

I. Introduction to the Draft Requirements Analysis for *Decision Support 2000+*

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A New Conceptual Model: One Information System Serving Many Purposes

Today's technology makes possible a revolution in information: multiple users, *if* they adhere to established standards for data collection, can participate in what is virtually a single information system that will enable them to share data and communicate effectively. This virtual system can be used to meet all their information needs, whether they are consumers or providers making choices about treatments, payors deciding among health plans, managers allocating financial and human resources, or researchers determining the need for services in a community. Furthermore, participation does not require purchase of costly new systems or staff retraining — it requires only that we use what is currently available in a new way.

Goals of the Information System

One goal of the new information system is improved decision support. Whether decisions are made by consumers and family members, providers, payors, managers, or researchers, they will be enhanced by an information system that provides all the data they need, quickly, accurately, and efficiently. A second goal is improving the quality of mental health services. An information system that makes available for stakeholders reliable data on a community's mental health needs, services used and service users, costs and revenues, performance and outcomes, is critical to improving care. A final goal of the information system is to facilitate effective communication within the mental health system and between it and other human service systems.

How the Model Operates

Figure 1 and 2 illustrate the information system model. They show that the information system is part of and serves the needs of the mental health care system and that both the mental health care system and its information system are linked to the care and information systems of other human service agencies. The stakeholders in the mental health care system—consumers and family members, providers, plans, programs, and payors— provide data for and receive data from the information system. These data, collected and reported in uniform ways, are of various kinds, and include information on the population, plan enrollees, encounters with service providers, and the financial, organizational, and human resource characteristics of clinical and administrative entities within the care system; on the system and clinical guidelines currently in use across the care system; and on the results of system performance measures, consumer outcome measures, and surveys of consumers, providers, and others.

These data can now be used for descriptive purposes: How many people in the population need mental health services? How many and what kinds of people are enrolled in plans? How many people used services, what types, and at what cost? The data can be analyzed to show the extent to which the actual system operations performed and the actual clinical services provided adhered,

respectively, to the system and clinical guidelines. Finally, the data can be used to determine what system performance indicators were met and what consumer outcomes¹ were achieved to demonstrate where and what kinds of improvements are needed in system performance and clinical services.

Stakeholders receive data from the information system to answer a wide variety of questions. Clinicians and consumers have treatment decisions to make: What practices lead to the best outcomes for individuals? Payors must choose among and negotiate contracts with health plans, while consumers also must decide which plan and providers best meet their needs. Managed care organizations and public mental health agencies have administrative and business decisions: What practices lead to the best outcomes for systems? Private and public payors want to know which plan will provide the best care for the best price and what services should be included in a benefits package. Public policymakers must decide how much to spend on mental health services, while researchers want to know which treatments are most efficacious and how many people need care.

Key Features of the Information System

The key features of the information system are that it:

- contains several types of information;
- can answer many questions by using multiple units of analysis and by linking data across the mental health system and other systems of care;
- makes use of existing data collection practices and systems; and
- establishes standards for data collection and use.

Types of Information

The information system model contains data of four different types: descriptive, evaluative, prescriptive, and corrective. Each type of information has its value for addressing particular types of questions.

Descriptive Information: What are we doing?

The various data sets —population, enrollment, encounter, financial, organizational, and human resources— can be used to answer the question: what are we doing? They describe, for example, what services are needed and provided, who provides them, who uses them, how often they are used, what they cost, and how they are organized and financed.

Evaluative Information: How well are we doing?

The quality tools within the information system prototype —consumer outcome measures, system performance indicators, and consumer-oriented report cards— can be used to answer the question: *How well are we doing?* They provide information on the outcomes of services and treatments for

¹ Outcome measures characterize a person (consumer of services); report cards characterize health plans and service entities such as hospitals; performance indicators characterize larger systems such as national healthcare networks and corporations and state mental health authorities.

care recipients and indicate how well individual providers, programs, and the system as a whole perform in regard to provision of accessible, appropriate, high quality, and cost-effective care. When data are collected in uniform ways, quality tools support comparison across systems, plans, programs, and persons.

Prescriptive Information: What should we be doing?

The clinical and system guidelines in the information system provide direction: *What should we be doing?* They tell us what the literature or clinical or managerial experience indicate will produce the best results.

Corrective Information: Does what we are doing match what we should be doing?

In the model, fidelity measures compare actual clinical and system practices to the practices recommended in guidelines: *Does what we are doing match what we should be doing?* What corrective action must be taken to increase fidelity? System performance measures —performance indicators and report cards —measure administrative, managerial, and program performance directly while consumer outcome measures provide an indirect assessment of provider performance.² When desired effects are not achieved, the information obtained through these measures focuses and directly quality improvement activities.

Answers for Many Questions by Using Different Units of Analysis

Because these different kinds of data are contained within a single information system, great many questions can be answered. To answer some questions, a population will be the unit of analysis; for other questions, a person will be the unit of analysis; and for still others, a plan or a program will be the unit of analysis. Exhibits A-C contain vignettes that demonstrate the ways the information system can be used to answer a wide variety of questions using different units of analysis.

The Population as the Unit of Analysis

The vignette in Exhibit A takes the population as the unit of analysis, in this case, the people living in a particular county, as well as various sub-populations—groups of people with certain mental illnesses, of certain ages and ethnic groups, living in certain neighborhoods, etc. Using the population, enrollment, encounter, and financial data in the information system, a county mental health agency determines what kinds of services to establish, where to locate them, and how to develop a performance-based contract for mental health services.

The Plan as the Unit of Analysis

The Exhibit A vignette also shows how population, enrollment, encounter, and financial data are used when the plan is the unit of analysis, that is, when the questions concern the kinds of services a plan provides and the accessibility and the quality of those services. In the vignette in Exhibit B, the unit of analysis is also the plan. Using various data sets, purchasers of services and consumer and family advocates conduct analyses that help them evaluate and choose among competing plans. For example, they use the enrollment and encounter data reported by different plans to compare their accessibility to people with serious mental illness, rates of service use, and array of services actually available. They use plan-reported data from performance and outcome measurement to see

² Outcome measures characterize a person (consumer of services); report cards characterize health plans and service entities such as hospitals; performance indicators characterize larger systems such as national healthcare networks and corporations and state and county mental health authorities.

how each plan performs in regard to indicators of access, quality, and appropriateness and how consumers in the plan fare in regard to clinical and functional status outcomes.

The Person as the Unit of Analysis

In Exhibit C, the vignette describes how a consumer might use the information system to help make good decisions about treatment. Here, the unit of analysis is the person: what are the outcomes for persons who use this treatment and how do they compare to the outcomes for persons who use an alternative treatment; how did this particular person's symptoms change as a result of the treatment; how satisfied are persons in this program with treatments they received.

