



## HUMANIZING DECISION SUPPORT SYSTEMS\*

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## INTRODUCTION

The mental health service delivery system is facing unprecedented challenges in this current period of fiscal crisis and system change. The Chinese ideogram for crisis suggests this situation presents the twin possibilities of opportunity and catastrophe. Unlike the Chinese ideogram, efforts to humanize this system offer the twin positive possibilities of opportunity and collaboration. These possibilities can only be realized through a commitment to all stakeholders involved in the management of mental health information systems to dialogue about values and goals and to bring this collaborative knowledge and skill into all areas where quality in mental health services is ensured and policy decisions are made. Most critical to the success would be the dedication of all stakeholders to make the mental health system responsive, effective and egalitarian. Fluid and continuing system reform can only be guaranteed when all stakeholders work together as equals and consumer participation is fully supported as the primary value.

- The SAMHSA Strategic Plan (March, 1993) sees such an empowerment agenda as the way to achieve a "better, healthier America for all its citizens." The document states the following: . . . mental illnesses may be most effectively reduced when consumers of prevention and treatment services, their families, and their neighbors share in making decisions about services they receive and the community they live in."

The recognition of human values in a decision support information system is the key that opens the door to real information about where we are, what we are doing, and if what we are doing is really working. This understanding has long been realized within the consumer movement. Over a year ago, with the support of the Mental Health Statistics Improvement Program (MHSIP), consumers began to explore how to define and measure meaningful service outcomes. After two focus groups they identified a considerable number of positive and negative outcomes, many of which had never been articulated (C/S Research and Policy Work Group, 1993). Dr. Jean Campbell, Director of the Office of Research, Quality Assurance and Information Services for Maine's Department of Mental Health and Mental Retardation, and Dr. Jeanne Dumont, co-chair of the Research and Policy Work Group Outcomes Task Force, have since drafted and presented to MHSIP in December, 1992, a research design and protocol to refine and expand this original work by going to the field and working with diverse populations. The method they chose was concept mapping because it is participatory in nature and had been uniquely adapted to answer such questions by Jeanne Dumont in her doctoral research.

A related consumer project recently piloted concept mapping as a means to provide input into the NASMHPD State Mental Health Profiling System and to develop consumer defined service outcome domains. The work products include a report of the concept mapping results, an assessment of concept mapping for developing consumer measures and a recommended consumer component for the Profiling System (Trochim, Dumont and Campbell, 1993). This preliminary effort is invaluable in understanding the importance of the

existential context of individuals: the "map" generated by the group is a landscape of experience and identity of people diagnosed with mental illness. The domains include:

- . . . identity
- . . . self actualization/personal sovereignty
- . . . damaging effects of the system
- . . . inner process of healing
- . . . quality of life
- . . . alternatives to the system
- . . . citizenship
- . . . legal system issues
- . . . consumer impact on service delivery
- . . . consumer impact on system development
- . . . degree of voluntariness & control over treatment
- . . . autonomy versus coercion.

A review of the MHSIP Current Status and Directions for the Future (May, 1992) provides the opportunity to critically examine MHSIP's vision of a decision support system. Some of the questions raised by a review of this document are:

- 1) What are the political factors that influence data collection, standards and uses?
- 2) What is the responsibility to ensure confidentiality, informed consent and prevent collection burden?
- 3) How can we obtain data that reflects the role of self-help, support and advocacy groups?
- 4) What can be learned from people who don't use mental health services?
- 5) How can the process of healing and recovery be captured in the bits and pieces of information electronically strung out across the mental health system?
- 6) And most importantly, how can a decision support system that is truly responsive to the information needs of all citizens be created?

The thrust of these questions leads to an exploration of the nature of a truly voluntary information system that embraces human subjects protection for data collection and its uses.

The following concept paper, prepared for the Center for Mental Health Services, provides some background on and insight into the growing consumer/survivor movement, and offers the vision of an architecture of decision support that is person-driven. It promises to challenge thinking about what decision support really means and advances the argument that health care reform ought to and can enhance individual choice, power and knowledge.

IN PURSUIT OF WELLNESS

There is increasing evidence that persons who experience mental illness and the people who try to help them often see the world from very different perspectives. Ridgeway (1988) has provided a recent review. Wide differences between consumers and professionals have been found for the relative importance of various treatment goals (Dimsdale et al., 1979), problems (Mitchell et al., 1983), barriers to service (Lynch and Kruzich, 1986), and residential needs (Ridgeway and Caning, 1987; Goldberg, et al., 1988). In an unpublished study of community support needs in Maine, Harvey et al., (1984) found that over half of the clients wanted to live in their own home or apartment, while only 12% of the clinicians would recommend this for the same clients.

Even though self-determination is a basic tenet of rehabilitation and social work practice (Anthony et al., 1983; Meenaghan and Mascare, 1971), consumer perspectives are often ignored in the development of programs, service systems, and individual service plans. Many basic attitudes, processes, and prejudices contribute to this situation. For example, mentally ill persons are stigmatized not only by society, but sometimes also through labeling by the very system that is trying to help them (Goffman, 1961). This serves to dehumanize the person; to make a presumption of incompetence that invalidates sense of self. Mental Health professionals believe that they are the keepers of special knowledge or frame problems in their own conceptual scheme or treatment approach, sometimes ignoring the perception or framework of the person they are trying to help (Kopolow, 1979). System planners and managers may also assume that they know what is best, or respond to their own constituencies instead of listening to consumers.

Historically, changes in and "improvements" to health services in general have been based on the opinions and studies of professionals in the field. While opinions may have been influenced by research that examined clients, they are, nonetheless, the professionals' own opinions. John McKnight writes in "Regenerating Community" that "Each of us has a map of the social world in our mind, and the way we act, our plans and opinions are the result of that map." (1987). Health professionals share common assumptions that "the expert knows best" about the operating principles of the service delivery system: (1) they know the scientifically correct way to deliver services: (2) they know the values and preferences of their clients: (3) they are disinterested and objective without preferences and biases of their own; (4) they choose for their clients what the client would choose for themselves if they had the same knowledge (Silberman, 1993).

