

XII. Overarching Issues

A Consumer and Family Perspective

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Introduction

The time has come for the field to examine and take action to develop a high-caliber information system. For too long, consumers and families have had extremely limited information on which to base their choices of health plans, services, and providers. While the field has made great strides in the development of innovative services and practices, our ability to uniformly collect and evaluate data is far behind the curve.

If we do not possess the necessary data to determine the quality of care, we cannot make healthcare systems accountable. If we do not give consumers and families the tools to make informed decisions about their own healthcare, we put them at risk for failure. We must develop and implement a new mental health information system if we are to provide consumers and families with the data and tools they need and if we, as a field, are to meet our potential for excellence.

Will the Year 2000 bring consumers and families closer to the goal of choosing a healthcare plan based on uniform data and information? Is the field any closer to developing a type of *Consumer Reports* for healthcare plans, effectively providing constituency groups with the means to make meaningful choices in determining the “best” health plan that closely meets the preferences of consumers and their families? What are some of the information needs consumers and families would like included in a new information system?

Will the mental health and healthcare fields be capable of measuring quality, outcomes, and performance across health plans? How can health plans compete on an even playing field when we currently have no standardized way of measuring success? And, will we be able to convey this information in a way that is meaningful and relevant to consumers and families?

What are the benefits and challenges of a uniform data and information system for consumers and family members? What unique considerations should be addressed in the development of such a system?

What are the Information Needs of Consumers and Families?

Consumers and families are primary stakeholders in today’s mental health field. Although data and information systems have traditionally been geared to policymakers, administrators, and mental health agencies, consumers and families have recently become key customers for information in order to select health plans, make individual choices when determining needs and preferences for care, and to advocate for needed services. The need for person- and system-level data has become more urgent as managed behavioral healthcare becomes the primary vehicle for monitoring and administering mental health services in many states and local communities.

Data and information requirements under managed behavioral healthcare are often predicated on the needs of the payer. The extent to which these data are consistent with consumer and family demands for information is not completely clear. Even though consumers and families are involved in determining performance indicators and outcome measures for a system of care, the data that are collected are not generally based on customer needs, but on fiscal and political concerns.

Although information needs of consumers and families vary according to geography, funding, availability of services and the maturity of the mental healthcare system, the following list presents some of the common basic information needs of consumers and families:

- types of services offered and excluded
- costs of services (co-payments, benefit limits)
- types and numbers of providers and specialists
- accreditation status
- provider and program credentialing
- travel time to facilities and providers
- physical accessibility of facilities
- quality assurance reports
- complaints and grievances filed against providers, plans, MCO's
- sanctions
- reinvestment history
- utilization review procedures
- unduplicated count of clients served, services provided

What are the Benefits of the Information System Prototype to Consumers and Families?

Some of the ways the information system prototype would be of benefit to consumers and families include:

- reducing fragmentation
- promoting accountability
- raising standards of excellence for care
- raising standards of excellence for information
- promoting visionary policy development
- reinforcing the link between service delivery and quality of care
- promoting integrated services
- promoting competition and the use of consumer report cards

Reducing Fragmentation

Too often, consumer and family advocacy groups have complained about fragmentation within and across mental health, substance abuse, and health care systems. As a result, consumers often receive services that are not based on and do not support a continuum of care and do not attend to their long-

term care needs. One example is a consumer who uses psychiatric services but who cannot obtain needed substance abuse services to address a drug problem.

Fragmentation also occurs from a data and policy perspective. If the field is unable to collect uniform data on the service needs of people with mental illness and on the costs and outcomes of providing these services within and across care systems, policy makers cannot make informed decisions about mental health policy and administrators cannot decide about resource allocation and planning. This lack of integrated and cross-system information to support integrated services and a continuum of care has a direct and lasting negative impact on the rehabilitation, recovery, and clinical goals of consumers and families.

Managed care has enabled some states to track service use more effectively by population, region, and type of service offered. In some instances, quality measures are being used to ensure accountability at the local level. Such data can be used to advocate, plan for, and support the development of additional services and to earmark limited resources for services most preferred by consumers and families. The more comprehensive the data made available from an information system, the better they will reflect the full range of family and consumer service needs and preferences.

One example is the use of data to foster development of housing in a community where homelessness has become epidemic. Data on persons who are homeless and mentally disabled can be used to examine the linkage between the outcomes associated with improved housing and receipt of mental health services. Such data can then be used by advocacy groups to convince public officials to invest resources to design and develop housing options that meet the special needs of people with mental illness who are homeless.

Fragmentation is not only a problem for the service system—it affects information systems as well. At present, information systems are wrought with problems that arise from disparate methods of data collection and non-comparable ways of measuring quality. Currently, there are many initiatives underway in the field that are designed to identify sets of performance indicators and outcome measures; while the number of such projects is impressive, have they served to perpetuate a segmented system for identifying needed information? Still, there are several efforts in states and at the Federal level to bring this work together, for example, the summit on performance measurement that is being planned by the Survey and Analysis Branch of **CMHS**.

Promoting Accountability

All state systems are generally guided by state planning processes, as required by the State Mental Health Planning Act (P.L. 102-321). Within the framework of such plans, programs and services are outlined and priorities for funding received through the Mental Health Block Grant are identified. States are now required to track progress on implementing these priorities through the use of performance indicators. With performance indicators, Federal officials can more effectively monitor state's use of resources and consumers and families can be better positioned to ensure that services proposed by states are implemented. Performance indicator data can also show how well the services meet consumer and family needs. Block Grant funding also provides more flexibility to develop unique services that are tailored to local consumer and family needs. Because of its flexibility, the information system can include performance indicators for programs common to many states as well as performance indicators for programs unique to a particular state.

Raising Standards of Excellence for Care

There are currently no viable mechanisms to compare data on care and outcomes across state lines. In this respect, consumers, families, and advocacy organizations are hard-pressed to use data to compare managed care plans in regard to quality of care on a regional or national basis. Consumers and families who relocate may wish to base a move on the quality of care in another community. In addition, some may consumers live in states where it's more feasible to receive care in a neighboring state. Mobility is a reality for many consumers and families in today's society: care systems should adapt accordingly to ensure services are easily available and that information about accessing services is provided.

In order to raise the standards of excellence for care we must be able to measure the quality of care provided by different plans and compare the results across the plans. Many plans shift their priorities for measuring quality of care over short periods of time, often as a result of changes in the payer's priorities. If comparisons across plans are to remain meaningful in the face of such changes, standardized measures must be available for a wide range of quality indicators.

From a policy perspective, consumers and families demand excellence, and they have not been convinced that a comprehensive approach is available to ensuring that the highest quality and most cost-effective services are, in fact, delivered. This fundamental "missing piece" of the system has promoted dependency on what *exists* rather than on what we should *expect*. If we have little or no information about the highest level of quality, we are not promoting quality of care **B** rather, we are promoting the *status quo*.

