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Speaking With A Common Language: The Past, Present And Future Of Data Standards For Managed Behavioral Healthcare

Prepared by:

Ronald W. Manderscheid, Ph.D.

and

Marilyn J. Henderson, M.P.A.

**Center for Mental Health Services
Division of State and Community Systems Development
5600 Fishers Lane 15C-04
Rockville, MD 20857
(301) 443-3343**

Change is obvious at every level of the mental health and substance abuse enterprise. Currently, more than 107 million persons are covered by some form of managed behavioral healthcare, and 17 States have received waivers for Medicaid managed care that include mental health and chemical dependency. This dramatic change demands a new look at the state of information development, particularly data standards.

In a managed care environment, consumers, providers, payers, and management services entities will all be concerned with and affected by the quality, appropriateness, and coverage of the data standards that are employed. For example, consumers will want informative report cards with which to choose behavioral healthcare plans; providers will be concerned with the instruments used to measure the outcomes they achieve, with their relationships to the volume and type of clinical encounters, and with capitation rates paid for care; payers will seek accurate information on costs and the effectiveness of expenditures; and management services entities will need to understand how well capitation systems are working. Thus, for different reasons, all participants in the mental health and substance abuse enterprise will be concerned with data standards.

Within each of the examples cited above, statistical information systems need to be based upon data sources that employ common data standards if they are to be successful. In other words, summary information is only meaningful if based upon a common metric and common definitions. Hence, data standards form the basis for the mental health and substance abuse information enterprise.

The purpose of this chapter is to examine the degree to which current mental health and substance abuse data standards must be updated to be responsive to the dramatic evolution of mental health and substance abuse services under managed care financial arrangements. This will be accomplished by reviewing previous efforts at development of

data standards and examining these from the perspective of managed care information requirements. The chapter will conclude by discussing potential partnerships to facilitate needed changes and by presenting recommendations for specific courses of action.

Early Efforts At Standardization

More than a century ago, the U.S. Census Office worked collaboratively with the New England Psychological Association to define seven distinct forms of mental illness (mania, melancholia, monomania, paresis, dementia, dipsomania, and epilepsy) to be used in the 1880 census of the population. This collaborative undertaking set the tone for subsequent work that was to ensue in national census activities.

Later, these efforts were expanded to mental health providers. Starting with the 1923 Census of Patients in Mental Institutions, conducted by the then U.S. Bureau of the Census, diagnosis was used as one of the descriptive variables in State mental hospitals. This resulted from the joint efforts of the National Committee for Mental Hygiene and the American Psychiatric Association to introduce a standard classification of mental diseases into most of the State mental hospitals in the country. Subsequently, this classification was adopted by the Surgeon General of the Army, the U.S. Public Health Service, and by almost all public and private mental hospitals.

In 1949, Federal mental health statistical operations were moved to the newly-created National Institute of Mental Health (NIMH). Almost immediately, NIMH set up the Model Reporting Area for Mental Hospital Statistics, a joint endeavor with the State mental health agencies. The first step involved a study of the 11 states with central mental health statistical offices to determine definitions used, types and frequency of data collections, types of reports generated, etc. A major finding was that only 2 of the 11 states used the same definition of first admission, and that wide variation existed in the definitions of discharge and resident patient.

To remedy the situation, NIMH invited the 11 states to a meeting in 1951 (the first National Conference on Mental Health Statistics) to agree on a course of action and to begin the process of developing and implementing comparable data standards. By 1965, 34 states were participating in this voluntary, collaborative project. In 1966, NIMH expanded the project to include ambulatory mental health care and designated the annual National Conference on Mental Health Statistics as the principal vehicle for consensus building and standards development. Generally, this endeavor was very successful and set the stage for subsequent progress. Dr. Morton Kramer, currently Professor Emeritus at Johns Hopkins University in Baltimore, was largely responsible for these developments and the progress achieved.

Mental Health Statistics Improvement Program (MHSIP)

By 1976, NIMH had effected a reorientation from data standards for State mental hospitals toward one focused on mental health statistical standards for all mental health organizations. A new program was initiated at this time--the Mental Health Statistics

Improvement Program (MHSIP)--to continue and expand the collaborative relationship with the states and to evolve data standards that reflected current developments in mental health services.

For the first decade of the MHSIP, all work involved contributions in-kind by participating states since federal grants were not available. To the present, the states continue to contribute in-kind by encouraging staff to participate in MHSIP committees and by participating in national, voluntary data collections operated by the Center for Mental Health Services (CMHS) National Reporting Program (NRP) for Mental Health Statistics.