Linking Data

The enormous potential of the information system prototype lies in its capacity to link data from different sources, both within the mental health system and between mental health and other service systems, and in its ability to link different units of analysis. By drawing from several different data sets, the prototype makes it possible to answer a prodigious number of questions ranging from the outcome of a single individual's treatment to complex projections of service needs and financing requirements for entire populations.

Information in mental health has, up until now, focused primarily on the encounter as the unit of analysis, with the person in the role of client. Persons, however, have other roles — population members, enrollees, decision-makers — and the variety of organizational and financial arrangements within the mental health care system means that we must incorporate information from other levels — plans, programs, and population — if we are to fully understand this complex system and how to improve it. It is a many-faceted and dynamic system in which change at one level produces changes at other levels — and it needs an information system that can handle large volumes of data and multifactorial analyses.

By linking data sets, information about persons can be used to evaluate plans and programs. For example, if a plan is contracted to provide mental health services to certain percentages and categories of a state's population, then enrollment and encounter data aggregated for all persons served by the plan will show whether these standards have been met. Similarly, linking data from consumer satisfaction surveys and other performance measures with aggregated enrollment and encounter data can show the relationship between such factors as satisfaction, availability of specialists, denials of services, and rates of enrollment in and disenrollment from the plan

Advantages of Linking Data

Linking data will meet many needs in mental health including:

- *The need to coordinate care more efficiently and effectively.* A primary barrier to effective and efficient delivery of mental health and human services for children with severe emotional disturbances and adults with serious mental illness is the lack of a coordinated communication system that allows for the sharing of timely, accurate, and appropriate information among all the agencies and service systems involved in their care.

- *The need to meet reporting requirements.* Most mental health organizations are accountable to Federal and local payors and are required to report on a great variety of matters. Exchange of core data sets, agreement on data exchange protocols, and use of web-based Internet and intranet applications would go a long way toward increasing the efficiency and cost-effectiveness of data collection and reporting.
- *The need for research.* Mental health phenomena at both the person and the system levels are enormously complex. Our ability to understand current circumstances and predict future trends depends on being able to look at how the many factors that affect outcomes and performance interact in multi-dimensional analytic models; this, in turn, depends on being able to link data.

Challenges to Linking Data

There are many challenges to linking the components of an information system (intrinsic linkages) and linking that system to others (extrinsic linkages)³. These include creation of privacy-protected unique client and provider identifiers, linking structurally different databases, and collecting and reporting real-time data. When linking data sets, it is critical that data elements and coding be clearly specified to avoid misunderstanding and unwanted variation in coding items. Data collection procedures and databases that serve multiple purposes such as reimbursement and quality measurement are more likely to be adopted by users than more limited ones; but this increases the need for instruments that are straightforward and transparent and that minimize additional staff training and development of training materials and documentation.

Use of Existing Data

The information system would be impossible to build, implement, and finance if it had to be created de novo. Many of the components of the system already exist in one form or another—the Federal and some state governments collect population-level data; managed behavioral health care organizations and providers collect enrollment, encounter, and outcome data, use financial and human resource data, and report on performance indicators; many clinical guidelines are available; and we have standards for systems and some prototypical system guidelines. Certainly, we need to expand and standardize these data collection efforts, but we must not minimize how much exists. The issue is one of improving what we have and reaching consensus on how to do so, not on building anew.

The same is true for information systems. Clearly, there are problems of incompatibility in hardware and software — systems that cannot “talk to” one another cannot share information. But the Internet is an untapped resource and advances in data warehouse and object-oriented technologies are enabling us to overcome local differences. Other technical issues, of course, must

³ Intrinsic linkages connect data and databases within the mental health information system to answer questions related to quality improvement at all levels of the service delivery system (population, plan, program, and person). Extrinsic linkages connect information systems and their components across programs, organizations and systems for the purposes of clinical coordination, quality improvement, cross-system performance monitoring and research.

be resolved: we need unique identifiers before we can link data on persons, programs, or plans across databases; we need dependable ways to ensure privacy and confidentiality; and we need minimum data sets so that we will all collect comparable information in an efficient and affordable way. Again, the issue is one of improvement and consensus, not starting over.

Establishes Standards

The information system recommends standards for data reporting including minimum data sets, measures and instruments, and procedures for collecting and analyzing data. It builds on the work of the Mental Health Statistics Improvement Program (MHSIP) in developing standards for mental health data (see Appendix D and www.mhsip.org). In the late 1980's, MHSIP created a Task Force to reconsider existing data standards and recommend revisions. In its 1989 report, *Data Standards for Mental Health Decision Support Systems* (commonly known as FN-10), the Task Force noted that:

“the adoption of standards permits communication, judgements, and comparisons. Communication is enhanced because standards provide clearer definitions of terms and concepts used in the conduct of the business. Judgments can be made against the standards — does an item, product, or degree of performance meet, exceed or fail the test? And once standards are operationally in place, comparisons are possible by allowing the manager to aggregate data to foster an understanding of differential performance....Comparisons and judgments about performance permit decision makers to make alterations in their service programs intended to improve their approaches to the care of the mentally ill.” (National Institute of Mental Health, 1989, p 4)

This 200-page report presented minimum data sets for patient/client data; event/encounter data; human resources data; financial data; and organization data; subsequently, recommendations were made in regard to data elements relevant to children (MHSIP, 1992). Owing to the quality of MHSIP's work, all states have now voluntarily adopted many of these standards. The MHSIP FN11 workgroup began the process of updating and refining FN10; it is being continued through development of this model information system and elaboration of minimum data sets for each of its components.

An Historical Perspective

The past decade has seen dramatic changes in the roles and types of stakeholders in the mental health care system: consumers and family members now have greater opportunity to participate and more power to influence personal and system-wide outcomes; and health maintenance organizations (HMOs) and managed behavioral health care organizations (MBHCOs) are now as much a part of the mental health care system as are care recipients, clinicians⁴, and those who have traditionally paid for care (employers, the Federal government, and state and county mental health authorities). Stakeholders need ready access to information on a wide range of issues in understandable, easy-to-use formats if they are to make wise decisions.

⁴ We use the term clinician to refer to the individual who provides care to a consumer and the term provider to refer to the entity—HMO, MBHCO, public mental health agency, group practice—that organizes, delivers, manages, oversees care to groups of consumers.

The trend to “carve out” mental health has widened the gulf between the mental health care system and other human services such as medical care, social welfare, vocational rehabilitation, and housing. Both deinstitutionalization and the failure of the system to provide high quality, appropriate care to people with serious mental illness has resulted in increased homelessness and incarceration in jails and prisons. With care occurring in these multiple and varied settings, there is greater risk of fragmentation, duplication, and gaps in services and greater need for effective communication among agencies and systems of care.

These changes—stakeholders with new kinds of decisions to make and a more complex human service system with vast amounts of data to share—have created a need to expand and improve information. The quality of information will determine the quality of care: without good data stakeholders cannot make good decisions and without good decisions, the system cannot continue to operate.

