



MOVING MHSIP TOWARD A PERSON-CENTERED PARADIGM

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INTRODUCTION

MHSIP has evolved along with the mental health service delivery system, progressively broadening its scope as the locus of care has been decentralized. The MHSIP best-practice guidelines for data standards and information system design already have had a significant influence on information systems in the public mental health specialty sector. Yet the present guidelines risk becoming obsolete in the face of continuing evolution in the service system.

The range and scope of decisions that need to be supported within the mental health service system are changing as a result of both structural and attitudinal trends. Relevant structural changes include the continuing decentralization in the locus of care, increased reliance on services outside the specialty mental health sector, and potentially major structural changes in the financing and organization of service delivery (e.g., managed care and the inclusion of mental health within health care reform) (Schulberg and Manderscheid, in NIMH, 1989b). These structural changes are occurring within the context of broader societal trends related to decision-making: a broadened concept of public accountability (Ziglin, 1991); widespread popularity of "customer-driven" approaches to management, in general (Osborne and Gaebler, 1992), and in mental health (Rago and Reid, 1991); and recognition of the legitimacy and value of having persons actively participate in making decisions related to their well-being, demonstrated in general health care settings (Emanuel and Emanuel, 1992; Davies and Ware, 1988); and, particularly, by the blossoming of a vibrant mental health consumer empowerment movement (Bevilacqua, 1993; Scott, 1993; Consumer/Survivor Mental Health Research and Policy Work Group, 1992).

In the context of these changes, the MHSIP faces the question of whether and how to reorient its best-practice data guidelines. This paper attempts to inform the decision process by discussing issues related to shifting MHSIP's focus from persons *served within* individual specialty mental health *organizations* toward *persons with significant needs* for mental health services and supports, *regardless of* the number or type of *organizations* that may or may not serve them. Such a person-centered approach to decision support systems, driven by the needs of the person to be served in addition to the needs of the organizations that fund and provide services, would support the most effective investment of the limited service system

resource portfolio (Hogan and Essoic, 1991).

The Advisory Group's May 1992 paper on MHSIP's "Current Status and Directions for the Future" makes the case for three-pronged development of the MHSIP program in order to meet the need for a "person-based orientation." It suggests that the MHSIP:

- (1) "...systematically expand the scope and coverage of mental health organizations that are involved in...the program";
- (2)reinforce decision support especially at the system or auxiliary level.; and
- (3)highlight the person as the crucial level for data integration, and the managed system as the crucial level for data analysis.. (pp 22-24)

Development of a truly *person-centered* approach to MHSIP will indeed require adopting each of these suggestions. But achieving this vision will also require the MHSIP to broaden its conception of the mental health information system stakeholders to include potential and actual recipients of mental health services. Program evaluators have long recognized the need to include program service recipients as key constituents in having evaluation results used successfully (Mowbray, 1992; Mark and Shotland, 1985). Information systems developers, too, have emphasized the importance of recognizing multiple stakeholders' needs (Newcomer and Caudle, 1991). And both medical and mental health services researchers have shown the feasibility and benefits of providing patients and clients with the information they need to make an informed choice about their treatment (Bronson et al, 1978; Cassidy, 1992; Davies and Ware, 1988; Deber, in press; Kasper et al, 1992).

For the purpose of this discussion of the person-centered information system, key stakeholder groups to be discussed include:

- mental health service consumers (present and potential)
- individual service providers performing case management functions
- mental health program managers
- policy makers and researchers
- advocates and citizens
- third-party payers

STAKEHOLDERS' DECISION SUPPORT NEEDS

Existing MHSIP data standards, as expressed in FN-10 (NIMH, 1989a), are geared primarily toward the decision support needs of managers in mental health specialty provider organizations and auxiliary level organizations. As such, they are useful to describe and compare the characteristics, resources, clients, and services provided by mental health specialty organizations. The standards include an implied assumption that clinical data are already sufficiently available to clinicians elsewhere (see Task Force on Enhancing MHSIP to Meet the Needs of Children, 1992). The FN-10 standards are clearly not designed to support decisions made by or on behalf of *individual* mental health service consumers.