From the perspective of the professional, diagnosis refers to pathology, a process abstracted from the person and his/her suffering. To an individual, the diagnosis of mental illness becomes an assault on identity and sense of self with concomitant erosion of autonomy and control. It is an existential process. People judge the quality of and appropriateness of services by their impact on the quality of their lives (Campbell and Schraiber, 1989; Trochim, Dumont, and Campbell, 1993) while professionals monitor functionality, recidivism, and symptom control. This fundamental difference in cognitive maps compromises the process of communication between individuals. Kay Toombs reports, "this inability to communicate does not result from inattentiveness or insensitivity but from a fundamental disagreement about the nature of illness. Rather than representing a shared reality between us, illness represents two quite different realities, the meaning of one being significantly...different from the meaning of the other" (1987).

Since information about what a person thinks and feels has been considered soft or subjective science, objective data has led the development of knowledge and practice in mental health. By making this distinction, professionals have ignored the personhood or humanity of individuals and all the factors that differentiate them from symptoms, brains, or molecules.

#### Personhood: A Humanistic Philosophy for Decision Support

"I prefer not to be labeled. Labels make me feel like I will never get well, like I'm not a human being, like I'm not a person. But I don't hold with that in my thoughts. I just feel I'm a well-being person and I'm going to speak up and say that I'm a human being and I'm to be treated like a human being. Like everybody else, I'm a person like everybody else."

testimony of Barbara F. Mickens

(Campbell and Schraiber, 1989, p.48)

Validation of one's personhood is essential for well-being. The recognition of common humanity and acceptance of individual difference enables people to survive the stress and uncertainty of modern life with dignity and joy. Nowhere is the importance of personhood as a philosophical and operational principle of social organization more appropriate than in the field of mental health. Mental health is essentially the formation of an acceptable identity-acceptable to oneself and others. It is therefore ironic that the extent to which a sense of self is derived from social context is seldom recognized in the planning, delivery, and evaluation of mental health services.

Traditional mental health systems are based on a medical model, emphasizing illness rather than wellness, patienthood rather than personhood. It is common practice to call people by their diagnosis or simply label them as "mentally ill". However, a diagnosis of mental illness permeates all aspects of a person's life. It captures the ideological, material, and emotional resources people have to give meaning and to act in everyday and political life by stripping away the objective power and will to power of people as they encounter the social world and participate in the reproduction of daily life. Personhood is subsumed by a global sentence of illness and disability even though people are never constantly, nor in all aspects, and not for all time "out of their minds". It is presumed that people with a psychiatric diagnosis do not know what is in their own best interests. Feelings of anger and joy are scrutinized for signs of pathology and violence. Needs and desires are imputed as if consumers were mute. They are routinely consigned to everyday lives emptied of quality, vitality, and dignity. Many ex-patients are angry at treatment they have received or witnessed in the mental health system (Chamberlin, 1988).

Significantly, in a survey of mental health consumers in California to determine what factors promote or deter well-being, the Well-Being Project found that invalidation of insight, failure to provide treatment information, and lack of respect by mental health professionals and agency personnel towards the people who received mental health services had the greatest effect on their well-being when compared with other variables such as poverty, loneliness, employment, health and safety. Conversely, consumers reported that the quality of their lives improved when they were treated as people first and provided with the necessary information to make knowledgeable judgements about their lives (Campbell and Schraiber, 1989). The tendency to discount and ignore consumer's dissatisfaction with the mental health system is particularly salient in research and data collection. For example, researchers have lacked the insight to ask questions that capture detrimental or iatrogenic effects of services and institutionalization. Further, in a review of quality of life instruments no measures of coercion or personal freedom were found, even though liberty represents a deep-seated cultural value (Campbell, 1993).

#### From TQM to Person-Driven Decision Support

Structural changes are presently occurring in the development, organization, and management of information Systems in health care to accommodate a person-driven perspective. These changes appear to be a response to a broader humanistic societal trend related to the definition and production of knowledge and the democratization of decision-support. As identified by Susan Buckley in her paper "Moving MHSIP Toward a Person-driven Paradigm" (1993), indicators of this emerging humanistic paradigm include:

"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)."

Further, the Picker-Commonwealth survey found that Americans are eager to use survey data to help them decide where to seek medical and hospital care (Cleary et al., 1991) and to play an active role in decisions about the health care delivery system in general, and in their own treatment choices.

In the confluence of forces creating the climate for a paradigm shift to person-driven information systems, one important development has been leadership from business, human service systems and state legislatures to implement Total Quality Management (TQM) procedures to capture customer focus and customer satisfaction through answering such questions as who are the customers, what do customers prefer, what do customers need, are customers satisfied with processes, and what are customer outcomes?.

Faced with the need to regain the ability to compete in world-wide service and manufacturing markets, American business is in the process of reframing its conceptualization of how to achieve quality. Lead by such thinkers as Deming (1982; 1986). Crosby (1984; 1989), and Juran (1988; 1989), traditional thinking about quality has been transformed to a focus on customer satisfaction. The table below contrasts some principles of traditional Quality Assurance (QA) with principles from TQM.

TQM	QA
1. Consumer/customer centered	Management centered
2. Quality definition	Quality intangible
3. Process focus	Product focus
4. Preventive	Reactive
5. Error-free attitude	Acceptable quality level
6. Management by fact	Management by intuition
7. Consumer and employee empowerment	Consumer and employee control
8. Total organization	Quality department
9. Continuous improvement	Status quo
10. Supplier/provider partnerships	We-they relationships
11. Team	Individual
12. Flexible/flat	Rigid/hierarchical
13. Sampling, customer and community surveys, focus groups concept mapping, longitudinal follow-up	Client identification, client tracking, vertically integrated information, mass inspection
14. Consumers define quality:	Management defines quality; quality is provided

determines if measures developed to determine if consumer requirements are met

The basic essence of TQM involves empowering the entire system to improve the quality of goods and services continuously in order to satisfy the customer. In business, high performance organizations seek not only to meet customer expectations, they go the extra mile to try to delight their customers. They develop a strategic plan to find out what customers want by involving and asking them. Only customers know, and their expectations and needs are likely to change over time. Therefore, the organization's information gathering needs and activities involve a wide range of methodologically conservative methods for acquiring customer feedback so that the product can be redesigned. These include customer surveys, focus groups, consumer councils, complaint tracking systems, and test marketing (Osborne and Graebler, 1992). The organization adopts a service orientation as the primary means of achieving their mission. There is no effort to develop vertically-integrated information Systems to identify individuals. This would be too expensive and is oriented toward management versus consumer needs. It is like using mass inspection rather than sampling to monitor quality in manufacturing.

