

Decision Support 2000+
(DS2000+)

This document provides a brief overview of the *Decision Support 2000+* informational framework. More detail can be obtained on the web site for the Mental Health Statistics Improvement Program (MHSIP) at www.mhsip.org.

Marilyn J. Henderson^{*}, Sarah L. Minden[†], and Ronald W. Manderscheid^{*}

^{*}Center for Mental Health Services,
Substance Abuse and Mental Health Services Administration;

[†]Abt Associates, Inc.

Decision Support 2000+ (DS2000)

The Federal government has been very involved in supporting the development of data standards and infrastructure that is driving the e-healthcare boom of today. Efforts to develop common data standards in the mental health arena are currently conducted through the Center for Mental Health Services within the Substance Abuse and Mental Health Services Administration; previously, they were carried out at the National Institute of Mental Health within the Alcohol, Drug Abuse, and Mental Health Administration. This chapter provides insight into the Government's efforts as we enter the new Millennium. Current efforts however would not have been possible without the groundbreaking efforts of the 1970's and 1980's.

History of data standards development

In the early 1950's, the Federal government set up the Model Reporting Area for Mental Hospital Statistics to work on data standards for hospitals. With the shift from institution-based to community-based services, the Mental Health Statistics Improvement Program (MHSIP) was initiated in 1976, to expand the Federal government's collaboration with states in developing and implementing data standards and information systems. Initial standards were prepared in 1983 that encompassed both hospital and community programs (NIMH, 1983). These standards were based on the mental health organization as the principal reporting unit.

MHSIP continued to change along with the mental health system, and in its 1989 report, *Data Standards for Mental Health Decision Support Systems* (the now famous FN 10), MHSIP recommended standards and presented minimum data sets for patient/client, event, human resources, financial and organizational data (see figure 1). Within FN 10, the clinical event (encounter) was viewed as the basic unit of the system, to which patient/client, provider and financial information could be linked within an organizational framework.

Figure 1

1989 Mental Health Statistics Improvement Program (MHSIP)

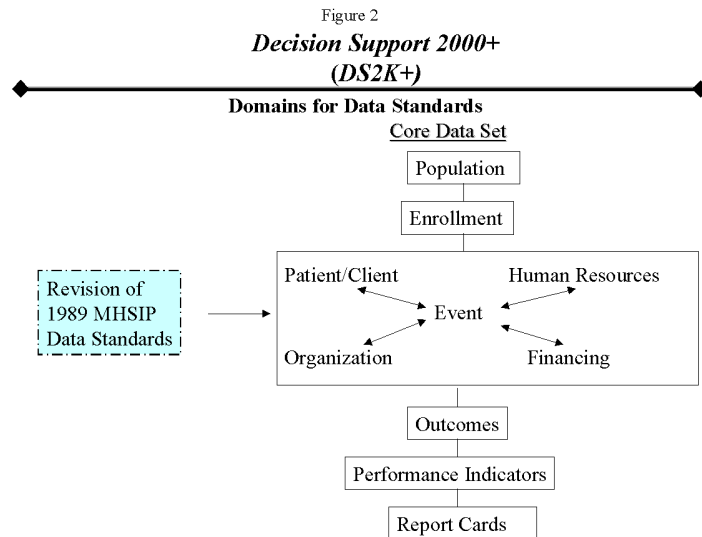
Domains for Data Standards

<u>Focus</u>	<u>Minimum Data Set</u>	<u>Description</u>
Who	———— Patient/Client	———— Person receiving service
What	———— Event	———— Service received
Whom	———— Human Resources	———— Person providing service
How much	———— Financial	———— Service cost
Where	———— Organization	———— Service location

Adapted from Leginski, WA, Croze, C, et al, *Data Standards for Mental Health Decision Support Systems*, 1989

The FN 10 data standards were voluntarily adopted by many state mental health authorities. They are still viewed as the codification of the recommended minimum content needed to facilitate mental health program management as well as the basic guideline for the system needed to collect and report this information in a way that is useful in making decisions. However, the organization and financing of mental health and substance abuse care (behavioral health care) has undergone tremendous changes since the FN 10 report was published in 1989. The MHSIP community has initiated a number of task forces including an FN 11 Task Force to facilitate enrollment tracking, include encounter and performance indicator data, and address the special needs of children. Recognizing the need to take a person-centered approach, MHSIP's efforts have included the design and implementation of a Consumer-Oriented Report Card, work on consumer outcomes measures, and system performance indicators. (MHSIP, 1992, 1996, 1997).