Existing guidelines are person-based to the extent that they specify use of a unique client identifier which can relate data about a person's characteristics and service utilization over time within an organization. Yet, as described in the following sections, many of the key decisions stakeholders need to make cannot be sufficiently supported with the data available through the existing guidelines. This suggests that MHSIP's basic question needs to be reformulated to include the needs of consumers. MHSIP data should provide consumers with the information they need to make informed choices about mental health and other services that can support them in the process of recovery.

Mental Health Service Consumers

In their role as customers of the person-centered information system, potential mental health service consumers are likely to have as their basic question: "What resources are available to meet my needs, at what costs, and with what effectiveness?. (Guidera, 1993) Much of the information needed to support the multiple components of this question is available, at least theoretically, from information systems that are consistent with existing MHSIP data guidelines. Where the data exist, the issue of adequate decision support for consumers goes beyond data content, requiring consideration of how best to provide the policies, technology, and support for data access by consumers. (Family members of a person in need of mental health services and supports are likely to have similar information needs.)(Davies and Ware, 1988)

To address this question, some MHSIP data elements would need to be modified, others would need to be added. Examples of some changes related to organizational and human resources data elements may be found in Appendix A. Others might include resource *access* questions (e.g., hours of service, telephone number and contact person, any eligibility restrictions, program costs and consumer fees); *appropriateness* (e.g., services available, staff and organizational characteristics, satisfaction expressed by persons with similar characteristics); and *effectiveness* (e.g., typical outcomes for persons with similar characteristics, amount of time and other resources typically invested to achieve those outcomes).

Case Management Service Providers

Case managers (and other clinicians performing case management functions) need an information system that enables them to answer the following basic question: Given the particular circumstances (needs, resources), experiences, and preferences of this person, what can I provide and/or recommend that may help this person achieve his or her goals for a higher quality of life?

This question suggests that the system needs to provide case managers with the same sorts of "access" information about mental health and other resources that consumers would want, as well as the capacity to obtain and use data from assessments of the consumer's mental health status, as well as related needs, resources, and preferences.

Providers also need information to help them assess how well they are doing at meeting the needs of identified consumers. In addition to direct assessment of consumer satisfaction, the system needs to include repeated measures of needs, resources, and functioning to allow longitudinal comparisons for persons involved with the service system over a prolonged period.

It also needs to measure satisfaction indirectly, by identifying persons who repeatedly miss appointments or drop out after one or two visits. Although one or two contacts may suffice for some, for persons who voluntarily seek help with serious, ongoing mental health problems, it is more likely an indication that the provider is not meeting whatever needs the person hoped would be met.

Mental Health Program Managers

Program managers need the information system to allow them to answer the following basic question: Do we provide the program with the greatest "quality" to the largest number of individuals possible within our service mission (e.g., clinical and demographic policy priorities) and resources? This question is similar to what managers would in manufacturing or other service industries would ask if they were active participants in a Total Quality Management (TQM) model.

To address this question, mental health program managers will need information on outcome (i.e., do persons who participate in this program benefit from it) and satisfaction (are they satisfied with what is available and with what is provided). They will need data to help identify, among the persons using their services, unmet needs that suggest a need to establish

linkages or otherwise improve access to other community resources. They will also need community based epidemiological studies to identify whether additional persons in the community need to be encouraged to use their services, and/or whether they need to expand their choice of services provided. Additionally, mental health program managers will need information on reimbursement options to encourage their programs to be fiscally viable.

Policy-makers and Researchers

Policy makers and service system researchers need the information system to allow them to answer the following basic question: Are public resources achieving the greatest possible benefit, both for individuals with specific characteristics and for the service system? This question includes issues of *access* (i.e., Are the persons with greatest need being served? And, if not, how can acceptable services be made available to them?); *appropriateness* (e.g., Are the persons who *are* being served receiving what is most needed, when it is most needed?); and *effectiveness* (e.g., What types of service utilization patterns have the best (most effective and satisfactory) outcomes for consumers with specific characteristics? How can these outcomes be achieved in the most cost-effective manner?).

