

**FINAL REPORT ON A STRATEGIC
VISION AND COMPREHENSIVE
EVALUATION OF THE ILLINOIS
PUBLIC MENTAL HEALTH SYSTEM**

**Illinois Department of Human Services
Division of Mental Health
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Final Report On A Strategic Vision and Comprehensive Evaluation of
The Illinois Public Mental Health System

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Final Report On A Strategic Vision Report and the Comprehensive Evaluation of The Illinois Public Mental Health System

Executive Summary

The purpose of this report is to describe the work that is being undertaken to develop a strategic vision and a three to five year strategic plan to guide the efforts of the Illinois Division of Mental Health in transforming the mental health system to one that is recovery-focused and consumer and family driven. The recommendations of the President's New Freedom Commission on Mental Health are used as an organizing framework to provide context for this effort.

The Final Report of the Commission, which was released in July 2003, calls for a fundamental transformation of the Nation's approach to mental health care. Noting that "[t]he time has long passed for yet another piecemeal approach to mental health reform," the Commission identified six principal goals of a reformed system of care and made specific recommendations to facilitate the implementation of these goals:

- (1) Americans understand that mental health is essential to overall health.
- (2) Mental health care is consumer and family driven.
- (3) Disparities in mental health services are eliminated.
- (4) Early mental health screening, assessment, and referral to services are common practice.
- (5) Excellent mental health care is delivered and research is accelerated.
- (6) Technology is used to access mental health care and information.

All of the Commission's goals and the recommendations associated with them are organized around one key principle: that public mental health systems should be fundamentally altered "to make recovery from mental illness the expected outcome from a transformed system of care." This principle is consistent with the major goals of the Illinois System Restructuring Initiative (SRI) – consumer choice, financial and programmatic accountability, consumer access to services, and continuity of care – and provides a clear direction for transformation at all levels of the mental health service delivery system.

The public mental health system has a number of key strengths that provide a foundation for implementing a new vision:

(1) Illinois has a core base of experienced, dedicated mental health providers that provide a safety net for people diagnosed with mental illnesses and are committed to serving non-Medicaid as well as Medicaid populations.

(2) Illinois has a strong academic base for research and evaluation activities in mental health. Northwestern University, Rush University, the University of Illinois, the University of Chicago, and other academic institutions are home to nationally-recognized psychiatrists and researchers in mental health, helping to ensure continued quality of mental health leadership in the state, as well as attracting Federal support for research.

(3) There is broad momentum within DMH and its stakeholder communities to move toward a recovery-oriented system of care. The SRI Task Force, for example, has developed a document called “A Philosophy of Recovery Oriented Services in Illinois,” which describes the philosophy as “plac[ing] an overriding emphasis on the potential of all individuals to recover from the challenging impact of psychiatric illness.”

(4) DMH has begun to develop and strengthen relationships with other state agencies that are essential to a comprehensive system of care for people diagnosed with mental illnesses. There is also involvement in statewide initiatives related to housing, employment and children’s mental health as an indication of growing collaboration.

(5) The issue of mental health has the current attention of the Illinois Legislature, Governor, and other stakeholders. The System Restructuring Initiative has facilitated the perception that the system is in motion, and most stakeholders understand that change is inevitable.

The Illinois system also faces a number of significant challenges, including the following:

- 1) Resources are inequitably distributed; there is a very wide variation in access to mental health services throughout the states;
- 2) Illinois ranks 31st among states in *per capita* mental health funding;
- 3) The Division of Mental Health has a very small number for persons on staff to develop policies, to plan, and to manage the system, given the size of the State

and its population. There are now approximately 100 persons who work in either the DMH Central Office or one of its area network offices. That is approximately half of the number who were working in these offices two years ago and one-quarter of the number in a smaller state (Massachusetts) with similar organization.

- 4) As the President's New Freedom Commission recognized, significant transformation requires the collaboration of all state agencies that serve the population of people diagnosed with mental illness.

Key Issues

This report provides an in-depth look at the following topics/issues in relation to development of a vision for the Illinois Mental Health System: developing and supporting a recovery agenda, financing issues, assuring the delivery of culturally competent services as an integral and underlying principal of quality services, identifying and addressing disparities in access to services, and using information technology to support accountability.

Developing a Vision to Address the Mental Health Needs of Illinois Residents

The work to develop a strategic vision for Illinois Mental Health Services arises out of the Memorandum of Understanding that was developed for the DMH System Restructuring Initiative. Transitioning the financing mechanism from a mostly grant-in-aid system to fee-for-service funding with a focus on generating increased revenue from Medicaid, has major implications for service delivery, access to services and service quality and outcomes. The development of a clear vision and mission to guide planning and service delivery efforts is imperative for maintaining a focus on those persons who are served by the public mental health system. The timing of the decision to initiate work on a strategic vision was fortuitous. DMH had recently begun work on developing a three to five year strategic plan; the opportunity to access resources and consultation to support this effort was beneficial. In an effort to gather information to for the development of the vision, an assessment of the mental health system focusing on six key areas was initiated. The areas of focus were:

- Organizational and structure issues that are likely to impact mental health service delivery
- Adoption of a recovery orientation
- Financing issues
- Access to services and a focus on identifying and reducing disparities in treatment access
- Cultural competence in service delivery
- The use of technology to support accountability

Work on the development of a strategic vision was initiated in January 2005. In preparation for this work, several consultants were retained to work with DMH staff to facilitate the development of the strategic vision. Focus groups and interviews were conducted with key stakeholders including consumers; family members of persons with mental illnesses, DMH contracted providers, DMH staff and other stakeholders over a two-month period. In addition, the outputs of the DMH Workout Groups that were convened in 2004 to provide input for mental health planning efforts were used as input to the strategic vision process. Sources of other information obtained for the assessment included: data extracts from the DMH Reporting of Community Services (ROCS) management information system which contains clinical and service information for consumers receiving services from DMH-funded agencies; data extracts from the Illinois Department of Public Aid; and information on National trends in mental health service delivery from the National Association of State Mental Health Program Directors Research Institute (NRI).