There are significant differences between service and manufacturing organizations (Deming, 1986). An important difference is that the worker in manufacturing not only has a job, he or she can point to an end product and has an immediate sense of quality. The worker providing services may not be aware that the product IS both the service and the process of providing it. Another difference is that in most service industries, especially those that are government-sponsored, there is a captive market with very little consumer choice. Despite these differences, the principles and methods for quality improvement are the same for human services as for manufacturing. These principles and practices are being applied in a wide variety of health care and government organizations (Berwick et al., 1991; JCAH, 1991). The principles can be summarized as follows:

- 1) top leadership must 'walk and talk' the principles and work to create a quality culture,
- 2) strategic planning must occur for both short and long-term goals,
- 3) the focus must be on consumer needs and expectations,
- 4) processes, rather than people, must be improved.
- 5) adequate training resources must be provided,
- 6) data and statistical sampling tools must be used, as opposed to mass inspection, and
- 7) teamwork must be actively fostered.

#### Coming to Voice

The rapid development of the mental health consumer/survivor movement in the past ten years has enabled people to speak for themselves about their needs, the damages of involuntary treatments, the vital importance of making informed choices, and the empowering process of taking responsibility for their own treatment. A growing number of professionals and

policymakers have responded to demands for change and reform in the mental health system by redesigning professional roles and creating opportunities for people who receive services to provide input and perspective (Blanch et. al, 1993).

In 1969 the National Association of State Mental Health Program Directors (NASMHPD) approved a position paper that "recognizes that former mental patients/mental health consumers have a unique contribution to make to the improvement of the quality of mental services in many areas of the service delivery system" The paper goes on to recommend that consumer contribution should be valued and sought in areas of program development, policy formation, program evaluation, quality assurance, systems designs, education of mental health service providers, and the provision of direct services. The growth and acceptance of mental health professional and consumer partnerships in research, services, and public policy shows clearly the potential for change when people work together in relationships of mutuality and respect.

Research has accepted the practical value of including consumers when evaluating psychiatric services (Davies and Ware, 1988; Distefano et. a, 1981; Feddolino, Fleishman, and Moxley, 1987; Giordano, 1977; Justice and McBee, 1978; Landsberg, 1973; Lebow, 1982; Prager and Tanaka, 1980; Windle and Paschall. 1981). However, these efforts are not comprehensive and do not provide for comprehensive participation of persons diagnosed with mental illness at all key stages of the research and data collection process.

In its 1992 amendments reauthorizing the Rehabilitation Act of 1973, Congress indicated a strong desire for the beneficiaries and constituencies of the National Institute on Disability and Rehabilitation Research (NIDRR) to participate meaningfully in the research and implementation process. An initiative entitled Constituency-Oriented Research and Dissemination (CORD) was undertaken to draft a policy statement for the agency that would insure that constituencies would actively participate in identifying research needs, setting priorities, RFP development, the application preparation process, peer review, making awards, conducting projects, dissemination and utilization of results, and conducting evaluations. This is a blueprint for generating research inputs in a person-driven information system. It promotes the opportunity for each individual to share and utilize his/her unique skills and background so that common objectives could be defined and achieved in partnership with people with disabilities (Fenton, 1993).

Out of personal anger and the struggle to heal, individuals have fought to redress perceived injustices in the delivery of mental health services by organizing advocacy groups, building a self-help movement and participating in research and evaluation of traditional mental health services. The growth of the mental health consumer movement is perhaps the most important factor in the drive from service-driven to a person-driven information system. Offices of Consumer Affairs in state mental health agencies, model consumer case-management programs, state-wide consumer conferences, consumer-directed social centers across the nation, and the proliferation of consumer research efforts indicate the momentum of consumer/survivor movement. More consumers are now speaking for themselves about their needs, are making more informed choices, and are more empowered to take responsibility for their own treatment and care. Consumers now are gaining access to all levels of the system in the areas of program development, policy formation, service provision, training, research, and public policy. They have lead the effort to determine consumer housing preferences (Tanzman, 1988), to define outcome measures (Campbell & Schriber, 1989, Trochim, Dumont and Campbell, 1993) and to develop professional/consumer research partnerships (C/S Research and Policy Work Group, 1993).

The tension in civilization between the necessity for systems of government to control, monitor and rationalize efficiency and the necessity for human communities to nurture freedom, democratize information exchange and empower individuals is played out through the medium of communication. The profound issues of power and knowledge are oftentimes translated or conceived of in terms of knowledge exchange and decision support.

Therefore, it is of great importance that "the public should have a voice that matches or even surpasses all others, (in) how the structure of the proposed network will shape its content, its character, and its influence on society" (Chapman and Rotenberg, 1993), because it is at the level of people communicating with each other that human values have the greatest potential for becoming incorporated into and humanizing the institutions of society.

The principles, characteristics, and implications of a person-driven mental health service system are yet to be clearly articulated. It is clear, however, that the potential of humanism to propel system change goes beyond attitudinal and behavioral changes of people within the mental health system to a refashioning of the very foundations of how mental health services are conceptualized and delivered. This marks the fundamental difference between a person-centered approach and a person-driven approach. A person-centered approach is only an expansion of the existing service driven-model (Fig. 1) which, though it adds substantial information about persons, continues to reserve knowledge and decision-making power within the system. A person-driven approach, on the other hand, seeks to turn the model on its head by giving the person who is subject of the system control of knowledge and decision-making.