Current Status of Mental Health Information

The mental health field (and, indeed, the human services system as a whole) currently lacks the standardized data needed to manage mental health care systems effectively. The field also lacks the measures to evaluate the quality of the care the system provides, with respect to both practices and outcomes. There are no widely-accepted clinical or system guidelines with which to standardize practice or to provide criteria for judging provider and system performance. Finally, we do not have data systems for collecting this information in a uniform and comparable way or for enabling communication across systems of care.

In response to this situation, the **Survey and Analysis Branch of the Center for Mental Health Services** (which is responsible for providing descriptive information on the Nation’s mental health service delivery system and for developing and implementing the data systems to collect this information) undertook development of an information system prototype to address the field’s need for standardized data, useful guidelines, consistent quality measurement tools, and efficient information sharing. A group of experts and stakeholders was convened in January 1998 to guide the development of the information system. The group recommended that the information system should:

- link clinical and system guidelines with standardized population, enrollment, encounter, organizational, human resources, and financial data, consumer outcome measures, system performance measures, and consumer-oriented report cards;
- meet the needs of a broad group of users including consumers, families, providers, payors, managed care organizations, state mental health authorities, administrators, researchers, policy makers, and advocates;
- collect individual and aggregated data at both the consumer and system levels, i.e., data on individual consumers, groups of individual consumers, individual organizations, and groups of organizations (systems);
- collect data on consumers of services and persons in the community who are not consumers of services;

- collect data on adults, children, adolescents, elderly, and persons with co-occurring disorders;
- ensure privacy and confidentiality of data;
- be flexible enough to incorporate cross-cultural information and assessment tools;
- produce information that can be used to enhance the quality of care for individuals and groups of adults with serious and persistent mental illness and children with serious emotional disturbance;
- facilitate clinical and organizational decision-making and monitor the outcomes of decisions taken;
- collect, analyze, and report longitudinal data;
- be able to expand in terms of numbers and types of data elements and numbers and types of subjects and to be modified over time;
- be able to link with information systems in a broad range of agencies, locations, programs, organizations (e.g., social service, corrections, consumer-run programs, and “wrap-around” services such as housing, vocational rehabilitation);
- be designed for use on personal computers by persons with limited technical expertise.

Related Efforts

In addition to the work of MHSIP on data standards, the mental health field has been active in developing clinical guidelines, quality measurement tools, and information systems. Unfortunately, sparse resources slow the pace of change, leave much work unfinished, and limit dialogue within the field. As a result, there is fragmentation of what should be an integrated and cooperative effort, overlap and duplication of activities, and gaps that could be resolved by enhancing communication and collaboration.

Federal administrative and regulatory agencies have broad authority to establish requirements and performance standards for data collection and reporting and to monitor and enforce the compliance of public and private entities. Other legislation limits the collection, use, and disclosure of information by these agencies to reduce expense and burden and to ensure confidentiality and protect privacy (Rosenbaum et al., 1998).

Recognizing that electronic methods for health insurance-related transactions such as enrolling members, paying premiums, checking eligibility for services, obtaining authorization for specialist care, filing claims, coordinating benefits, etc. could substantially reduce administrative cost and burden, Congress included Administrative Simplification provisions in the Health Insurance Portability and Accountability Act (HIPAA) of 1996 (P.L. 104-191) to establish a single, uniform set of standards for these transactions. Specifically, HIPAA requires the Secretary of Health and Human Services (HHS) to adopt national uniform standards for electronic transmission of health

data and to require adherence by health plans, providers, insurers, and clearinghouses that transmit data electronically (Fitzmaurice, 1998).

HIPAA also includes specific provisions to protect the security and confidentiality of health information associated with individuals. It requires the Secretary to recommend health record privacy legislation to Congress; if Congress does not enact such legislation, HHS is to promulgate the regulations itself prior to the implementation of electronic transaction standards.

The HHS process for implementing HIPAA standards (and the parallel process to ensure privacy) has included internal interdepartmental working groups⁵, external groups of experts, and a Federal advisory committee. By requiring HHS to adopt standards developed by organizations accredited by the American National Standards Institute (ANSI) and consult with specified national committees such as the National Committee on Vital and Health Statistics (NCVHS), Federal and state agencies involved in health care, and private organizations, HIPAA enunciates principles of “openness, consultation, and industry acceptance” and facilitates a process that is intended to be inclusive, consensus-based, and involves public and private sector collaboration. (Fitzmaurice, 1998)

This process has, thus far, produced a set of guiding principles for developing, evaluating, and improving data standards and a set of candidate standards. It has addressed issues of testing the standards; determining and certifying compliance; security and privacy provisions; modifying standards to conform with changes in information technology; establishing identifier registries; and updating and maintaining standards over time. (Fitzmaurice, 1998) Appendix E provides additional information on the HIPAA initiative.

The Relationship between Health and Mental Health Data

The concurrent activities of HHS and CMHS offer a unique opportunity to create data standards that address the information needs of both the medical and mental health communities. The two initiatives have much in common. First, they take the same approach to adopting standards. Both seek to identify existing candidate standards; identify gaps and conflicts in existing standards; and develop recommendations for the standards to be adopted. Second, they both struggle with similar issues of developing unique identifiers, protecting privacy and confidentiality, and implementation. Finally, both have recognized that the process should be open, inclusive, and allow for input from all stakeholders.

In May, 1998 the Secretary of HHS proposed standards for eight electronic transactions and for code sets to be used in those transactions (Federal Register, 1998). While this was certainly an impressive beginning, it is unfinished in regard to mental health data. There are such significant differences between the care needs of persons with mental illness and those with physical illness and between the types and extent of mental health and medical services they require, that standards and code sets applicable to mental health *must* be added to the current HIPAA standards to address

⁵ Working groups exist for health insurance claims and encounters; health insurance enrollment and eligibility; health identifiers for providers, health plans, employers and individuals; code sets and classification systems; security standards and safeguards; and information infrastructure and crosscutting issues.

adequately the kinds of data that are produced in regard to people with serious mental illness. For additional comments on this issue, see Appendix F.

Uniform data standards are a necessary, but not sufficient, condition for improving the quality of care for people with mental illness. Data must be integrated with standards of care, measures evaluating performance and outcomes, and continuous quality improvement based on systematic evaluation; it is the linking of standardized data with guidelines and quality tools that will make the information system prototype so useful. Therefore, there must be standards not only for the components of the system, but for the *linkages* among them. There must be standards for linkages that are *intrinsic* to the system, linkages that enhance efficiency in data collection and analysis, as well as for *extrinsic* linkages between the mental health information system and the information systems of related agencies and programs.

Purpose of this Report

This report specifies the requirements for the new information system that will enhance collection and reporting of mental health data. Designed to meet the service, business, and research needs of the mental health care system, this system builds upon 150 years of work in the mental health statistics field that has produced uniform core data sets for enrollment, encounter, and administrative data, clinical practice guidelines for many mental disorders, and a variety of tools for measuring outcomes, performance, and the quality of care.