Raising Standards of Excellence for Information

The information system will undoubtedly raise the bar for excellence for information across the field. Right now, data requirements tend to vary state-by-state and are, at best, minimal requirements generated by public payers, regulators, and managed care plans. The requirements vary in their appropriateness and adequacy. As a result, consumer and family efforts to ensure not only that appropriate services are delivered, but also that information about such services is accessible and understandable are compromised. Clearly, the data and information industry will have to re-tool and adapt to the demands of these primary customers.

Most mental health care systems are not able to address all the service needs of every person in a given community. Limited resources, profit-driven systems of care, and political will all contribute to this phenomenon. In spite of these realities, consumers and families continue to advocate so that needed services are provided to those in need. A state-based planning process is one avenue where consumers and families have an impact to identify unmet needs and to effect change in a state's policy for provision of care. Indeed, information is critical at all phases of the planning process. Advocates must have accurate counts of the number of people with particular needs in the communities to show where changes in provision of care must be made. After changes are instituted, they need the same kinds of data to determine whether the changes actually met the community's needs.

Advocacy to expand services to populations in need can also lay the groundwork for expanding prevention services. Although policymakers and administrators do not universally embrace prevention, there are data to show that these services offset more expensive treatment. Consumer and

family advocacy organizations can be more effective at obtaining resources for prevention and need-based services if they have access to such information. Research that demonstrates cost-offsets in a particular community is especially useful.

Promoting Visionary Policy Development

Information uniformity can enhance policy development and increase support for needed services and improved systems of care. Although healthcare policy remains close to home **B** with individual state legislatures embroiled in the healthcare policy debate **B** the nation as a whole suffers from lack of a comprehensive and cohesive strategy to address the ills of our healthcare system. The lessons we have garnered from state experiences now lay the framework for national action: uniform information will be essential to implementation.

Consumers and families are desperately seeking a common goal of improved outcomes, availability of and access to needed services, and hope for recovery. Consumer and family organizations have become the change agents in many states **B** pushing for parity and services. The paucity of services and the limited number of providers committed to serving people with severe mental illness, persons who are homeless, or individuals who are incarcerated, has led to problematic and controversial issues such as involuntary outpatient commitment.

A strong advocacy movement must have access to data to press for change. Legislators are often the most impressed when advocacy organizations have a command of information to make a clear case for additional services or to argue for the closure of a state-run institutions or programs. Without adequate and accurate data, such efforts to improve service systems is for naught. Even worse, advocacy efforts can have unintended consequences, such as reduction of a mental health budget or allocation of resources to other departments. State mental health administrators cannot make appropriate changes in response to advocates if data are outdated or incomplete.

Current estimates of the number of uninsured Americans have fueled the debate over healthcare reform. Clear, simple numbers (data), such as these, help keep this issue on the front page of most newspapers and at the top of healthcare advocacy community's agenda. This information, the implications of which are so direct and obvious, has provided presidential candidates and others running for public office an opportunity to shape the public debate. Large advocacy organizations use using information to convince Congress and others to pass laws pertaining to portability, parity, pre-existing conditions, privacy, and other reforms.

In the mental health field, shaping policy has become reactive rather than careful and strategic. This is exemplified by the resurgence of involuntary outpatient commitment proposals as a means to address the public's call for accountability following high-profile incidents of violence and tragic episodes involving people with mental illness. While a uniform information system is not a panacea, it will provide the field with the information it needs to think about the implications of short-term policy goals and plan more effectively for the future.

Reinforcing the Link between Service Delivery and Quality of Care

The new information system may finally bring us closer to understanding the important link between service delivery and quality of care. These two areas have often been treated as separate colonies, with no direct link or only a remote relationship.

Treatment guidelines, for example, are pivotal to determining what type of and for what duration clinical services should be provided to a consumer. A system for assessing quality must not only measure the clinical intervention provided, but also be able to measure whether the provider actually adhered to a guideline and whether application of the guideline resulted in improved outcomes for the consumer. Fidelity measures help us better understand what services consumers are actually receiving.

If we ask consumers in a satisfaction survey how pleased they are with the services they received, but fail to ask whether other services are needed to meet their goals for recovery, then we are not measuring quality. By comparing the treatments provided with the guidelines, we can see what is missing that prevents recovery from being achieved. Guidelines are most useful, however, when they address all aspects of a person's functioning. Medication algorithms, for example, can tell us about newer and more effective psychiatric medications, but algorithms alone cannot tell us how psychosocial interventions should play a role in medication compliance or in improving level of functioning.

Grievance and appeal data also play critical roles in determining the effectiveness of service delivery approaches and quality of care. This information has an important impact on a consumer or family's decision about services and plans, but behavioral healthcare organizations tend not to make such data available.

Promoting Integrated Services and Integrated Information Systems

Consumers and families have served as important stakeholders in the design of innovative services and the articulation of quality standards. These groups clearly see the value of linkages that need to be made across disciplines and systems.

Uniform data and linkages across information systems support integrated systems of care; they also support the changes needed to bring such systems about. For example, accurate data on supportive housing will facilitate a consumer's re-entry to the community from an institutional setting. In this regard, the mark of an excellent provider will be the extent to which he or she advocates for improved information linkages along with advocacy for integrated care.

Providers' dedication to the concept of creating and supporting information will ultimately improve the quality of life among consumers. Likewise, the ability of consumer and family organizations to access such data will assist advocates in building additional community supports and other services.

Promoting Competition and the Use of Consumer Report Cards

A well-functioning information system will clear the way for more broadly based competition in the industry to provide a higher grade of services so that quality is at least equal to price as a determining factor. Too often, contracts are awarded solely based on price and not on standards for quality. While cost is an important issue in today's healthcare marketplace, it is not the overriding issue for consumers and families.

In the instances where cost is placed high on the decision-making tree, the market loses the ability to allow consumers to drive the system. Consumers cannot choose among plans when the payer limits

competition and bases it largely on cost. In this respect, consumer choice is non-existent. Choice between plans selected only on the basis of the lowest price, is not choice. Quality competition needs to be included with cost competition; uniform and comparable information on performance indicators and consumer outcomes will facilitate this.

The field has embraced the concept of consumer report cards. Although they are not yet widely used, research and development in this area has gained momentum. Ideally, report cards will serve as an incentive for plans to show improvement over time and in domains such as: consumer satisfaction with services; provider satisfaction; costs to consumers and co-payments; availability of specialists; factors of choice; complaint and grievance resolutions; and availability and accessibility of psychiatric medications. A “smart” consumer will then be able to make an informed choice among plans that goes well beyond cost considerations.

What are the Challenges of a Uniform Data and Information System to Consumers and Families?