The MHSIP data standards provide an excellent foundation for the information systems currently required by managed behavioral healthcare. The new *Decision Support 2000+* (*DS2000+*) effort builds on and expands these MHSIP efforts by including the health status of the population, enrollment, encounter and outcome data as well as system description and performance information (see figure 2).



Today's mandate

The need for information versus data has expanded exponentially in the managed care era. Dramatic changes are taking place in the roles and types of stakeholders involved in the mental health care system. These changes have created a need to expand and improve information, and to provide support for decisions made on a daily basis. *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. This chapter seeks to provide a glimpse into the emerging purpose, features, principles, and data standards for *DS2000+*.

Information should be available quickly, electronically, and in an easily accessible format. Currently, this situation does not prevail in the mental health field because of dramatic underinvestment in modern information systems and lack of application of modern information technology to mental health problems.

Information should also be confidential, protect personal privacy, be available for consumer review and correction, and be used only for medical purposes to improve personal well-being. Currently, this situation does not exist in the mental health field because medical records are fragmented, maintained on paper, transmitted through facsimile machines, sent electronically over the Internet without protection, and available for commercial exploitation.

The mental health field (and, indeed, the human service system as a whole) needs standardized data to manage care effectively. The field also requires measures to evaluate the quality of the care provided, with respect to both practices and outcomes. No widely-accepted clinical or system guidelines exist with which to standardize practice or to provide criteria for judging provider and system performance. Availability of data systems for collecting this information in a uniform and comparable way will enable communication among participants and across systems of care.

Today's technology makes possible a revolution in information: multiple users can participate in what is virtually a *single information system* that will enable them to share data and communicate effectively. If they adhere to established standards for data collection, this virtual system can be used to meet their information needs, whether they are consumers or providers making choices about treatments, payers deciding among health plans, managers allocating financial and human resources, or researchers determining the need for services in a community. This can be accomplished while protecting the privacy and confidentiality of personal medical records.

To be useful in the current environment, mental health information needs to span from population characteristics through the effects of services. The Survey and Analysis Branch within the Center for Mental Health Services (CMHS) is currently supporting work to develop the framework and core data sets for such a system. Support and buy-in from all major stakeholders in the system is critical to the success of these projects. To this end, CMHS is working with Abt Associates, Inc., the National Association of State Mental Health Program Directors - Research Institute (NASMHPD- RI), MHSIP, and a broad array of expert consultants from major stakeholder groups, such as mental health consumers, family members, the managed behavioral healthcare industry, individual service providers, payers, researchers, and experts in mental health electronic records and information technology.

Purpose of *Decision Support 2000+*

To respond to the mental health field's lack of standardized data, uniform measures, and an accessible and effective information system, the CMHS project team is developing data standards, core data recording requirements, procedures, and an information system for mental health services. These activities build on what the field has already accomplished, using

resources currently in place and focusing on areas that need further work. *Decision Support 2000+* is being designed to:

Improve Decisions. Clinical and administrative decisions made by consumers and family members, providers, payers, managers, and researchers will be enhanced by an information system that provides all the data needed, quickly, accurately, and efficiently.

Improve Services. An information system that makes available to stakeholders reliable data on a community's mental health needs, services, service users, costs, revenues, performance and outcomes, is critical to improving care.

Improve Accountability. To be most beneficial, information on accountability needs to be readily available within the framework of continuous quality improvement.

Improve Communications. Effective communication within the mental health system as well as between it and other human service systems is essential for delivering quality care.

A group of experts and stakeholders was convened to guide the development of *DS2000+* and to address the goals identified above. This group recommended that the information system should be able to:

- span the entire mental health system, from epidemiology, to service delivery, to outcomes;
- link with information systems in a broad range of agencies, locations, programs, organization;
- meet the needs of all relevant groups, including consumers, families, providers, payers, managed care organizations, state mental health agencies, administrators, researchers, policy makers, and advocates;
- make use of modern technology while ensuring privacy and confidentiality of data;
- be flexible enough to incorporate information and assessment tools that measure the cultural competence of services;
- facilitate clinical and organizational decision-making and enhance the quality of care.

Description of *Decision Support 2000+*

Decision Support 2000+ contains four categories of data: descriptive, prescriptive, evaluative, and corrective. Each type of information has its value for addressing particular types of

questions:

Descriptive Information: What are we doing?

Prescriptive Information: What should we be doing?