Developing a Mental Health Vision

The overarching themes that emerged from meetings with key stakeholders are:

- (1) Recovery from mental illnesses should be the guiding principle and the expected outcome for the mental health service delivery; The goal of mental health is recovery;

- (2) Mental health services should be consumer and family driven; Services that are developed and provided should be based on consumers' needs and preferences;
- (3) Mental health is a public health issue, and as such should be provided within a public health framework that incorporates primary prevention and early intervention; there is no health without mental health.
- (4) The expertise and knowledge within the mental health system should be used to develop mental health policy statewide
- (5) Decision-making and policy development should be data-driven, and
- (6) Mental health services should support recovery; they should be evidence-based, outcome focused and provided in a culturally competent manner.

Issues in Developing a Recovery Vision and Orientation

As DMH begins to focus more intently on a recovery vision, in essence working to transform the Illinois Mental Health System to one that expects recovery as an outcome, there will be challenges to overcome. Some of the issues identified by mental health stakeholders during the interviews and focus groups that were conducted include:

- A need for a change in attitudes and values of mental health stakeholders to support the recovery-orientation and to reach a consensus on the vision of recovery
- A need to increase meaningful consumer and family involvement
- The development of services that support recovery, including evidence-based and best practices
- Strategies to address issues related to lack of housing and employment
- The recovery-orientation and vision adopted by the Illinois mental health system should be the vision that guides the purchase and delivery of mental health services by other agencies/providers. Because people served by DMH often access services from multiple systems, and because of different messages received, there is a need for continuity of care and practices.

Recommendations for addressing these issues include:

- Educating all stakeholders about recovery philosophy and practice.
- Supporting independent stakeholder constituency groups and strengthening consumer and family involvement in decision-making.
- Collaborating with stakeholders to build a consensus on a recovery vision and an implementation strategy.
- Continuing development of the Disability Services Plan pursuant to the Disability Services Act of 2004 for implementing the *Olmstead* Decision focusing on alternatives to institutional residential care.
- Systematically reviewing and addressing current policies and practices that interfere with recovery.

Mental Health System Assessment: Challenges, Strengths and Recommendations

As noted above, challenges, strengths and recommendations were identified for each of the key areas that were a focus of the assessment. Examples of some of these issues are displayed below, however it should be noted that this is not a comprehensive and complete list. Specific information that provides more context for the issues and recommendations will be found in the appropriate section of the mental health system vision and assessment report.

Organizational/Structural Issues

Challenges:

- DMH is understaffed; over the last two years there has been a 50% reduction of staff in the Central/Administrative Office resulting in many people performing multiple jobs
- It is difficult to recruit, retain and hire the people with the right skills for DMH positions.

Strengths:

- DMH has a local structure in place, through its Networks, to monitor service delivery and provide technical assistance to providers.
- Currently, the Governor's office is applying for a federal grant, the Mental Health Transformation State Incentive Grant (MHT-SIG), designed to fund planning and infrastructure changes necessary to implement the recommendations of the President's New Freedom Commission (2003). This process has brought together virtually all state agencies involved in delivery or funding of mental health services ranging from prevention to long-term care. While implementation of the envisioned transformation will be challenging and may require new legislation, this initiative will provide the resources and structure to implement a recovery oriented, consumer-driven public health approach across all funders of mental health services.

Recommendations:

DMH should aggressively work to fill vacant positions with people with the appropriate skills. DMH should also continue the efforts that it has undertaken to collaborate with agencies with which it shares its service population. As noted above, these efforts will be enhanced if Illinois is a recipient of Substance Abuse Mental Health Services Administration, Center for Mental Health Services (SAMHSA, CMHS) Mental Health Transformation Grant.

Financing Issues

Challenges:

- The Illinois mental health system is underfunded in comparison to other comparable states.
- Financing mechanisms are not currently in place for services that support recovery such as evidence-based practices.

Strengths:

- DMH has worked collaboratively with a wide range of stakeholders to plan implementation of the System Restructuring Fee-for-Service initiative.
- The fee-for-service initiative provides an opportunity for collaboration with stakeholders to develop strategies for funding services that support recovery.

Recommendations:

The design of the service delivery system should be used as the basis for developing financing mechanisms for mental health services. Focus on developing services that support recovery and allocate dollars for these services.

Delivery of Culturally Competent Services

Challenges:

- There is generally a lack of awareness regarding different cultures, religions and how this impacts treatment.
- Within DMH state hospitals there is limited access to staff who speak languages other than English.
- There is an inability to recruit and retain bi-lingual and bi-cultural professionals.
- There is no specific budget allocation associated with cultural competence activities.

Strengths:

- DMH has appointed a cultural competence coordinator.
- Data is routinely collected that permits the assessment of service access and utilization by race and ethnicity.
- DMH has received expert consultation regarding the development of a cultural competence plan.

- DMH is a member of a DHS Limited English Proficiency (LEP) taskforce that has focused on identifying services gaps and developing policies to address the needs of this population.

Recommendations

Some of recommendations for addressing some of the challenges discussed above include allocating resources to advance the cultural competence agenda; systematically reviewing data periodically to determine disparities in service delivery and acting on findings; development of system-wide standards for culturally competence service delivery.

Access to Mental Health Services

Challenges:

- Access to the amount and type of service varies widely across the state.
- Disparities exist in the provision of treatment to several ethnic populations served by the public mental health system.
- Disparities exist in the provision of treatment to children and older adults.
- The implementation of some evidence-based practices has been limited.

Strengths:

- DMH has received several grants that permit pilots for evidence-based practices to be implemented.
- Active collaborations exist between DMH, providers, consumers and other state agencies to implement several Evidence-Based Practices (EBPs).
- Consumer perception of care surveys have been implemented across the mental health system; this provides a basis for gathering important

feedback directly from consumers regarding their ability to access to mental health care.

Recommendations:

Expand the access analysis that was performed as part of the system assessment to include data from other important service providers so that a comprehensive assessment of access can be undertaken; follow-up on findings that geographic and some population disparities exist for defined populations.

Use of Information Technology (IT) to Support Accountability

Challenges:

- DMH IT needs to be updated to support the timely generation of information that is needed to support fee-for-service financing.
- The DMH ROCS system needs to be reconfigured to collect performance and outcome data across time.
- Although lots of information is gathered, it is difficult to get data in a timely manner to support decision-making.