A person-driven information system would eliminate the tendency in data collection and analysis to pathologize undesired human behaviors, to label consumer choices from the perspective of system goals or values (e.g., when a consumer chooses to reduce or stop a traditional mental health treatment it is usually seen as noncompliance or lack of insight), to ignore socio-economic factors as significant in both positive and negative outcomes, and to attempt to establish correlations or causal connections between a person's personality, abilities, needs, preferences and aspirations on the basis of a psychiatric label. Further, the analysis and labeling of sub-populations based on diagnosis, service use, and demographic variables such as "the young, adult chronic" would be rigorously examined as artifacts of the system or the analysis.

The formal elements of the system would also resist psychiatric labeling by being responsive to the information needs of citizens who prefer to avoid seeking mental health services. A citizen would not have to risk psychiatric labeling by entering the mental health system in order to have access to information on psychiatric treatment outcomes such as self-help, personal coping strategies, hospitalization or types of psychotropic medications. Such information could be provided through access to public computer terminals or some other form of public information technology. Information provision and use by citizens could be self-initiated and be assisted by persons outside the mental health system instead of exclusively locating such services in a clinical environment.

## THE NEXUS OF CHANGE

Knowledge is a social construction: partial, colluded and inscribed with power relationships. In the social world the dominant epistemologies of science and techniques of data collection and analysis take material and ideological form. This has "profound impact on what we study, how we study it, and how we relate to people or 'subjects' and what actions may be taken on the basis of findings" (Chesler, 1991). Therefore, the meaning of the word "paradigm" lies at the nexus of the forces of knowledge and power.

According to Thomas Kuhn in *The Structure of Scientific Revolutions* (1962), a paradigm is the world view of the community of scholars. It circumscribes the known world and defines the activities of scientists. In this sense, the production of knowledge is more accurately described as problem solving rather than exploratory. Still, anomalous phenomena inextricably emerge in the data which eventually subvert the paradigm. Anomaly intrudes through unexpected consequences, the social resistance to domination of disempowered people, and autonomous moments of experience and consciousness. A shift in world view occurs as the processes of interpreting what is known must accommodate these forces. Such a sea change reorganizes the production and reproduction of society and gives meaning to the construction of identity of self and community. Thus, in the history of civilization humans have created not only complex social cultures, but in a very real sense, have created themselves.

Most profoundly, a paradigm shift places the individual's heart and mind within an intimate relationship between the knower and the known and demands that one look with new eyes. The point of departure is visionary. It lies in the hopes and dreams of people and comes into existence through what they know, do, and value.

## EMERGING PARADIGM IN INFORMATION SYSTEMS

*It is time to break away from the obsolete images of the world of the 1960's, the 1970's, and the 1980's. That world no longer exists. Now is a rare moment, a clearing horizon of historic opportunity, for all nations to promote peace, liberty, and global prosperity through partnerships. It is a unique time for creativity, comparable to the era immediately after World War II. Concepts, laws and institutions must change. The stakes are high. So are the chances for success.*

(Carnegie Commission, 1992)

As people witness the closing years of the twentieth century, they see the world changing all around them. Many of these changes are beyond their control, impelled by an inexorable process which is fast moving the world towards an integrated global society. They have lived through a period in history which has seen an astonishing, ever-increasing rate of change in all areas of human endeavor. The results of these changes are seen in every aspect of human society and have caused widespread speculation and interest as to where they will lead in the next century.

One of the fastest-moving areas of change is that of electronic technology and information systems. Among these changes is the widespread proliferation of network technology throughout the computer world. There is a growing perception that lack of networking ability is a *disability* in our increasingly technological, information-based society. We are "rapidly approaching the point where lack of network will become our competitive disadvantage" (Keyworth and Abell, 1990). In response to this perception, the Clinton administration has proposed a new technology policy which centers around the concept of an "information highway." According to Vice-President Gore, "Digitized information is now the lingua franca of the entire world. Those companies, those universities, and those nations best able to deal with information in that form turn out to be most successful." (Chapman and Rotenberg, 1993).

The emphasis on civilian technology development by the new administration is a strong indicator that the United States will soon have a national information infrastructure. The emergence of such an infrastructure, linking into the global Internet which presently connects over 11,000 networks in 102 countries (Chapman and Rotenberg, 1993, pg. 5), could well mark a point in the development of society that future historians would come to see as rivaling the industrial revolution in its impact upon all our institutions of commerce, education and government. Indeed, every aspect of society and of the development as individuals within that society will be revolutionized by the removal of barriers to communication on a world-wide scale. More than merely a revolution in information, it will be a revolution in communication. James Carey, in "A Cultural Approach to Communication," asserts that "Communication is a symbolic process, whereby reality is produced, maintained, repaired and transformed."

This concept has vast implications for fostering distribution of resources and knowledge, for development of common cultural reference points, and for every aspect of the development necessary to bring coherence and peace to a struggling, fragmented global society. Communication can be seen not merely as a mechanical or electronic process serving the needs of individuals and groups within society, but as the basic fabric underlying every aspect of societal interaction and development.

Over time, the institution of a national information infrastructure will become the foundation of enhanced capabilities for delivery of all types of services, including those for mental health. If it is well designed, it will strengthen individual participation in community development, encourage noncommercial sharing of resources, provide flexibility in design and technology so it can continue to evolve in new directions, and support informed public access at a reasonable cost. New and undreamt of possibilities for social development will emerge from the use of it.

In contrast to the fast-moving pace of technology, one of the slowest-moving areas of change is governmental policy and bureaucracy. What happens when the policies and institutions of government refuse to adapt to the forces of societal change has been demonstrated in other countries in recent years. The government can choose, if it wills, to embrace the vision of the future and employ the tools provided by the process of change to enable the inevitable transformation to progress more smoothly. Or, it can resist. It can try to preserve the vision of how life was in some earlier time. But change will come perforce. Mankind can neither retard these changes nor prevent them. The challenge facing the mental health system, which is largely

government funded, regulated and managed, is whether it will adapt to the changes necessary to meet the demands of an evolving society or whether it will break apart in attempting to resist the tumultuous forces propelling society into the twenty-first century.