Evaluative Information: How well are we doing?

Corrective Information: How do we improve?

Figures 3 and 4 illustrate the *DS2000+* model. Figure 3 summarizes the key information modules (see descriptions below) and shows how they can be linked together and transformed to answer a range of critical stakeholder questions. The key information modules are:

- population-based core data set and plan enrollment core data set for persons enrolled in health and behavioral healthcare plans;
- encounter core data set and the related financial core data set, organizational core data set, and human resource core data set;
- core data sets for clinical and system guidelines that reflect adherence to best practices in each of these; and
- core data sets on results, including a consumer outcome core data set, a report card core data set (including surveys of consumers, providers, and others), and a performance measure core data set.

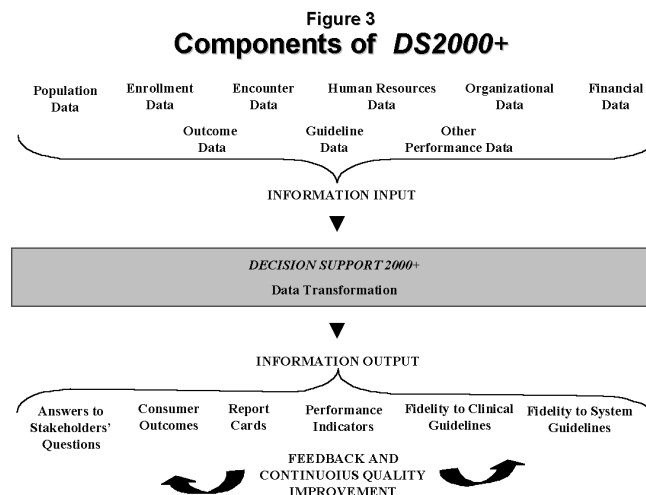
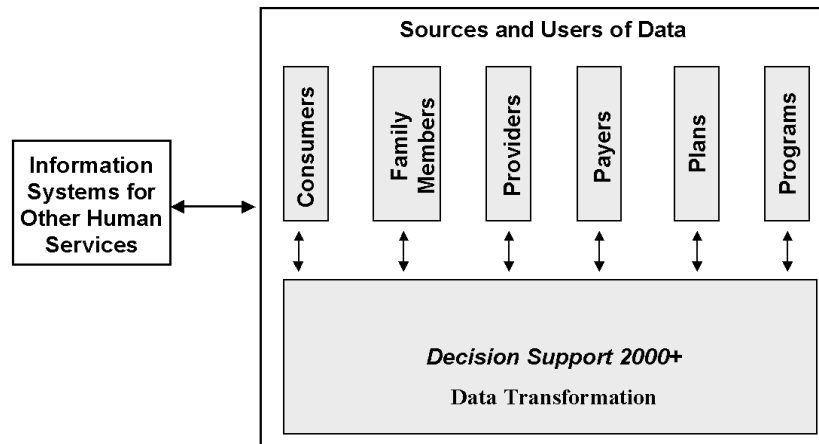


Figure 4, by contrast, shows how both the mental health care system and *DS2000+* are linked to the care and information systems of other human service agencies. The stakeholders in the mental health care system provide data for and receive information from *DS2000+*. Stakeholder

queries can range from questions about plan quality to questions about adherence to practice guidelines.

Figure 4
Decision Support 2000+ in Context



The information system will record data from various sources that are needed to manage mental health systems effectively. *Population data* will describe demographic characteristics, medical and mental health status and level of functioning, as well as quality of life of community members. *Enrollment data* will describe demographic, insurance, and baseline health and mental health status of enrollees and their family members. *Encounter data* will 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. *Financial data* will reflect costs of services, administrative costs, other expenditures and revenues. *Human resource data* will describe the characteristics of providers of care, support staff, and other personnel. Information about organizational structure and process will be reflected by *organizational data*.

Clinical guideline data will serve three primary functions: clinical decision support (selection of the most effective treatments for conditions), treatment process tracking (a detailed and standardized record of clinical interventions), and guideline variance tracking (the congruence between guideline-recommended treatment and actual treatment delivered). While significant progress has been made in establishing the importance of clinical guidelines and their measures, guidelines are currently unavailable for many disorders. There is no consensus on which guidelines are the best, and few clinicians have been trained in their use; clinical guidelines software has only recently become available. Implementation of measures for treatment process and guideline variance tracking systems awaits a standard terminology of treatments with associated definitions and codes that can be integrated into routinely used software. Clinical decision support, in turn, depends upon building interfaces with treatment process tracking and consumer characteristics. As we develop this component of *DS2000+*, we will involve end-users in the development of guidelines, taxonomies, measures and software so that they are meaningful, reputable, and user-friendly.