Some of the challenges consumers and families may face with the development of the information system include guaranteeing informed consent, regulating access to medical records, expanding choice, and ensuring valid interpretation and reporting. As with all things, these concerns should not be obstacles to developing the system, but rather challenges that drive creative problem solving. Any major reform will come with technological, training, and start-up difficulties. Change can only take place when plenty of mistakes have been made. An effective response by consumers and families to these challenges will form the basis for a well-designed and functional system.

Weakened Informed Consent

Informed consent is the basis for consumer participation in any research protocol or innovative therapy. Unfortunately, this is often the only time consumers have a legitimate voice in their treatment. Consumers have a fundamental right to make informed choices about the services they may use in the beginning and over the course of their treatment. In addition, consumers may seek more control over their treatment at critical junctures, such as at a time when crisis occurs or in decisions pertaining to the selection of a specialist (e.g., trauma counselor). Consumers also have a right to know about and consent to data about them being collected, researched, and reported. Clearly, an accessible and multifaceted information system presents challenges to ensure that informed consent is obtained, adhered to, and appropriately administered. As we develop a uniform method for data collection and analysis, issues of consent must be addressed along with related issues of privacy and confidentiality. It has been difficult to develop a unique identifier that will allow access to information about a person and still ensure privacy and protect confidentiality. Restricting access to only those persons who need the information within a provider agency or MCO has been effective at stemming the flow of confidential information.

Aside from the obvious implications for consumers and families, there are many issues associated with provider performance and adherence to standards for informed consent procedures. Policies and procedures need to be developed along with standardized and mandatory training for providers who regularly encounter these issues. Clinical training must also emphasize the importance of informed consent so that the next generation of providers will be adequately prepared.

Ability to Access Medical Records

Consumers and their families today face numerous challenges in accessing medical records. Consumers and families need their medical records to monitor ongoing treatment or when seeking redress from an institution that has allegedly been abusive. Specialized advocacy organizations, such as the Protection and Advocacy (P&A) agencies that are charged with investigating incidents of abuse or neglect must have ready access to medical records.

Furthermore, ease of access to records and information is important to many consumers. It is time consuming and frustrating to repeat lengthy medical and psychiatric histories; with adequate privacy protections, histories could be readily available to whomever consumers choose to share them. While there has been a focus on the collection and analysis of aggregate data, there must be the ability to maintain notes and other data in a format that can be accessed by the consumer or family.

The extent to which consumers and families can access medical records in this developing information technology environment is unclear. The system should be relatively straightforward and user-friendly, not only for researchers, providers, and managers, but also for consumers and families with little or no experience with data, computers, or other technologies.

Expanded Choices for Consumers and Families

The key to developing and sustaining consumer choice in any system is to provide the vehicle for choices to be made. The information system itself is one such “vehicle”; within it, other “vehicles” are report cards and consumer outcome measures. Still others are clinical guidelines for treating depression, schizophrenia or other disorders, system guidelines for assertive community treatment, and flow charts describing models for disease management.

Not only must all this information be reliable, but it also must be presented in ways that will be understood by consumers and families if they are to use it to make choices about plans, providers, programs, and overall quality. Realistically, the information system cannot meet every need, but it must, at a minimum, be able to translate complex data into practical and usable information for consumers and families to understand and make choices about key aspects of their care.

Consumer and family advocacy organizations will also demand information on the progress and implementation of the information system. They will want to be assured that the domains that are most critical for their organizations are included in the information system. They expect to continue to be involved in the planning, development, and implementation processes so that their information needs are met and so that they can help monitor the system.

Data Interpretation and Reporting

An important step in implementing the information system prototype will be to identify stakeholders to interpret data and draw policy and research conclusions. From a theoretical standpoint, the ideal model will include consumers, families, and advocacy organizations, among others. Such a coalition is an essential ingredient in any decision support system.

Consumers and families are critical to successful and meaningful interpretation of information. They are the primary audience—and, as such, have a unique ability to bring data to the attention of

policymakers, legislators, and other concerned with systems improvement. They can communicate easily in lay terms and explain the implications of information to their constituents and to the public.

Experts in the field can capitalize on these special skills and know-how by including consumers and families in activities involving analysis and interpretation of data. Consumers and families can help make sense of data by using their own experiences to explicate a finding. A consumer who has been homeless, for example, might be particularly helpful in trying to understand and explain why homeless persons do not access traditional services. A consumer may understand the system's intricacies that are often so elusive to analysts who do not use services. Family representatives know first-hand the problems involved in obtaining services.

Consumer and family organizations have become more familiar and respectful of the need to collect and analyze data for improved information. Their expertise and direct interest in system improvement make them not only worthy but also essential participants in the process to understand and shape policy through the use of data and information.

All efforts to interpret, report, and analyze data must ensure that the information is accessible to consumers of all levels of education, all cultures, all languages, and all levels of capacity for understanding. In addition, information should be available in alternative formats and via computer as appropriate.

Conclusion: Prevent the Loss of Individuality

The act of establishing a new information system presents us with the chance to think in "big picture mode." There will likely be broad and much-needed policy advances as a result of this system. In many respects, this project presents the field with a unique opportunity to reach beyond our current capabilities to a future bright with change and improvement. Clearly, this project has broad reaching possibilities.

No matter how far we reach, however, we cannot forget the people who will be affected by this major paradigm shift. Consumers' and families' abilities to shape treatment plans, appeal or file grievances, choose providers, or refuse treatment must not be adversely affected by the development of an information system. Consumers' and families' relationships with providers should in no way be diminished by the implementation of such a system. With the promise of improved information come numerous opportunities for the field. We must be vigilant in our efforts to ensure that such advances will not prevent consumers and families from reaching their goals for treatment and recovery.

Cultural Competence

Christine Hale and Mario Hernandez

What is a Culturally Competent Information System?

Mental health providers are increasingly recognizing the impact of culture and that cultural competence is a vital component of effective mental health services (CMHS, 1997). Indeed, "culture clearly governs normal and dysfunctional behavior, thresholds for distress and seeking out services, coping strategies and attitudes about illness and receiving services" (Pumariega, 1996). Culturally competent quality assessment requires determining whether appropriate care is being provided to all cultural groups.

Cultural competence means that services are provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving services and in a manner that has the greatest likelihood of ensuring their maximum participation in the program. Cultural competence also refers to a program's ability to honor and respect the diversity of consumers and of staff who are providing services. A culturally competent health and mental health care system incorporates these values at the levels of policy, administration, and practice. Cross et al. (1989) and Isaacs (1996) note that cultural competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that promote effective cross-cultural work.