To address these questions, policy makers and researchers will need: data describing demographic characteristics, service utilization patterns, outcomes and levels of satisfaction for consumers of mental health services; fiscal data for cost-benefit analysis; and epidemiological data for individuals not receiving mental health services. They also have a great need to be able to link person-specific data across time and across organizations and service sectors.

Advocates and Citizens

Advocates and other citizens share many interests in information with consumers and policy makers. Their basic question for the information system may be: Are there changes needed in the mental health system to improve its capability to serve individuals and demographic groups in need?

To address this question, advocates will need epidemiological information, consumer satisfaction information, and outcomes data.

Third-party Payers

Public and private sector payers have become critical stakeholders in mental health information systems as service providers have come to depend on third-party reimbursement to support the bulk of their operations. Payers' data demands have become more influential than those of the government agencies whose grants used to be the largest part of providers' budgets.

Third-party payers need the information system to allow them to answer this basic question: Is our money being spent in the most efficacious way?

To address this question, third-party payers will want to identify eligibility criteria, effective programs and services for consumer subgroups, costly programs, heavy users of mental health services, and programs whose benefit-to-cost ratio is high.

Common and Conflicting Interests

The decisions to be supported by the person-centered information information system may differ dramatically among the stakeholder groups, yet much of the data needed to support those decisions is common to them. It is important to recognize other conflicting stakeholder interests, related to data content and access.

As data elements are eliminated, modified, and added to a person-centered information system, the issue of stakeholder participation in definitions is highlighted. Mark and Shotland (1985) extensive discussion of value judgments in stakeholder-based evaluation may also illuminate consideration of stakeholder roles in a person-centered information system. The selection of participating stakeholder groups may be based on desires for increasing utilization of information, accurate representation of the decision-making process, and empowerment. Each rationale involves value choices related to the stakeholder groups' perceived power and legitimacy. They suggest that there is a significant risk of "pseudoempowerment" of low-power, high-legitimacy groups (i.e., consumers) involved in processes for which there is no clearly defined structure for their effective participation. Mark and Shotland allude to another thorny issue: "Who speaks for a particular stakeholder group?" The MHSIP will need to address the representation, effective participation, and values issues in determining data priorities required by limited resources.

The stakeholders interests may also conflict with regard to access to person-specific data. Adequate support of the decisions described above will require that a greater level of detailed data about individuals be maintained in an automated information system. While the amount of sensitive information will still be significantly less than that maintained in the traditional paper clinical record, consumers and providers alike will have concerns about how access to the data will be controlled and safeguarded. This issue will be discussed further in the design implications section.

Beyond the crucial issues of data security and integrity, stakeholders' interests may conflict with regard to who should have access to how much of the data. Consumers may want complete access to information stored about themselves; providers may believe some consumer access to some portions of the record would be not useful, or even harmful. Case managers may want access to information about a broader spectrum of the consumer's life (e.g., criminal justice, education, housing, employment) than the consumer wishes to share. Program managers may want access to more information than the clinicians and case managers wish to provide. Third-party payors may want information that neither consumers nor program managers believe is necessary or appropriate. Policy-makers and researchers are likely to want more information than *anyone* wants to provide.

IMPLICATIONS FOR DESIGN

The decisions that would need to be supported by a person-centered information system suggest design requirements of two types: (1) data element content guidelines; and (2) data access and usage guidelines.

Content Guidelines

Unique Client Identifiers

The linkage of person-specific data across organizations and over time requires that a unique client identifier be standardized across service sectors, at least at the state level. The Agency for Health Care Policy and Research, in its 1991 report to Congress on the feasibility of linking research and administrative data bases, identified the lack of a standard personal identifier as "the greatest technical impediment to linking personal data files." (p. 3-2).