Even though *system guideline data* are essential for improving the quality of care and efficiency of operations, they are only in the earliest stages of development. They specify measures with respect to infrastructure, executive, and management functions; service components directly operated; and service functions outside of mental health that support clinical programs. Prototypical system guidelines and measures exist in several locations, including the National Alliance for the Mentally Ill's recently published manual on the Program for Assertive Community Treatment (PACT) (Allness and Knoedler, 1998); operational manuals prescribing organizational practices (accreditation, credentialing, personnel and financial management, buildings maintenance); clinical interventions (involuntary commitment, seclusion and restraint); and in the quality improvement tools used by some State mental health agencies for assessing provider and organizational performance. The area of system guidelines is being defined and clarified for the first time through the work of the CMHS project team. As core data sets are developed, we will also clarify the measurement of system guidelines.

Performance indicators, report cards, and consumer outcome data are critical for the accountability, quality improvement, and management of mental health systems. Although the field lacks uniform sets of performance indicators and outcome measures, there is an emerging consensus on the critical components for each, and steady progress toward standardization. Several initiatives are underway to standardize measures and definitions across systems, to develop methodological and implementation guidelines, and to analyze, interpret and present results in comparable ways.

Key Features of *Decision Support 2000+*

Decision Support 2000+ has several hallmark features that deserve mention. The first is protection of privacy and confidentiality of personal medical records. The second is evolution of field-wide standards for data recording. The third is reliance upon existing information whenever possible in order to reduce the cost of implementing the new system. The fourth is the linkage of data from different sources using Internet-based query technology. Each of these features is discussed below.

Protecting Privacy and Confidentiality. *Decision Support 2000+* is being designed to protect privacy and confidentiality of personal medical records using modern information technology. An overarching concern in conceptualizing the new system was the need to specifically address these issues throughout the development and implementation process. In preparing the requirements analysis for *DS2000+* (Minden, Davis and Ganju, et al., 2000), a document was commissioned regarding the issue of privacy from the consumer point of view. This document is available as part of the requirements analysis on the web site, www.mhsip.org.

Privacy and confidentiality are of concern to most people. Stigma, loss of control, exploitation, and potential negative consequences all combine and form a fear that becomes magnified when considering medical records, mental health records in particular. Such considerations have provided strong motivation for passage of a healthcare bill of rights giving the consumer community the ability to gain access to medical records and correct errors in them. The bill

would also bring forces together to promote human rights preservation and enhancement through better privacy and confidentiality protections.

In mental health, human rights and dignity are basic values. Any effort to address privacy and confidentiality must start with human values and ethics. Hence, these values must provide a foundation for any work undertaken in this area. In recognition of this, the Workgroup for the Computerization of Behavioral Health and Human Services Records has designed a virtual medical record for behavioral healthcare in which the key to the medical record is controlled by the consumer (The Workgroup,1998). This proposed virtual record is also based upon technology that makes it feasible to protect privacy and to control confidentiality. *Decision Support 2000+* will incorporate the fundamental concepts elaborated by The Workgroup.

The U.S. Department of Health and Human Services has developed Federal regulations to protect privacy and confidentiality of medical records. These regulations released by the Department in December 2000, provide another element of the foundation for *DS2000+*, thus ensuring that it is fully compliant with these regulations (DHHS, 2000(a)).

Establishing Standards. *Decision Support 2000+* recommends standards for data recording that permit information reporting at the person, health plan, local, State, and national levels, including core data sets, measures and instruments, and procedures for collecting and analyzing data. It builds on the work of MHSIP in developing standards for mental health. MHSIP created a Task Force in the late 1980's to review existing data standards and recommend revisions. The Task Force presented minimum data sets for patient/client, event/encounter, human resources, financial and organization data (NIMH, 1989) in its 1989 report, *Data Standards for Mental Health Decision Support Systems* (commonly known as FN-10). Subsequently, MHSIP task forces were convened and recommendations were made regarding data elements relevant to children (MHSIP, 1992) and the Enrollment/Encounter domains. Thanks to the quality of MHSIP's work, all states have now voluntarily adopted many of these standards. The updating and refining of FN-10 (MHSIP, 1997) is being continued through the development of *DS2000+* and elaboration of core data sets for each of its domains, taking into account the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Standards for Electronic Transmission (DHHS, 2000(b)). For a fuller discussion of HIPAA, including privacy issues, please refer to the web site of The Workgroup (www.workgroup.org)