Applying the principles of cultural competence to information systems means developing methods to ensure that the information included in the system is relevant to the populations served and has meaning for them when analyzed. A culturally competent information system would have, for example, assessment tools developed by and for the specific cultural groups served. It would also have the capacity to capture data on the cultural context of mental illness and recovery and on the cultural factors that influence utilization patterns, access, outcomes, and satisfaction with care. Typically, such data require qualitative methods of data collection and analysis and specialized techniques for identifying, reaching out to, and interviewing hard-to-reach populations such as the homeless, the seriously and persistently mentally ill, and drug users. Kleinman (1977) suggests that cultural explanations for the person's illness, cultural factors related to the psychosocial environment and levels of functioning, and cultural elements of the relationship between the individual and the clinician can be gleaned from focus groups and in-depth interviewing. Software packages for ethnographic data analysis are now available and reduce the burden of qualitative data analysis.

Experts in cross-cultural mental health research also advocate for community-based approaches to gathering information on a population of interest. For example, geocoding allows researchers and program staff to examine communities' access to and utilization of services and to target groups that are not being served (Roizner-Hayes, 1996). Effective outreach and community-based needs assessments can be used to develop prevention and early intervention strategies for entire neighborhoods.

Challenges to Culturally Competent Data Collection and Analysis

Who collects the data, how they are collected, and how they are analyzed are key determinants of the cultural relevance of the results. Many data collection tools are available only in English, thereby limiting the range of persons for whom they can be directly administered. Instruments translated into other languages often fail to capture the intended meaning of the original question and do not withstand rigorous validity and reliability tests (Hicks, 1996). If poorly translated, an instrument cannot provide reliable information and comparisons between English-speaking and non-English speaking respondents are not valid. Moreover, instruments normed for white, middle class populations do not account for cultural differences and are less useful among communities of color. In addition, interviewers who are sensitive to culture and fluent in the primary language of the respondent will be more likely to obtain accurate information. Finally, comparing data across cultures and making accurate interpretations requires attention to the special meanings each culture assigns to particular terms and concepts (Hicks, 1996; WICHE, 1998).

Classifications of race and ethnicity on survey instruments have become an area of controversy, and will only become more confusing as the cultural composition of this country expands and shifts. For example, categorizing a person as Asian obscures the differences among the 31 ethnic groups within the Asian population (CMHS, 1997). These distinctions are essential to understanding differences in health care utilization and service needs between subgroups (Freiman, 1998). A comprehensive understanding of a person's identity requires more than a simple classification of race and ethnicity; it may be important to know how he or she came into this country, what language is spoken and with what proficiency (Santiago, 1996). Misclassification of race, first language, disability, gender, sexual orientation, religion, or ethnicity can bias a data set. Specific coding categories with detailed definitions of these types of data elements need to be developed for accurate reporting (Pumariega, 1996).

Although data need to be specific enough to correctly represent distinct subgroups within ethnic and racial groups, these groups need to be large enough to allow for analysis. Many ethnic and racial subgroups are not prevalent enough in the population to generate a statistically significant sample. By incorporating these subgroups into a larger group, however, important distinctions that can influence how individuals react to a health care system and its services may be missed. Again, it is necessary to combine quantitative and qualitative data collection methods to ensure that valuable information is gathered and analyzed.

Toward a Culturally Competent Information System

Perhaps the biggest challenge to developing a culturally competent information system is the nature of the mental health care system itself. Although cultural competence is not yet a reality in either care or information systems, data collection tools and strategies are increasingly available. For example, the Mental Health Statistics Improvement Program (MHSIP) Consumer-Oriented Report Card includes seven indicators of the cultural competency of an organization (CMHS, 1996).

Although there are numerous efforts around the country to address cultural competence in the delivery of mental health services, one effort is particularly relevant to the development of information systems. The Center for Mental Health Services (CMHS) has sponsored a major and ongoing initiative to develop cultural competence standards at both the system and clinical levels. Its

initial publication, *Cultural Competence Standards in Managed Mental Health Care for Four Underserved/Underrepresented Racial/Ethnic Groups* (1997), was based on the work of national panels from Asian/Pacific Islander, Native American/Alaska Native, African American, and Latino communities. The document includes standards for information systems and asserts that creating a culturally competent information system is the backdrop against which to create a culturally competent service delivery system. The authors recommended that the database include qualitative and quantitative data on the four cultural groups, that the data be linked to other service systems to provide cross-system utilization information at the Federal, state, and local levels, that the system have the capacity to code multiple subgroups and those of mixed race and ethnicity, and that the system be able to track aggregated diagnostic and assessment information, service utilization trends and costs, drop-outs, and behavioral and functional outcomes. Perhaps most significantly, the authors recommend that input should be sought from consumers' communities on attaining culturally competent staffing at mental health service organizations.

A subsequent document, *Cultural Competence Performance Measures for Managed Behavioral Healthcare Programs* (1998), recommends that information systems include indicators and measures of cultural competence and that consumer and family surveys be redesigned to enable assessment of the cultural competence of the organization. It also contains measures to assess the cultural competence of mental health service organizations.

Components of a Culturally Competent Information System

A culturally competent mental health information system would include the following elements:

- Culturally competent instruments informed by community representatives from racial and ethnic groups that represent the population of consumers, clinicians, and academics with cross-cultural expertise;
- Voice driven/touch screen technology that offers choices of language and visuals that reflect the cultural diversity of the population served;
- Decision support tools such as guidelines that can be written and programmed to account for cultural variables prior to making recommendations for interventions;
- Capacity to code multiple subgroups and persons of mixed race and ethnicity;
- Access to information on cultural issues via Intranet to supplement intensive in-person training;
- Internet and video-teleconferencing to increase access to information for consumers and mental health care providers in remote rural areas;
- Geocoding by zip codes, allowing for the study of community and population diagnostic and utilization trends;
- Capacity to store and analyze both qualitative and quantitative data;

- Ability to track culturally specific behavioral and functional outcomes;
- Satisfaction measures that are culturally relevant;
- Performance Indicators and measures that assess the degree to which organizations achieve cultural competence standards.

Technology alone will not improve service delivery to persons of diverse cultural backgrounds; an information system simply supports decisionmaking, makes knowledge and resources widely available, and assists in planning and prevention. Without adequate, culturally competent staffing and services, an information system is of diminished value.

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Privacy

People and Privacy in Mental Health Information Systems: Comment from Consumers in the Electronic Village

Caroline L. Kaufmann

Introduction

My thoughts on mental health information systems are influenced by junk mail. My mailbox is filled regularly with colorful brochures from vendors wanting to sell me something. How do they know my address? How do they know I need what they have to offer? I am not the only person to raise this question. Recently **HHS** Secretary Donna Shalala reported on a young woman who received a brochure from a company that manufactures feminine hygiene products. The brochure arrived after she had filled her doctor's prescription for treatment of a vaginal infection (Plain Dealer, 1999).