Ziglin (1993) has developed a rationale for use of unique client identifiers in mental health. Minsky, et al (1993) surveyed all the states to discover current and proposed use and concerns related to unique client identifiers. They then conducted a benchmark test of the various approaches. Results of their work suggest that (1) the vast majority of states are attempting to use some form of unique client identifier; and (2) no single approach (existing, assigned, or constructed identifiers) yet predominates in usage, advantages, or disadvantages. They present a useful set of arguments for and against each approach, and suggest further work to be done before any one approach could be universally recommended.

Data privacy, confidentiality, and security issues that will be highlighted by the adoption of a unique client identifier are discussed under the section on data access and usage.

Outcome Assessment

All the stakeholders share an interest in data on outcomes. Although existing MHSIP data elements can be used to construct many useful performance indicators, they will require enhancement in order to be truly useful in assessing consumer and system outcomes. Fortunately, the groundwork has been laid.

The National Plan of Research to Improve Services (NIMH, 1991) identified outcomes as a key area for development, and recommended that future outcome assessments incorporate seven principles:

- 1) multidimensionality of outcome -- suggested useful framework proposed and described by Hargreaves and Shumway (NIMH, 1989b, p. 255);
- 2) multiple perspectives - assess, compare, and blend stakeholders' perspectives;
- 3) individual utility differences -- need work to assess how individuals value certain outcomes as desirable; an individual's values are shaped by age, gender, and culture;
- 4) balance between standardization and specificity of measures and design;
- 5) longitudinal designs;
- 6) costs as an outcome measure -- must include costs to consumers, family members, and society of not receiving services, as well as the costs of the services provided;
- 7) relevance and impact--for multiple stakeholders.

Recent reviews of outcome measures in the identified rehabilitative (Cook, 1992), public welfare (LaFond, 1992), humanistic (Lehman, 1992) and clinical (McGlynn, 1992) domains suggest that although there is not yet a consensus on outcome measures, "good-enough" measures exist to allow pilot testing on a wider scale. Although individuals have specific desired outcomes, managed care and similar approaches will need to (and should) assess outcome measures that are generic enough to apply to a broad spectrum of individuals and programs. The Agency for Health Care Policy and Research (among other organizations) has begun publishing treatment guidelines for a number of conditions, including depression. Although primarily used now for education of consumers and service providers, they have also begun to be used in medical malpractice defense, and it is likely that they will begin to be used to guide reimbursement decisions.

John Wennberg's work in the 1970s to explain significant variations in surgical procedure rates led him to believe that, except for persons who are very likely to suffer increased or additional damage without a procedure, "...the 'correct' incidence of [procedures] is determined by subjective judgments of [individuals], who have to weigh the risks against potential improvement of symptoms and quality of life" (Cassidy, 1992, p. 36). Since individuals vary in their tolerance for symptoms, side effects, limitations on freedom, and other possible consequences of treatment or non-treatment decisions, an informed decision about an appropriate treatment approach needs to include a factually-based (or at least, probability-based) discussion of possible outcomes.

Wennberg and others formed the Foundation for Informed Medical Decision Making in 1989, to promote treatment decisions based more heavily on scientific outcomes research and patients' preferences for outcomes than on practitioner habit and presumption. Since consumers need both knowledge and experience to make informed decisions about treatment, the Foundation's Shared Medical Decision Making interactive videodisc program attempts to provide them with a "vicarious experience" of available treatment options. The videodisc provides information from the viewpoint of persons diagnosed with the condition who have made each treatment choice, tailored to each person's clinical situation and learning style. Already they have been found very useful and popular for use with men whose prostate conditions can be treated with either surgery, medication, or "watchful waiting" (Kasper et al, 1992; Deber, in press).