Strengths:

- The ROCS system has been successfully employed to generate claims for Medicaid and to track non-Medicaid and Medicaid services provided to individuals receiving services. Information is also generated for access and some limited quality and outcome performance measures.
- DMH has experience in designing and implementing performance measures.
- DMH has developed the Service Inquiry System (SIS) Online, which is Web based application providing information about funding and the populations served through the Illinois Mental Health System. The application is used by DMH, as well as DHS program offices, while also permitting inquiry by the providers with whom DMH contracts.

Recommendations:

Update the DMH IT system design to produce data that serves administrative and management information needs. To do so will mean an investment of resources; however these resources provide the basis for ensuring accountability. Internal staff has the skills to implement these recommendations, but required the resources to do so.

Next Steps

DMH is poised to move forward with implementing a vision of recovery that is the centerpiece and the driving force for the DMH strategic plan. However, significant challenges need to be addressed to move this agenda forward. The mental health system is not without it's strengths however. Building on these strengths, a concerted effort will need to undertaken by all stakeholders, in partnership and collaboration, to truly implement a vision where recovery is the expected outcome for all consumers.

I. INTRODUCTION

The Illinois Division of Mental Health and its supervising agency, the Department of Human Services, pursuant to an agreement between the Governor, the Legislature and the Department, initiated this report. A team of consultants were retained and charged with assisting the Division in the development of a Strategic Vision Report for Mental Health based on an assessment of the mental health system. In performing this assessment, over 200 consumers, family members, providers, other constituents, and State government staff were interviewed both in groups and individually.

The report produced based on this input focuses on the following issues:

- The strengths of the Mental Health System
- The challenges of the Mental Health System
- Problems faced by people diagnosed with mental illnesses who are receiving services in other systems (*e.g.*, criminal justice, child welfare)
- Specific recommendations relating to mental health service delivery and development

This stakeholder input will be used as a basis for the DMH strategic planning process.

This planning effort also incorporates:

- An assessment of the concerns and values of mental health consumers, family members, DMH staff, mental health advocates, mental health providers and other mental health system stakeholders
- Recommendations and goals based on the findings of the President's New Freedom Commission Report on Mental Health with adaptations for the unique features and context of the Illinois Mental Health System
- An assessment of factors that facilitate and hinder recovery with a focus on promoting recovery and resilience for persons served by the Illinois Mental Health Service Delivery System
- The delivery of culturally competent and culturally sensitive services
- The delivery of services with an evidence-base, and of services that are identified as "best or promising practices," wherever possible
- Incorporation of financing strategies that enhance the provision of Medicaid and non-Medicaid services

II. BUILDING A FOUNDATION FOR TRANSFORMATION

In a landmark Final Report released in July 2003, the President’s New Freedom Commission on Mental Health called for a fundamental transformation of the Nation’s approach to mental health care. Noting that “[t]he time has long passed for yet another piecemeal approach to mental health reform,” the Commission identified six principal goals of a reformed system of care and made specific recommendations to facilitate the implementation of these goals as listed below:

- (1) Americans understand that mental health is essential to overall health.
- (2) Mental health care is consumer and family driven.
- (3) Disparities in mental health services are eliminated.
- (4) Early mental health screening, assessment, and referral to services are common practice.
- (5) Excellent mental health care is delivered and research is accelerated.
- (6) Technology is used to access mental health care and information.

All of the Commission’s goals and the recommendations associated with them are organized around one key principle: that public mental health systems should be fundamentally transformed “to make recovery from mental illness the expected outcome from a transformed system of care.” This principle is consistent with the major goals of the Illinois System Restructuring Initiative (SRI) – consumer choice, financial and programmatic accountability, consumer access to services, and continuity of care – and provides a clear direction for mental health systems transformation at all levels of the service delivery system.

The Commission’s Final Report provides an important opportunity and a framework for states to assess their own mental health delivery systems in the context of these key goals and recommendations, and to use this information to develop a strategic vision and plan for transformation. The DMH has begun a strategic planning process to develop a 5-year action plan designed to ensure that mental health services and supports actively facilitate recovery and resilience. The strategic planning process includes the following core elements: (1) gaining a clear understanding of the statutory and

organizational context for transformation; (2) assessing strengths and challenges in the current system; (3) developing a revised mission and vision focused on consumer recovery and resilience as the critical outcomes; and (4) developing strategies for attaining and evaluating goals and objectives associated with the plan to ensure accountability. Most of the activities that have been undertaken to support the strategic planning process have occurred through focus groups with consumers, family members, advocates, providers and DMH staff. The process began with a retreat with DMH Executive Staff in late January 2005 that was facilitated by the team of consultants described above. The remainder of this chapter will describe the context in which the strategic plan is being developed, findings to date from the strategic planning process and recommendations for next steps.

Statutory and Organizational Context for Planning

From 1961 until 1997, the Illinois Department of Mental Health and Developmental Disabilities¹ was responsible for providing inpatient services and certain community-based services to people with mental illnesses in the state. In 1997, the powers and duties of that Department were consolidated, along with certain powers and duties of several other state agencies, into a single Department of Human Services.² 20 ILCS 1705/1 and 1705/2.

The Secretary of Human Services is authorized, by statute, to create subdivisions within the Department as appropriate. Currently, a Director who reports to the Assistant Secretary of Human Services heads the Division of Mental Health (DMH, formerly called the Office of Mental Health). The Director oversees staff and services provided to people with mental illnesses across nine geographic areas, known as Comprehensive Community Service Networks (or just “Networks”). These Networks are permitted but not defined by statute:

¹ The Department of Mental Health became the Department of Mental Health and Developmental Disabilities in 1973.

² The Departments of Mental Health and Developmental Disabilities, Alcoholism and Substance Abuse, and Rehabilitation Services, as well as parts of the Departments of Public Aid, Children and Family Services, and Public Health, were consolidated into the new Department of Human Services.

The Department may divide the State into districts for the purpose of regulating the admission of recipients to mental health facilities for persons with mental illness. 20 ILCS 1705/8.

Although the authorizing statute specifically provides a general mission statement for State-operated facilities,³ it does not articulate a mission for DMH or a specific mental health mission for DHS. However, state law does outline the authority and obligations of DHS with considerable specificity, including many clinical and programmatic matters such as discharge planning and the establishment of “continuous treatment teams” for individuals with three hospital admissions within a 12-month period.

