realistically and meaningfully* throughout the scope and span of a particular project, from a project's goals/objectives, through its activities, and through evaluation.
- Finally, *the need for a data set that will allow for useful cross-program and cross-project analyses.*

3. Methods

Given the issues raised thus far, and the formative research carried out to develop the pilot UDS, we determined that the UDS would be configured as an *activity-based, core and module data set*. The data reporting form contains a small set of *core data* questions that all awarded grantees/cooperative agreement recipients can fill out, together with a set of *activity categories* and their respective data questions that can be filled out based on the activity types undertaken by a given project. A particular project will fill out data only for those activity categories that are applicable. Thus cross-site comparisons can be made in the only way feasible given project variety—by comparing apples to apples; that is, activity types to similar activity types. The categories that have been included in the pilot UDS, and the data requirements for each category, are based on focus groups, interviews, and site visits with a sample of OMH grantees and cooperative agreements. The UDS attempts to obtain reasonable documentation of process and outcome (intermediate outcome) for each category, and, where possible, some qualitative description of impact in a regularized form. Specifically, for each activity category, we attempt to capture:

- *Demographics of those served.* Characteristics (e.g. age, gender, race/ethnicity) of the persons served under the specific activity. *Shows program reach.*
- *Numbers served.* An unduplicated count of the number of people/organizations served by the project while conducting the activity. *Shows program reach.*
- *Process.* The number of times a particular activity (e.g. training) was conducted, the number of materials developed and disseminated, the number of referrals made, organizations contacted, etc. as applicable to the activity. *Shows program intensity.*
- *Short-term or intermediate outcomes.* Short-term gains made as a result of conducting the activity (e.g. gains in knowledge, awareness or skills, short-term changes in diet, referrals made after health screenings). *Shows program impact at the key intermediate level.*
- *Longer-term outcomes (if possible).* Actual changes (over time) in health outcomes or health risk behaviors as a result

of the activity. Most OMH projects will not be measuring long-term outcomes, but some projects that do include components such as cardiovascular exercise, or violence prevention skills training, can measure such outcomes—using the previous two examples, these would include blood pressure and self-reported involvement in violent behavior. *Shows program impact.*

- *Qualitative description of client impact (where possible).* This type of data is intended to allow projects to record or describe (in a brief format) how the particular activity impacts clients in a way that is not necessarily reflected in the other data that is reported. It is a place for each project to 'tell the story' of this activity as they see it. *Shows, in descriptive form, program impact.*

Identifying impact/outcome data elements for each category involved an assessment of what OMH, as an agency, needed in terms of impact information, together with an assessment, based on grantee feedback and the formative research process, as to the desired or projected impact of each activity, and the kinds of data that would be feasible to collect vis à vis such impacts. For example, since few OMH grants were longer than three years, long term impact was generally not feasible for any activity category. For many activity categories, impact was limited by very practical concerns. As an example, for the activity category 'training health care providers', the *desired* impacts typically centered on improved provider–patient interaction, increased ability of providers to incorporate cultural understanding and/or language competence into their practice, and so on. However, to evaluate this kind of impact, followup surveys or observations of trainees would be necessary. Few grantees had the staff or funds to carry out such followup work; thus, impact had to be restricted to short-term gains in knowledge, skills, and awareness. There were some exceptions. The Family and Community Violence projects were funded under a cooperative agreement and were typically structured within a risk and protective factors framework (e.g. Hawkins, Catalano, & Miller, 1992). A wide range of evaluation tools and instruments are available to assess program impact under this framework, and some of these were in fact used across these projects. For activity categories where such tools were realistically available, the activity module called for summaries of pre-post data.

The process for developing the pilot UDS was assisted by an Advisory Group (Federal and private organizations who are or have been implementing UDSSs), and involved literature and program reviews, focus groups, interviews and site visits with OMH grantees to develop a draft UDS. Site visits included staff and client interviews as well as observation of program activities. A pilot test of the draft UDS was recently completed, during which a small sample of OMH grantees used the UDS as their data reporting system for one reporting period. Based on the pilot test results, a final draft UDS was developed. In addition, as a demonstration,

a *web-based version of the UDS*, in partial form (only three activity modules) was developed in response to grantee requests for a simplified data entry protocol.

4. Results and discussion

Based on the formative research, the pilot UDS includes the following data elements. It is important to note that, where possible, we have and will continue to draw on data elements and reporting formats already developed by other Federal/private agencies, to ensure compatibility as much as possible.