The Wennberg approach has not yet been applied in mental health, but it clearly has potential for helping consumers and family members make informed choices about treatment options. The shared decision-making process, with or without use of interactive videos, is consonant with the theories and practices of psychiatric rehabilitation. Because of the availability of data, a first application might be decisions about medical interventions with significant risks and benefits, such as use of neuroleptic medications and electroconvulsive treatments. As services research data grows, expansion of the concept to other, psychosocial, interventions would be possible. But, as Deber (in press) and Kasper et al (1992) have noted, constructing these discs is expensive and complicated; it requires prior knowledge of treatment possibilities and outcomes, and the relevant patient-related characteristics that affect optimal choice. What this means for a person-centered information system in mental health, is that significant care needs to be taken to develop the data needed to develop well-informed statements about outcomes of interventions for persons with specific characteristics. The hope is that, most importantly, "... quality of care will improve as clinical decisions are based on scientific knowledge and patient preference" (Cassidy, 1992, p. 36).

Consumer Satisfaction

Another unaddressed data domain required for a person-centered information system is that of consumer satisfaction. Satisfaction needs to be measured with respect to the specific types of service and support interventions received and, more broadly, with respect to the array of what is available to be chosen. Consumer satisfaction has been shown to be crucial to determining continued use of services (Davies and Ware, 1988).

Consumer satisfaction with both services received and the possibilities available may be assessed directly or indirectly. Direct measures involve asking consumers for their opinions; indirect measures may be constructed from data on consumer behavior (e.g., not pursuing referrals, leaving a program without mutual agreement, frequent and/or exclusive use of crisis services). The MHSIP could begin to develop measures of both types in conjunction with consumer and family groups. Another option would be to focus only on defining some indirect measures that could be constructed from other data elements, for purposes of comparison, encouraging development of direct measures at the local level.

Modifications to Promote Consumer Access Decisions

In addition to these new domains of data elements, a person-centered information system would modify existing elements to incorporate information relevant to potential consumers in choosing among resources. These would include some indicators of consumer involvement in program operation. Examples of possible modifications to existing elements and new elements are found in Appendix A.

Data Collection Strategy

Because of its use of outcome and satisfaction measures, as well as the expansion in scope of services and persons included, a person-centered information system necessarily includes a larger volume and greater level of detail of data. To maximize the quality, manageability, cost-effectiveness, and usefulness of the data for decision support, it will probably be advisable to develop a tiered approach to data collection. In the tiered approach, the volume of required data about an individual is proportional to his/her need for system supports. The volume of required data about an organization is related to the proportion of its clientele who are likely to have a mental illness diagnosis. The next sections will describe tiered approaches to both person-specific data and organization-specific data, concluding with a rationale for the tiered data approach over an approach that samples persons at every tier.

Tiered Approach to Person-Specific Data



With respect to person-specific data, the tiered approach might begin with linkage to larger-scale epidemiological surveys of the general population to provide estimates of the size of the population "at risk" of needing mental health services. Examples include the Epidemiological Catchment Area studies and the National Center for Health Statistics surveys that are planned to include more questions related to mental health (*Toward a National Health Care Survey*, 1992). This would provide a sparsely detailed epidemiological base to the data pyramid.

The next level of person-based detail would include individuals with limited contact and/or minimal needs for mental health services, including those persons who may be receiving services and supports only from nonspecialty mental health organizations. Greater scope and detail of data would be collected and maintained than for the surveyed general population, but would represent a subset of the data relevant for persons in the next tier.

The greatest level of person-based detail, particularly for data related to outcomes, would be maintained for the subset of persons who need extensive and/or prolonged mental health services and supports. This has the greatest potential for return on investment of data resources, as well as being the most feasible for data collection and security purposes.

Tiered Approach to Organizational Data

A similar pyramid describes the distinctions in the numbers and types of organizations and the scope of detail to be maintained about organizations in a tiered system:



The top of the pyramid would include all the specialty mental health organizations that already are included in the scope of the MHSIP guidelines. In addition to the current data content guidelines, the scope and content of data would reflect aggregated consumer satisfaction and outcomes data, as well as changes to incorporate the consumer access suggestions outlined above.