The initial set of data standards evolved by the MHSIP were published in 1983. These standards were based on the mental health organization as the principal reporting unit. Separate minimum data sets were proposed for organizations, for the clients they served, and for the human resources available to provide care. By the middle of the decade, these data standards had been widely adopted by the states. The approach employed was viewed by the World Health Organization (WHO) as a model for emulation by other countries.

The 1983 MHSIP data standards were quickly accepted by the mental health field. However, the environment was changing rapidly--block grants were being introduced; a new focus was emerging on the population with serious mental illness; and State mental health planning was mandated under federal legislation. Managed care was also beginning to emerge in the early part of the decade, but was not a major force until 1990.

As experience developed with the MHSIP data standards and as changes occurred in the environment, the MHSIP community recognized the need to update the standards. In 1989, two new minimum data sets were added--one for financial information, the other for events. The original minimum data sets--organizations, human resources, and clients--were updated. In addition, a conceptual framework was developed for the MHSIP, based upon hierarchical, relational concepts. The clinical event was viewed as the basic unit of the system, to which one could link client, provider, and financial information, within an organizational frame. The revised and expanded set of standards was published in 1989.

These standards were subsequently expanded with specific recommendations for performance measures and for data standards for child mental health programs. The Ad Hoc Advisory Group to the MHSIP, a set of state, local, and consumer representatives, has played a particularly important role in developing the data standards and providing leadership to the field. Dr. John Hornick, Director of Planning for the New York Office of Mental Health, is the Chairperson for 1994-95.

In this same period, the National Institute on Drug Abuse (NIDA) and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) worked with the states and local providers to define a minimum data set for a Client Data System (CDS) to be reported on every substance abuse client who received care from a public provider. Items included in the minimum data set were designed to be compatible with the MHSIP, and MHSIP

representatives were invited to participate in the standards development process. The CDS is still in operation at present.

NIMH awarded the first grants to states to implement the MHSIP data standards in 1989. The original grants (type 1) were for \$100,000 per year, for up to 3 years of support. By 1994, virtually all states and territories had received one of these grants. Throughout this early period of MHSIP development, two persons were instrumental in its success, Mr. Cecil Wurster, formerly Chief of the Branch with responsibility for the MHSIP program, and Dr. Walter Leginski, currently Chief of CMHS programs for persons with mental illness who are homeless.

In 1992, the NIMH grant announcement was expanded to include a second phase of implementation grants (type 2) and decision application grants (type 3) for the states. The second phase grants were intended to facilitate more complete implementation of the MHSIP standards; the decision application grants were for the purpose of developing and demonstrating the capacity to apply actual data to administrative, policy, or research problems. Both types carried stipends of \$125,000 per year, for up to 3 years of support. As of 1995, when the grant announcement was revised by CMHS, the current organizational location of federal mental health data collection activities, about three-fifths of the states and territories had received second phase implementation grants; about one-fifth, decision application grants.

Current Efforts At Standardization

In 1995, CMHS adapted the grant announcement to the dramatic changes that were occurring in the environment. The new announcement focused attention on use of information for problem resolution; capacity development received less attention. The 1995 announcement was directed toward the facilitation of comprehensive State mental health planning and adoption of the State mental health agency to health care reform initiatives being planned or implemented by the state. These topics are described immediately below.

Historically, most State mental health agencies have employed statistical information to plan only for state-operated or funded programs. This planning typically has not included mental health organizations or practitioners from other not-for-profit or private sector entities. Similarly, mental health services delivered through primary care organizations or practitioners, social service organizations, or self help groups have not been encompassed in this planning.

As the states move toward managed care, it is essential that their planning be expanded to encompass the entire population with mental illness, as well as high risk groups. This will permit each State to understand the dynamics of clients who move from private sector plans to public sector managed care programs or other safety net programs operated by the state. The new MHSIP grant announcement encourages the acquisition and analysis of quantitative data for such planning.

State health care reform initiatives are proceeding at a rapid pace. In most states, these initiatives center on application for a federal waiver to transform the State Medicaid program into a managed care plan operated by a private-sector management services organization. Frequently, these waivers are designed to develop separate managed care plans for populations with mental illness or substance abuse problems, i.e., a "carve out" program.

To plan for managed care programs, the State needs to design a benefit package, develop homogeneous risk pools of consumers who will use different types and intensities of services, estimate the per client per year cost for each of the risk pools, develop a plan for how essential ancillary services will be provided and reimbursed, and prepare baseline service information prior to implementation of the managed care program so that performance can be assessed.