As the world nears the beginning of the 21st century and the advent of a new millennium, there is a widespread feeling that we are witnessing the emergence of a new era, one that will upend many of the most salient features of the current century.

(Chapman and Yudken, 1993)

#### BUILDING AN ARCHITECTURE OF DECISION SUPPORT

The Clinton administration has announced support for the development of a new "national information infrastructure" (NII) based on high speed computers and high speed, high bandwidth communication links, such as fiber optic cables. Building on the present worldwide computer network called the Internet, the NII will eventually allow the near instantaneous communication of voice, still and moving images, data, and high quality sound simultaneously. The NII has the potential to revolutionize communications. *It also has the potential to increase the gap between the 'haves' and 'have nots' within the United States and between nations.*

(Chapman and Yudken, 1993)

In order to create a decision support system that can effectively meet the demands of the person-driven model, the establishment of a formal information infrastructure is necessary. The complex issues of access, connectivity, universality and privacy which are involved in developing a real-world implementation of the person-driven model must be addressed on a public policy level as well as at the technology level.

"Public interest values such as equity, enhanced access to public sources of information, privacy, and freedom of expression should be built into the National Information Infrastructure's design and implementation process from the very start."

(Chapman and Yudken, 1993)

The concept of a person-driven information system is made possible by electronic networking technologies which open the way for development of information systems based on the human model of communication, i.e., interactive dialogue. The ability to interact, not only with other stakeholders, but with the mental health information system itself would empower people who receive mental health services by removing barriers to access to information, services, and both peer and professional support. This could provide the foundation for a "shift from the person as object to a person choosing services based on information about providers. their effectiveness and costs of services" (Guidera, 1992).

If the values of personhood become part of an architecture of decision support rather than just the embodiment of a humanistic philosophy within social relations, the interactive person-driven system will replace the hierarchical service-driven model currently used throughout mental health systems and persons will no longer be acted upon as the objects or units of data collection, nor will they be merely the passive recipients of information.

In a person-driven model, the mental health system would not expand in response to the demands of its information and decision support system, but would find ways to reintegrate and meet such demands within the community and/or through non-specialty human and community services. For example, the role of case-managers in helping to determine a consumer's

unmet needs and in providing assistance in meeting those needs through researching resource directories and boundary-spanning is not a clinical function.

Such services could be provided through access to public computer terminals with resource directories and interactive needs assessment programs. Also, evaluations, performance indicators and satisfaction surveys of particular institutions and service providers could be made available to the public, as well as unit costs of services.

A person-driven information system would respect and be responsive to the data concerns of all stakeholders and seek acceptable solutions. Greater attention would be paid to the presentation of data. The usefulness of data would be evaluated by all stakeholders on the basis of its user-friendliness and relevancy. Many concerns could be resolved by providing incentives and additional benefits to outweigh perceived liabilities. For example, many providers see data reporting as a burden and resist any attempts to change or introduce new data elements. In data integration efforts this has been particularly problematic. Usually, providers are told that ultimately their reporting efforts will be reduced, but that is rarely the case. A person-driven approach might be to make special efforts to develop and distribute information to them that would be useful in meeting their needs

In a person-driven model (Fig. 2), the individual citizen determines the level of his/her involvement with service providers, if any, in their healing and recovery processes: they may access universally available information resources, do independent self-assessments, combine self-assessment with traditional service provision, or rely entirely on providers for whatever services they receive. All citizens would be empowered to choose among available information and services, and, if desired, have the ability to track their own history in a secure and confidential environment, and to disengage from the system at their own discretion.

Underlying the concept of the person-driven model is the notion of participatory design as paraphrased from the principles of participatory research put forth by the International Council on Adult Education (Toronto, 1977):

Participatory (design) is an approach to (system design) by which the full participation of the community is sought in analyzing its own reality for the purpose of promoting social transformations for the benefit of the participants in the (system).

Such an approach implies full collaboration between all stakeholders in the design of the system itself including purpose, structure, content, access, security, timing, and relevance with particular emphasis being placed on the value of insight from the persons the system is intended to benefit. Without this approach, the movement towards a person-driven decision support system would be undermined by a poverty of vision in systems design and a resistance to implementation.

### The Electronic Gateway Model

There is a growing recognition that people from all walks, in all phases of life; may at sometime in their lives have a need for mental health services to cope with events and transitions of life. The need for such support services is beginning to be widely recognized and, with that recognition, the lines between those considered "mentally ill" and those considered "normal" are beginning to blur.

The concept of an electronic gateway to mental health information and services (Fig. 3) sees the citizen/consumer as both user and subject of an open architecture information network designed to aid the individual in managing his/her own mental health care and life development, as well as providing information and access to the community at large. The electronic technologies necessary to implement a person-driven information system are presently being developed and examples of some early attempts are described below.

A dramatic effort at the transformation of a provider-driven state job training infrastructure to a person-driven information and resource allocation system was attempted in Michigan in the 1980's. Kiosks with automatic teller machines were planned that would enable customers to electronically browse through training and educational options, and a "smart" credit card was designed that would credit funding for training to the account and debited as the person utilized services. However, the state government administration changed and funding for the project was lost. (Osborne and Gaebler, 1993).

In 1988 the legislature in Hawaii passed an act to develop a state electronic information system in response to media criticism that geography prevented citizens from having the opportunity to voice their concerns and participate in the legislative decision-making process. To date, Hawaii is providing general information services to more than 4,000 users on the existing gateway (Gamble-Risley and James, 1989).

The York County Parent Awareness, Inc. in Maine recently established an electronic network for disabilities issues accessible to anyone with a terminal and modem through a state-wide 800 number. It provides the opportunity for networking among individuals with disabilities and their family members as well as access to many varieties of information on assistive technology, consumer education, and supported employment, among other topics. This person-driven model promises to be cost-effective as well as an effective way to inform and empower the disabilities community regardless of age, location, or disability. (York County Parent Awareness "The Maine Meeting Place" Proposal, January, 1993).