The middle level of the pyramid would encompass the many organizations that provide mental health services and/or supports as part of a broader mission (e.g., general hospitals, primary health care and chronic health care settings, residential programs for delinquent and/or troubled youth). The scope of data content would include a large subset of what is recommended for specialty mental health organizations, but with some limited to describing only the mental health portion of the organization.

The base of the organizational data pyramid would include a subset of the MHSIP organizational data elements, describing the characteristics of the numerous programs in a community that provide non-mental health services that are likely to be particularly useful to persons diagnosed with a serious mental illness. These programs might include general health and dental care providers, affordable housing, legal and advocacy services, employment and income maintenance resources, educational, social, and recreational opportunities. Data content would be designed to inform consumers and case managers interested in accessing these important other types of resources. Data could be as narrow in scope as each program's category, name, address, phone, or as broad as a description of services, eligibility requirements, directions, hours, and any available outcome and satisfaction data (from the program itself or from surveys of persons with a mental illness diagnosis who have been referred to or used them).

Why not just sample?

It may be argued that one way to compensate for the increased data requirements concerning an individual is to collect data on only a sample of persons in each tier. Detailed data on a sample of the population of interest is indeed likely to be sufficient for many questions of concern. Thus, the epidemiological data base of the pyramid is derived from sample surveys of the general population. A sample of persons in treatment would also be sufficient for many of the other questions raised by policy makers, researchers, and third-party payors. Yet, unlike the data needed to answer a pre-determined research or policy question for a stakeholder, the multiple stakeholders identified for an ongoing person centered information system will have a multitude of questions from their perspectives, questions that cannot all be identified in advance. This does *not* mean that the PCJS should attempt to include data to answer every conceivable question; rather, it means that it is difficult to formulate a reasonable sampling strategy when the research question has not been specified (S. Banks, personal communication).

For most analysts at the service system level, it may be sufficient to identify broad trends related to needs, utilization, outcomes, and satisfaction. But individual consumers and their families, advocates, program managers, and service providers functioning in a case management role will want to know about the performance of individual programs in relation to persons with specific characteristics. Few programs designed for persons with significant needs for mental health services and supports are large enough that a sampling approach would begin to describe them adequately. Enumeration of both the persons in this group and the programs designed to serve them (i.e., the tops of both data pyramids) will be needed. Enumeration will also provide a reasonable basis for drawing samples for more detailed research.

Data Access and Usage

Linkage of personally identifiable data across organizations and time requires development of technical capabilities within and across organizations and service sectors. Existing innovative technologies for records management include voice recognition, digital dication and transcription, chart deficiency tracking, optical disk-based document storage and retrieval systems, and facsimile networks (Walker, 1992). Ellwood (1988) has described the exciting decision support opportunities made possible by powerful integrated database capacity.

The sorts of linkage envisioned for a person-centered information system in mental health also requires serious consideration of the controls needed to balance the individual's rights with those of society, as represented by other stakeholders. With deepened detail and potentially broadened access to data come heightened concerns for the privacy, confidentiality, and security of the data in the system. *Privacy* has been defined as "an individual's right to control the use of facts about his life and his willingness to share data concerning himself"; *confidentiality* as "the organization's administrative handling and its policies and rules for disclosure of personal information"; and *security* as "the specific procedural and technical means to provide the desired degree of confidentiality" of the data in the system (Cotter, 1981, p.59). The Agency for Health Care Policy and Research (1991) has reviewed many of the policy considerations and federal and state legal requirements and protections related to linkage of research and administrative databases that contain personally-identifiable data.

While all stakeholders have responsibilities and concerns related to system integrity, consumers clearly have the greatest reasons to be concerned. After all, the personally-identifiable information in the system has great potential for harm if misused. Yet, when concerns have been expressed, the loudest voices are often those of service providers. In their nationwide survey of state mental health authorities' use of unique client identifiers, Minsky et al. (1993) found that service providers were a source of resistance to the use of unique identifiers in nine of the ten states that reported any type of resistance. Six states reported resistance from consumers, five from staff and one from advocates and/or family members.