In the implementation phase for privatized managed care programs, State activities will change from planning to monitoring the performance of programs. In this phase, additional data are needed on population health status, enrollment, encounters, outcomes, and system performance indicators, the latter of which need to be synopsized in report cards for payers or consumers. The new MHSIP grant announcement is designed to encourage states to use statistical information for these planning and implementation activities.

Key Consumer Input

Since 1990, NIMH and, more recently, CMHS have provided support for a Mental Health Consumer/Survivor Research and Policy Work Group comprised of consumer leaders from the field. The purpose of the group has been to provide advice to the government and to the MHSIP on the development and implementation of data standards for mental health. The Work Group has helped to define person-centered data systems that reflect a major shift in philosophy toward persons who use services. This has heightened awareness of consumer perspectives on service delivery, outcome, and recovery processes.

As a second major endeavor, the Consumer/Survivor Work Group has engaged in research through focus groups to define the cognitive maps that consumers use to think about service outcome. Currently, the Work Group is participating with CMHS and MHSIP in the development of a managed care report card for mental health and substance abuse. Development of this report card will create a method of providing feedback to consumers on plan performance. The final product will be made available to the states for use in their contracts with managed care organizations.

Data Standards For Behavioral Healthcare

The MHSIP data standards provide an excellent foundation for the information systems required by managed behavioral healthcare. However, the current system of standards requires expansion and modification to meet the full range of information needs in the

future. Essential developments in content, recording, and transmission standards are identified below.

Content Standards

Essential components of a good information system for managed care include, at the person level, data on the health status of the covered population, enrollment and encounter data for each covered person, and outcome data. In addition, the system will include information on disorder rates in the general population, descriptive information on the organization and operation of managed care entities and the providers that contract with them, and performance information on individual managed care plans.

Health status data should be collected at the individual level in order to assess the individual's need for treatment. This would include information on the nature of the mental health or substance abuse problem being experienced and the impact of that problem on the functioning of the person. The essential concept is to identify problem and functioning measures that are predictive of the need for mental health or substance abuse services and that can be used in the development and assessment of clinical treatment plans.

Some work has been completed in this area. The National Co-morbidity Survey is based on the Composite International Diagnostic Instrument (CIDI). The CIDI is an instrument through which lay interviewers can assess psychiatric and substance abuse diagnoses. Dr. Ron Kessler has completed methodological work on the CIDI to identify stem questions that are highly predictive of diagnosis. At present, the "CIDI stems" need to be codified into data standards, and a parallel set of items on functioning needs to be added to these standards (see discussion of outcome measures below).

Enrollment and encounter data are required to monitor managed care plans. Enrollment data should be collected at the individual rather than aggregate group level; they can provide an overview of the sociodemographic characteristics of an enrolled population. Together with health status data, enrollment information permits the construction of different risk pools when coupled with service use information. By contrast, encounter data are needed to provide a running account of services received AND their costs for each client. Such information can be used by providers to determine whether they are exceeding agreed upon capitation rates; it can also be used by states and other payers to monitor what types of persons are receiving what types of care and how this compares with the health status. MHSIP provides an excellent foundation for encounter data through the event data set developed as part of the 1989 standards.

Currently, the Subcommittee on Mental Health Statistics of the U.S. Department of Health and Human Services National Committee on Vital and Health Statistics is debating what should be recommended for enrollment and encounter minimum data sets. The Subcommittee will pay particular attention to what would differ in enrollment and encounter data standards for populations with mental health and substance abuse problems, compared with other populations. The overall National Committee is preparing

to issue proposed enrollment and encounter minimum data sets to the entire health field; the work of the Subcommittee will be incorporated into this product. In anticipation of this product, the Ad Hoc Advisory Group to the MHSIP is preparing a report on enrollment and encounter data to submit to the Subcommittee.

Outcome data are a necessary component of an integrated, managed care management information system. Yet, a major deficit of the mental health and substance abuse fields is the lack of agreement among consumers, family members, clinicians, rehabilitation specialists, administrators, and researchers about how to measure the outcome of services. This deficit has hampered the development of improved clinical protocols, as well as the standing of these fields in the broader clinical community.

In recognition of the need for rapid developments in the area of outcome assessment, the National Alliance for the Mentally Ill (NAMI) has entered into a collaborative project with CMHS, NIMH, NIDA, NIAAA, and the Eli Lilly Co., to engage in three tasks: the development of a set of principles for outcome measures and systems; the implementation of a longitudinal demonstration to document an improved outcome measurement system; and the evolution of a communication strategy that can highlight the progress being made in this area. Broad-based input will be sought from the mental health and substance abuse fields on the products from this project.