In the sections that follow, we present for review and comment, reports on the status of each component of the information system including the standards that currently exist, the gaps and conflicts in those standards, and recommended next steps. We also discuss overarching issues critical to the prototype such as the consumer perspective on data, privacy and confidentiality, cultural competency, and technological concerns.

We have organized the field's achievements and remaining work in terms of the degree of consensus that exists on *domains* (issues, categories or topics of interest), *indicators* (measurable activities, events, characteristics or items that represent a domain), and *measures* (the instruments used to assess, evaluate, and measure an indicator); whether the measures have been experimentally *field tested and/or implemented*; and whether the component is fully *ready for inclusion* in the information system.

Each section addresses the same set of questions:

- What is the intended purpose or function of the component? What functions will it serve in the information system?
- What information must be put into the information system to accomplish this purpose?
- Who⁶ provides the information for the component?

⁶ Consumers, family members, providers, payers, managed care organizations, administrators, support staff, etc.

- What information is produced by the component to accomplish this purpose?
- Who uses the information that is produced by the component?
- How ready is the component for inclusion in the information system?
- What future efforts are needed for readiness of the component?

We invite you to respond to the requirements analysis by completing the questionnaire on the MHSIP website (www.MHSIP.org) or emailing us through the direct the link on the website.

Figure 1

Components of *Decision Support 2000+*

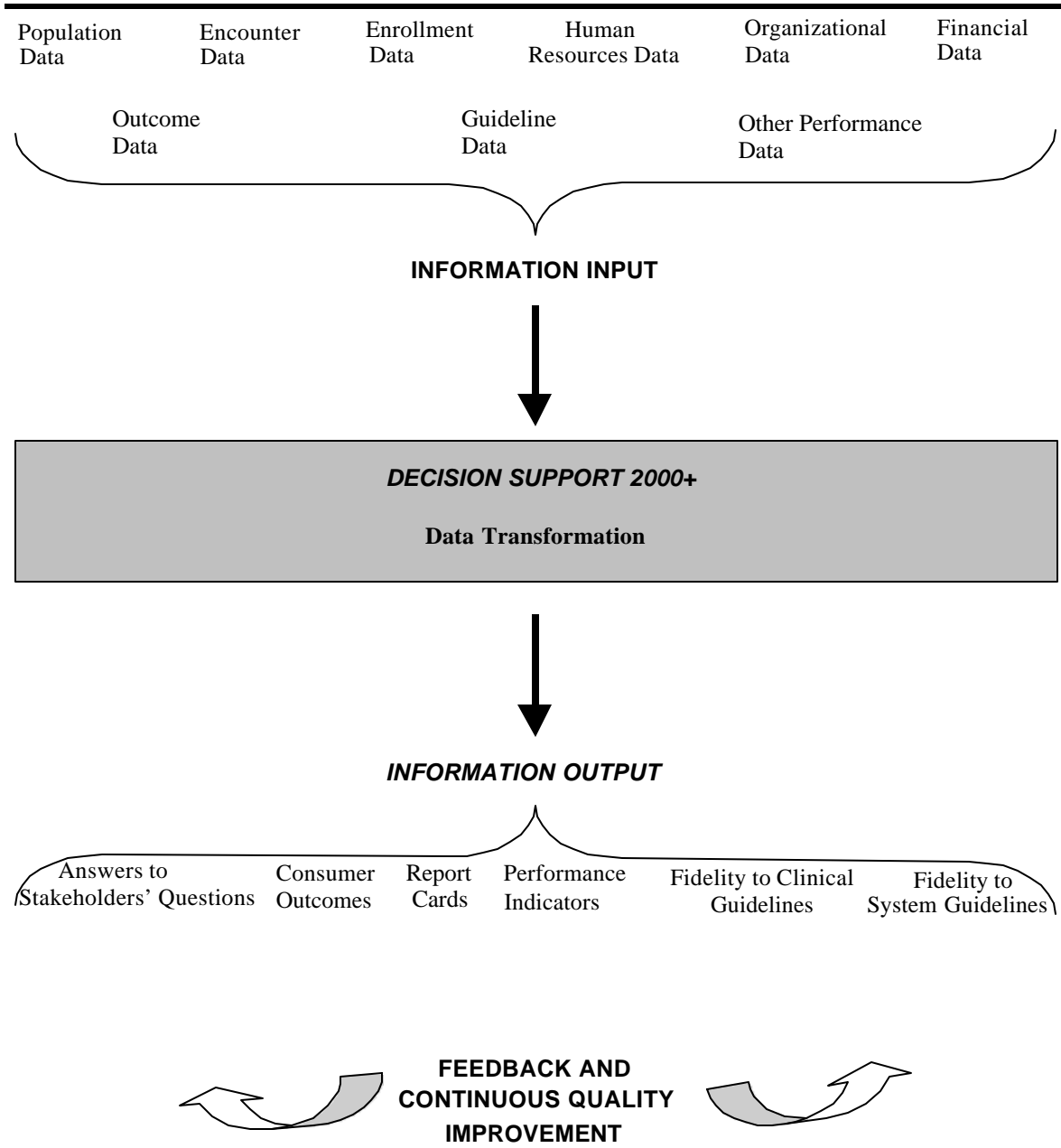
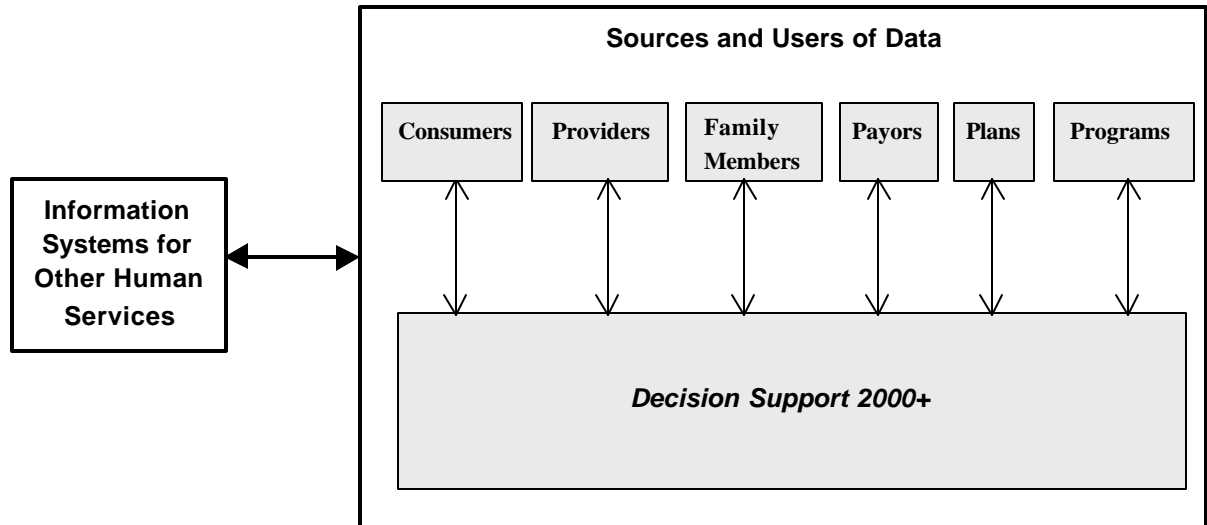