4.1. Core data

This refers to a limited, minimum data subset across program and activity types, which will include very basic, largely descriptive data—that is, not tied to specific activity types. These data will be routinely reported by all projects. On several other Federal efforts of this nature, such data were collected. The core data elements and their definitions are as follows:

- *Organization type*. This is a simple check-off data item, using a list of possible organization types that includes: community-based organization, community health center, community recreation center, day care facility, Historically Black College or University (HBCU), national minority organization, faith-based organization, public school, refugee assistance center, government social service agency, other government agency, transportation authority/service, university or college (other than HBCU), other medical provider, technical assistance provider, or 'other'.
- *Organizational budget and funding*. Includes the total budget, as well as how much (and source) of funding for the activities supported by OMH. If there is overlapping funding this will be noted here.
- *Location of project activities*. A checkoff category that includes urban, suburban, rural and US–Mexico border. The focus is on project activities, not main offices.
- *Other activities*. This category is intended to identify other activities that the organization engages in that are not funded by OMH. This information is useful in determining whether or not, for example, organizations that provide complementary and supporting services fare better in terms of OMH project implementation and outcome.
- *Staff*. Records number of staff funded for the OMH project and staff mix (paid staff, consultants, volunteers).
- *Collaborations*. Identifies whether or not the funded organization has collaborators involved in the OMH-funded activities. Again, this helps in understanding the kinds of organizational structures that contribute to successful implementation/outcome.

These core data items can be used as independent variables in understanding factors related to program outcome.

4.2. Activity checklist and activity categories

Following the core data is a simple checklist in which projects identify the activity categories (out of 18 total categories) that represent what they do—regardless of what was in their original goals and objectives. We add this qualification because at least some change in activities and strategies over the course of a grant is common among community programs. The activity category checklist is a guide to the activity modules for which the project should report data.

As noted, collection and categorization of data by activity type is necessary because each different program funds a number of activities per project, such that comparison of even two projects under the same program may not be possible, if done *by project*. Collecting data by activity type allows activities across projects to be evaluated, and for activity types to be assessed against each other. Thus, the first step was to develop an adequate typology of project activities, and this was done both from project documentation and qualitative research (focus groups, interviews, and particularly site visits) aimed at identifying what grantees actually do. The following is the current list of 'activity categories', together with definitions for each category, and for each definition, indicators/data types that would serve to measure that activity. Where possible, reference is made to typologies and definitions already identified in other Federal efforts. In addition, the definitions are broad enough to allow for a culturally-appropriate range of options under each activity type. This list of activity types and definitions is included in the instructions to the UDS reporting form. The current set of activity categories can be divided into *services impacting individuals* and *services impacting organizations or systems*, and is as follows.

4.3. Services affecting individuals

1. *Training health care providers*. Structured instruction or education sessions administered to health providers (doctors, nurses, staff) on issues related to racial/ethnic minority health (includes development/adaptation of a curriculum).
2. *Language Interpretation*. Interpreting for racial/ethnic minority clients who do not speak English (or do not speak it well) while clients are at appointments with health providers, case managers, social services providers, and other related services, or in connection with written materials that clients need to understand and fill out. In addition, this involves interpreting what the client is saying for the health provider.

3. *Target population health education and outreach.* Any kind of educational activity (whether individual or group) concerning health information, promotion, and prevention directed to the minority target population(s), including workshops, home health parties, health fairs, and outreach. Violence, substance abuse and delinquency prevention should be included under this category. (Note: Materials development and dissemination is counted as a separate activity category).
 4. *Target population health educational materials development/dissemination.* Original development or adaptation of educational materials (concerning health issues, risks, prevention, treatments) to be provided to minority and/or under-served populations, and dissemination of those materials, via outreach, presentations, in doctor's offices, etc. Specifically, development is the creation of original documents and other educational pieces for use in information dissemination activities, while adaptation is the modification (for the target population) of materials already developed by others. Dissemination is simply distribution of written and audiovisual prevention information. This category can be divided into *print* materials and *broadcast* materials.
 5. *Screening and referral.* Any diagnostic screening procedure to detect health risk or presence of a health problem. This could include dental screening, cholesterol screening, mammograms, stress tests, blood pressure, eye exams, and others. Referral means that, as a result of the screening, the client was referred to actual medical services.
 6. *Case management.* Planning and monitoring of specific prevention or treatment protocols for individual clients (e.g. through the use of individual treatment plans or other tools), and coordinating referrals and access to services based on the individual protocol.
 7. *Wellness and exercise.* For the purpose of this database (to distinguish wellness from education), any structured physical/mental activities designed to address a health risk. This could include exercise classes, stretching, meditation, yoga, and others.
 8. *Academic support/career preparation.* Any structured activity designed to improve client educational performance (e.g. remedial sessions, tutorial, academic enrichment) and improved skills/knowledge related to jobs/careers. (Note: Organizational internships and staff development programs should be included under category #16, Technical Assistance and Organizational Capacity Building).
 9. *Mentoring.* Structured, ongoing adult–youth relationship for a specified period of time in which the adult spends regularized time with the youth and provides support, information, encouragement, and role-modeling.
 10. *Parent skills training/family counseling.* Any structured activities (e.g. workshops, regular meetings, classes, family counseling, family education) with parents as participants, in which parents receive instruction and/or practice in parenting and family management skills.
 11. *Self-esteem building.* Any structured activities (workshops, sessions, curriculum segments) designed to increase client youth self-esteem.
 12. *Cultural activities.* Any structured activities including workshops, curriculum segments, sessions, ceremonies/rituals or field trips whose primary purpose is to increase client youth awareness of their cultural background, and increase bonding to cultural background as part of their sense of identity.
 13. *Recreational/sports.* Any structured sports activities, outdoor or indoor.
 14. *Crisis intervention.* Unplanned activities, directed to clients and/or the target community, that are deemed necessary in order to resolve a crisis, or solve a problem that poses a barrier to client participation in project activities, or to help solve a problem that is diverting attention from the health issues of importance to the project.
- 4.4. *Services affecting organizations or systems*
15. *Linkage-building/community coordination.* Linkage-building is a broad category that includes the formation and maintenance of coalitions, the formation of referral arrangements, and any other activity that is specifically part of grant activities and is intended to expand the impact of the grantee by developing and maintaining linkages with other organizations and/or health providers. Here, as in the next several categories, clients are *organizations*, rather than individuals.
 16. *Technical assistance and organizational capacity building.* Activities that increase the capacity of the grantee organization, its linkage partners, or client CBOs to provide improved services, improved health promotion, and improved access to health care for its target minority population(s). This could mean staff training, hiring bilingual staff, instituting an internal training program or training materials, implementing internal policies designed to ensure a growth of cultural competence, adding administrative resources, technology, staff, or new systems, and other similar actions. The range of technical assistance provided, and the outcomes expected, will vary depending on the state of the recipient organization, and the data required in this section will include some basic reference to client 'starting point'.
 17. *Resource coordination.* The identification, coordination, and facilitation of resources to aid