Kelly (1992) reports on the implementation of the Nassau (County, New York) Service Coordination Network (NSCN), funded by the MHSIP program. Development of this automated, county-wide system for sharing client and service information within and between agencies was spurred by a desire to improve quality and continuity of care for persons who need and use emergency services in the county. The NSCN offers a model of a system that is flexible enough to accommodate multiple agencies having differing internal reporting requirements,

varied levels of skill and comfort with technology, at the same time providing extensive safeguards for privacy, confidentiality, and security. A client waiver system determines the amount of information that is available to users outside that agency. During implementation, the county found that although many *service providers* challenged their participation, citing client confidentiality issues, very few *clients* expressed problem with it. Anecdotal reports suggest that persons who needed emergency services were particularly likely to appreciate crisis workers having access to information about any medication alerts or allergies and information about how to contact someone else who might be familiar with their experiences and resources during times of crisis. Despite its strengths in the area of interorganizational data sharing and provisions for privacy, confidentiality, and security of data, the NSCN lacks several of the criteria that would qualify it as truly personcentered; inclusion of data on satisfaction and outcomes, data on service needs and utilization outside the specialty mental health sector, and any provision for consumer access to data.

The New York State Target Cities System (TCS) provides another example of inter-organizational data networking for the benefit of consumers. As part of the Target Cities initiative of improving substance abuse services to high-risk populations in New York City, TCS was designed a tool for intake counselors to use in making appropriate matches between the individual needs of a client and specific services available in the community, while tracking and evaluating client progress and program effectiveness. A set of integrated modules provide an online, simplified, efficient system through which information is gathered during the intake, case management, referral, and placement processes. Although the TCS now includes only intake centers, case managers, and substance abuse services providers within the Target Cities initiative, there are plans to increase its scope to include mental health and other types of services their clients are likely to need (personal communication with Dorine Fuller, NYS OASAS, May and June, 1993).

Beyond enhancements and refinements in the scope of data, persons, and organizations included in the information system, a person-centered information system will be distinguished by the potential service recipient's access to data to be used in making decisions about their own use of resources to aid in their recovery. Effective access to data will require: education about the availability of data and how, where, and when to access it; interactive software to allow matching of the individual to other persons with similar characteristics for the purpose of assessing the probabilities of certain outcomes and of satisfaction; and access to hardware. Several examples outside the mental health field illustrate the possibilities.

The "Shared Medical Decision-Making Program" introduced earlier represents an exciting and innovative approach to using technology to help consumers become well-informed participants in the medical decision-making process. Persons diagnosed with certain conditions for which there is more than one reasonable treatment approach (this would apply to much of mental health) interact with a video that has been customized to their circumstances (e.g., diagnosis, age, gender, symptoms, level of functioning, co-morbidities). It describes possible treatment approaches, interviews persons in similar circumstances who have experienced those approaches, provides the statistical likelihood of various outcomes for a person with the patient's characteristics, and offers opportunities for more detailed information. Experience so far shows that persons who use the video to prepare for a discussion of their options are more likely to choose conservative approaches, with no ill effects (Kasper, Mulley and Wennberg, 1992; Cassidy, 1992; Deber, in press).

CONCLUSION

The MHSIP guidelines will never be a completed product, nor should they be. During its history, the MHSIP has shown itself to be adaptable to the evolving mental health service system. FN-10 represents a strong effort to identify the audience for MHSIP data, and to codify the questions that need to be answered. But it was designed within the constraints of being a voluntary, cooperative effort among government mental health authorities and the specialty service providers associated with them. The "system" of services and supports available for persons diagnosed with a serious mental illness has grown far beyond that context. An increasing proportion of such services and supports are now provided in other, non-specialized settings (such as generic health care, social service, housing and vocational settings) and by consumer-run programs. Because these providers may have only informal or tenuous connections to government mental health authorities and face their own constraints, they have not been easily incited in the MHSIP purview.