How did the drug company get her address and know that she was potentially "in the market" for their intimate feminine products? The answer resides in shared electronic data systems. Drug companies have access to electronic data bases generated by pharmacies. Data bases contain names, addresses, and insurance information on millions of people who take prescription drugs. This information is shared with insurance companies and other for-profit vendors. Through a system of electronic communications, information that a person provides in a confidential relationship with a physician is transferred to other for-profit companies that make their livings through mass mailings and telephone marketing. So, why should I worry?

Every month, I refill my prescriptions for several psychotropic medications. There is nothing particularly shameful to me about this. I have announced at many national meetings that I am a consumer of mental health services and that I take psychiatric medications. So, I have nothing to hide in that dimension. However, I don't want direct mail from a pharmaceutical company promoting the latest psychotropic balm. My mailman doesn't have to know that I take these medications. The neighbor who occasionally brings in my mail when I'm away doesn't need to know that I have a mental illness. The office staff in whatever direct marketing firm handling the pharmaceutical company's mass mailings don't need to know, either. And I never want a call from a telemarketer offering me a coupon for dollars off on my next refill of Prozac.

This paper briefly examines the pros and cons of access to and use of personal information in mental health information systems. I want to split a particular hair on the difference between knowledge and use. Knowledge of my mental illness and the drugs I take is important information for my caregivers in the mental health delivery system. The psychiatrist, pharmacist, and other providers are able to provide me with better care because this information can be shared accurately and rapidly. I have no complaints about providers sharing information about me if they use the information to improve their ability to care for me – what may be called clinical uses. I object to the use of information from my medical and pharmacy records for purposes other than my own care – non-clinical uses. If anyone is going to use information obtained in a clinical setting for purposes other than treatment, I want to know about it. I want the right to decide who can have access to my medical information.

Mental Health Information Systems – The Good, The Bad, The Uncertain

Mental health information systems have the potential to increase the efficiency and effectiveness of mental health services. They also have the ability to destroy personal privacy. Between these rocky coasts lies a sea of moral and legal ambiguity. Our efforts to navigate that sea – to construct a coherent, accurate, and useful information system for mental health services -- should be guided by open discussions among all interested parties.

Among these interests, those of the individual consumer are paramount. Why? Because in most cases of mental health treatment, the consequences of decisions made by mental health providers are born by the consumer. Principles of distributive justice dictate that, in decisions affecting multiple constituencies, the interests of those most affected by the decisions should prevail (Rawls, 1981). Consumers, while not the most powerful constituents in the debate over shared electronic data systems, are the most personally vulnerable to its effects.

Good Things about an Integrated Mental Health Information Systems

An integrated mental health information system has many advantages. The good things about such a system are shared by consumers, providers, and researchers. I will focus on the benefits to consumers in the section that follows.

Consumer Review of Records

An integrated mental health information system collects information from multiple sources and organize it so that there is a common point of access. Culling records from numerous agencies and providers is arduous, and an integrated information system eases this task. With a click of the mouse, or a touch on the screen, any authorized user could access personal information from multiple sources. The consumer would be able to examine his or her own records without having to visit every place where s/he has received mental health care. Consumers could pass their records along to providers. They could create an abbreviated version of records that contain a summary of their advance directive. All this could be stored in an electronic wallet, similar to those currently available through a web browser, that keys into a central electronic server containing the mental health information system. The consumer would control access to the database through some personally unique means, such as a password, thumbprint, or retinal scan. Most importantly, consumers could add information to their own records and challenge items that were inaccurate.

Standardization

With an integrated mental health information system there can be standardized data on an entire population of individuals. This allows researchers to calculate population level descriptives. It is important to calculate these population descriptives so that epidemiologists can examine what is happening with the mental health of a population, not just an individual. If data were not standardized, as is often the case presently, then data could not be combined as well to gain an accurate picture of what was happening with the mental health of a population. In addition, an integrated mental health information system enables researchers to expand the scope and depth of information at the group and individual level. The consumer benefits in the long run from this

research in terms of improved service systems. Advances in the treatment of mental illnesses have improved the quality of life for some consumers, and mental health services research has contributed some findings to this body of work. So, in the long run, standardized data sets do benefit consumers.

Service Coordination

Integrated mental health information promotes service coordination. Consumers usually receive care from more than one provider. Communication among providers is difficult using existing information systems, especially between the medical and psychiatric systems of care. With an integrated mental health information system, a primary care physician could access records from a behavioral health care agency to check for potential drug interactions and coordinate treatments. An emergency room physician could access consumer data to aid in rapid diagnosis and treatment.

Increased Linkages

An integrated mental health information system increases the linkages within the mental health care system and with outside service systems. Internal linkages among service providers allow for rapid transmission of patient data. This allows for the possibility of “outcome-based” treatment planning. In the area of children’s services, medical and psychiatric information could be shared with child welfare agencies. Decisions regarding family interventions could be made with a clearer understanding of the child’s medical and mental health. School systems could share information with treatment providers on behavioral issues among children. Providers could thereby tailor treatment plans to better fit the needs of the child in the classroom.

Bad Things about an Integrated Information System

While the proponents of an integrated mental health information system point to the many benefits it provides, there are those who are skeptical. The skeptics point to the potential for consumers to lose control over their own data. Having a streamlined computer system where data can be transmitted instantaneously poses more of a risk to privacy than does a file locked in a physician’s filing cabinet. When data is placed in a data system, the number of people who have access to this information increases significantly.

Restricted Access to Psychiatric Records

Mental health consumers do not have access to their own medical and psychiatric records. In a formal sense, the records are “owned” by whatever provider agencies generated the records. A thick veil of secrecy shrouds individual records from review by the persons most affected by its content – the consumer. Granted a psychiatric record often contains information about other people in the consumer’s network of family and friends. These people have a right to have their privacy protected. However, the need to protect third parties need not limit a consumer’s access to basic information contained in the psychiatric record. Diagnosis and medications, social history, psychiatric and medical history, and current treatment plans could be accessible for consumer review.

When consumers provide data about themselves, they lose control over who will be able to access the information (Campbell, 1997). The American Psychiatric Association notes that “Americans don’t realize that their most personal medical information is frequently being disclosed to a wide range of commercial interests and government entities”(APA Online, 1999).