Using Existing Data. *Decision Support 2000+* makes use of existing information technology and data collection activities and allows users to bring their current practices closer to their ideal without major overhauls and massive investments. It would be impossible to build, implement, and finance *DS2000+* *de novo*. Most components of the system already exist in one form or another. The Federal and some State governments collect population-level data; managed behavioral healthcare organizations and providers collect enrollment, encounter, and outcome data, use financial and human resource data, and report on performance indicators. Measures are currently being developed for clinical and system guidelines because of the rapid evolution of this field. We need to expand and standardize these data collection efforts, but should not minimize how much exists. The issue is one reaching a consensus on how to improve on what we have, not on rebuilding.

The same is true for information systems. Clearly, problems exist with incompatibility in hardware and software — systems that cannot communicate with one another cannot share information. But the Internet is an untapped resource and advances in data warehousing and object-oriented technologies are enabling us to overcome local differences. Other technical issues, of course, must be resolved: we need unique identifiers in order to link data concerning people, programs, or plans from different databases. We need dependable ways to ensure privacy and confidentiality; we need to be able to collect comparable information in an efficient and affordable way. Again, the issue is one of improvement and consensus, not starting over.

Linking Data. Part of the enormous potential of *DS2000+* lies in its capacity to link data from different sources, both within the mental health system and between mental health and other service systems. By drawing from several different data sets through an Internet-based query system, it is possible to answer key questions ranging from the outcome of a single individual's treatment to projections of service needs and financing requirements for entire populations.

By virtual linking of data sets, information about persons can be used to improve the quality of care and to evaluate plans and programs. For example, quality of care could be greatly enhanced through the implementation of a virtual integrated patient record spanning the mental health, health, and human services delivery systems (The Workgroup, 1998). Linking together the enrollment and encounter data aggregated for all persons served by a plan can be used to show whether standards within a contract have been met, such as requirements for providing mental health services to certain percentages and categories of a State's population. 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 plan enrollment and disenrollment.

The virtual linking of data will meet many mental health needs including:

- *The need to coordinate care more efficiently and effectively.* A primary barrier to competent delivery of mental health and human services is the lack of a coordinated communication system that would allow for the sharing of timely, accurate, and appropriate information among all the agencies and service systems involved in care.
- *The need to meet reporting requirements.* Most mental health organizations are held accountable to public or private payers and are routinely required to report to them. Exchange of core data sets, agreement on data exchange protocols, and use of web-based Internet and Intranet applications would increase the efficiency and cost-effectiveness of data collection and reporting.
- *The need for research.* Mental health phenomena at both the person and the service levels are enormously complex. Our ability to understand current circumstances and predict future trends depends on our knack for

examining the many factors that affect outcomes and performance. This, in turn, depends on being able to link data.

Many challenges exist in linking the components of an information system, and then linking that system to others. 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; this increases the need for instruments that are straightforward, transparent and that minimize additional staff training and development of training materials and documentation.

Status and Next Steps

With guidance from a Technical Expert Workgroup, the CMHS project team has completed the requirements analysis for *DS2000+*. For each component, this analysis describes 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 reflect an indicator); if the measures have been field tested and/or implemented; and whether the component is fully ready for inclusion in the information system.

The complete requirements analysis is posted on the MHSIP web site (www.mhsip.org) for broad review and comment by the field. For those who do not have the time to review the entire requirements analysis, brief summaries for each component are available on the web site.

Organizational and financial arrangements have changed considerably under managed behavioral healthcare, however, no typology that captures these arrangements has been available to the field. The team is addressing this critical gap in our knowledge base and will assess the extent to which the requirements analysis fits each of the major arrangements identified within the typology. This analysis will ensure that *DS2000+*, as it is refined, is appropriate for and relevant to the needs of evolving organizational and financial arrangements.

The project team has completed an initial design of the typology, and is currently in the process of modifying this draft based on comments by experts in such arrangements and participants in focus groups. The focus groups will critique the conceptual and pragmatic aspects of the typology; specify the types of information needs of the different arrangements; and discuss modifications to *DS2000+* to reflect current arrangements and meet their information needs. A number of focus groups will meet: two groups will consist of researchers and experts in organizational and financial arrangements who will discuss the conceptual accuracy of the typology; two groups will consist of consumers, family members and clinical providers with direct experience in these arrangements who will examine how well the typology fits their real-world experience; one group will consist of State representatives of the MHSIP Regional User Groups, who will work on the design, testing and implementation issues, and one group will

consist of behavioral healthcare software vendors, who will discuss implications for software development for the field.