Another significant development has been the growth and legitimacy of consumer empowerment movement and quality-through-participation techniques that rely heavily on data to

promote informed participation in decision making for a broader spectrum of stakeholders than previously recognized.

These developments in the structure and culture suggest that the MHSIP's next natural evolutionary step is to develop a person-centered orientation. This would include accountability to a broader range of stakeholders' decision support needs; adding a focus on consumer preferences and satisfaction; emphasizing consumer outcomes over time, rather than only the proximal outcome of an intervention; increasing the range of organizations included; promoting use of technology to enable appropriate linkage of person-specific data across time and settings, with sufficient provisions for privacy, confidentiality, and security of the data; and providing means and opportunities for access and effective use of data by consumers, family members, advocates, and other nontraditional stakeholders of the information system.

Increasing the scope and accessibility of data will not occur without significant investment of time, effort, and money; all of these investments are justifiable. Persons in need of mental health services and supports are the primary customer of the service system. It is in everyone's interest for the needs of *all* stakeholders to be considered in the design and use of data. Continuing constraints on resources for services demand greater accountability for the cost-effectiveness of services. The technology needed to manage and distribute the data securely in such a system already exists. Even though it may not be widely available yet, technological dissemination needs to be planned for and supported.

The MHSIP has a responsibility to continue to develop guidelines that can serve to define *best practice* with regard to mental health data, rather than to recommend guidelines based on the *least common denominator* of current system capacity. Even without definitive and universally accepted guidelines for many of proposed additions to the MHSIP guidelines, researchers in both mental and general health services have established an adequate basis for MHSIP to justify adopting some preliminary outcome and satisfaction data guidelines.

RECOMMENDATIONS

The purpose this paper was to raise and discuss issues related to adoption of a person-centered orientation for the MHSIP, rather than to outline steps for implementation of such a system. The following recommendations suggest broad tasks that need to be considered by the Advisory Group:

For data standards

- Modifications to existing MHSIP data sets and elements for mental health organizations
 - Work toward establishing common unique client identifier across other service sectors and geographic sectors within mental health.
 - Separate the current "Patient/Client" minimum data set into three sections: demographic; (2) service history (A/D/T); (3) functional status and outcomes.
 - (1) Work on inclusion of outcome measures -- need some well-tested and accepted in other sectors (e.g., HIE health outcome measures) for universal use, and support development and eventual implementation of consumer-defined measures which may be implemented more locally.
 - Work on development of satisfaction measures.
- Establishment of standards for non-mental health organizations
 - Decide on priorities for types of data elements
 - Assess compatibility of their existing data requirements with what is planned for MHSIP
- For data access, usage, and cross-service sector integration
 - Continue to develop linkages with larger-scale epidemiological projects (e.g., NCHS, Children's ECA).
 - Work on improving technological capacity of service system.
 - Work on educating all stakeholders about uses of and access to the redefined MHSIP.

- Decide on possible tiered approach -- data-collection focus proportional to consumer needs for service system supports.

Appendix A

Possible modifications to existing elements include:

- Organization element #6 (Type of ownership/control) to include "Consumer group" as a specified category
- Organization element #9 (Type of organization) to include "Self-help" or "Mutual-help" as a specified category
- Human Resources element #9 (Discipline/training/profession) - to include a category akin to TMpeer specialist" to reflect persons whose experience as a consumer of services provided a significant qualification for their job;

New elements could be added to reflect:

- Presence or Absence of a consumer advocate or ombudsperson; Consumer involvement in
 - Organizational Leadership:
 - entire board are consumers
 - majority of board are consumers
 - majority of board are not consumers no board members are consumers
 - Program Staffing:
 - majority of staff are also consumers
 - some staff are also consumers
 - no staff are also consumers

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