There are risks associated with providing complete and accurate information about oneself. As barriers to access by providers and others are removed in an integrated mental health information system it increases risk. When others have easy access to data this can lead to personal surveillance, abridgment of constitutional rights, inappropriate monitoring and control, access to personal data for private profit or criminal use. “If people are afraid that their personal information will be used to hurt them then they are discouraged from giving a complete and accurate history” (Cushman and Detmer, 1997)

Data Trends Become Self-fulfilling Prophecies

Standardization of treatment information may cause consumers to be pigeon-holed into pre-determined modes of treatment. For instance, one of the benefits of an integrated mental health information system is supposed to be that aggregate statistical data can help providers determine what kinds of needs consumers have. A problem with this is the fact that providers, basing their decisions on aggregate statistical data, may make decisions about treatment needs that become a self-fulfilling prophecy. Evidence that ECT has worked in the past for a particular consumer may bias clinical decision in favor of continued use of this procedure. (For an overview, see [APA](#) Tasking Force on Electroconvulsive Therapy, n.d.) Although this is not necessarily unwise in all cases, the prior history may prevent a clinician from trying new treatment modalities as they develop. ECT may become the treatment of choice simply because it has been used before, and without recourse to “new generation” drug therapies.

Personal nuance can be lost in a standardized system of information. Information that does not fit into the standard form may be ignored. It may be “recoded” into a form that distorts its original content. In addition, multiple data sources introduce multiple potential for errors.

Internal Linkages Limit Consumer Alternatives

When one’s psychiatric history becomes proscriptive, the consumer’s choice among alternative treatments is diminished. As a consumer’s file follows him/her the most current provider may be tempted to simply provide the treatment that the previous provider tried. This situation is fine if the treatment was successful, but a consumer under an integrated mental health information system could receive the same unsuccessful treatment repeatedly. Information about mental health services can be examined for purposes other than the consumer’s treatment (Cushman and Detmer, 1997).

Expanded Information Systems Do Not Increase Availability of Service

Collecting information about the mental health system is not the same thing as providing mental health services to consumers. In fact, the two activities may compete for scarce resources in public mental health systems. Constructing electronic information systems is an expensive enterprise. It is labor intensive, and requires costly upgrades in computer systems. Public dollars allocated to mental health are shrinking as demands for improvements in outcome measurement and reporting increase. The public system is bombarded with requests for information on outcomes of treatment at the same time it facing cuts in services designed to improve those outcomes.

An Uncertain Future for Mental Health Information Systems

Privacy protections in mental health information systems face an uncertain future.

“An atmosphere of distrust about the confidentiality of computer-resident information...breeds fears of personal humiliation, loss of reputation, and risks to financial status” (Cushman and Detmer, 1997). Although public systems of service are ultimately accountable to public officials, legal restrictions on private sector use and disclosure are limited. State and Federal elected officials hold the final authority to impose sanctions that protect personal privacy. In the public mental health arena, a consumer’s rights to privacy usually are weighed against the perceived public safety needs of the community. Legislators tend to support access to publicly held psychiatric information when there is a documented threat to the community or to the individual. In this context, a person with (or without) a mental illness can have medical records subpoenaed by the courts. In contrast, the private sector has little or no privacy protection, and for-profit companies can access psychiatric records without legal warrant. Little or no privacy protections exist in the private sector service system for most types of data relevant to a person’s mental health treatment.

In general, the public does not “trust” managed care organizations or insurance companies (Mechanic and Rosenthal, 1999). Private corporations have the money available to purchase information about mental health consumers. Pharmacy mailing lists, HMO enrollment lists, and medical data from insurers are all available for purchase by private sector companies wanting to use the information for marketing and monitoring, and background on prospective customers. “Little Brother” companies have access to a great deal of information about mental health consumers. This includes information on psychotropic medications, psychiatric visits, and prior psychiatric hospitalizations. There is more to fear in private sector invasions of consumer privacy than in the “Big Brother” nightmare foretold by Orwell.

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Technology

Tom Rich

Designing, building, and implementing a mental health information system raises a number of technological questions, including technical feasibility, ease of use, data quality, and analytic capability. The most basic issue, however, is what technologies will be used to make the system operational? Accordingly, this section addresses two fundamental technological issues—data integration strategies and database technologies.

Data Integration Strategies

Perhaps the most daunting technological challenge in making *Decision Support 2000+* fully operational, is to find a way to integrate data that are currently stored on numerous computers throughout the country—computers at managed behavioral health care organizations, public mental health agencies, and local mental health providers. There are essentially two ways to achieve data integration: (1) centralize the data or (2) keep the data at local sites but develop systems and procedures to link data across sites on an as-needed basis. Hybrid solutions are also possible, where some data are centralized and other data remain decentralized.

The Centralized Approach

Under a centralized data integration strategy, a central database would be created to store and maintain the data collected through the components of the information system—the data sets and the decision-support and quality assessment tools. This does not mean that all relevant data would be stored at the central repository. Rather, the repository might hold only certain types of data (e.g., population data, but not enrollment or encounter data) or there might be a series of regional repositories with either the full suite or a subset of the data types.

Regardless of the number of central repositories or the types of data in the repositories, the centralized approach requires development of a data standard, rules for transmitting data extracts, and methods for making data queries.

- **Data standard.** The managing authority, in consultation with stakeholders, would publish a data standard for the repository that details what data are in the repository, how those data are organized, and what codes are used. A database would then be built around that data standard.
- **Data extracts.** Organizations contributing data would extract data from their local databases and transmit those data to the repository. The central authority could either require the data be in a precise format and be transmitted in a particular way or accept the data in different formats and transmission methods (e.g., electronic and non-electronic). The latter option would require the central authority to transform the data so that it complies with the data standard.

- Data queries. Using some sort of query front-end, users would submit queries to the central repository, perhaps from a Web page or from a terminal linked to the repository. Query results would then be transmitted back to the requestor. The telecommunications link between the user and the repository could either be public (i.e., the Internet) or a private wide area network.

Both private and public mental health organizations currently use a centralized approach to collect data from local providers. One managed behavioral health care organization, for example, obtains enrollment data from approximately 1,500 sources, including third-party vendors, employers, and payers. Enrollment data can be sent to the organization's central office either on paper or electronically. For those wishing to submit enrollment data electronically, the organization specifies how the data must be organized and formatted and staff work with local providers to help them use their own information systems to create data extracts that conform to the specifications. Enrollment data are then stored centrally on the organization's mainframe computer.

Similarly, one state mental health agency has given community mental health centers free rein to develop their own information systems, as long as they continue to transmit certain kinds of data to the state's central mental health enrollment system. For sites that want to avoid duplicate data entry (i.e., entering data in both their system and the state system), the state specifies how local sites should program their systems to produce the required data extracts and how data are to be transferred from the local to the state system.

A growing trend in mental health and other industries is, in addition to having a central database containing operations data, to use a *data warehouse*. Data that are collected as part of day-to-day operations—enrolling clients, reporting encounter data, filing a claim, paying a claim—are typically structured so that transactions can be quickly processed; they are not designed to facilitate management decision making. However, with a data warehouse, an organization can transform these operational data (e.g., by aggregating the data by time, geography, or other variables) into a new database specifically tailored to support management decision making. It is this aspect of a data warehouse that makes it appealing as a technology for *Decision Support 2000+*: it reduces burden on would-be providers of operational data in that their information now can facilitate decision-making without additional data collection. As traditionally defined, a data warehouse combines information from databases across an entire organization; by contrast, *data marts* encompass only a subset of an organization's data.

