

Transforming Mental Health and Substance Abuse Data Systems in the United States

Rosanna M. Coffey, Ph.D.

Jeffrey A. Buck, Ph.D.

Cheryl A. Kassed, Ph.D.

Joan Dilonardo, Ph.D.

Carol Forhan, M.B.A.

William D. Marder, Ph.D.

Rita Vandivort-Warren, M.S.W.

State efforts to improve mental health and substance abuse service systems cannot overlook the fragmented data systems that reinforce the historical separateness of systems of care. These separate systems have discrete approaches to treatment, and there are distinct funding streams for state mental health, substance abuse, and Medicaid agencies. Transforming mental health and substance abuse services in the United States depends on resolving issues that underlie separate treatment systems—access barriers, uneven quality, disjointed coordination, and information silos across agencies and providers. This article discusses one aspect of transformation—the need for interoperable information systems. It describes current federal and state initiatives for improving data interoperability and the special issue of confidentiality associated with mental health and substance abuse treatment data. Some achievable steps for states to consider in reforming their behavioral health data systems are outlined. The steps include collecting encounter-level data; using coding that is compliant with the Health Insurance Portability and Accountability Act, including national provider identifiers; forging linkages with other state data systems and developing unique client identifiers among systems; investing in flexible and adaptable data systems and business processes; and finding innovative solutions to the difficult confidentiality restrictions on use of behavioral health data. Changing data systems will not in itself transform the delivery of care; however, it will enable agencies to exchange information about shared clients, to understand coordination problems better, and to track successes and failures of policy decisions. (*Psychiatric Services* 59:1257–1263, 2008)

About 30% of U.S. adults experience a mental or substance use disorder during the course of a year (1). Co-occurring disorders are common: about 9% of those with a mental disorder and about 60% of those with a substance

use disorder struggle with both (2). Many people with behavioral health problems also have serious physical health problems. These individuals are often the most in need of coordinated care in many aspects of their lives.

How data systems can enhance care quality

Optimal service delivery to individuals with co-occurring mental and substance use disorders requires an integrated approach—providers of various client services who communicate with each other about what the client needs, support clients to obtain referral appointments without delay, follow up with clients to be sure they obtained care, and monitor patients' medication use for compliance and outcome. In addition, for this population, services that wrap around clinical care are essential—social support services (jobs, housing, social networks, and peer support groups), community reentry programs for people who have been incarcerated, ongoing monitoring and maintenance of client progress and compliance with treatment regimens, and so on. Effective data systems can enhance the delivery of such services without making success dependent on a single service coordinator and without losing clients through handoffs and disconnections between services and programs. Data systems that link information from different program and care settings can facilitate coordination and, at the same time, support evaluations of programs to determine what works to improve patient outcomes. Better data systems have the potential to help researchers and clinicians understand clinical interventions on a large scale.

Typically, public treatment systems for mental disorders in the United

Dr. Coffey, Dr. Kassed, Ms. Forhan, and Dr. Marder are affiliated with the health care business of Thomson Reuters, 4301 Connecticut Ave., Washington, D.C. 20008 (e-mail: rosanna.coffey@thomsonreuters.com). Dr. Buck and Ms. Vandivort-Warren are with the Substance Abuse and Mental Health Services Administration, Rockville, Maryland. Dr. Dilonardo is a consultant for Thomson Reuters.

States are separate from those for substance use disorders, and both are distinct from states' Medicaid programs (3,4). Silos of information do not communicate with one another (5), which inhibits effective and efficient coordination of services, continuity of care, and assessment of treatment outcomes and costs, resulting in suboptimal patient care (6). The President's New Freedom Commission on Mental Health recognized this fragmentation and further noted that reducing service fragmentation in behavioral health care required transformation of data systems (7). The commission recommended steps to harness the power of health information technology and to leverage human and economic resources through better federal, state, and local collaborations (7). The importance of these recommendations was emphasized by an Institute of Medicine (IOM) report that highlighted how mental health and substance abuse services lag behind general health care in using information technology to promote improved, evidence-based patient care (8). The IOM recommended the development of policies and infrastructures to link patient records and other mental health and substance abuse service data, as well as to standardize data requirements at the national, state, and local levels.

