

II. Requirements for Population Data

Steven Davis

Summary

Population-based data are intended to provide a means to plan services for persons in need, and for monitoring the extent to which the overall system is addressing those needs. Two large survey projects that have focused on mental health service needs of the general population are the Epidemiological Catchment Area Study and the National Comorbidity Study. In addition, the National Health Interview Survey, National Household Survey on Drug Abuse, and others have included questions aimed at identifying mental health treatment needs. A review of analyses of these studies identified several steps that need to be accomplished before the requirements for population-based mental health data collection are clearly defined:

- future surveys must cover the full range of ages in the population to identify the full range of service need;
- instrumentation must be developed that is appropriate for assessing mental disorders in children and adolescents;
- coding for demographic and geographic variables must be standardized across data collection projects, or acceptable cross-walks must be developed;
- a sufficiently large sample or appropriate estimation methodology must be used to permit disorder rates to be established for age, race, gender, etc.;
- measures of functional impairment must be developed for adults and children to produce more reliable estimates of prevalence of SMI and SED;
- items must be included to identify sub-clinical symptoms and conditions, and evaluate the demand, as well as the need, for treatment;
- existing surveys need to be identified and examined for their inclusion of mental health data items and their applicability to mental health policy questions;

Four additional areas to study have been identified. First, new vehicles for data collection need to be considered, such as system-based surveys like those used by employers, health plans, counties and catchment areas. Second, strategies employing technology and methodology to increase response rates should be used, e.g., proven follow-up methods and computer-based survey systems. Third, measures should be changed to reconcile differences between clinical assessment instruments and population surveys. Calibration must be done between smaller surveys with fewer items and larger surveys with items that specify clinical conditions. Persons with unmet needs must also be identified. Finally, incentives for surveyors and respondents should be investigated, e.g., involving community service organizations in surveys by appealing to citizenship, and using innovative, low-expense items like calling cards to attract respondents.

II. Requirements for Population Data

What is the Intended Purpose or Function of this Component?

In the context of this project, “population data” refers to information about the frequency and rates of various “states” and “occurrences” in the general population.¹ Such frequencies and rates are determined by compiling records of events or by conducting sample surveys. The resulting data may include information about mental and emotional disorders and symptoms; or events that may be indicative of the mental health status of the population; and/or risk/protective factors for mental illness occurring in the population.

The purpose for the periodic collection of population data, as described in the U.S. Public Health Service *Healthy People 2000* report (U.S. Department of Health and Human Services, 1990) and by Manderscheid and Henderson (1995), is to allow for assessment of the overall health status of the general community population, so that adequate planning for services for persons in need can be accomplished and overall system performance can be monitored.

Shapiro and colleagues (1984) discussed using population data for planning. They described four purposes for mental health information collected from population surveys like those conducted for the Epidemiologic Catchment Area (ECA) program: to determine patterns and levels of utilization of general health and mental health services by persons with and without mental disorders; to determine the influence of personal characteristics and health services resources on service utilization; to estimate the distribution of mental health care received by service sector and setting; and to estimate the need for services, the gap between need and services received, and factors affecting the size of the gap.

What Information is Required to Accomplish this Purpose?

Domains of Data to be Collected

Adequate planning for mental health services in a state, region, county or city cannot be done by analyzing only enrollment and encounter data from existing consumers. While those sources may provide useful information about consumer characteristics and “met demand” for treatment, they do not address unmet demand or need for treatment. Although some indicators of unmet demand and need may be available from other sources (McAuliffe et al., 1994), to provide information adequate for planning, surveys of the general population must be conducted. Table 1 shows a number of population surveys and the agencies that developed them.

¹ In this section, “population” is used to describe one of the minimum data sets in the information system, in contrast to the Introduction, where the term is used to describe a unit of analysis. The population data set contains information about people *independent* of and *unrelated* to their status as plan enrollees or as consumers of services—simply as people who are part of the general population in a community, a county, a state, or the nation. When specifying a unit of analysis, “population” is used to refer to the set of people being considered, i.e., all enrollees or all users of a service or all people who have experienced a similar outcome— as distinct from consideration of a single individual as when the “person” is the unit of analysis.

The domains of information to be collected from general population surveys may vary depending on the desired level of planning and the availability of resources to conduct the survey. The *minimum* domain requirements are (1) mental health status questions that directly, or through established algorithms, provide information on diagnoses, symptoms, and functional status, and (2) respondent demographic and location information. Both the mental health status and demographic information should correspond directly to data elements collected by treatment providers during their assessments of consumers. In this way, the same questions asked in the surveys can be used to collect data for assessment, treatment planning, and progress monitoring for individual consumers; individual-level data can then be aggregated and compared with estimates of unmet demand and need calculated from survey results.