Were *Decision Support 2000+* to use a centralized approach, operational data from participating entities would be transmitted to and maintained on a mainframe computer. (Where this mainframe computer would be located and who would operate it remains, of course, to be determined—but for purposes of this example, we can call it the “centralized data authority”. This authority would develop the data standard, rules for transmitting data extracts, and methods for making data queries as described above, as well as assume responsibility for day-to-day management of the data and analytic and reporting functions.) While some direct querying of data on the mainframe would be possible, users would rely primarily on data warehouses for decision support. Each week, data on the mainframe would be transformed into a series of data warehouses—one for the centralized data authority and one for each of the participating entities. Thus, local entities would receive a new data warehouse (a multi-gigabyte data set) each week, which central data authority staff load on their own computers for analysis and reporting.

The Virtual Database Approach

While the idea of integrating disparate data into central repositories has been around for decades, the idea of using a virtual database to integrate data is relatively new. The term “virtual” is used to distinguish a database that is merely conceptual from one that has physical reality. With the virtual database, there is no central database—the data remain in their local databases. When a user formulates a query against the virtual database, perhaps using a Web page, a query processor fires off a series of queries to the appropriate local databases. The processor then receives and assembles the responses from the local databases and presents the results in a unified manner to the user. All the background processing and querying of multiple disparate databases is “invisible” to the user: to the user, the many local databases appear as a single database. The virtual database embodies the concept of interoperability—the ability of a system to work with other systems without special effort on the part of the user. It is this aspect in particular that makes it appealing as a mechanism for *Decision Support 2000+*—there would be no investment in a centralized database (instead, it would go into developing complex computer programs) and no need for participating entities to transmit and receive data.

The most common examples of virtual databases that currently exist are on the Web, particularly at e-commerce sites. For example, Yahoo’s shopping site (shopguide.yahoo.com) allows visitors to enter a desired item and browse through offerings by a variety of on-line stores. For example, a search for “baby cribs” yielded 62 cribs from 14 different on-line stores. To the user, it appears that Yahoo has a centralized crib database; in fact, the user’s query spawned a series of queries to on-line stores that feature cribs. Other Web sites allow a job seeker to enter a description of a desired job (title, location, salary), which is then compared to job listings on multiple Web sites. The Web is a natural environment for virtual databases, because all Web sites adhere to a set of standards, including rules for communications (i.e., TCP/IP), display (i.e., HTML), and file exchange (i.e., HTTP).

A slightly different virtual database approach is used by some corporations attempting to analyze data that reside on various types of computers and databases throughout the country. A new class of virtual database products are attempting to solve this problem. One virtual database vendor (Enterworks) describes its product as follows:

“Imagine that you had a database composed of links and pointers to all the data sources in your organization — flat file, relational, hierarchical and networked databases, in any format, on any platform. Imagine that you could work with this database to build business models, develop applications, make ad hoc queries, and do everything else you typically do with data.

In other words, imagine that you could get all the value you need from your data without having to move, replicate, or even physically interact with the actual data sources themselves. For all practical purposes, all of your data throughout your organization is in a single location that’s easy to access and easy to use—and the data is always fresh, always accurate, always ready to serve your users.

That's what Virtual DB® is and does.”

Rather than enforcing standards on each of these disparate systems (e.g., TCP/IP, HTML, and HTTP), products such as Virtual DB® use sophisticated “middleware” applications that allow different computer systems to talk to one another. In particular, computer programs akin to “brokers” translate

queries into a language and format that the different data repositories can understand and, in turn, translate and aggregate query results from the local databases back to the user.

Were *Decision Support 2000+* to use a virtual database approach, there would be no centralized database and no transfer of data back and forth between the central data authority and local entities. Data would remain in the local databases of participating entities. A user would present a query to the central data authority through a Web page; the query processor at the central data authority would then send the query off to the appropriate local databases, receive data back from the local databases, assemble them into a coherent response, and present the results to the user. For example, a state mental health authority wants to know how its spending on a particular service compares to spending by other states for the same service. It asks the central data authority to provide it with information on expenditures for the service by state, the central data authority queries all states participating in *Decision Support 2000+*, these states provide the requested figures, and the central authority compiles them for responding to the original query. The central data authority also makes this information available to all the other participating states who may use it themselves at a later date. To paraphrase the Enterworks statement quoted above: the participating states ‘get all the value they need from their data without having to move, replicate, or even physically interact with the actual data sources themselves.

Data Technologies

A second technological issue concerns the possible systems that could be used to store, manipulate, and retrieve the data. This issue has relevance for either data integration strategy noted above—if a new repository is to be built, how should it be constructed, or, if data are to remain locally based, what type of system should be encouraged?

Database management systems (DBMSs) are computer applications that enable users to enter, manipulate, and retrieve information. In the 1960s, when DBMSs first became commercially available, there were hierarchical DBMSs and network DBMSs, depending on how the data were internally organized. As both models had major limitations, primarily in terms of their flexibility and the level of expertise required to access the data, hierarchical and network DBMSs were replaced in the 1980s by an alternative design—the relational DBMS, or RDBMS—which became the *de facto* standard for DBMSs. Today, RDBMS is a multi-billion dollar industry, with IBM and Oracle controlling over half the market.

RDBMSs offer a very simple and conceptually appealing model for organizing data, particularly for the kinds of data in *Decision Support 2000+*. A relational database consists of one or more tables, with each table consisting of rows and columns. The “enrollment table”, for example, has columns for the enrollee’s name, unique identifier, address, zip code, date of birth, enrollment date, etc. Each row in the enrollment table contains this kind of information on a particular enrollee. An “encounter table” has columns for the unique enrollee identifier, the date of the service, the type of service provided, etc., with each row containing data on an encounter between an enrollee and a provider. Using a standard query language associated with RDBMSs (i.e., the structured query language, or SQL), multiple tables can be “joined” together on an *ad-hoc*, as-needed basis. For example, joining the enrollment and encounter tables described above could answer the question “how does utilization of a particular service vary by zip code.”

In the early 1980s, about the same time that RDBMSs became the *de facto* DBMS standard, a new type of DBMS began to emerge, the object-oriented DBMS, or OODBMS. In part, this was due to the increasing popularity among software developers of object-oriented programming.

Although the terms “object” and “object-oriented” are widely used, they are often misused and misunderstood. In fact, an Internet dictionary of technical terms, Webopedia, starts its definition of object-oriented with the statement “[a] popular buzzword that can mean different things depending on how it is being used.” A standard definition of an object—a self-contained entity that consists of both data (referred to as properties) and procedures to manipulate the data (referred to as methods)—is not very instructive, however. Instead, think of a telephone—it has properties such as its physical characteristics (e.g., shape, size, color) and its status (e.g., on hook or off hook). The telephone also does certain things, like dial a number. A computer-based object, then, has characteristics (i.e., properties or data) and “does things.”