Figure 2

Decision Support 2000+ in Context



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Appendix A: A Vignette ³/₄ How a County Planner Might Use Population Level Data

Below is a vignette describing how county officials might use data from the information system to develop a new infrastructure for the delivery of health, mental health, and other human services. They begin with a baseline understanding of the demographic characteristics, medical and mental health conditions, health status and level of functioning, and quality of life of the county's population. Next, they examine enrollment data for the currently available health plans to understand demographic, insurance, and baseline health and mental health status of enrollees and their families and to determine whether there is an equitable distribution of people and services throughout the health plans. To determine the extent to which the current health plans meet enrollee and community needs, the officials study encounter data. These data characterize all users of services (e.g., health and mental health status, diagnosis, symptoms, functional status, etc.), types of services used, and frequency of use; linking encounter and financial data provides information on the costs of services and episodes of care. Human resource data are used to characterize providers and organizational data provide information on the organizational structures and processes of plans and programs.

Please allow me to introduce myself. I am the county commissioner of mental health and human services. We are in the midst of reorganizing the mental health services for our county. Let me tell you what we have done and why. We kicked off the entire re-organization effort by developing a baseline understanding of the demographic characteristics, medical and mental health conditions, health status and level of functioning, and quality of life of our community members. Our analysts prepared a report on the mental health status of residents using population, enrollment, and encounter data that included a detailed analysis of the most common presenting diagnoses (aggregated multiple plan enrollment data), a breakdown of the demographic characteristics of those who accessed mental health services (aggregated multiple plan encounter data) and a breakdown of the demographic characteristics of those who needed but had not yet accessed mental health services (population data).

From this report, we learned that the most common diagnoses in our community were affective disorders, conduct disorder, and eating disorders. We were disturbed to find a high rate of successful suicides among young women in one neighborhood. We also learned that in one region of our county there is a preponderance of children who report that they live with a parent who has abused alcohol and other drugs.

Because our information system includes access to expert decision support tools we were able to look up clinical and system guidelines for treating these behavioral health problems. We were also able to look up the regulations regarding these interventions and learned, for example, that the privacy of persons in substance abuse treatment must be particularly well protected.

We made an important decision early on not to restrict our planning efforts to providing services for only the most common mental health problems, but, rather, to develop mental health promotion, prevention, and early intervention programs for our community. For that reason, we dug deeper into our information system to determine most-common diagnoses by neighborhood (sub-population) and to understand the unique neighborhood characteristics that might contribute to those problems. For example, eating disorders appeared to be concentrated in one neighborhood, a white, suburban,

wealthy community with a high divorce rate, higher than usual use of private school education, and a highly competitive neighborhood sports program. Using our expert decision support tool and querying our contracted health plans' websites, we developed a portfolio of state-of-the-art intervention strategies for treating eating disorders which we plan to include in a bidders library when we re-bid our health plan contracts. We also plan to commission a study to examine provider compliance with one or more of these clinical guidelines and the impact of fidelity on treatment outcomes.

This kind of detailed analysis of data from our information system has proven useful in other ways. For example, we noticed that substance abuse diagnoses were very rare among our adolescent population. Further examination revealed that clinicians were not using these diagnoses codes on encounter and billing forms, presumably to protect the confidentiality of these children. Unfortunately, this reluctance to use these diagnoses contributed to a lack of substance abuse programming for teens in the county; we have since obtained more accurate estimates of the prevalence of substance abuse by looking at types of services delivered and out-of-county referral patterns, and created the programming we need. We have also developed school-based programs for teachers to identify students at risk, peer counseling programs, and parent education materials. We have asked the plans to monitor provider performance with regard to the early identification of and appropriate intervention with teen substance abusers.

By comparing plan performance in the area of timely access to services, we discovered that many urgent care cases were women with affective disorders and post traumatic stress syndrome. A query of aggregated encounter data and enrollment histories led us to believe that there were significant problems in several neighborhoods with domestic violence. A review of the county's ability to respond to the needs of these women showed a dearth of shelters and inadequate domestic violence prevention and education programs for providers and the public. In one community, we discovered that among women who attempted or completed suicide, more than 90% were 16-22 years of age, living at 125% or less of the poverty rate, with a high prevalence of sexually transmitted diseases, and all were first generation Vietnamese immigrants. Due to the stringent preservation of privacy in the Vietnamese community, it was not easy to identify the source of this problem. We met with leaders of the Vietnamese community and developed a community-run outreach program for women; the county provided back-up intensive out-patient and mobile crisis services and resources for translation services for outreach materials.

Finally our decision support system, which gives us population trend information, confirmed what we already knew from clinical experience, namely, that the children in our community whose parents abused alcohol and drugs would most likely, over time, need behavioral health services themselves. To try to prevent problems in these children, we developed interagency agreements between the departments of education, Medicaid, children's health insurance program, substance abuse prevention and treatment divisions to develop a comprehensive array of preventive interventions for these children and their families. We offered counseling to pregnant drug abusing women and encouraged them to enroll their drug-exposed infants in early intervention programs; we developed educational and early identification programs in the schools, support groups and peer-led substance abuse programs in the schools and community drop-in centers; and we developed student assistance programs to help youth transition from substance abuse programs back into school environments.

In addition to our planning and intervention programs, we have also made preparations to rebid our health plan contracts. We want bidders to demonstrate competence in delivering mental health

services and have required them to show past performance on several key indicators. For example, we want to know that they have the ability to increase access to needed services (which can be gleaned through aggregate encounter data reports), increase the array and cultural appropriateness of services (demonstrable by correlating population, enrollment, encounter, and outcome data), improve outcomes for target populations and communities (outcome data analysis), improve the quality of services (outcome, financial, organizational and performance data), and contain the cost of quality services (derived through the correlation of enrollment, encounter, organizational performance, outcome, and financial data).

For the mental health component of the bid, we need to decide whether we should carve in or carve-out the behavioral health benefit. We want the services delivered by a health plan to be consistent with the principles of a system of care: family and consumer driven, community based, culturally relevant, and properly coordinated. We have, therefore, instructed our health plans to conduct differential assessments and medical cost-offset studies (financial, system, and outcome data) to determine the relative impact of mental health services being included or excluded in a comprehensive health package. These studies have indicated that it is cost effective for our county, given its demographic characteristics and the nature of its risk pool, to move to a fully integrated system. Whereas our last competition allowed for both carve in and carve out programs to coexist, this time the bid will be restricted to integrated health plans. Having developed this evidence, and presented it to the public, our business community purchasers now are willing to take the risk to invest in integrated packages. As a result, this year we will experiment with a few jointly purchased public/private integrated health plan contracts and test the impact of this collaborative effort.