Finally, John Wennberg, M.D. established the Foundation for Informed Medical Decision-Making in 1989, a medical education and research organization that furnishes physicians with interactive videos to be used in everyday clinical practice to inform patients who are facing a treatment decision about the likely outcomes of various choices. Patients enter personal data about their age, symptoms, and test results and then receive information tailored specifically to them so they can assess their own likelihood of and preference for experiencing the various outcomes. These outcomes are discussed through interviews with other patients who have chosen the different treatments--some with good outcomes and some with bad (Cassidy, 1992).

### Protecting Privacy and Confidentiality

There are affordable and free-access networks now emerging in communities around the nation which will enable the person-driven model to come into widespread use and be of practical value to real people. However, implementation of a networked information system which does not adequately protect privacy and confidentiality would be a significant barrier to service delivery for mental health clients. This is due to the natural reluctance of all people, not just mental health consumers, to be tracked and monitored in the most personal aspects of their lives.

Furthermore, for those who have already been labeled as mental health consumers, the practical consequences of stigma associated with psychiatric labeling can be profound. Loss of or denial of employment, inability to obtain housing and a cascading host of other problems which are not related to diagnosis or disability but to inaccurate assumptions regarding persons who have received mental health services are among the threats presented by breach of confidentiality. For this reason, the issues of personal privacy and confidentiality loom very large in the minds of mental health consumers. The right of confidentiality must include the right to informed consent, to have controlled access to one's own health history, and to correct inaccuracies, as well as the right to withdraw from the system.

But there are many complex issues which must be faced and resolved in order to obtain the desired results rather than ones which are unanticipated and undesired. An improperly thought out and implemented system could result in invasion of privacy, personal surveillance, abridgement of constitutional rights, inappropriate monitoring and control of individuals, access to personal data for private profit or criminal use, and other problems. No segment of the population is potentially more vulnerable to this than those who have received mental health services. It is imperative to move forward with the implementation of privacy and confidentiality standards while national policy is favorable towards institution and enforcement of such

standards.

The FN-10 Data Standards for Mental Health Decision Support Systems (Legenski et al., 1989) calls for the use of the social security number as a patient/consumer identifier, and assumes that it is both possible and legitimate to convince consumers that the use of unique client identifiers would pose no risk or minimal risk to the privacy of an individual. However, consumer privacy under such systems cannot be totally safeguarded (Rotenberg, 1992; Ziglin, 1993).

For decades, corporate and government bodies have utilized the social security number as a unique identifier for tracking information about individuals. Originally intended only to identify workers to the Social Security Administration for tax purposes, its use has expanded to provide every form of individual record keeping identification. It has become ubiquitous. One must supply it even to obtain a supermarket check cashing card. The widespread use of this single, unique identifier has seriously eroded personal privacy.

The growing amounts of information that different organizations collect about a person can be linked because all of them use the same key--In the U.S. the social security number--to identify the individual in question. This identifier-based approach perforce trades off security against individual liberties. The more information that organizations have, the less privacy and control people retain.

(Chaum, 1992)

Not only has privacy been eroded, but personal security has been endangered through this practice.

Thieves routinely use a stolen credit card number to trade on their victims' good payment records; murderers have tracked down their targets by consulting government-maintained address records. On another level, the U.S. Internal Revenue Service has attempted to single out taxpayers for audits based on estimates of household income compiled by mailing-list companies.

(Chaum, 1992)

In a person-driven information system, these concerns would be acknowledged and validated. Any use of an identifier would be fully waived with complete disclosure of use of information. Further, only minimal information would be anchored to a unique identifier. If expanded information for longitudinal studies were determined to be necessary by participating stakeholders, sampling technologies that require the fewest number of respondents would be employed with scheduled destruction of identifiers at the completion of the study. If a person still refused to have a unique client identifier, services would not be withdrawn or denied. Given the stigma associated with mental health labeling, not only are the risks of using the social security number, or any universal identifier, substantial, but the use of it constitutes a barrier to access for those unwilling to take the risk.

However, there are alternatives. One of the most promising appears to be that of the "digital signature." International cryptography expert David Chaum, has been in the forefront of developing and implementing a model for digital signatures, employing the use of sophisticated "smartcard" technology. The prototype is a "smart credit-card-size computer containing memory and a microprocessor. It also incorporates its own keypad and display so that its owner can control the data that are stored and exchanged". (Chaum, 1992). According to Chaum, it would also be possible to incorporate fingerprint identification technology within the card itself to prevent anyone other than the owner from using it. Such a device could be an effective means for empowering individuals to gain and control access to their own personal records while excluding unauthorized persons from similar access. The use of encryption to ensure privacy of data and communications is a subject of widespread interest and debate in the computer community (Chapman and Rotenberg, 1993)

CHARACTERISTIC	PERSON-DRIVEN MODEL
Purpose	
Values	Equity of knowledge and power; reciprocity between persons in the system and other stakeholders; respect freedom/empowerment; and democratic and participatory processes; person-first language to ensure freedom from stigmatizing terminology (labeling);
Focus	On the whole individual rather than personality, behaviors or problems. Provision of educational and decision support resources to citizens in the community.
Goals	Improve cost, quality and access for all citizens. Use education and prevention to enable people to heal and recover, to provide supports to enable people to control and self-monitor, to empower people through knowledge to facilitate reaching self-defined goals. To promote well-being and quality of life of all citizens.
System Principles	<ol style="list-style-type: none"> <li>1) System exceeds minimum legal requirements allowing access to data in favor of empowering persons to exercise choice.</li> <li>2) Person in the system has ultimate control over the data.</li> <li>3) Person in the system and citizens have access to information at his/her convenience.</li> <li>4) Person in the system is able to withdraw from the system at any time.</li> <li>5) Person in the system is able to dictate limitation of access.</li> <li>6) Person in the system has immediate recourse in the event of errors.</li> <li>7) Evaluation of the system includes determination of benefits offered to the person and the weaknesses in the system, e.g. errors and iatrogenic effects.</li> </ol>