Among the nice features of (computer-based) objects is that they can be reused and combined with other objects to make more complex objects. If a developer needs to build an application that can dial a list of phone numbers stored in a database, wait for a person to answer the phone, and then play a pre-recorded message, the developer can simply buy a telephony object from a vendor and insert the object into the application. Thus, object-oriented programming focuses on objects and manipulating objects, as opposed to traditional (procedural) programming which focuses on logic—reading input data, processing the data, and producing the output.

Just as object-oriented programming focuses on objects, OODBMSs focus on objects. In fact, the term “object-oriented *database* management system” is a misnomer—it should be called an “*object*base management system,” since OODBMSs store, manipulate, and retrieve objects, rather than data. Thus, rather than just storing passive entities (i.e., data doesn’t inherently “do” anything) OODBMSs store active entities (i.e., objects “do things”).

The value of objects and OODBMSs started to become apparent to RDBMS vendors in the early 1990s. Around that time, multimedia computing was born and computers were no longer just manipulating numbers and character strings. It became clear to RDBMS vendors that they needed a way to deal with “complex data,” such as audio, video, images, and drawings. At first, these vendors simply stored these data like they stored numbers and characters, and advertised that their RDBMSs handled what they called BLOBs (Binary Large Objects). The problem was that the RDBMS did not know anything about the BLOBs—what they looked like or what they could do—unless the user explicitly entered data about the BLOB.

The RDBMS vendors’ solution to this problem was to develop a new database that tried to be both relational and object-oriented—a hybrid system that is sometimes referred to as an object-relational DBMS or a universal database. This brought some capabilities for handling objects and complex data, although, being a hybrid approach, the object-relational DBMS did not have the same object capabilities as the OODBMS.

However, even with the increasing importance of the Web, which heavily uses audio, video, and other complex data types, and the fact that object-oriented programming is used by the vast majority of professional software developers, the OODBMS market is still relatively small—annual sales of OODBMSs are around \$200 million, compared to over \$7 billion for RDBMSs. In large part this is because, in spite of the Web, the vast majority of information in databases, particularly large

corporate databases, is still just numbers and character strings, for which the RDBMSs were designed and built.

In determining which type of database is best for *Decision Support 2000+*, or for the entities that participate in it, it is critical to keep in mind that the primary objective is always to provide efficient access to information. If the information to be accessed is entirely numbers and character strings, as is the case with most mental health data, an RDBMS will provide faster and easier access to the information than an OODBMS. If the information is primarily video, audio, images, and other complex data, particularly if these objects need to be manipulated through virtual reality or other techniques, then an OODBMS is a better choice. If the information is primarily character strings and numbers, but includes some of the more complex data types, the hybrid object-relational DBMS may be the most appropriate choice.

Discussion

The overall technology approach ultimately selected for *Decision Support 2000+*—be it one based on some degree of centralization or complete decentralization or some combination approach—must be judged by how it impacts the various stakeholders, including the central data authority, data contributors, users, and consumers.

The central data authority will be responsible for building and maintaining the system infrastructure. This includes a telecommunications system for processing queries and data transfers, which could utilize a new private wide area network or the existing public network (i.e., the Internet), possibly in combination with a virtual private network to allow for greater security. The central data authority should also oversee development of query, reporting, and data mining tools to allow users to effectively use the data. Finally, if the data are to be centralized to any degree, the central data authority will be responsible for building, operating, and maintaining the central repository. All of these varying options imply different levels of effort and costs, including one-time expenses and on-going annual expenses.

For public and private organizations that will contribute data to the system, the technology options also require varying levels of effort, start up costs, and on-going costs. For an entity that already has centralized, comprehensive mental health data, the level of effort required to participate *Decision Support 2000+* may not be overwhelming—in the case of the centralized system, the organization need merely build a series of data extract programs to gather the required data, while for a virtual database oriented system the organization may need only to develop systems that accept a query (presumably already tailored to the organization's systems) from the central query processor.

Users—including mental health providers, researchers, and consumers—are perhaps more concerned with issues such as the implementation time frame, ease of use, data quality, analytic capabilities, and system response time. Users would obviously prefer a minimum number of hardware and software requirements for accessing the system and running queries, and thus would probably prefer access via a Web browser. Users must also be shielded from all the underlying complexity of the database(s). A wide array of query and data mining tools must be made available, including tools for the inexperienced (e.g., a series of canned reports) and experienced user (e.g., a flexible report writing system). Privacy and security is also a critical issue, particularly for consumers.

Finally, all stakeholders are concerned with perhaps the most fundamental issue—is the information system technologically feasible, will it work? In this regard, there is little doubt that the central repository approach is technologically feasible. National data repositories have existed for decades and many private and public mental health entities are experienced at producing and manipulating data extracts. On the other hand, the central repository obviously depends on the on-going cooperation of the data contributors and the ability of the central data authority to meet their needs. Furthermore, the idea of “another, big massive central database” also seems at odds with the new emphasis, due in large part to the increasing importance of the Internet, on decentralization and interoperability.

A reasonable question is “If the data are already stored in databases and we have sophisticated networking and telecommunications systems, why bother to move the data to a new location?” Still, virtual databases and wide-scale interoperability are relatively new, perhaps not well tested concepts, and, compared to the central repository approach, are more technically challenging to implement. This approach also appears to require more on-going system development—as new data contributors join the virtual database, the central query engine that manages queries and translates them into languages that the various local databases understand must be updated to include procedures on how to translate a general query (e.g., service utilization by type and zip code) into a language and format that the new contributor’s database can understand.

At this point, it appears that a centralized approach to *Decision Support 2000+* could probably be implemented faster and have greater analytic capabilities than the virtual database approach. On the other hand, the virtual database approach would no doubt result in better data quality, particularly data timeliness (since, in theory, once the data were entered in the organization’s database, they would be immediately available to users of the integrated system), and offer better data security. All the relevant impact measures—costs, data quality, privacy, analytic capabilities, implementation time frame—require further examination.

While these impact measures are being studied, two additional steps should be taken. First, data integration attempts in other industries, such as the banking industry, should be carefully examined, so as to benefit from both their successes and failures. The experiences of criminal justice agencies also might be of interest, in that they are pursuing both centralized data collection (via the FBI’s National Incident Based Reporting System) and interoperability (via county and state-wide integrated criminal justice information systems). Second, policymakers and researchers should encourage data consolidation at the local and state levels. The more data are consolidated at these levels the easier it will be for these organizations to either contribute data to a central repository or make their data accessible to a virtual database.