In our RFP we have made clear that we want to be assured that the successful plan will be committed to continuous quality improvement and to establishing a system of care with full stakeholder participation in the design, implementation, and evaluation of the system. We require that the plan establish neighborhood-based community health networks in which local public health data and services are reviewed regularly by citizens and the community sets a neighborhood agenda for its service system. To evaluate performance in this regard, we require that the successful plan participate in pilot tests of system of care standards such as those recently developed at Georgetown University (1998) and the criteria in the recently revised and OMB approved version of the “systemness measure”. Because we also want to develop a case rate for wraparound services and better understand the cost sharing and cost shifting activities that occur in systems of care, we have asked the health plans to develop interagency data sharing agreements with other health and human services departments to determine the total cost of care for persons involved in systems of care oriented programs.

Appendix B: A Vignette $\frac{3}{4}$ How Purchasers and Consumer Advocates Might Use Plan Level Data

Below is a vignette describing how a purchaser of services (a public mental health authority or an employer) and a consumer and family advocate would use plan-level data to choose among competing health plans. They would use plan enrollment data to determine how many and what types of people in the community have access to the plan's services: for example, is the plan open to people with serious mental illness? They would use encounter data to understand the extent and cost of service use; and combine them with population data to consider how well actual use matches estimated need and how financial and human resources should be allocated. The purchaser and advocate would want to know what system- and clinical-level guidelines the plan has, how they are used, and how adherence is monitored. They would also want to know the following: how the plan performs in regard to certain benchmarks and to other plans in regard to indicators of access, quality, and appropriateness; how consumers of plan services fare in regard to clinical and functional status outcomes; how the plan maintains fiscal well-being without compromising the quality of care; how the plan monitors provider and administrator performance; and how it makes improvements.

We have been asked to report to our respective organizations — a corporation that purchases mental health services for its employees and a national consumer and family advocacy group — on this plan's ability to help its members achieve and maintain good mental health status, function well in their communities, easily get the services they need, and have positive outcomes as a result. We will gather information about the plan from several sources, including its enrollment, encounter, organizational and human resource, and financial databases.

We will use these data to see how well the plan has performed in areas that are considered indicators of access and quality such as follow-up after hospitalization and use of state-of-the-art medications. We will also see how consumers of various age and diagnostic groupings scored on a comprehensive measure of functional status when they enrolled in the plan (to get a sense of their status at baseline), after they used any services (to see the impact of those services), and after using particular services (to learn which ones were associated with better outcomes for different groups). If the plan does not have information on enrollee and consumer satisfaction, we will ask it to conduct a scientifically sound survey. We could even do our own research study to determine the types and duration of interventions that were most helpful to subgroups of enrollees who shared similar presenting problems; we would be sure to control for culture, age and gender of the subpopulation to ensure the cultural relevance of our findings.

Once we decide whether this plan meets our community's needs, we will present it with a performance-based and risk-based contract. This contract will hold the plan accountable for cost containment and quality services delivery. The plan must be able to continuously demonstrate to us that it balances services outcome and cost containment and prove that one does not happen at the expense of the other. Therefore, we will require the plan to collect the kinds of data and produce the kinds of reports that will identify both service and administrative problems quickly as well as develop acceptable procedures for addressing problems that threaten high quality, cost-effective care for our constituents.

Appendix C: A Vignette $\frac{3}{4}$ How Consumers and Providers Might Use Person Level Data

The vignette below describes how person level data help consumers and providers in their decision-making. Person level data characterize people in many ways: in their roles as members of the population, enrollees in plans, and as users of services; by age, gender, race, ethnicity, income level, and education; by health, mental health, and functional status and how these change over time and in relation to particular treatments and interventions; by preferences, attitudes, satisfaction, and dissatisfaction. The sources of information include direct observation; interviews with or surveys of consumers, other family members, and providers; and review of medical records. Data on a single individual can be used to make decisions about a treatment plan and to monitor its impact; aggregated person level data can be used to evaluate treatment effectiveness for specific diagnostic and demographic groups. When person level data are linked to population, plan, and program level data, they bring into the analysis important contextual factors that contribute to outcomes.

Hello, my name is Emilia Alvarez. I rely on food stamps and low income housing to get by. My employer offers a limited health plan. I had been feeling tired and unhappy for several months. My primary care doctor did a thorough evaluation and concluded that I was having an episode of major depression. She recommended that I take an antidepressant and talk about my troubles. She said I should decide whether I wanted her to prescribe the medication or whether I wanted to see a psychiatrist; and whether I wanted to talk with the psychiatrist or with a social worker or psychologist.

I knew very little about these things so I asked a friend to help me think this through. My friend Andrea and I went to the library to use the Internet. We looked up depression, depression treatments, and read about the merits of using medication with and without psychotherapy and the pros and cons of psychiatrists, social workers, and psychologists. We learned about the prevalence of depression, the number of Latina women who suffer from depression, the most common reasons for their depression, and the most effective strategies for preventing and treating depression among Latina women. I discovered that my health plan posts “practice guidelines for depression” on its website; I printed a copy so that I could discuss my treatment with my providers.

After reviewing this information, I decided I would like to see a psychiatrist for medication. Since my plan covered more visits to a social worker, I thought the combination of a psychiatrist for medication and a social worker for talking about my problems would be best. My plan sent me a list of names of both kinds of providers who were near my home with descriptions of their backgrounds and professional interests and experience. I found providers who were bilingual and a social worker with experience in helping people access medical and social services. Both providers received high satisfaction ratings by plan enrollees and Latina enrollees in particular.

I met with the psychiatrist and social worker. They talked with me about my problems, talked with each other, and discussed their ideas with me. I completed a questionnaire during the evaluation and then at various times during treatment. My providers and I used the information from our discussions and from these questionnaires to develop treatment goals and a plan and monitor how we were doing along the way. Together we built a record of encounter data which let us measure our progress, take stock periodically, see what interventions worked and what didn't. If I hadn't done so well, we could

have compared my record with those of other people (including Latina women as a special group) to see if treatments they were using might have been better for me.

I learned many things as a result of this process, but one stands out: the importance of information. If reliable information had not been available to me, I could not have made such good decisions about my treatment. If my providers had not had evidence-based treatment guidelines, or data specifically about me and my treatment, they may not have done such a good job or been able to monitor my response to treatment over time. I was pleased enough with my treatment to take the time to fill out my health plan's consumer satisfaction forms: now it is up to them to figure out what my treatment cost, what impact it had, and how cost-effective it was.