In addition to the *minimum* elements described above, the *ideal* domain requirements include physical health status, functional status, socioeconomic status (including social support resources, employment and housing information), life events, and treatment history. Including these domains will substantially improve the utility of the survey data for planning and policy analysis purposes. For example, Shapiro et al. (1984) used data on “personal characteristics” (sociodemographic, economic, health insurance, functional status, and co-morbidity information) and information about health services resource availability to analyze utilization data from the Epidemiologic Catchment Area (ECA) program. Similarly, in results from the National Comorbidity Survey (NCS), Kessler et al. (1996a) found significant correlations between serious mental illness (SMI) and gender, education, and marital status, and that service use among persons with SMI was significantly related to age, race, and income. Kessler et al. (1997a) stress that one of the “main advances” NCS made over ECA was that the NCS was designed to be a risk factor study as well as a prevalence and incidence study. NCS contains a comprehensive risk factor battery, including family history, assessments of parental psychology, questions about childhood and family adversity, measures of social networks and support, and information about stressful life events and difficulties.

Other Requirements and Considerations

Population data should be collected from a sample of sufficient size, selected with a statistically appropriate method, to permit calculation of reliable estimates for each geographic region and/or population subgroup for which planning is desired. In particular, surveys should collect information and include data elements to identify age groups (children, adolescents, adults, elderly), target groups (persons with SMI, serious emotional disturbance [SED] and co-occurring mental health and substance abuse disorders), and geographic regions (census tract, zip code, city, county, catchment area). Surveys should address not only need for treatment, but also demand for treatment, to best estimate the potential workload for treatment providers, and to provide the most useful information for planners of outreach services (McAuliffe et al, 1994).

Issues of survey protocol, confidentiality, security, language appropriateness, and cultural competence must be addressed to ensure respondent rights are honored, and all groups in need of service are identified. In addition, since Shapiro et al. (1984) found about one third of those seeking mental health treatment had symptoms or conditions, but no Diagnostic Interview Schedule (DIS) disorder, surveys will need to be designed to identify mild symptoms and sub-clinical conditions if they are to be useful for estimating the full demand for treatment. Data must be consistent and comparable across survey periods to permit comparisons and assessments of change. At the same

time, surveys must allow for expansion in terms of data elements and topics addressed, to ensure innovations can be evaluated.

Sources of Population Data

In addition to *de novo* data collection, there are also supplemental, surrogate or indicator sources of population data. In a working paper on estimating the 12-month prevalence of serious mental illness, Kessler et al. (1997b) recommended two approaches to improving SMI estimates that can be applied to prevalence estimates of mental health diagnoses in general:

1. “add marker information about SMI to ongoing annual federal surveys,” such as the National Health Interview Survey (NHIS), the Behavioral Risk Factor Surveillance System (BRFSS), and the National Household Survey on Drug Abuse (NHSDA) and integrate this direct information into the estimation of SMI, and
2. “integrate aggregate indicators that are available on an ongoing basis,” including outcomes of SMI (e.g., suicides), triggers such as disasters and major increases in unemployment, and markers for ambient community-level stress (e.g., population density and crime rates).

The authors propose that more detailed and expensive assessment surveys such as the NCS be conducted at less frequent intervals, e.g., every 10 years, and their results be linked with data from more frequent, but less detailed surveys to produce estimates in intervening years.

Mental health questions have already been added to several national surveys that could contribute to the types of analyses Kessler et al. recommend. The 1996 NHSDA (Office of Applied Studies, 1998) included modules administered to adolescents (12 to 17 years old) and adults (18 years and older) that were “composed of items derived from mental health epidemiologic surveys.” The source for the adult items was the Composite International Diagnostic Interview (CIDI) questions for major depressive episode, panic attack, generalized anxiety disorder, and agoraphobia from the National Comorbidity Survey (NCS). For adolescents, the Youth Self-Report Checklist (Achenbach, 1991) was used.

In calendar years 1994 through 1997, the National Health Interview Survey on Disability (NHIS-D) Phase 1 and Phase 2 interviews were conducted (NCHS, 1998). The NHIS is an annual face-to-face interview designed by the National Center for Health Statistics and administered by the U.S. Census Bureau to members of randomly selected households. In 1994 and 1995, special questions on disability were added to the basic NHIS questionnaire. During Phase 1, families were screened for any indication of disability; in Phase 2, completed in early 1997, identified families received follow-up interviews to collect additional information. Mental disorders identified by the survey include senile and pre-senile organic psychotic conditions, schizophrenic psychoses, affective psychoses, other psychoses, neurotic and personality disorders, alcohol dependence syndrome, and drug dependence. Persons with mental illness were asked about housing and long-term care utilization, access to public transportation, specialist service providers, inpatient and outpatient mental health care in the past 12 months, availability of needed care, barriers to care, and links to mental retardation services. Data from those surveys are now available (National Center for Health Statistics, 1998) in public use files on CD-ROM.