Both the New Freedom Commission and the IOM endorsed electronic health records, better coding and reporting of mental health and substance abuse interventions, and collection of client-level information by use of payment transactions standardized under the Health Insurance Portability and Accountability Act (HIPAA) (7,8). The application of information technology has improved care for chronic illnesses, including mental illness (9). Within the context of a "comprehensive quality improvement model," information technology has been critical in improving chronic disease management (10).

This article focuses on one aspect of mental health and substance abuse treatment transformation in the United States—the need for interoperable information systems. Our aim is to reach high-level state policy makers

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who have the authority and ability to make information more accessible across their health and social service programs. The article describes current federal and state initiatives for improving health data interoperability and the special issue of confidentiality associated with mental health and substance abuse treatment data. Some achievable first steps for states to consider in reforming their behavioral health data systems are outlined. Even though the article focuses on data systems in the United States, the general principles of data integration may be applicable in any country that has separate data systems for administering separate public programs of health care.

Current federal and state initiatives

Data interoperability is the ability of dispersed, separately owned, and separately managed information systems to communicate with one another electronically to share specific bytes of data. Agreements between owners of information systems define the purpose, parameters, and safeguards for the exchange. Although businesses across the U.S. economy have rapidly driven data interoperability and

exchange, the adoption has been painfully slow in health care and even more so in behavioral health care. As a result, a number of government initiatives over the past decade have attempted to make the case for why and how health data systems should interoperate.

The value of interoperability for mental health, substance abuse, and Medicaid data was demonstrated in a project sponsored by the Substance Abuse and Mental Health Services Administration (SAMHSA) (2,11, 12). The Integrated Database Project assembled data from state agencies for program evaluation purposes and revealed challenges to interoperability among existing data systems. Data collected at the client level and analyzed within three states and across three public programs—mental health, substance abuse, and Medicaid—revealed duplication of services and costs among the three systems in each state, especially for clients with complex co-occurring disorders. Of note, the project highlighted many challenges to implementing interoperability among existing systems—different concepts and data elements, incompatible definitions for the same data elements (clinical, demographic, or resource related), local coding schemes for concepts (substance use problems, procedures, and provider identifiers), varying record-keeping practices (service records bundled together versus service-specific records), and missing clinical elements (physical and behavioral health history, diagnostic specificity and completeness, medications records, response to medications, and outcomes and disposition of the patient). State and local data systems need a better foundation to support interoperable mental health, substance abuse, and Medicaid data systems. Standards that have evolved over decades for physical health services have barely infiltrated data collection for mental health and substance abuse services.

Various federal and state initiatives have aimed to improve the data environment to allow exchange of health information to benefit patient care. Establishment of electronic payment transactions with related standards

for data content, confidentiality, and security and promotion of the adoption of comprehensive electronic patient records are setting the foundation for interoperability of electronic health data for integrated behavioral health care.

HIPAA, which was enacted in 1996, outlined a vision for administrative simplification and set national health data standards for health care business transactions (13). HIPAA data content standards have been set for eligibility determination, enrollment, and health care claims used in fee-for-service systems. In addition, HIPAA required the eventual adoption of a standard unique identifier for health care providers, and in 2007 the National Provider Identifier (NPI) became effective for all HIPAA standard transactions.

The Health Information Technology initiative of 2004 of the U.S. Department of Health and Human Services set a ten-year goal of implementing electronic health records for most Americans in order to prevent medical errors, decrease paperwork, improve quality of care, and expand access to affordable care (14). SAMHSA identified data interoperability and electronic health records as major goals of its data strategy (15) and has addressed—and continues to consider—the special issue of patient privacy and behavioral health data confidentiality (16).

The Medicaid information technology architecture (MITA), created by the Centers for Medicare and Medicaid Services (CMS), aims to support improved care quality through integrated and patient-centered information systems and program administration (17). The MITA framework was developed to enable state Medicaid enterprises to meet common objectives while still supporting unique local needs (18). It incorporates existing and evolving standards developed by national organizations, fosters shared leadership and partnerships, and encourages use of nonproprietary systems and open-source code for data interoperability. SAMHSA and CMS are collaborating to promote integration among Medicaid data systems, state mental health data systems, and state

substance abuse data systems by using the MITA framework.