My providers told me about many of the ways they and my health plan might use information about me. They assured me that the data collected on me would be kept confidential. They said that my data would become part of a large database that would expand our understanding of what is effective for different people and help other providers and consumers make good decisions. They said, for example, that health plans collect individual enrollment and encounter data and compare it to population trend data to gain a better understanding of consumer needs and effective interventions for meeting those needs. My data will add to their knowledge of how many Latina women in my community suffer from depression and show whether this rate is higher or lower than national averages. My data will contribute to understanding more about the kinds of providers Latina women choose, how many appointments and what kinds of medications are associated with positive outcomes. For me, they will see that having bilingual providers, both a psychiatrist and a social worker, and the newest medication were all important — they will see this from both the encounter and outcome data and from the consumer satisfaction survey I completed.

I know that the plan must report on its performance to my employer. I know that I will not be identified in any way, and that my employer will use these reports to decide whether this plan meets our needs. I know my employer will hold the plan accountable for providing for accessible, appropriate, high quality, cost-effective care. I trust my employer will want to know whether the plan identifies the mental health needs of Latina women in the community and provides preventive and early intervention services. They will want to know whether my treatment experience was typical, and, if not, why not. Did I, for example, use more or less services than other Latina women? If so, why, and what difference did it make?

Appendix D: The Mental Health Statistics Improvement Program

Prepared by John Hornik and Steven Davis

The Mental Health Statistics Improvement Program (MHSIP) began in 1976 as a collaboration between states and the National Institute of Mental Health (NIMH) to develop national data standards for use by state and local governments and individual mental health providers. The aim was to promote uniform collection and reporting of mental health statistical information through the voluntary adoption of data standards by mental health organizations. MHSIP is a community of people who share the belief that improvements in mental health services can occur when decision-makers—be they service providers, those who pay for services, or those who receive them—make rational decisions based on objective, reliable, and comparable information about those services. The first MHSIP product was FN-8, *The Design and Content of a National Mental Health Statistics System*, published in 1983. The concepts in that report were expanded and refined in 1989 with publication of FN-10, *Data Standards for Mental Health Decision Support Systems*. Also in 1989, NIMH, and later the Federal Center for Mental Health Services (CMHS), began awarding grants to help states and treatment agencies develop mental health data systems and use the data collected in those systems.

Over the past 20 years several additional MHSIP reports have been produced about mental health data, its uses, and its users. Examples include *Enhancing MHSIP to Meet the Needs of Children*, *Humanizing Decision Support Systems*, *Performance Indicators for Mental Health Services*, and the *MHSIP Consumer-Oriented Report Card*.

MHSIP has grown so that its mission is now well beyond the task of producing only uniform standards for data collection: MHSIP now represents a set of values centered around the commitment to the use of statistical information for decision support in the mental health service system, and in the inclusion of consumers and other stakeholders in all aspects of system processes. MHSIP also supports an evolving set of guidelines for best practices for the development of mental health data systems, including common definitions of terms and measures and reporting that are accessible to all stakeholders. Finally, MHSIP is an informal community of professionals, service recipients, and other advocates committed its goals.

MHSIP is supported in part by a Federal funding stream, that includes set-aside funds from the Mental Health Block Grant. The funds have been employed to assist states' efforts to improve their statistical systems and to initiate task forces that have produced data standards for mental health data systems and best practice guidelines for performance indicator and report card development.

Although MHSIP itself is just over 20 years old, it has roots that go back into the last century. The history of MHSIP is the history of Federal reporting of mental health information, beginning with reporting on the numbers of persons in mental health institutions. These data were collected by the United States Census as far back as the 19th century. When the National Institute of Mental Health was established in 1946, federal efforts to maintain mental health data were incorporated into its functions. Today that responsibility rests with the Survey and Analysis Branch of the national Center for Mental Health Services, a part of the Substance Abuse and Mental Health Services Administration.

The direction of MHSIP is determined, in part, by an ad hoc group that meets several times each year to review and work on current projects, and to initiate new ones. Once limited to Federal and state mental health officials, the committee membership has diversified to include recipients of mental health services, local providers of mental health services, staff of the National Association of State Mental Health Program Directors, and officials of other Federal agencies.

The MHSIP community meets annually at the National Conference on Mental Health Statistics, usually the week following Memorial Day Weekend. The National Conference provides a forum for discussing major changes in Federal and state policies and the direction of the public mental health system, as well as presentations of new ideas about best practices, workshops focusing on how to implement statistical methods, and reports on uses of mental health information.

Appendix E: HIPAA

Below are tables summarizing aspects of the HIPAA initiative that are particularly relevant to the mental health information system.

Table 1

Summary of Data Collection and Reporting Requirements for Health and Human Services (HHS), States, and Medicaid-Participating Managed Care Organizations (MCOs) *

Performance standards: HHS must specify performance standards for eligibility, benefits, payments, coverage, and management of the Medicaid program; for electronic transmission of encounter and other data (per HIPAA); and for quality assessment and improvement. States and MCOs must comply with these standards.

Financial data: States must report expenditure data to the federal government; MCOs must report to state, Federal, or independent auditors ownership and financial information.

Administrative data: MCOs must submit, and the states must approve, marketing materials.

Enrollment data: states must provide enrollees with comparative information on plans (including quality and performance indicators); MCOs must provide enrollees with information on how care is structured and what services are covered; states and MCOs must report aggregated enrollment and disenrollment data.

Encounter data: States with Medicaid waivers must submit 100 percent encounter data and report utilization data on Early and Periodic Screening and Detection Testing (EPSDT).

Utilization data: States must submit summary clinical data annually and quarterly utilization reports based on their Medicaid Management Information System's payment history files; states with Medicaid waivers must report utilization data on EPSDT.

Access to care: MCOs must prove that they have adequate service capacity.

Quality of care: States with Medicaid waivers must report results of focused studies on four clinical outcomes.

* Relevant legislation includes the Medicaid statute, the Social Security Act (sections 1115, 1915 (b), 1932, Title XX1), the Balanced Budget Act of 1997, Health Maintenance Organization Act of 1973, the Civil Rights Act of 1964, the Health Insurance Portability and Accountability Act of 1996

Source: Rosenbaum S, Markus A, Repasch L. An overview of data submission requirements applicable to managed care organizations under federal law. Report prepared for the National Committee on Vital and Health Statistics Subcommittee on Population Specific Issues. July, 1998.

Table 2

Electronic Transactions that Require Standards According to the Health Insurance Portability and Accountability Act (HIPAA)

1. Health claims or equivalent encounter information
2. Health claim attachments
3. Enrollment and disenrollment in a health plan
4. Eligibility for a health plan
5. Health care payment and remittance advice
6. Health plan premium payments
7. First report of injury
8. Health claims status
9. Referral certification and authorization
10. Coordination of benefits information
11. Unique identifiers for each individual employer, health plan, and health care provider
12. Code sets for appropriate data elements
13. Security
14. Electronic signatures

Source: Fitzmaurice JM. A new twist in US health care data standards development: adoption of electronic health care transactions standards for administrative simplification. *International Journal of Medical Informatics* 1998;48:19-28.