The BRFSS and the Youth Risk Behavior Surveillance System (YRBSS), administered in all 50 states with support from the Centers for Disease Control and Prevention (CDC), have included items that may contribute to both methods of estimation recommended by Kessler et al. The Morbidity and Mortality Weekly Report (CDC, May 1, 1998) includes data on self-reported “frequent mental distress” (FMD) among adults, a BRFSS quality of life question that has been collected since 1993. Respondents are asked to report how many days during the past 30 days their mental health was not good. Persons reporting 14 or more days are defined as having FMD. If this item were included in a survey with a sufficient number of CIDI items so that mental health diagnoses could be derived from responses, correlations with CIDI items could be calculated and future BRFSS results could then be used to estimate prevalence of related mental disorders.

The BRFSS has also included questions about health insurance that permit estimation of the prevalence of insured and uninsured persons in the US. This could prove useful to mental health service planners since underinsurance or lack of insurance has been related to delayed care and adverse health consequences (CDC, July 3, 1998). Similarly, the YRBSS (CDC, August 14, 1998) is a source of information about priority health-risk behaviors among youth and young adults aged 10-24 years C behaviors that contribute to unintentional or intentional injuries, including suicide attempts C that could be correlated with diagnoses derived from more detailed surveys.

Vital statistics (e.g., suicides and other mortality data) from state health departments and the CDC, emergency department reports of selected services, and single vehicle fatality reports from the Fatality Analysis (formerly Fatal Accident) Reporting System (FARS) are other sources of indicator data that may be correlated with prevalence of mental illness in the general population. The US Census is a source of non-mental health information that can be used for certain rate calculations and estimations of prevalence based on correlations with data from other sources.

Two surveys co-sponsored by the Agency for Health Care Research and Quality (AHRQ) (formerly the Agency for Health Care Policy and Research [AHCPR]) may be resources for mental health planners and policy analysts. The first is the Medical Expenditure Panel Survey (MEPS) (AHCPR, 1998). MEPS is “a nationally representative survey of health care use, expenditures, sources of payment, and insurance coverage for the U.S. civilian noninstitutionalized population, as well as a national survey of nursing homes and their residents.” MEPS is sponsored by AHRQ and NCHS. It is designed to provide data on the level and distribution of health care use and expenditures, the health care delivery and insurance systems, and health care policy. Besides collecting data from household respondents, MEPS includes a Medical Provider Component designed to reduce estimate bias by collecting provider-reported charge and payment data. An event level “condition” field, reported by the household respondent, can include mental health and substance abuse problems. The condition and expense data are not yet available for analysis.

Who Provides the Information?

The initial source of most information described above are selected individuals in the general population who may respond to surveys; others may be included in public health or public safety registries or in vital statistics reporting programs. The AHRQ-sponsored surveys described in the preceding paragraphs collect data from consumers, providers, and facility administrators. The information may be collected by surveyors, public health or public safety personnel, or health care providers, e.g., emergency department physicians.

What Information is Produced to Accomplish this Purpose?

The information from general population surveys, disease registries, vital statistics repositories, the Census and other sources can be used for several purposes. First, the data will provide rates of mental disorders among those from whom or about whom the data were collected. If sufficient input information is available, i.e., if the *ideal* domain requirements are met, output information will include reliable and valid rates based on accepted diagnostic criteria (e.g., those outlined in the American Psychiatric Association's Diagnostic and Statistical Manual, Fourth Edition) that are specific to population sub-groups and sub-state regions. States, health plans or other interest groups may choose to fund supplemental surveys of specific populations to permit production of statistically reliable, comparable estimates to support planning, budgeting or bidding to provide services to a specific group of consumers.

Second, information from these surveys will be available to produce the previously-described population-based report card proposed by the CMHS Survey and Analysis Branch. Patterns and levels of health and mental health service utilization can be determined; correlations between consumer history, other personal characteristics, treatment history, and service utilization can be calculated; the distribution of services received by service sector and treatment setting can be estimated; and the unmet need and demand for various mental health services can be determined.

Finally, the resulting data on counts and rates of persons suffering mental distress, attempting suicide, and committing suicide; on emergency department visits for selected services; on single vehicle fatality accidents; and other indicators of mental disorders in the general population can be applied to producing surrogate disease-rate estimates in geographic areas, or time periods, for which general population survey results are not available.