Other projects are evolving to examine how current instruments, such as the Behavior and Symptom Identification Scale (BASIS-32), the Medical Outcomes Study Short Form (SF36), and the Global Assessment of Functioning (GAF) can be abbreviated and adapted for a managed care environment. Clearly, a need exists for the evolution of data standards for outcome measures.

Disorder rates in the population data should be collected on a sample basis to allow for assessment of the overall health status of the general community population. These data comprise a necessary component for adequate services planning at the system level. The collection of these data over time, can be used to provide information on overall system performance with respect to its effect on the general population.

The ability to obtain this type of data hinges on the efforts underway to develop and test good predictive health status measures that can be used within general population samples. The "CIDI stems", described earlier, have already been incorporated into the 1994 National Household Survey of Drug Abuse, an annual household survey conducted by the Office of Applied Studies within SAMHSA. It is anticipated that they will also be included in the triennial periodic modules of the redesigned National Health Interview Survey, scheduled for initiation in 1996 by the National Center for Health Statistics.

Descriptive information is required on managed care entities and on the mental health organizations and providers that contract with them. Characteristics, such as organizational structure and linkages, types of plans and services, types of payers and enrollees, types of organizational and individual providers, and sources of revenues and expenditures, are relevant. This information is similar to that collected through the

Inventory of Mental Health Organizations and General Hospital Mental Health Services (IMHO), currently conducted by CMHS.

The 1994 IMHO had already been modified to collect information on the participation of mental health organizations in managed care plans. In addition, a checklist was developed to collect information on the range of services available through these organizations. The evolution of the IMHO will continue in the future to reflect the changes being made in managed care practices.

Plans are developed to collect information from managed care entities that operate or contract for networks of providers, as well as for health maintenance organizations (HMOs) that provide directly or contract for mental health services. Initial work in this area will be undertaken in late 1995 through a CMHS meeting with managed care entities. Clearly, organizational data standards will require revision to accommodate to these new requirements.

Performance information is required to evaluate managed care plans. Report cards are one specific form of performance information that will spark dialogue among key groups as they are developed. As noted above, CMHS is currently collaborating with the MHSIP and representatives of the consumer community to develop a mental health and substance abuse report card, primarily from the consumer perspective. This report card will encompass the key dimensions of access, appropriateness, outcome, prevention, and satisfaction. It is anticipated that this report card will be available in prototype form for critical review by early fall 1995.

Simultaneously, CMHS is working with other key groups developing behavioral healthcare report cards to facilitate coordination among them. One meeting has already been held among these groups, and additional meetings are planned. These groups are the National Committee on Quality Assurance (NCQA), the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), the American Managed Behavioral Healthcare Association (AMBHA), the Institute for Behavioral Healthcare (IBH), and NAMI. A collaborative endeavor among these entities can provide the framework for data standards in this area.

Recording and Transmission Standards

Equally of concern to the mental health and substance abuse fields are the recording standards for clinical data and the transmission standards for sharing electronic versions of clinical and financial information. Recording standards are needed for the mental health and substance abuse components of an electronic patient record, which is currently being developed. Transmission standards are concerned with the form in which information is sent and received electronically, as well as the format that is employed for such information. Both areas are intimately linked with privacy and confidentiality concerns.

Recording standards are very important at present because they will ultimately define the clinical information that is captured about clients and the services they receive. In most instances, derivative statistical information will be limited by the nature and scope of this electronic information. CMHS is currently supporting an Ad Hoc Work Group for the Computerization of Behavioral Health and Human Service Records that will prepare recommendations for recording standards.

At present, most work on transmission standards is outside the fields of mental health and substance abuse. The National Institute on Standards and Technology (NIST) of the U.S. Department of Commerce is currently working in this area, and the European Common Union (ECU) has set up a project to identify appropriate transmission standards. At minimum, information representatives of the mental health and substance abuse fields need to stay abreast of this work.

Partnerships for the Future

As we prepare for the 21st century, we need to envision how we will develop data standards for the future and the new partnerships and joint ventures that will be needed to make this possible. Clearly, task focus and partnership linkage are interdependent and synergistic. Suggested below are several major partnerships that could be very productive at the present time, together with a brief comment on the partners who are needed in order to make these endeavors successful.

Partnerships to revise current MHSIP data standards must be a high priority in the short-term future. The areas that should be incorporated or revised have already been described above--health status, enrollment and encounter, outcome, and system description and performance. The key to future work in this area is to add new partners, such as managed care entities and HMOs, while continuing the excellent collaboration of CMHS with consumers, providers, and states initiated in the past. This work should be undertaken as soon as possible in order to maintain consistency of information collected on managed behavioral healthcare, as this field evolves rapidly.