A Network Manager heads each of Illinois’ nine Networks. Each of the Networks is responsible for administering one state hospital and purchasing community-based services in that geographic area, including services provided by community hospitals and Community Mental Health Centers (CMHCs).

Across the state, there are nine state-operated psychiatric hospitals, as well as seven private psychiatric hospitals and 34 general hospitals with psychiatric units. Many of these hospitals receive funds from DMH from its Community Hospital Inpatient Psychiatric Service (CHIPS) program for the provision of community based inpatient care. In addition, DMH contracts for services, through its regional Networks, with approximately 160 community mental health providers.

The statutory authority and organization of the Illinois Division of Mental Health create several issues and challenges for consideration as part of systems transformation:

(1) The authorizing statute is comprehensive in outlining powers and responsibilities for the Department of Human Services to provide mental health services

³ The statute provides that the “mission of State-operated facilities for persons with mental illness is to provide treatment, rehabilitation, and residential care to recipients admitted voluntarily or involuntarily because of their need for intensive services in a protective, secure setting. The Department shall offer services to a recipient within a State-operated facility as long as is necessary to accomplish stabilization of the recipient’s psychiatric status and treatment regimen or arrangements for appropriate continued services.” 20 ILCS 1705/4.1(a[0]).

The statute also requires each State-operated facility to develop and publish a mission statement that “specifically defines its role in the system of services for persons with mental illness” and to review and revise these statements every three years. 20 ILCS 1705/4.1(b). It is not clear to what extent State-operated facilities have complied with this statute.

in Illinois. It clearly contemplates a subdivision with authority over mental health services, but does not assign specific powers and duties to that subdivision (other than clinical and medical decisions, which are assigned to a board-certified psychiatrist serving as either the administrative director or the Chief for Clinical Services). 20 ILCS 1705/2 (e).

In fact, with the 1997 consolidation of the Department of Mental Health and Developmental Disabilities and other state agencies into the Department of Human Services, specific powers and requirements previously assigned to the Department of Mental Health and Developmental Disabilities became the responsibility of the Department of Human Services. Many stakeholders interviewed perceived the state's mental health authority as having a declining role in state policy decisions affecting people with mental illness and believed that the "transfer" of authority to an umbrella agency was a contributing factor.

(2) The authorizing statute emphasizes the Department of Human Services' responsibilities in meeting the medical/psychiatric needs of people with mental illnesses. In general, the statute does not address core principles of recovery, self-direction, or evidence-based practice. While the absence of statutory language supporting these goals does not bar the state from pursuing them, system transformation may be easier to accomplish when the legislature clearly articulates the goals and principles driving systems change.

(3) Effectively managing a system of nine Networks requires a clear vision for the respective roles of the Networks and the DMH Central Office in establishing policies related to the delivery of community-based services. Several people interviewed for this report suggested that the trend has been toward consolidating control over services in the DMH Central Office. The reasons for this are likely related to a need to maximize efficiencies with limited resources and to closely monitor the system during the transformation to a fee-for-service payment methodology. Several individuals advocated for strong Networks with significant authority to ensure that local needs and protocols are addressed. A lingering issue is the question of how DMH can lead Networks to embrace and implement core principles of recovery and strategies to achieve a recovery-oriented system.

(4) The management of the mental health system at the state level is somewhat complicated by the fact that key “Central Office” personnel are located both in Springfield and Chicago. The remote location of key staff is not unique to Illinois – several other states have large urban centers outside their capital cities and have key staff at all locations. Although technology has made it easier to bridge the distance between locations throughout the state, it remains a challenge for this system and others.

Roles and Functions of State Mental Health Authorities

States have a range of different powers that enable them to shape the public mental health system. To the extent that they are excluded from a role, their decision authority is significantly diminished. To the extent they are given sole responsibility for decisions, their decision authority is significantly enhanced.

The following are key elements of these powers:

- Allocation of funds available to support mental health programs of specific types (*e.g.*, case management, residential)
- Developing and disseminating new program models
- Contracting with specific providers to implement programs
- Approving new licensed capacity for services
- Licensing of programs
- Rate setting for reimbursement of services
- Determining population eligibility requirements for programs
- Assuring accountability of programs

In order to articulate and implement a coherent, effective policy, a state mental health authority must accept responsibility for the population of persons with a mental illness; historically this has focused particularly on adults with serious mental illness and children with serious emotional disturbance. However, the New Freedom Commission Report also emphasized a role in prevention. The difficulty faced by state mental health authorities, is that the powers enumerated above are not exclusively within their purview. Other state agencies often have a significant part of these responsibilities, despite the fact that consumers, family members, and advocates often expect that the state mental health authority can develop policies that shape the

screening, assessment, treatment, rehabilitation and support services available across the mental health system.

Shaping Service Delivery – The Role of DMH as the State Mental Health Authority (SMHA)

DMH has adopted a vision of recovery from serious mental illness as a guiding principle for the future (see below and Chapter III of this report). The two State agencies, in addition to DHS DMH, that have the authority to significantly shape mental health services are the Department of Public Aid (the State Medicaid agency) and the Department of Public Health. These two agencies are responsible for general hospital psychiatric care, both inpatient and outpatient, and residential care provided in nursing facilities. These agencies control significant mental health resources.

While DMH has been working toward major changes in policy and direction for the public mental health system, the programs managed by DPA and DPH may not move in the same direction. For example, as DMH has sought to move acute psychiatric care away from State-operated facilities into general hospitals, significant difficulties have been encountered in transferring this responsibility to the general hospital sector. While much of the country has been developing supported housing as a more appropriate model for residential mental health services, significant resources remain invested in nursing facilities, including many units that are not eligible for Federal Medicaid reimbursement, that follow an institutional model of care.

Although critical to implementing a different vision of the public mental health system, DMH does not have the authority to implement changes in policy that affect general hospital and nursing facilities. DPH and DPA are not the only other State agencies with which DMH shares its client population. The Department of Children and Family Services, the Department of Corrections, as well as local jails, and other agencies within the Department of Human Services (*e.g.*, the Division of Rehabilitation Services) also serve significant numbers of children and adults with a diagnosis of mental illness.