Who Uses the Information that is Produced?

Population data are useful to a broad group of stakeholders. Consumers, advocates, state mental health authority administrators, and regional planning groups for people with mental illness will use population information to identify treatment needs and inequities. Those needs can then be compared with the demand for and availability of services to justify requests for resources and plan their allocation. Managed care organizations and providers will use population information to help assess the risk they would accept for contracting to serve a given region or population group. Health plans will compare behavioral healthcare needs identified in surveys of their population areas with proposals by managed care firms for the care of their members to determine the extent to which the managed care organizations are offering appropriate services. Evaluators will examine resource allocation, service delivery, and changes in population data to determine whether, or under what circumstances, interventions made by administrators and providers had the desired effects. Researchers will study life event, social support, service history and health status information to identify risk and protective factors that will guide planning for prevention and early intervention services.

How Ready is this Component for Inclusion in the Information System?

Although significant work has been done in the past 20 years to develop population surveys and other sources of data useful for mental health planning and policy making, there is still much that must be done before this component of the system is completely operational. Large studies like ECA and NCS are invaluable resources that researchers, planners, and policy makers are using to assess the prevalence and distribution of mental disorders, determine levels of service utilization, and answer important planning questions. Unfortunately, those studies do not meet all the domain and other requirements recommended here for the population data standards.

Kessler and his colleagues (1997 a,b) compared characteristics of the ECA and NCS studies, identified improvements made in the latter, and suggested additional modifications to make to future population surveys. The NCS, for example, was based on a nationally representative sample from the 48 contiguous states, which made producing national, state and sub-state estimates of prevalence possible (e.g., NCS results were used to make estimates of the numbers of adults with serious mental illness for each county in every state), whereas the ECA was based on a sample of only five local areas. The ECA included institutional populations that permitted better sampling of psychotic individuals while the NCS was limited to the household population and student housing. The ECA included an unrestricted age range in its sample; the NCS only surveyed persons 15 through 54 years old. The NCS used items that identified DSM-III-R diagnoses; ECA items derived from the earlier DSM-III diagnostic codes. As noted above, the NCS added items to identify risk factors and used better recall methods; and improvements to the Diagnostic Interview Schedule made after the ECA studies led to increased validity and higher prevalence estimates. Neither the NCS or the ECA surveys comprehensively assessed all DSM disorders, nor did they provide good measures of functional impairment, a factor in assessment made important by recent definitions established for SMI and SED. Kessler et al. (1996a) conclude “it is important for future work to generate measures of functional impairment” based on “nationally representative samples that cover the full range of adult years.”

Work must be done to establish a methodology for developing estimates of the prevalence of childhood and adolescent mental disorders as well. Although the NCS made several improvements on the ECA work, it did not include children in its sample. Child and adolescent disorders such as conduct disorder were omitted and information was collected from only one informant. The report by Friedman et al. (1997) that provides the background for the national SED prevalence estimates concludes “there is no one study of national scope from which to derive a single estimate of prevalence” for children with mental disorders, and “there are insufficient data to assess how or if prevalence rates vary for different age groups, racial and ethnic groups, genders, and socio-economic groups.” The authors commend the NIMH-funded Utilization, Need, Outcomes, and Costs for Child and Adolescent Populations (UNOCCAP) effort to survey children aged four to 17, but also call for more work to measure functional impairment. Unfortunately, this survey was developed, but never implemented in the field.

Another area of endeavor mentioned by Kessler and colleagues (1997b) in which insufficient work has been done is the collection, compilation, and analysis of data other than that collected in expensive, detailed surveys like the ECA or the NCS. Methodologies need to be established for correlating and/or combining information from smaller studies with the larger surveys to improve

estimates of prevalence, need, and demand made from the latter, and to produce estimates for those areas and times where data from the larger, more detailed surveys are not available.

What Future Efforts are Required for Readiness?

Populations Surveys

Future efforts should involve building on the accomplishments of the ECA, NCS and other studies to produce population surveys and estimation methodologies that more closely match the ideal domain requirements described above. Specifically:

- future surveys should cover the full range of ages in the population to identify the full range of service need.
- survey items need to be developed and tested to identify a broader range of diagnoses, diagnostic categories and sub-clinical conditions than were addressed by the ECA or NCS to achieve a more complete picture of disorders in the general population;
- items should be included to identify sub-clinical symptoms and conditions to evaluate accurately the need for various treatment modalities and levels of care;
- a sufficiently large sample or appropriate estimation methodologies should be used to establish estimates of disorder rates by age, race, and gender within target groups and geographic areas of interest to planners, consumers, providers, and other decision makers;
- instruments need to be developed to assess mental disorders in children and adolescents and produce reliable and valid prevalence estimates as in the UNOCCAP survey instrument developed with NIMH support;
- measures of functional impairment should be developed for adults and children to produce more reliable estimates of prevalence of SMI and SED, to better predict the need for services, and to examine outcomes of services or specific interventions;
- diagnostic items must be updated to match DSM-IV, ICD-10, and future coding systems;
- the definition of serious mental illness (SMI) needs further psychometric analysis, including ways to combine short screening measures of the impairments associated with SMI into a comprehensive assessment of SMI;
- further work is needed to determine the validity of short screening instruments for symptoms of mental illness and functional status;
- coding for demographic and geographic variables should be standardized across data collection projects, or acceptable cross-walks must be developed, to permit comparison of survey findings with treatment utilization and outcomes data;

- “marker” items, e.g., the BRFSS frequent mental distress question, that correlate with diagnoses of mental disorders should be identified and included in frequently administered surveys to provide ongoing prevalence estimates;
- Kessler et al. (1997b) recommended that the field develop methodologies for correlating surrogate and indicator data with prevalence, need, and demand information from detailed population surveys and use these data to provide estimates in periods between large surveys;
- survey protocols need to be examined, and standards established, for surveyor-respondent interaction (including issues of respect, cultural competence, and response to emergency needs identified in the interview process), assurances of confidentiality and data security, and secondary uses of data;
- existing surveys, e.g., MEPS, need to be identified and examined for their inclusion of mental health data items and their applicability to mental health policy questions;
- biostatistical simulations need to be performed to examine the feasibility of including screening versions of mental health assessment measures in the BRFSS, the NHIS, and other population surveys and doing so in conjunction with small local surveys to develop reliable estimates at the planning district (e.g., county) level;
- the technology of surveying needs to be studied to determine whether Computer-Assisted Telephone Interview (CATI) systems be made more automated or web-based technology can be used;
- innovative and inexpensive new ways of collecting data at local area levels need further development, for example, Interactive Voice Response (IVR) technology where respondents call a toll-free (1-800) number and use the telephone touch tone pad to key-enter their responses to a pre-recorded survey (such data collection is essentially free from the collector’s perspective but potential survey respondents must be motivated to make the call and it is necessary to adjust for biases in the surveys);

- new methodologies and methodologies from other disciplines need further development in regard to their applicability to mental health; these include internet-based data collection, snowball sampling, and capture-recapture analyses (adapted from wildlife studies to estimate numbers of homeless persons needing treatment).

Population-based Report Cards

The Survey and Analysis Branch, Division of State and Community Systems Development, within the Center for Mental Health Services, is in the process of developing a prototype population-based report card that would use a common data collection strategy with comparable core indicators for public sector health insurance plan participants, private sector plan participants, and the uninsured population within a county, state or other geographic area. This multi-stake holder initiative has proposed data elements to be collected and identified existing national surveys that would be suitable sources of such data—either through secondary analyses of existing data or inclusion of new data elements.

Questionnaire Design and Statistical Analysis

Issues of instrument reliability and validity should be addressed with any new survey as well as the need for shorter instruments to reduce burden on both surveyors and respondents. To do this, and to be able to correlate results from shorter surveys with those that include the more extensive sets of questions needed to determine diagnoses, “marker” items should be added to the larger surveys. Analyses must then be performed to demonstrate that the marker questions correlate with the larger sets of items; once this is done, disorders can be identified more quickly and cheaply identified with fewer items. Accomplishing this task requires more planning and coordination among survey projects than has occurred in the past. Another coordination task is the standardization of demographic and geographic questions across data collection projects so that results can be correlated and compared more easily. Geo-coding from data items at the Census block group level would be more useful than zip codes.

The NCS survey questions were constructed to elicit full, honest responses. Applying lessons learned in that study would be helpful in designing future surveys. Questions should focus on measuring *demand* for treatment, not just prevalence of disorders that *need* treatment, since a portion of the people assessed to *need* treatment never seek it (demand). The ECA study showed the opposite situation: people with transitory symptoms may seek (demand) treatment, even though they may not be assessed as needing treatment (based on the prevalence of disorders). To calculate useful rates of demand and need, technical decisions must be made about whether and how to include persons who have transitory symptoms. To plan adequately for workload, demand must be accurately estimated; to plan properly for outreach, need must also be estimated accurately.