States have been trying to overcome the problems of fragmented, nonlinkable health data that were highlighted by the SAMHSA Integrated Database Project. One approach has been for states to develop “data warehouses” that combine siloed data to increase their utility. For example, Washington State linked client data across community mental health centers and state Medicaid claims (but not with substance abuse system data). Integrated data allowed administrators in that state to analyze and understand that providing outpatient mental health treatment to the most needy and disabled clients was likely to reduce medical care costs in the state (19). South Carolina linked data from a large number of its health and social service programs. The state’s integrated database has allowed it to identify and serve children with special health care needs and those without health insurance (20). Another approach taken by states has been linking and then deidentifying data for specific research projects. Connecticut successfully linked data between the Department of Mental Health and Addiction Services and the Department of Corrections and showed the value of treating substance abuse among prison inmates—much lower reincarceration rates among those treated, with cost savings to society of 1.8 to 5.7 times the costs of the treatment programs (21).

Aligning state data systems with each other and with national standards can have an enormous positive impact on transforming mental health and substance abuse treatment systems and showing the social value of better treatment systems. Informed by the lessons of the SAMHSA Integrated Database Project, a few state efforts are focusing on front-end harmonization to create interoperability for existing administrative behavioral health data systems. Oklahoma, Maryland, and Indiana are exploring ideas for mental health and substance abuse data system integration projects with Medicaid (22–24), using MITA strategies. The states are developing consistent

client identifiers within the state, aligning data element definitions, and considering secure Web-based technologies for data sharing. These projects exemplify steps toward achieving the goals outlined by the New Freedom Commission.

Ideally, investing in new point-of-care information systems would help states reach these goals, but such systems are expensive and in their infancy. Restructuring existing mental health and substance abuse administrative data systems presents a more practical, affordable, and manageable approach to client-centered information exchange in the immediate future.

The special issue of data confidentiality

Strict laws and regulations about the confidentiality of client information, which have existed for decades, complicate data exchange for behavioral health care providers and programs. Such rules are a consequence of the stigma and discrimination that has been associated with mental and substance use disorders. Social and legal risks continue to be associated with disclosure of protected behavioral health information, including removal of a child from a parent, lost employment, and criminal prosecution (25–29).

Because of such rules and risks, mental health and substance abuse treatment providers and program administrators are reluctant to share patient data for any purpose, even including treatment (30). The state-administered programs, to which providers must report individual patient data for eligibility and coverage determinations, also must abide by federal and state confidentiality restrictions on the use of behavioral health data. Specifically, these include the HIPAA Privacy Rule, which applies to all health data used for payment transactions, including for mental health and substance abuse services; 42 CFR Part 2, the more stringent federal confidentiality regulation associated with substance abuse treatment; and any applicable state laws or regulations.

Each of the federal rules permits disclosure of deidentified health data and of identified data under restrict-

ed circumstances. Some state laws also regulate how information about treatment for mental health or substance abuse conditions can be shared and may restrict disclosure to deidentified data (31,32). Here we discuss the federal laws to clarify how state program administrators in states that do not impose more stringent rules can link and share data to improve programs while adhering to federal confidentiality laws.

HIPAA defined individually identifiable health information and criteria for its protection (33). Personally identifiable health information comprises any past, present, or future physical or mental health data that also includes direct or indirect person identifiers. These identifiers include direct identifiers such as name and address, as well as identifiers that are not unique, such as birth date and zip code, that might inadvertently identify a person. Such data must be protected through administrative policies and procedures specified by HIPAA. When protections are in place, HIPAA encourages use of personally identifiable health data for routine health care operations, public health activities, and research without the administrative burden of patient consent for each discrete disclosure (34). HIPAA permits the use of protected health information for research if an institutional review board approves the use and the researcher certifies that the request is for the minimum data necessary, that the identifiable data will be used only for the research, and that the data will not be removed from the organization (33).

However, 42 CFR Part 2 (often referred to as Part 2) has tighter requirements that organizations with personally identifiable substance abuse treatment data must follow in addition to HIPAA. Part 2 permits disclosure and use of person-level substance abuse treatment data without patient consent for limited program purposes—audits, program evaluation, and research (35). Without patient consent, personally identifiable substance abuse treatment records cannot be redisclosed for routine health care operations outside the organization from which the data

were obtained; thus, independent treatment professionals may not share data about individual clients without client consent. Because the most restrictive disclosure rule applies, overlapping federal and state rules add to the complexity of interpreting and applying appropriate data-sharing procedures.