Despite the fact that each of these agencies purchase or provide mental health services for a portion of the population that they serve, mental health is not their

primary focus. DMH as the state mental health authority has the expertise and knowledge to serve as the principle architect of mental health policy in the State. DMH should partner with other state agencies in the development and implementation of a shared vision for public mental health services. As the President's New Freedom Commission recognized, significant transformation requires the collaboration of all state agencies that serve the population of persons with mental illness. At present however, DMH lacks the statutory authority and staffing to take this role. As noted previously, because of early retirement and attrition, currently DMH is challenged to properly implement its responsibilities for the programs that are directly under its control. Expanding its authority and its resources is necessary for DMH to be able to move forward in implementing a new vision of the public mental health system.

System Strengths and Challenges

At the January 2005 Executive Staff retreat, and during subsequent focus groups and meetings, stakeholders were asked to identify the strengths and challenges in Illinois' existing mental health system that can help to form a foundation for system transformation. Many stakeholders observed that a system's strengths and challenges are often related, and should be discussed in relationship to each other. While a broad range of strengths and challenges were suggested, a consensus emerged around a few key themes:

- (1) Illinois has a core base of experienced, dedicated mental health providers that provide a safety net for people diagnosed with mental illnesses and are committed to serving non-Medicaid as well as Medicaid populations.

There is acknowledgement by DMH administrators and providers that the SRI's transition to Medicaid fee-for-service reimbursement could have a significant impact on the ability of some providers to continue to provide the same level of services to the same consumers. DMH administrators and system stakeholders have also noted, however, that the transition to fee-for-service provides a unique opportunity to expand the adoption and implementation of evidence-based practices that are effective in promoting recovery.

All stakeholders emphasized the important role of providers in planning and implementing mental health transformation efforts. For example, the resiliency and experience of the state’s provider community provide stability and knowledge, but can also undermine efforts at reform if providers perceive that the proposed changes are against the interests of their agencies or the consumers of their services.

(2) Illinois has a strong academic base for research and evaluation activities in mental health. Northwestern University, Rush University, the University of Illinois, the University of Chicago, and other academic institutions are home to nationally recognized psychiatrists and researchers in mental health, helping to ensure continued quality of mental health leadership in the state. In addition to providing knowledgeable consultation and technical assistance, these stakeholders feel that the potential for partnerships between DMH and these academic leaders has been under-realized, and should be a focus of DMH’s strategic vision and plan.

(3) There is momentum within DMH and its stakeholder communities to move toward a recovery-oriented system of care. The SRI Task Force, for example, has developed a document called “A Philosophy of Recovery Oriented Services in Illinois,” which describes the philosophy as “plac[ing] an overriding emphasis on the potential of all individuals to recover from the challenging impact of psychiatric illness.” Stakeholders also cited a growing emphasis on developing a broad array of community-based services as an indication that the mental health system is relying less on inpatient and psychiatric treatment and embracing a broader understanding of services that can help consumers achieve recovery.

Some stakeholders pointed out, however, that there is not yet a clearly definition of what a recovery-oriented system of care is, and there is a widespread belief, particularly among consumers, that not all DMH staff, providers and consumers have a clear or shared understanding of the basic principles of a recovery-oriented system. Some consumers, for example, described “A Philosophy of Recovery Oriented Services in Illinois” as a list of available services rather than a discussion of *how* to deliver services to achieve the goal of recovery. Most stakeholders, including DMH leaders and staff, agreed that the current service delivery system will require a major transformation to become a recovery-oriented system of care.

(4) DMH has begun to develop and strengthen relationships with other state agencies that are essential to a comprehensive system of care for people with diagnosed mental illnesses. In particular, several stakeholders noted that an early, growing partnership between mental health and criminal justice was developing in some parts of the state. DMH has also been involved in statewide initiatives related to housing, employment and children's mental health as an indication of growing collaboration. Several stakeholders observed however, that DMH does not play a leadership role in many of the interagency activities in which it is involved. Many stakeholders felt that DMH's ability to foster effective relationships is hindered in part by underfunding, since DMH is not able to bring significant resources to the table in proposing collaborative initiatives.

(5) The issue of mental health has the current attention of the Illinois Legislature, Governor, and other stakeholders. The System Restructuring Initiative has facilitated the perception that the system is in motion, and most stakeholders understand that change is inevitable. While this creates obvious risks and concerns, it is also a unique window of opportunity for fundamental transformation.

(6) The Mental Health Transformation State Incentive Grant application process has already generated helpful cross agency dialogue with consumers around the statewide mental health system principles, vision, gaps and strategies. The momentum of this work will aid in the creation of the public health approach to mental health in Illinois. When Illinois receives funding, additional resources will be available to further this approach.

(7) DHS is the lead for developing and implementing a disability services plan with the Disability Services Advisory Council, which by law includes other state agencies. This plan will improve client choice about where they receive service, consistent with the Americans with Disabilities Act and the Olmstead decision.

Mission and Vision

The development of clear and meaningful mission and vision statements is essential to guide mental health transformation consistent with the goals and recommendations of the President's New Freedom Commission on Mental Health and the SRI. An important principle is that the mission and vision statement must be

developed in consultation with a broad range of stakeholders, especially those who receive services from DMH, and should focus on recovery as the goal of public mental health services.

In the strategic planning retreat attended by senior DMH staff and regional managers in January 2005, participants identified redefining the role of DMH within state government – and the role of mental health within the broader health and human services communities – as a principal goal to be achieved over the next 3-5 years. The following objectives were identified as key components of effective mental health transformation in Illinois:

(1) Increase DMH’s leadership role, consistent with state statute, with respect to policies and the allocation of resources for programs and services that affect people diagnosed with mental illnesses. Retreat participants emphasized that this objective did not suggest greater *control* over resources or policy decisions. To the contrary, this objective would diffuse ownership over DMH programs in the sense that it would invite greater collaboration across agencies and service systems, along with a recognition that DMH is the locus of mental health expertise and direction. It would also increase DMH involvement in policies and programs administered by other agencies, encouraging collaboration to ensure that all programs and services affecting people diagnosed with mental illnesses support a common recovery-oriented vision.