Survey design and analysis work are needed to improve the specificity and sensitivity of items used to identify persons with SMI and SED. Questionnaire design must also address face validity with attention to cultural differences, i.e., surveys must incorporate the views or constructs that different cultures hold of mental health (note the work by Elliot Green in Puerto Rico). In regard to children, alternatives to DSM-IV need to be identified as sources for survey items because that manual does not encompass the breadth of common diagnostic sub-types for children. Since previous attempts to estimate the number of children with SED were made for varied purposes, with different associated

errors, their methods should be applied to future surveys with caution. Marker items like those described above for adults need to be identified for children and other sub-populations.

Sampling and Data Collection

It will be necessary to prioritize questions asked, population sub-groups surveyed, and geographical areas surveyed, to balance the need for data with the cost of data collection. Reports of significant numbers of persons with mental illness being incarcerated in jails and prisons raise the importance of surveying institutional populations. Criteria for selecting priorities will need to be established. In addition to costs of surveying, the cost-offset of identifying and treating a disorder or trends in the prevalence or incidence of disorders, may be used as the basis for setting priorities. Varying the data collection method according to the difficulty of collecting the data (e.g., for homeless and other elusive populations) may be cost-saving. Special methodologies, such as capture-recapture strategies, may need to be employed for some target populations.

Technical issues that must be addressed include defining the sampling frame, especially for household surveys, and specifying how survey methods may lead to bias, for example, when telephone surveys exclude persons without phone service or access to a phone.

Broad, System Issues

Population-based data collection needs to be moved from national projects to local and regional levels. One means of accomplishing this task would be to develop toolkits to guide the design and implementation of local population assessments and the application of results. A second important factor would be to provide an infrastructure to support these efforts from the national level. Another step would be to link population monitoring with education interventions as **NCQA** is now asking health plans to do. Knowing the health of the population and how it changes over time would be helpful for planning and outcome assessment. Being able to use information at the provider level to anticipate service demands, to plan outreach for at-risk populations, and to design prevention and education programs would also be useful. State mental health authorities and managed care organizations should provide population information with contracts to providers.

Providers and managers need to be better informed as to how population data can be used to determine the percent of the population in need of treatment and to support service delivery decisions. When building a database of population data, it is necessary to develop methods to assess quality, ensure timeliness, and estimate standard errors; use appropriate statistical analyses; and arrange resources for database maintenance and support. It is also necessary to determine ways to use data for needs assessment of populations whose members move from one funding stream to another, or from public to private sector coverage, or who have multiple sources of funding for care, e.g., children.

Focusing attention on “covered lives” under managed care, and not just the general population, might permit linkage to more detailed information for analysis. Administrative data (e.g., Medicare and Medicaid) could be used to validate self-report data and test correlations among treatment history, demographics, clinical measures, and service utilization variables.

Vehicles for Data Collection

System-based surveys such as those used by employers, health plans, counties and catchment areas to collect “health risk appraisal” information from constituents (e.g., the Stay-Well survey) could be used for service planning and demand management. These surveys are usually done as a census, not on a sample, but can be adapted for sample use. Self-insured companies often use these survey results to plan services and programs such as smoking cessation. This is an inexpensive method of data collection, and despite its often low response rate, could provide employers or governments with a good assessment of employee or citizen status that can be used for outreach. Mental health experts would have to identify a standard set of questions to be used in this type of survey.

New Technologies and Methodologies

Utilizing available technology and various methodologies can yield better survey results in terms of response rate and cost-effectiveness. A low response rate (e.g., 30 percent) for a typical mail survey to 5,000 people can be improved by following the initial mailing with a postcard reminder (to get, perhaps, 2,000 responses, instead of the initial 1,500). Further improvement can be made by identifying a sub-sample of non-respondents (e.g., 300), sending people to the field to solicit responses, then weighting those responses to complete estimates.

Interactive voice response (IVR) and audio computer-assisted self-interviewing (CASI) can use either a live operator or a computer voice system to present interview questions that respondents answer by using their phone touchtone keypad. CASI systems can be programmed in different languages with a specified set of questions. People who are non-readers or prefer not to fill out a survey by hand might prefer such procedures. Local surveys using IVR can include questions that address barriers to engagement and retention in the local treatment system. It would be useful to have a parallel survey for people who sought treatment.

Measures

Current crosswalks between clinical assessments and survey measures do not work well. The former focus on what is happening to the client at the time of assessment and the latter generally ask about problems in the last six months, year or lifetime. This problem can be addressed by blending from both sides, e.g., by adding more here-and-now items to surveys. Likewise, long clinical interviews need to be shortened, such as has been done with the revised Hamilton 17-item depression rating scale and its redesign as a self-administered instrument.

Calibration between surveys remains a problem to be addressed. Small-scale surveys do not have large enough samples to determine accurately the questions to ask. Large-scale studies should be used, in part, to test instruments, especially calibration between short and long instruments and identification of good “marker” items. There needs to be national benchmarking studies every five to 10 years to update these analyses.