racial/ethnic minority/community health organizations in expanding access to prevention and health care for target minority populations.

18. *Needs assessment.* The conduct of a community or target population needs assessment as part of grant activities (not as part of preparing a grant application). The needs assessment may include surveys of community attitudes and practices, available services, and other factors which would inform the targeting of project activities.

To assist OMH grantees in using the UDS form, it will be enclosed as part of a 'data collection kit' which includes sample record-keeping forms for each activity category and instructions for their use—to help in the ongoing process of data collection and maintenance. Another option is for the forms and kit to be made available via the proposed web-based version of the UDS along with other technical assistance functions.

4.5. Technology, process, and format for the new UDS

There are several ways to format the UDS so that the data collection process is flexible and maximally useful for both OMH and grantees. 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 (by fax or mail) 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 Committee, utilized 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 email the file or transmit it in some other way to OMH or a data coordinating center.
- 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—is that it also allows for a considerable amount of interactive capability, where grantees could report problems with certain data elements, or suggest new ones, or discuss other matters related to UDS.

With regard to format, we know that a balance must be achieved 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 may apply, and fewer of those that do will be the CBOs that are such a vital link to the community.

The site visits and other formative research—including a survey of grantee technology capabilities—indicated that the UDS should be presented to grantees/cooperative agreements in several forms. All awardees should receive paper versions of the forms. At the same time, Internet accessibility—while still problematic for a few grantees—will most certainly be increasingly salient and familiar by the time a UDS is implemented. The option of entering data through a website (by project ID number) opens a wealth of possibilities in terms of ongoing and productive contact between OMH and its grantees/cooperative agreements, and in terms of data management. We have therefore, recommended a combination of paper and Internet formats for projects to collect and report their data.

Paper forms can be utilized 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 utilize the Internet. However, at the 'agency' level, this will require a webmaster and database for storage and processing of the data.

Another option is to collect and maintain UDS data through a data coordinating center. 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/cooperative agreements;
- technical assistance to grantees/cooperative agreements in collecting/reporting the data;
- troubleshooting; and
- preparing summary reports for use by OMH.

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

Overall, the proposed UDS system represents a practical means to obtain a significant amount of the data needed by OMH, the grantee organizations, and the community health field. More generally, the UDS represents a basic tool for documenting the kinds of processes and outcomes that are important and appropriate to community-based projects that are contributing to the elimination of health disparities.

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References

- Hawkins, J. D., Catalano, R. F., & Miller, J. Y. (1992). Risk and protective factors for alcohol and other drug problems in adolescence and early adulthood: implications for substance abuse prevention. *Psychological Bulletin*, 112, 64–105.
- Kellogg Foundation (1998). W.K. Kellogg Foundation Handbook. Available at <http://www.wkkf.org/publications/evalhdbk/1565.html>.
- United Way (1996). *Measuring program outcomes: A practical approach*. Alexandria, VA: United Way of America.
- Wells, B. L., & Conviser, R. (1998). Evaluating the elimination of disparities: issues and approaches to health status and outcomes assessment. *Journal of Health Education*, 29, 16–22.