(2) Integrate mental health services with other health and human services so that they are seamless – or appear to be seamless – to consumers and their families.

(3) Emphasize relationships and partnerships across agencies and service delivery systems.

In subsequent meetings with DMH staff, providers, and other stakeholders, these objectives repeatedly surfaced as essential components of a revised mission for DMH. Stakeholders suggested that the statute authorizing the mental health activities of the Department of Human Services contemplates such a leadership role; indeed, a principal purpose for the 1997 consolidation of agencies into the Department of Human Services was to promote integration across service delivery systems.

During the focus groups and meetings, stakeholders were also asked to describe key components of an ideal mental health system. Several areas of consensus emerged.

In particular, it was generally agreed that an ideal system of care in Illinois would have the following characteristics:

(1) The system would be focused on recovery as the goal of service delivery, and would emphasize outcomes rather than the services themselves. This is a significant departure from the current DMH vision statement, which does not address the effectiveness of services in helping consumers achieve recovery. In this new vision, consumer goals would be owned by the larger stakeholder community and embraced as system goals.

(2) Data and information would drive policy and program decisions. Many stakeholders observed that the DMH currently has a significant capacity to collect and process data, but not to analyze it or disseminate relevant information.

(3) Each person receiving services from the public mental health system would actively participate in developing an individualized service plan. An ideal system of care would avoid discrimination and other negative implications of labeling individuals with a specific mental health disorder and relying on that diagnosis to provide services. Stakeholders contrasted this with the current system, in which services and supports often are provided according to a person's diagnosis, often without regard to the kinds of services the person actually needs and wants.

(4) Mental health consumers and advocates would have an increased role in shaping mental health policy, including more influence in the allocation of scarce health and human services resources.

DMH administrators and other stakeholders identified several tensions within the mental health system that must be addressed and reflected in the revised mission and vision statement. Two inter-related issues are particularly important:

(1) **Target populations.** Traditionally, the target populations for the public mental health system in Illinois have been adults diagnosed with serious mental illnesses (SMI) and children diagnosed with severe emotional disturbances (SED). The prevalence rate for adults with diagnosed with severe mental illness in the state is approximately 5.4 percent and the prevalence rate for children with diagnosed with severe emotional disturbances is approximately 7 percent. (NASMHPD Research Institute, Inc., State Mental Health Agency Profiling System: 2002)

In a document describing core services that DMH purchases at the Network level, DMH distinguishes between target populations and other individuals who may be eligible to receive some DMH services:

[DMH] uses the concepts of eligible and target populations to demarcate a broader (eligible) population who meet minimum criteria for services and **may** be served, contingent upon availability of resources, and a narrower priority (or target) population who **must** be served.

Mental Health Programs and Services: Department of Human Services (effective date April 9, 1997), available at

http://www.dhs.state.il.us/mhdd/mh/pdf/dhs_mhdd_mh_progBook.pdf.

DMH's existing mission statement clearly identifies individuals with diagnosed with SMI and SED as target populations. Retreat participants and some other stakeholders expressed concern that this approach results in a very small number of people receiving large amounts of services, and large numbers of people who need services having no access to services at all. In separate meetings with other DMH staff, there was considerable agreement that the allocation of resources for specific populations and services should be reconsidered, often suggesting that some resources be diverted to provide preventive and early intervention services. One staff member noted: "If you only treat casualties, you'll always have the same number of casualties."

Some retreat participants suggested that target populations – and the range of services available to them – should be strategically redefined to ensure that scarce resources are used most effectively to maximize outcomes. This may lead to a tiered service system, based on the principle that the mental health system should provide the right services in the right amounts to the right people at the right time.

Some providers observed that, to some extent, financing strategies at the state level are driving a *de facto* definition of the target population as being individuals who are Medicaid-eligible. At least one provider placed this issue in the context of the relationship between DMH and providers. Historically, many providers have seen themselves as *partners* with DMH, receiving funding to develop programs and provide needed services to the target population, defined by DMH in its mental health

policymaking role. Under the SRI, providers are seen as *vendors*, providing services to individuals not because they are part of a target population but because they are eligible to receive Medicaid and the services are reimbursable.

(2) **The theoretical framework for the delivery of public mental health services.** DMH administrators emphasized that mental health is a public health issue, and that services should be provided within a public health framework. This approach is sometimes contrasted with a human services framework or a medical model of services, with implications for identifying target populations and allocating resources within the service system. For example, a public health approach to mental health likely would include primary prevention and early intervention services – concepts that have not traditionally been included in DMH’s current mission or vision statement, but are explicitly provided by the DHS.

A Vision For the Mental Health Service Delivery System

In summary, the information gathered from the series of meetings and interviews conducted with mental health stakeholders over the last few months, as well as the work of the System Restructuring Initiative, clearly point to a vision for the Illinois mental health system in which recovery is the expected outcome. This vision calls for mental health consumers and advocates to have an increased role in shaping mental health policy and more influence in the allocation of health and human service resources. All persons receiving services will actively participate in developing individual service plans that reflect their goals. Services provided/purchased through by the mental health system will be outcome-focused, and state-of-art treatments will be provided. The mental health system will be accountable to stakeholders by using data to drive policy, financing and program planning decisions.

There are many challenges to be faced in the transition to a recovery-oriented system. In effect, the mental health system must undergo a transformation in attitudes and values. Mechanisms must be put in place to support the development, delivery and financing of services that support recovery. The next chapter defines what is meant by recovery; the initiatives currently occurring in Illinois that support the transition to a

recovery oriented system, and recommendations and strategies for advancing the recovery agenda in Illinois.

III. Goal: Mental Health Care is Consumer and Family Driven

In its final report, “Achieving the Promise: Transforming Mental Health Care in America,” the President’s New Freedom Commission (2003) called for a transformation of the nation’s mental health system that would “involve consumers and families fully in orienting the mental health system toward recovery.” The report noted that currently “consumers and families do not control their care,” and went on to make recommendations for creating a recovery-oriented system that is driven by the self-defined needs of people who use mental health services.