Clinical assessments typically focus only on the problems and unmet needs of those presenting for treatment. HEDIS customer surveys have begun to address directly what people have experienced in the treatment setting. Although providers have complained that this is not a valid assessment of care because refusal to give certain kinds of treatment (e.g., inappropriately prescribing antibiotics for a viral infection) may be incorrectly viewed by a consumer as withholding treatment, this is less of a

problem with behavioral health consumers because self-reported perceptions of well-being are a main focus of care (e.g., do you feel depressed?).

Even with HEDIS, however, there remains the issue of measuring and correlating clinical factors, consumer experience, what is happening to drop-outs and what is happening to those who never received care. There needs to be a focus on why unmet needs have not been addressed and why people drop-out or never enter treatment. It is important to gather information from people who call for an appointment, are put on a waiting list, then fail to return; people who come for an assessment, but do not return for treatment; and people who drop out of treatment before meeting their goals. This will provide reasons why such individuals are not satisfactorily engaged by the treatment system.

Incentives

Attention needs to be given to providing incentives for people to respond to surveys and for organizations to collect survey data. Making client satisfaction surveys a requirement of certification is one way to encourage provider organizations to collect survey data. It is possible to use ideological influence to encourage survey response, e.g., by having church groups, Kiwanis or other social clubs appeal to citizenship or civic responsibility when publicizing surveys and collecting data. Soliciting citizens' experience to compare and improve services can increase response rate. Inexpensive incentives have also been used successfully, e.g., sending a one-hour phone card to subjects in a sample with an 800 number that requires completion of a 10-minute survey before the card can be activated; each card has an ID number to allow surveyors to identify subjects who have completed the survey and focus follow-up efforts on non-callers.

Even with incentives it is difficult to identify persons with mental illness or substance abuse problems when conducting a community survey; it is also more expensive to find these hard-to-reach respondents. Alternative methods are to use indirect measures, such as demand for treatment, service utilization at safety net provider organizations, or counts of persons seen at shelters. Surveys may also ask respondents about relatives who are currently homeless or who have been homeless for part of the year, have no phone, or who live in-group quarters.

Although statistical significance may be a goal of survey analysis, in truth, any results which provide more information than a 0.5 probability, i.e., 50-50 chance of being right, are a useful finding in a knowledge-poor situation.

Future Activities

In 2000, Ronald Kessler and colleagues will conduct a follow-back to the original NCS sample to study how mental health status and use of services have changed over time. In 2001, this group will replicate the NCS on approximately 12,000 people aged 12 years and older across the nation. Discussions are underway to determine whether a survey on minority mental health status will use the same protocol, enhancing the sample even further. These epidemiological studies will provide important data on the mental health status of the population and on patterns of use of mental health services.

Also nearly ready for widespread use is a new consumer survey that combines elements from the MHSIP Consumer Survey and the Harvard/AHRQ Consumer Assessment of Behavioral Healthcare Services (CABHS) survey. NCQA plans to initiate this common survey as part of its accreditation process in 2001, pending approval of its behavioral health advisory panel.

Table 1**General Population Surveys and Responsible Agencies**

Agency	Survey
National Institute of Mental Health (NIMH)	Epidemiologic Catchment Area (ECA) Program; Diagnostic Interview Schedule (DIS)
National Institute of Mental Health	National Comorbidity Survey (NCS); Composite International Diagnostic Interview (CIDI)
National Center for Health Statistics (NCHS)	National Health Interview Survey (NHIS)
National Center for Health Statistics	National Health Interview Survey on Disability (NHIS-D)
Centers for Disease Control (CDC)	Behavioral Risk Factor Surveillance Survey (BRFSS)
Office of Applied Studies (OAS), Substance Abuse and Mental Health Services Administration (SAMHSA)	National Household Survey on Drug Abuse (NHSDA)
Centers for Disease Control	Youth Risk Behavior Surveillance Survey (YRBSS)
Centers for Disease Control	Fatality Analysis Report System (FARS)
Census Bureau	U.S. Census
Agency for Health Research & Quality (AHQR) and National Center for Health Statistics	Medical Expenditure Panel Survey (MEPS)
Agency for Health Research & Quality	Health Care Cost and Utilization Project (HCUP-3)
National Institute of Mental Health	Utilization, Need, Outcomes and Costs for Child and Adolescent Populations (UNOCCAP)—this survey was developed, but never fielded