Nevertheless, a number of states have successfully shared personally identifiable information across agencies for research purposes. This is permissible under both HIPAA and Part 2 without patient consent, although specific requirements noted above must be met. Some state mental health, substance abuse, and Medicaid agencies may already be able to share information because of their organizational structure; Part 2 and HIPAA permit sharing of personally identifiable information between components of the same organization with authority to collect the data. Thus, for mental health, substance abuse, and Medicaid agencies in some states, it may be possible to house data sharing and analyses within the government office with authority over these agencies.

Some data system developers are designing patient consent into interoperable data systems (36). Rates of patient consent in one research study of nearly 16,000 patients showed that 90% of patients gave authorization for use of their data in medical research, regardless of their diagnosis; for patients with mental health conditions, the rate was 88% (37). For a patient in substance abuse treatment, a consent form for release of personally identifiable information must specify the authorized users of an information system, the period of time that the consent will be in effect, the specified uses of the data, plus all of the consent requirements of Part 2, HIPAA, and any relevant local restrictions (Wattenberg S, Substance Abuse and Mental Health Services Administration, personal communication, 2007). Although consent may be difficult to design and obtain for clients with substance use disorders, it is possible (35).

The future of electronic patient records for clients with substance use disorders hinges on innovative solu-

tions to maximize patient consent. Such a solution should address the benefits of sharing personal data and confidentiality protections afforded it. Existing Internet technology can address HIPAA-compliant security for personally identifiable information with authorized access on a “need-to-know” basis. Systems can be configured for access by various types of users with different preassigned authorizations. Secured access can be controlled with user identifiers, multilayered password protection, and electronic signature authentication. Privacy advocates argue for designing into these systems patient ownership of their own data, encompassing all associated issues in regard to access, tracking, and control of the data.

Achievable steps for reforming behavioral health data systems

The general principles for creating and sustaining interoperable data systems do not differ greatly from those that guide other operational or organizational restructuring efforts (38). For example, engaging a top-level champion, perhaps even the governor, can provide visionary leadership, remove political and financial barriers, and motivate separate agencies toward collaboration and data sharing (39). Benchmarks established by a multistakeholder planning group can facilitate consensus-building and transformation efforts. Identifying financial resources to sustain progress toward system change can enhance motivation and efforts to ensure the permanency of improvements once they are made. Small steps toward new standards for mental health and substance abuse data integration and transparency are a sensible way to begin, are achievable, and can provide an early and tangible return on investment. A return on investment is essential to ensure support for continuation and expansion of data integration efforts.

Within this general approach, there are concrete actions that states may find useful to consider as incremental steps toward increasing the interoperability of mental health and substance abuse data systems. Although systemwide change may seem over-

whelming, undertaking even some of the following activities can result in positive strides toward improvements in data linking and patient care.

Collect encounter-level transactions

Encounter data (that is, one record for each interaction between a provider and a patient) can be used to monitor access to, costs of, and quality of health care treatments provided, which is what administrators and consumers want to know. The advantage of collecting data at the level of the encounter is that it can be aggregated and viewed from many perspectives—services, conditions, providers, payers, and programs. Certainly, data content of encounter records can be improved; for example, codes for procedures can be developed that are more specific to mental health, substance abuse, and integrated treatments; and coding of all relevant diagnoses can be required. The improved coding that resulted from basing hospital prospective payments on diagnosis-related groups showed that reimbursement rewards are an effective way to stimulate improved coding and that using and reporting such data at the provider level results in improved data collection by providers (40).

Redesigning data collection to capture encounter-level transactions may seem daunting for mental health and substance abuse agencies that require only a record at intake or discharge from their provider networks, but many behavioral health providers already submit claims or encounter data to other payers. National standards for submitting encounter or claims data exist as a ready-made system that state mental health and substance abuse agencies can embrace with modest investment. Medicaid already adheres to these standards.

Use HIPAA-compliant coding

Collection of encounter-level transactions by using HIPAA-compliant national data standards will require states to harmonize mental health and substance abuse data elements with those standards. It is essential to review a state's mental health and substance abuse data element defini-

tions and coding and compare them with the appropriate implementation guides (inpatient, outpatient, and so forth) for HIPAA transactions (41). The National Association of State Mental Health Program Directors and the National Association of State Alcohol and Drug Abuse Directors are collaborating with partners in the behavioral health industry to ensure that the national codes represent the range of mental health and substance abuse treatment services (42). When aligned with national health data standards, behavioral health data could be analyzed with other data, such as that from Medicaid, private insurance, and statewide all-payer claims systems. Such linkages would provide comparative treatment data and information on clients' comorbid physical and mental conditions. Realignment of data systems at the front end (where concepts, definitions, and coding are established) to be compliant with HIPAA would not only yield savings in dollars and time for special projects but would also ease transition to electronic health records. HIPAA-compliant data will be a necessary condition for electronic health records that are fully interoperable. Once undertaken, these preparations will support behavioral health care systems at many levels in improving patient care.