Table 3

Guiding Principles for HIPAA Standards

Each HIPAA standard should:

1. Improve the efficiency and effectiveness of the health care system by leading to cost reductions for or improvements in benefits from electronic HIPAA health care transactions.
2. Meet the needs of the health data standards user community, particular providers, health plans, and clearinghouses.
3. Be consistent and uniform with the other HIPAA standards, their data element definitions and codes and their privacy and security requirements, and, secondarily, with other private and public sector health data standards.
4. Have low additional development and implementation costs relative to the benefits of using the standard.
5. Be supported by an ANSI-accredited standards developing organization, or other private or public organization that will assure continuity and efficient updating of the standard over time.
6. Have timely developmental, testing, implementation, and updating procedures to achieve administrative simplification benefits faster.
7. Be technologically independent of the computer platforms and transmission protocols used in the HIPAA health transactions, except when it is explicitly part of the standard.
8. Be precise and unambiguous, but as simple as possible.
9. Keep additional data collection and paperwork burdens on users as low as is feasible.
10. Incorporate flexibility to more easily adopt to changes in the health care infrastructure (such as new services, organizations, provider types) and information technology.

Source: Fitzmaurice JM. A new twist in US health care data standards development: adoption of electronic health care transactions standards for administrative simplification. *International Journal of Medical Informatics* 1998;48:19-28.

Table 4**Leading Candidates for HIPAA Standards**

	Leading Choice(s)	Comment
<i>Transactions</i>		
All except claims	ASC X.12N	
Pharmacy claims	National Council for prescription drug programs	
Medical, dental and institutional claims	ASC X.12N/837	
Claims attachments	ASC X.12N/275, HL7 (?)	Decision due in 1999, by law
<i>Identifiers</i>		
Provider	HCFA's national provider identifier	
Payer	HCFA's payer ID	
Employer	Department of Treasury's employer identifier number and social security number of salary source for small employers (?)	In development, no choice yet
Individual	ASTM standard guide for properties of a universal healthcare identifier (?)	In development, proposed. Lack of privacy law for linked information is an issue.
<i>Code Sets</i>		
Diagnosis codes	International classification of diseases (ICD)-9th revision-clinical modification (CM)	May move to ICD-10-CM in 2001
Procedure codes	ICD-9-CM Volume 3, American Medical Association's Current Procedure Terminology-4th revision, HCFA's Common Procedure Coding System (HCPCS)	May move to ICD-10-Procedure Coding System (HCFA) or CPT-5 (American Medical Association) in 2001
Security	Based on guidelines recommended by NCVHS, American Society for Testing and Materials, and National Research Council Report for the Record	
Electronic Signatures	ASTM (?)	In development

Source: Fitzmaurice JM. A new twist in US health care data standards development: adoption of electronic health care transactions standards for administrative simplification. *International Journal of Medical Informatics* 1998;48:19-28.

Appendix F: Summary of Key Characteristics of the Care Needs of Persons with Serious Mental Illness and Implications for Differences in the Requirements for Mental Health Data and Medical Data

Serious mental illness (e.g., schizophrenia, bipolar disorder, severe forms of depression, panic disorder, and obsessive compulsive disorder) affects 5.4% of the adult population of the United States and accounts for more than 30% of Federal disability payments. Serious mental illness presents major challenges for the delivery and financing of mental health services and, in turn, for the data collection, reporting, and information systems necessary to support those services. It also presents challenges to quality assessment and improvement efforts aimed at ensuring access to appropriate and quality care for all.

People with serious mental illness have care needs that differ significantly from those of people with acute medical illness. While their needs are more similar to people with physical disabilities and chronic medical conditions, some striking differences exist. These unique care needs have important implications for developing data standards and information systems — so much so that it would be ill-advised to assume that standards and information systems appropriate for the general health care system are simply and automatically applicable to the mental health care system.

People with serious mental illness suffer from long-term disorders with fluctuating clinical symptoms and ability to function in society. As a result, they require care that persists over the long term and involves both treatment of acute episodes of illness and ongoing management of symptoms and functioning over time. They require a broad range of different types of treatments and interventions including individual psychotherapy, group psychotherapy, couples therapy, family therapy, pharmacotherapy, hypnotherapy, case management, intensive case management, assertive community treatment, etc.

Serious mental illness affects all aspects of living, including work, family, and social life. Care needs include access to traditional psychiatric and medical services and to a comprehensive range of services including social and family services, housing, life-skills building, rehabilitation and vocational counseling, and legal services.

While most people with serious mental illness can live in the community with adequate support, they tend to move in and out of crisis and may require intensive care in the most expensive settings such as hospitals and emergency rooms.

There is enormous variability among individuals with the same illness in the severity of their symptoms and their level of functioning; in availability of support systems and ability to access them; and in other personal, social, and economic resources. Therefore, services need to be tailored to each individual's special needs.

Unless services are coordinated and integrated into a seamless system of care, there will either be unnecessary and costly duplication or people will "fall through the cracks" and needed services will not be provided.

Appropriate and high quality care for people with serious mental illness, then, has the following characteristics. It is:

- long term;
- comprehensive;
- intensive;
- individualized;
- coordinated; and
- integrated .

As a result, the mental health delivery system is significantly different from the general health care delivery system. This has important implications for developing data standards and information systems.

A single individual with a serious mental illness will tend to utilize a wider range of services than will a person with an acute or chronic medical condition, including emergency and crisis intervention services; full, partial, and day hospital services; traditional clinic and office-based treatments; and outpatient care that includes community outreach, supervised living situations, and clinical case management. Current procedure codes (e.g. CPT codes) do not adequately reflect the complexity, richness, and diversity of treatments and services that are delivered.

Care for persons with serious mental illness occurs in more and different types of care settings than does care for persons with medical conditions: free-standing private psychiatric hospitals, state hospitals, psychiatric units in general hospitals, locked and unlocked units, detoxification units, half-way houses, quarter-way houses, group homes, residential treatment communities, outpatient clinics, provider offices, rehabilitation programs, consumer-run programs, drop-in centers, etc. Again, traditional place of service codes designed for medical settings do not adequately cover such a diverse range.

Persons with mental illness see a great many different types of providers: psychiatrists, psychologists, social workers, psychiatric nurses, case managers, mental health workers, vocational rehabilitation professional, peer counselors, etc. As before, standard provider codes are inadequate to the task of capturing the differences in the mental health field.

Mental health care entails involvement with a far broader set of agencies than does general health care and includes ongoing interactions with social service, vocational rehabilitation, and social rehabilitation agencies; residential settings; departments of corrections and education; and all types of medical and healthcare entities. These clinically-derived linkages must be reflected in standardization across agencies of data elements and information systems.

Assessment of the outcomes of treatment differs dramatically for persons with medical and mental conditions. For the person with serious mental illness, the range of outcomes that are typically

assessed is both diverse and difficult to measure: employment, social skills, support network, symptom relief, personal satisfaction, adequate housing, integration in the community, etc.