Since the mid-1980s, much has been written about recovery and the environmental factors necessary to promote it, particularly by people with psychiatric histories (see, for instance, Campbell, 1989; Deegan, 1988; Zinman, et. al, 1987; Chamberlin, 1984). However, the idea has only recently begun to gain general acceptance in the public mental health field. In the last few years, there has been much discussion (and much confusion) about recovery within the field, but little in the way of concrete action to make the changes necessary to transform the system. This dearth of action may be due, in part, to a general lack of clarity among public mental health officials and clinicians about what is meant by recovery, and about what changes in policy, assumptions, attitudes, funding streams, and service delivery are required to create a system that will facilitate recovery.

What is “recovery?”

What is meant by the term “recovery” in the context of a diagnosis of serious mental illness? In general terms, “recovery” is short-hand for the idea that such a diagnosis need not preclude one from living a satisfying and productive life; that serious mental illness is not an inevitably deteriorating condition with a poor prognosis that results in life-long disability and dependency. It is the idea that most people with psychiatric diagnoses can, in fact, “get better;” that they are capable of moving beyond their illness labels, out of the socially de-valued role of “mental patient,” and can build their own lives as self-directed members of their communities.

The President’s New Freedom Commission (2003) defines recovery as “the process in which people are able to live, work, learn, and participate fully in their

communities.” The National Association of State Mental Health Program Directors (NASMHPD/NTAC, 2004) calls recovery the “basic human right to feel better.” According to consumer/researcher Ruth Ralph, “Recovery can be defined as a process of learning to approach each day’s challenges, overcome our disabilities, learn skills, live independently and contribute to society. This process is supported by those who believe in us and give us hope.” Ralph, along with an eight-member Recovery Advisory Group of consumer/survivor leaders (1999), developed a complex visual model of the recovery process. This model is based on the assumption that recovery is a highly individualized, non-linear process that is strongly affected by internal and external influences (both positive and negative), in which a person moves from despair toward healing, well being and wholeness.

Shery Mead and Mary Ellen Copeland (NASMHPD/NTAC, 2004) refer to “life change and transformation—not returning to a former way of being, but going forward to create a new, exciting, and rewarding life.” Patricia Deegan (2004) writes of “the innate self-righting capacity, or resilience, of people with psychiatric disabilities.” Resilience, a central premise in the conceptualization of recovery, is defined by Priscilla Ridgway (2004) as “the capacity of people faced with adversity to adapt, cope, rebound, withstand, grow, survive and even thrive.”

Is recovery really possible?

There is significant empirical evidence from a number of longitudinal studies across the globe demonstrating that between one-half and two-thirds of people diagnosed with schizophrenia either significantly improves or completely recover over time. In the seven such longitudinal studies from the 20th century, the criteria for recovery were: “no significant signs or symptoms of any mental illness, no current medications, working, relating well to family and friends, integrated into the community, and behaving in such a way as to not being able to detect [their] having ever been hospitalized for any kind of psychiatric problems,” a standard much more rigorous than the definitions discussed above.

Patricia Deegan points to even earlier studies demonstrating that recovery is not a modern phenomenon. She cites an 1881 study at Worcester State Hospital in Massachusetts that found that 51% of those discharged between 1833-1840 remained

well as long as they lived; a follow-up study found that 58% of patients discharged between 1840 and 1893 remained completely recovered (NASMHPD/NTAC, 2004). The evidence shows that recovery rates have remained fairly constant for the last 170 years, despite many changes in treatment philosophy and the introduction of psychiatric medications in the 1950s. It appears that something other than treatment must be involved in recovery.

What impedes and what promotes recovery?

What is known about the factors that create an environment that encourages and supports recovery? There is widespread agreement among practitioners and authors who are actively involved in the recovery field that many common practices of the existing mental health system do not promote recovery, but in fact create impediments to the process. These practices include: a lack of consumer choice in treatment, service provider, housing, and the use of medication; the lack of meaningful consumer and family involvement in decision-making, both at the system level and in their own service plans; focusing on people's perceived deficits rather than on their strengths; requiring consumers to fit into rigid program models that do not meet their individual needs; policies and service designs which ignore the fact that most psychiatric patients are trauma survivors; and the use of coercive measures such as restraint and seclusion, inpatient and outpatient commitment, forced medication, and the linkage of housing to treatment adherence (Onken, et. al, 2002; Ralph, 2000; Ralph & Recovery Advisory Group, 1999; Penney, 1997).

Patricia Deegan (NASMHPD/NTAC, 2004) finds that the biggest obstacle to recovery is “the creation of service models, and the organizing of services around models, as opposed to encouraging individualized supports with individual budgets for living in the community. She notes “services should be a means to an end—living a full and meaningful life in the community... Recovery is a person-centered phenomenon. You can't ‘do recovery’ to someone. You can't ‘do services’ that will force someone to recover. Recovery-based services will always be one small part or one small ingredient for a person with psychiatric disabilities to achieve a meaningful life in the community.”

Bill Anthony (2004) believes that “the vision of recovery is foreign to what has been masquerading as the mental health vision for the last century... If we are serious

about the vision of recovery, then the mental health system of the last century—which for the most part was a system characterized by low expectations, control, and no consumer-based vision—must disappear.” Anthony points out that these changes will not happen until leaders of mental health systems adopt the values that underlie a recovery orientation, and ensure that all of the decisions they make about policy, budgeting, human resources, and other matters are fully consistent with recovery values. He also emphasizes that consumers and family members must be integral to the planning process if a transition to a recovery-oriented system is to occur.

Among the values discussed in the literature as essential to a recovery-promoting environment are self-determination; hope; risk-taking and the freedom to fail; real choice among genuine alternatives; availability of self-help and peer support services; full and genuine partnership between consumers and providers; recognition that each person’s recovery journey is unique; putting people (not program needs) first; enhancing each person’s growth potential; dealing honestly with issues of power and control; and listening to consumers and understanding them in the context of their lives (Farkas, Gagne, Anthony, & Chamberlin, in press; Deegan, 2004; NASMHPD/NTAC, 2004; Ridgway, 2004; Penney, 1997; Deegan, 1988).

Implementing these recovery values will mean re-thinking most of the current assumptions under which the mental health system operates. Anthony (2004) notes that one way to determine whether a system is moving toward a recovery orientation is to look at its mission and policy statements. “To assist people to improve their functioning so that they are successful and satisfied in the environment of choice” is a recovery-oriented mission statement, he says; “To provide continuous and comprehensive services to mentally ill clients” is not. Creating an environment in which recovery can flourish is primarily a matter of changing assumptions and attitudes, abandoning policies and program structures that create barriers to recovery, and creating a system that has the flexibility to respond effectively to individual wants and needs.