Forge linkages with other information systems

There are many linkage possibilities with other state data systems. An obvious choice for most states and a helpful starting point would be linkages to Medicaid because of that program's substantial role in financing mental health and substance abuse treatment. Other linkages to emergency department records, inpatient data, and even criminal justice records, for example, would allow a deeper understanding of treatment effectiveness and offer opportunities for remedying disparities and service gaps. Because an increasing proportion of inmates in correctional facilities have a history of drug use that eventually leads to unmet health care needs (43), the corrections system offers a unique opportunity to link vul-

nerable populations with needed behavioral and physical health services, particularly after incarceration.

Align identifiers with those of other agencies

Provider-specific and client-specific identifiers that are compatible with other data systems are keys to interoperability. States could require each mental health and substance abuse treatment provider to obtain a NPI (44) and to report data using the NPI. Also, client identifiers should align among agencies whose data are to be integrated or linked with mental health and substance abuse agency data. Synthetic client identifiers can be created between data systems to enable alignment across agencies' client-level records while helping to protect patient privacy.

Invest in flexible and adaptable systems and processes

Agencies commonly purchase or create software and hardware systems that are unique to one agency. Alternatively, using nonproprietary software and open-source code fosters system interoperability and enables easy communication and rapid adaptation in response to changing agency and community needs (45). The CMS MITA framework can lead states through the possibilities for incorporating these capabilities (18,46). MITA also encourages interoperability between the Medicaid management information system and other health information systems to measure and improve client outcomes and manage health care costs. In addition, Medicaid MITA projects may be eligible for varying percentages of federal matching funds.

Analyze and generate information

To be viable and sustainable, information systems must demonstrate a return on investment. Patients, providers, policy makers, and analysts should decide together how the data will be used. They should make these decisions ahead of investments in the data system. Dedicated, trained staff should be available to address important policy questions with the client-linked, enhanced data systems. Unless the effort to integrate data sys-

tems shows projected and continuing worth in how it is used, governors, state budget officers, program administrators, legislators, and federal supporting agencies will be unwilling to invest in it.

Conclusions

Service fragmentation undermines effective mental health and substance abuse treatment, creating an often-insurmountable barrier when patients try to obtain, and providers try to give, effective treatment. Incomplete information about a patient's physical and mental health stymies treatment providers' abilities to apply best practices to help the patient achieve optimal wellness.

The IOM and the President's New Freedom Commission recognized the need to redesign behavioral health care, emphasizing the need for shared knowledge and cooperation among stakeholders. Strategies to achieve this aim have noted that the technology for information sharing exists but needs to be applied expeditiously to improve the lives of individuals who struggle with mental or substance use disorders.

In this article we have presented an approach to improving existing state systems of health data so that they are able to communicate and to describe health care comprehensively rather than piecemeal. The approach includes aligning behavioral health data systems with general health data systems; collecting encounter-level data; using HIPAA-compliant coding, including NPIs; forging linkages with other state data systems and developing unique synthetic client identifiers among state systems; investing in flexible and adaptable data systems and business processes; and finding innovative solutions to the difficult confidentiality restrictions on use of behavioral health data. Although we have focused on integration of mental health, substance abuse, and Medicaid data systems, these ideas also apply to other public data systems, such as criminal justice, child welfare, and school health systems. State agencies may want to focus on integrating one or two systems to demonstrate the feasibility of the concept in their

state, while keeping others in mind for future enhancements.

Data interoperability for behavioral health care is an important step toward sharing and use of data for significant improvements in patient care and public policy. Although linking data systems will not in itself transform the delivery of care, it will enable agencies to exchange information about shared clients, to better understand problems of coordination, and to track successes and failures of policy decisions. Several federal initiatives have provided an impetus for improving health care data interoperability and increasing the adoption of electronic health records. With public funding, dedicated support, and engagement from consumers, providers, administrators, and policy makers, behavioral health information systems may be poised for meaningful change and better quality of care for individuals with mental and substance use disorders.

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