CHARACTERISTIC	PERSON-DRIVEN MODEL
<p>System Principles</p> <p><i>(continued)</i></p>	<p>8) Evaluation of the system includes a cost-benefit analysis from the perspective of service</p> <p>9) Data elements collected are developed, approved, and re-evaluated regularly by a representative sample of people about whom data is/will be collected.</p> <p>10) Participation of persons in the system is based on informed consent, e.g., knowledge of the universe of individuals, and access protocols including who has access to the information, confidentiality and privacy protections.</p> <p>11) Citizens have immediate access to information regarding outcomes and evaluations of providers and treatments, directory of services, costs, and other relevant information to facilitate the choice of provider/services.</p> <p>12) People in the system evaluate the system's strengths and weaknesses, and provide citizens with the results of such evaluations. A representative sample of people in the community about whom data is being/will be offered continuously plan for the implement improvements.</p> <p>13) Problems, suggestions and comments are communicated democratically between the individual, the community and the system. Forms of communication such as dialogue are supported through the information system.</p> <p>14) System to user interface is easy to understand.</p> <p>15) Transactions with system are courteous, respectful, and assumes the competency of all participants.</p> <p>16) Participation in the system is voluntary for all citizens.</p>
Structure	
Distribution	<p>Universal distribution from/to: individuals through modem communications; community through access ports in Laundromats, schools, mails, libraries, etc.; service system stakeholders through integrated MIS.</p>

CHARACTERISTIC	PERSON-DRIVEN MODEL
Integration	Multiple levels of integration: The service recipient as human being; individual as member of community (public health model); services integration (human services), target populations, unit function such as research, quality assurance, information services; stakeholders in decision-making; Vertical integration between individual(s), state and federal systems, balanced with horizontal integration at the community level.
Flexibility	Highly flexible and interactive with built-in feedback loops; responsive; able to accommodate unique differences in system participants (adaptation); allows for alternatives in input and processing and distribution.
Content	
Purpose of Information	Expansion of human knowledge and potential; liberatory.
Domains of Concern	Proactive: Health (rather than illness); education; quality of private life/well-being; public health; healing and recovery; empowerment, autonomy/personal sovereignty, self-actualization/identity; citizenship; system change; legal issues.
Source of Information	All stakeholders
Information Inputs	Consumer surveys, community surveys, consumer councils, focus groups, electronic mail, test marketing, consumer inspection, complaint tracking system, 800 numbers, community bulletin boards
Types of Information	Subjective/objective, self-reporting, satisfaction, evaluative (based on human values), collaborative, non-hierarchical. Needs are defined based on use, desire and interest, not by stakeholder category (providers, customers, family members, government agencies and policy makers, researchers, etc.).

CHARACTERISTIC	PERSON-DRIVEN MODEL
Quality of Information	Rethinking validity, reliability, replicability. Focus on honesty, usefulness, and relevancy of findings. Constant re-evaluation of assumptions of the system and of the participants (reflexivity, self-criticism).
Analysis Strategies	Longitudinal studies, qualitative methods, concept mapping, sampling, survival analysis, citizen-defined system and individual outcomes. System Outputs information is available in increasing levels of complexity and detail in formats accessible to all citizens. Content defined by citizen feedback.
Control of Information	High security, privacy and confidentiality, egalitarian ownership; provisions that allow individuals to inspect information about themselves and to add information that they consider important or remove inaccurate information; that it be known in general what information is stored in the system and what use will be made of that information (informed consent); notice and consent for data merging; no secret data banks.

## DIRECTIONS FOR THE FUTURE

It is prudent to only commit resources to a person-driven model after a literal "researching of what constitutes essential components of care. In this process, the cost to individuals and systems by ignoring consumers would be enormous. Individuals would lose self-confidence, feel devalued, and lose their ability to make informed decisions. Systems would lose the ability to provide effective programs, services, and processes, which may delay or retard recovery and people's ability to leave the formal mental health system. Though active participation of system stakeholders to articulate services that are "done with, rather than done to" citizens, outcomes of services become congruent with the values, needs, and goals of individuals and communities. It is only when people are no longer acted upon as objects or units of data collection, nor are they seen as the passive recipients of information that they can function as independently as possible in living and working environments of their choice, with the level of support and services they need and prefer.

In order for MHSIP to be partners in the production of an information age system focused on servicing communities and individual citizens, its agenda must be broadened to include collaboration, analysis and distribution as significant areas of support and interest. Without this integration, the model proposed in this paper could not be operationalized through MHSIP leadership.

The "best practices" leadership of MHSIP in developing data collection standards has provided valuable and essential objectives for mental health delivery systems that are supportive of sound decision-support- structures and management of information. These standards reflect the values behind the support and service system. They articulate the manner that services and supports are to be organized and provided. Until now, the FN-10 has functioned as an ideal for practices and performance to guide state mental health agencies in their data collection efforts.

The review of data collection protocols in terms of an ideal has not been regulatory. but MHSIP has imposed incentives through grants and has provided technical assistance, feedback and encouragement designed to move mental health data collection systems towards best practices. Such standards also emphasize preferred decision support models. In this way, MHSIP has become part of a leadership process providing feedback and support to mental health delivery systems as attempts are implemented to improve upon services.

On another level, however, MHSIP has failed to provide leadership by embracing its own best practices approach. The FN-10 really reflects back to the "field" standards which articulate a consensus regarding what constitutes best practices. Until recently this consensus has been consistently reinforced by exclusively utilizing peers rather than consumers, family members or others who may have quite different points of view regarding the overall direction and quality of services provided. In a way, MHSIP's professionalism has been the principle obstacle to its own stated purposes by excluding the perspective of a diversity of stakeholders.