A parallel task is the completion of core data sets for each of the *DS2000+* domains. While users should collect specific data that meet their particular needs, widespread use of the core data sets will provide the field with uniform and comparable data to facilitate communication and to improve decision-making. Integral to the completion of the core minimum data sets, is the involvement of all stakeholders, particularly the MHSIP community where so much expertise exists. The *DS2000+* team plans to work formally with the MHSIP Advisory Group and the Regional User Groups to ensure that they are integrally involved in the process, as members of the work teams, as reviewers of draft materials, and as communicators with the States. Similar relationships will also be developed with other key groups, including the behavioral healthcare software vendor community.

Timeframe for core data set development: The enrollment and encounter core data sets will be developed first, in order to ensure consistency and avoid duplication across the components of *DS2000+*. They will serve as a focal point from which the other core data sets are built.

- March, 2001: drafts of the Enrollment and Encounter core data sets submitted to CMHS;
- April, 2001: drafts of remaining data sets submitted to CMHS;
- June, 2001: convening of a technical workgroup to review and make recommendations for refining the data sets and for discussing the fit between *DS2000+*, the core data sets and the typology.

The discussion of the technical workgroup will address such issues as: the linkages among the various domains of *DS2000+* and between it and other human service information systems; how well suited *DS2000+* and its domains are to various organizations and entities responsible for mental health care; recommendations for modifying *DS2000+* to improve the fit between it and the organizations and structures it is meant to support; and specific unresolved issues regarding *DS2000+* and the core data sets. Broad field review and input will be sought throughout this entire process.

Conclusion

Decision Support 2000+ is an integrated, public health-oriented information system that corresponds with the current and future information needs of the mental health field. Implementation of this information system will facilitate the availability of comparable data to the field for decision-support for planning, service design, clinical feedback, and evaluation. Widespread use of the information system will be of tremendous benefit to the entire mental health community.

References

Allness DJ and Knoedler WH. The PACT Model of Community-Based Treatment for Persons with Severe and Persistent Mental Illness. A Manual for PACT Startup. Arlington VA, NAMI, 1998.

MHSIP Ad Hoc Group. The Handbook of Mental Health Data - A Reference Manual for Anyone Who Wants to Collect, Find, Report, Understand or Use Mental Health Data. Draft 5/23/97. Rockville, MD: Center for Mental Health Services, 1997.

MHSIP Report Card Phase II Task Force. The MHSIP Consumer-Oriented Mental Health Report Card. Rockville, MD: Center for Mental Health Services, 1996.

MHSIP Task Force on Enhancing MHSIP to Meet the Needs of Children. Enhancing MHSIP to Meet the Needs of Children - Final Report. Rockville, MD: Center for Mental Health Services, 1992.

Minden SL, Davis S, Ganju V, et al. *Draft Requirements Analysis for Decision Support 2000+* www.mhsip.org, 2000.

National Institute of Mental Health, Series FN No. 8, *The Design and Content of a National Mental Health Statistics System*, by Patton, RE and Leginski WA. DHHS Pub. No. (ADM) 83-1095. Washington, DC: Supt. Of Docs., U.S. Govt. Print. Off., 1983

National Institute of Mental Health, Series FN No. 10, *Data Standards for Mental Health Decision Support Systems*, by Leginski WA, Croze C, Driggers J, et al. DHHS Pub. No. (ADM) 89-1589. Washington, DC: Supt. Of Docs., U.S. Govt. Print. Off., 1989

The Workgroup for the Computerization of Behavioral Health and Human Services Records, *The Virtual Consumer and Family-Focused Behavioral Health and Human Services Record*, The Workgroup for the Computerization of Behavioral Health and Human Services Records, Inc. 1998.

U.S. Department of Health and Human Services (DHHS). Health Insurance Reform: Standards for Electronic Transactions - Final Rule. *Federal Register* 65(160):50312-50372, 2000(a).

U.S. Department of Health and Human Services (DHHS). Standards for Privacy of Individually Identifiable Health Information - Final Rule. *Federal Register* 65(250):82462-82829, 2000(b).