References

- Achenbach TM. *Manual for the youth self-report and 1991 profile*. Burlington, VT: University of Vermont Department of Psychiatry, 1991.
- Agency for Health Care Policy and Research. Medical Expenditure Panel Survey, AHCPR website and electronic mail correspondence: www.ahcpr.gov and mepspd.ahcpr.gov, September 1998.
- Centers for Disease Control and Prevention. Age- and state-specific prevalence estimates of insured and uninsured persons--United States, 1995-1996. *Morbidity and Mortality Weekly Report*, Vol 47, No 25, pp 529-532, July 3, 1998.
- Centers for Disease Control and Prevention. Healthy people 2000 website: <http://odphp.osophs.dhhs.gov/pubs/hp2000>, September 1998.
- Centers for Disease Control and Prevention. Self-reported frequent mental distress among adults--United States, 1993-1996. *Morbidity and Mortality Weekly Report*, Vol 47, No 16, pp 325-330, May 1, 1998.
- Freidman RM, Katz-Leavy JW, Manderscheid RW, Sondheimer DL. Prevalence of serious emotional disturbance in children and adolescents. In *Mental Health, United States, 1996*, Manderscheid and Sonnenschein (eds), DHHS Publication No. (SMA) 96-3098, Washington, DC: Supt of Docs, USGPO, 1996, pp 71-88.
- Kann L, Kinchen SA, Williams BI, Ross JG, Lowry R, Hill CV, Grunbaum JA, Blumson PS, Collins JL, Kolbe LJ, and state and local YRBSS Coordinators. Youth risk behavior surveillance--United States, 1997. In CDC Surveillance Summaries, August 14, 1998. *Morbidity and Mortality Weekly Report*, Vol 47, No SS-3, pp 1-32.
- Kessler RC, Anthony JC, Blazer DG, Bromet E, Eaton WE, Kendler KS, Swartz M, Wittchen H-U, Zhao S. The US national comorbidity survey: overview and future directions. Abstract from the National Comorbidity Survey website, 1997a:<http://www.hcp.med.harvard.edu/ncs/>.
- Kessler RC, Berglund PA, Walters EE, Leaf PJ, Kouzis AC, Bruce ML, Friedman RM, Grosser RC, Kennedy C, Kuehnel TG, Laska EM, Manderscheid RW, Narrow WE, Rosenheck RA, Santoni TW, Schneier M. Estimation of the 12-month prevalence of serious mental illness (SMI): Working paper #8, April 1997b.
- Kessler RC, Berglund PA, Zhao S, Leaf PJ, Kouzis AC, Bruce ML, Freidman RM, Grosser RC, Kennedy C, Narrow WE, Kuehnel TG, Laska EM, Manderscheid RW, Rosenheck RA, Santoni TW, Schneier M. The 12-month prevalence and correlates of serious mental illness (SMI). In *Mental Health, United States, 1996*, Manderscheid and Sonnenschein (eds), DHHS Publication No. (SMA) 96-3098, Washington, DC: Supt of Docs, USGPO, 1996a, pp 59-70.
- Kessler RC, Nelson CB, McGonagle KA, Edlund MJ, Frank RG, Leaf PJ. The epidemiology of co-occurring addictive and mental disorders: implications for prevention and service utilization. *American Journal of Orthopsychiatry*, 1996b; 66:17-31.

National Center for Health Statistics. Data File Documentation, National Health Interview Survey on Disability, Phase 1 and Phase 2, 1995 (machine readable data file and documentation, CD-ROM Series 10, No. 10A), National Center for Health Statistics, Hyattsville, Maryland, 1998.

Manderscheid, RW and Henderson, MJ. Speaking with a common language: the past, present and future of data standards for managed behavioral healthcare. Center for Mental Health Services, DHHS, SAMHSA, Rockville, MD, July 1995.

McAuliffe WE, LaBrie R, Mulvaney N, Shaffer HJ, Geller S, Fournier EA, Levine E, Wang Q, Wortman SM, Miller KA. Assessment of substance dependence treatment needs: a telephone survey manual and questionnaire, revised edition. National Technical Center for Substance Abuse Needs Assessment, Technical monograph, 1995, Ch 8, pp 1-2.

Office of Applied Studies. *National household survey on drug abuse: main findings 1996*. Chapter 12, NHSDA Series: H-5. DHHS, SAMHSA, Rockville, MD, April 1998, pp 167-173.

Shapiro S, Skinner EA, Kessler LG, Von Korff M, German PS, Tischler GL, Leaf PJ, Benham L, Cottler L, Regier DA. Utilization of health and mental health services: three epidemiologic catchment area sites. *Archives of General Psychiatry*, 1984; 41:971-978.

US Department of Health and Human Services. *Healthy people 2000: national health promotion and disease prevention objectives*. Washington: Public Health Service, 1990.