Ironically, MHSIP's leadership is compromised by focusing on the standards rather than embracing a dynamic, inclusive process towards excellence. With the growing inclusion of a multi-stakeholder perspective and the participation of consumers in crafting the architecture of a person-driven decision support system, MHSIP has the means to move beyond reinforcing the status quo and the illusions of success and of quality.

if the prime purpose of best practices standards is to drive decision-support systems forward, then inclusionary means must be incorporated to provide direction, guidance, and supports in the struggle towards improving human services and promoting well-being in the lives of citizenry. Risk taking, innovation and even failing must be reinforced and encouraged to achieve these goals. The paradox is that while the intent of MHSIP's best practices approach has survived the test of time and has remained relevant through multiple system changes, the mechanics for addressing the intent have become institutionalized in the FN-10 and, therefore, are a potential barrier to implementing system change.

#### RECOMMENDATIONS:

We have tried to be as objective as possible in our analysis. but objectivity is not synonymous with lack of perspective. Our analysis makes no pretense at being 'value-free.' Our operating bias may be made explicit: t'e are partial to the values of equality, participation, and legality-in short, to those values we think of as the values of constitutional democracy. We believe in due process of law and look forward toward a society in which order is achieved through consent, not coercion.

(Skolnick, 1969, p. IX)

In order to move MHSIP to a person-driven decision support system, both incremental and comprehensive steps must be taken within the service system at the personal and system levels to embrace, in both theory and practice, the humanistic philosophy underlying the person-driven model. To reach those goals:

Promote person-driven values through:

- Supporting efforts in human resource development and education to promote such values as consumer dignity, respect, acceptance, integration, and choice in professional practice.
- 
- Seeking creative alternatives to all psychiatric labeling in both the form and content of data collection, processing, and distribution, including emphasis on community mental health surveys (epidemiology) and normalization of emotional and psychological problems.
- 
- Educating the community regarding the incentives and benefits of information access.
- 
- Emphasizing education in health-promoting lifestyles and environments, help-seeking, and coping.
- 
- Recognizing consumers as primary stakeholders and that all stakeholders should be dedicated to serving the self-defined needs/preferences of consumers.
- 

Provide protection by:

- Creating national and local data protection boards with representation of all stakeholders to monitor data collection protocols, establish protection standards and review use of human subjects, and respond to complaints of misrepresentation of information, misuse of human subjects (such as failure to gain informed consent from the provider of information), and issues of access or equity among stakeholders.
- 
- Initiating critical review of data collection levels on individuals towards minimal data set and appropriate content.
- 
- Eliminating coercive and/or involuntary use of subjects in information gathering, analysis or distribution.
- 

Ensure accessibility through:

- Locating primary loci of consumer and family information collection and use within the community in public spaces.
- 
- Eliminating barriers to information due to complex and specialized formatting.
- 
- Providing community support to assist people who cannot use information technology by themselves.
- 

Promote collaboration with:

- Policy-makers to integrate the decision support functions of research quality assurance and information systems within a public health model.
- 
- People who receive mental health services in the design of the system, including collection strategies, development of instruments and protocols, data processing, data presentation, and data distribution
- 
- Service providers to recognize and address issues of data collection burden.
- 

Collect and distribute information and data on:

- Alternatives to traditional mental health services such as clientoperated self-help and mutual support services.
- 
- Outcome measures, including consumer defined outcomes such as recovery, freedom, well-being, achievement of self-defined goals. and empowerment.
- 
- Iatrogenic outcomes of mental health services that create and exacerbate illness and problems such as trauma due to coercion and involuntary treatments (commitment, forced drugging, seclusion, and restraints), side-effects of medications (chemical illiteracy, obesity, lethargy), and learned helplessness.
- 
- Alternative information transaction, research, and monitoring schemes.
- 
- Needs of special populations, as well as the general population, to determine both similarities and differences.
- 
- Longitudinal studies on individual cycles of illness and recovery. Qualitative research findings.
- 
- Customer satisfaction.
- 
- Community mental health surveys.
-

Recognize the uneven development of existing state mental health infrastructures and budget federal funds for:

- States to insure their capacity to participate fully in the national information infrastructure (Suffington, 1993).
- 
- Support of efforts in MIS redesign and enhancement to implement the shift to a person-based model.
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#### DECISION SUPPORT AND DIALOGUE: THE NEXT STEP

At the point of encounter there are neither utter ignoramuses nor perfect sages; there are only men who are attempting, together, to learn more than they know now. Dialogue further requires an intense faith in man, faith in his power to make and remake, to create and re-create, faith in his vocation to be more fully human . . . the dialogical man believes in other men even before he meets them face to face.

(Freire, 1973, pp.79-SO)

MHSIP should take incremental steps that allow for dialogue, experimentation, failure, and personal and system growth. Further, people should be invited to provide their own thoughts to deepen the depth of diverse responses and facilitate dialogue. Collecting various insights concerning the nature of problems, benefits, consequence and critical factors is the means of identifying potential obstacles to success and pinpointing areas which may require policy decisions or outside support. There is also a need to do a problem analysis, to separate facts from inaccurate assumptions, differentiate between problems, symptoms of problems, and solutions masquerading as problems.

A second step would be to look at the development of mental health information systems in the concrete, to work from where people are currently by studying specific interventions. Examining the experience of functioning systems could provide important information about particular problems and specific recommendations to MHSIP.

A third step would be to conduct a nationwide survey of various constituencies within the States regarding their experiences and interests in person-driven information systems. The results of such a survey would be useful only if the groundwork described above had been laid to assure common understanding of concepts involved.

Although no definitive answers can be offered based on the above steps, the obvious need for a more accepting and compassionate process is indisputable if mental health consumers are to share in the American Dream. In the final analysis, the experiences of everyday life are always relative and bound by an individual's private and social history. For this reason alone, all people should be afforded the right and respect to speak for themselves. This is both the critical and conciliatory edge offered by a person-driven decision support system. Within a humanized framework, the efforts of MHSIP could propel dialogue to begin to reach out and nurture personhood. Paulo Freire was convinced that every human being, no matter how "ignorant" or submerged in the "culture of silence", is capable of looking critically at the world he/she experiences and participating in a dialectical encounter with others.

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