Partnerships to develop a mental health and substance abuse report card for managed care is another high priority. Previous work has been described above. The critical issue at present is to achieve an appropriate level of consistency in report cards across public and private plans and different service settings. For example, report cards for private plans may not require the same range of information as those for public plans because the clients are vastly different and their service needs are not as extensive. However, when the same topic is covered on different report cards, then it is reasonable to expect that it be measured in comparable ways. All major entities developing report cards for managed behavioral healthcare--CMHS/MHSIP, the National Committee on Quality Assurance, the Institute for Behavioral Healthcare, the Joint Commission on Accreditation of Healthcare Organizations, the American Managed Behavioral Healthcare Association, and the National Alliance for the Mentally Ill need to be partners in this endeavor. Private sector managed behavioral healthcare entities that already have report cards should also be consulted.

Joint activities with WHO hold promise for helping us learn from projects already carried out in other countries, as well as for developing a data base for comparative inter-country analyses. WHO also frequently serves as a conduit for the sharing of informal knowledge about regional projects being conducted in Europe, the Far East, etc. Within this context, joint projects with WHO on data standards can facilitate more rapid development of appropriate standards in the United States.

High priority needs to be given to the development of joint projects with WHO around data standards for health status and outcome, as well as data standards for a more discrete and operational array of mental health and substance abuse services. WHO already has projects underway on the former topic, e.g., revision of the International Classification of Impairment, Disability, and Handicap (ICIDH), and has held several preliminary meetings with the United States and other countries on the latter topic.

Collaboration with AMBHA and the Group Health Association of America (GHAA) is very important for establishing appropriate data standards for managed behavioral healthcare entities. AMBHA represents and understands managed behavioral healthcare entities that operate in a network environment; GHAA represents and understands HMOs and their mental health and substance abuse components. An opportunity exists to work with AMBHA and GHAA in the development of future information projects within their organizations, as well as to elicit their participation in broader projects. CMHS needs to employ the federal leadership role to convene these entities with others in common data pursuits.

Recommendations for the Future

Listed below are several general recommendations for the future that ensue from the review outlined above. Each reflects a different facet of the data standards enterprise for the mental health and substance abuse fields. Some will be relatively easy to achieve; others, relatively difficult. In the future, joint endeavors between government--federal, state, and local--and the private sector mental health and substance abuse industry will be the only feasible way to assure essential consistency in data standards. As all levels of government assume a smaller direct mental health and substance abuse service provision role with the growth of contracted managed behavioral healthcare, the focus of standards development will also need to shift to the private sector. Government will be able to make this shift and maintain accountability to the Congress and State legislatures through the types of partnerships and joint ventures described above. Such partnerships should be initiated in the short-term future.

Data standards development activities must reflect the views of all participants. Partnerships between government and the private sector reflect part of the picture. Consumers, family members, and providers are essential to complete it. Although the MHSIP has done an excellent job in bringing these groups to key partnerships, more needs to be done to bring their points of view on data and information to the managed behavioral healthcare industry.

Clearly, each of those groups is directly affected by any decisions reached by the industry; hence, they should have a voice in these decisions.

Adaptation to unanticipated future changes will be a necessary part of the data enterprise over the next decade. Managed behavioral healthcare is now established. However, the future course is uncertain with respect to which structures and methods will predominate: separate managed behavioral healthcare plans, integrated general healthcare networks, HMOs that include behavioral healthcare, or other forms. Likewise, the development and adoption of computer technology is proceeding at a fast pace, but the future course is not completely clear. The data standards enterprise needs to anticipate and adapt to new developments when if not before they arise, rather than to lag behind those changes by several years. This can only occur if careful attention is given to developments in services and technologies as they occur, with reflection upon their data implications.

Data standards should adequately reflect "virtuality" in service delivery systems. The most efficient, cost-effective way to achieve comprehensive, seamless service systems in the future is not likely to be through the development of a single service cafeteria in which all services are available, but rather through contractual and computer linkages among these services so that they are seamless from the perspective of consumers and providers. This approach represents a "virtual" organization. Such "virtual" organizations are likely to become very common as mental health and substance abuse services are linked with general healthcare services, and social services, housing, and other services are brought under the managed care umbrella. Data standards should reflect these "virtual" organizations and be capable of permitting interface among their service components.

The future holds considerable promise. We must be prepared to meet the challenges that it presents. Clearly, our past and present have positioned us to do this in an excellent manner.

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