Strengths - Current Efforts in Illinois to Promote Recovery

There are several recovery-oriented initiatives already underway in Illinois. Perhaps the most successful to date is the implementation of the Wellness Recovery

Action Plan (WRAP) throughout the state by DMH's Bureau of Consumer Services Development in 2002. WRAP is a recovery-based practice using a self-help framework to assist people in developing individual recovery plans based on their self-identified needs and wishes. The program, developed by Mary Ellen Copeland, is based on the principles of hope, personal responsibility, education, self-advocacy, and support. WRAP provides a simple system for people to monitor and manage their own emotional and mental states, and to learn to avoid habits or behavior patterns that are problematic for them. WRAP uses the concept of "wellness tools" — simple actions that anyone can do to feel better. Participants learn how to create a personal "toolbox" for their own use in times of stress. More than 100 people in Illinois (most of them people with psychiatric histories who are in recovery) have been trained as WRAP facilitators, and WRAP is available at 50 mental health centers across the state.

DMH's Bureau of Consumer Services Development is also planning a collaborative effort for later in 2005 with the Department of Rehabilitation Services and the Peer to Peer Resource Center to establish a training and certification process for Recovery Specialists, who will be people with psychiatric histories working inside the mental health system.

The Knowledge Corner, a Chicago-based organization of consumers of color, has developed a faith-based, self-help manualized recovery program for people with both mental health and substance abuse diagnoses. This program has been successfully implemented in the Cook County Jail and in mental health programs throughout the region.

"Stories of Recovery" is the title of a consumer speaker's bureau operating under the auspices of the Mental Health Association of Illinois Valley, funded by federal Block Grant monies. Based on the concept that sharing one's personal story is both a source of personal growth and the opportunity to demonstrate the possibility of recovery, the project creates a vehicle for people in recovery to tell their personal stories to community groups.

The System Restructuring Initiative (SRI) Task Force has acknowledged the importance of developing recovery-oriented services in Illinois by the development of a working document that discusses the philosophy of recovery. Under the System

Restructuring Initiative, there is also a pilot effort to implement the Recovery Oriented System Indicators (ROSI) measure, an evaluation tool developed by Steven Onken and colleagues (2002) as part of a national research project to develop recovery –oriented performance indicators. The ROSI instrument bridges the gap between the principles of recovery and self-help—choice, hope, purpose, relationships, self-determination, empowerment, citizenship, resources, opportunities—and the real-world application of these principles in the everyday work of staff and service systems.

Challenges to the Transition Toward a Recovery-Oriented System

Interviews and focus groups with consumers (inpatients, outpatients, and consumers who work inside the system), advocates, DMH staff, and community-based providers raised some significant policy and practice issues that must be addressed if the system is to become more recovery-friendly.

Medication and Treatment Issues

Complaints about treatment, particularly about medication practices, were the most frequently raised issues by consumers. There was general agreement that psychiatrists often do not explain medications to people, discuss possible side-effects, or give consumers enough information to make informed choices. In addition, several people voiced concern about being assigned caseworkers that were not a good fit for them. The lack of flexibility in the system with regard to affording consumers' choice in selecting staff to work with them was commonly expressed as problematic.

Housing

Housing was the second most frequently discussed issue by consumers, specifically their concerns about the approximately 15,000 people with psychiatric diagnoses who currently live in nursing homes. People felt strongly that nursing home placement is not conducive to recovery. Other people spoke about the difficulty of getting even poor-quality housing once landlords learned they were on disability benefits. Participants also mentioned the need for transition services to help people leave nursing homes, the need for more affordable housing, and the need for supported housing. Advocates, DMH staff and community providers spoke of the need for the expansion of supported housing in order to create a viable alternative to nursing homes.

Lack of Self-Help and Peer-run Services

There are only a handful of consumer-run organizations in Illinois, and none of them receive state funding. While some groups see that as a positive thing, because they are not beholden to DMH, others believe that DMH should be more actively involved in funding peer services. Consumers of color emphasized that there is a need for more self-help activities that are rooted in the African-American experience. Hispanic consumers also voiced a need for peer services that reflected their culture and were welcoming to Spanish-speaking people.

Lack of Meaningful Consumer and Family Involvement

As noted elsewhere in this chapter, consumers working in the system believe that task forces, advisory bodies, and other groups convened to provide input on both the state and local level are dominated by providers, and that there is at best only token involvement of consumers and families. This opinion was echoed by other DMH staff and by consumers who do not work in the system. This issue is closely connected to an issue raised above about the lack of self-help and consumer-run programs. DMH plays only a minor role in assisting consumer and family groups financially or with training and technical assistance. The lack of financially secure, mature and well-informed consumer and/or family constituency organizations will make it difficult to instill recovery values into the system.

Employment

For people who are current recipients of mental health services, the need for job training and employment was a key issue. As one man put it, “Half my problems would be over if I could get a job.” Many consumers expressed a desire to work, but said that they were either discouraged in their goals by staff, or that they were afraid that working would interfere with their benefits. Many noted that there are very few vocational programs available to them. Others expressed an interest in returning to school, but said that staff did not support this idea.

The consumers who work inside the mental health system expressed a range of concerns and frustrations. DMH consumer specialists reported that they did not receive equal pay and benefits across the networks; some are state employees with full benefits, and others are individual contractors without benefits. While health benefits were seen as vital to people in recovery, many consumer specialists felt relegated to “contract”

positions without benefits because they did not meet the standards for existing official job classifications.

Recommendations for Furthering the Recovery Agenda

1. In collaboration with stakeholders, build consensus on a recovery vision and educate all stakeholders about recovery philosophy and practice

There was a consensus among the stakeholders interviewed that there is little understanding within the public mental health system in Illinois about what recovery is and what changes are required to promote it, and this is a significant barrier to moving forward. One common mistake made when mental health agencies try to re-orient a system toward new values is to make firm plans and push through changes based on insufficient or incorrect understandings of the new values and the extent of change required. Therefore, consensus on a recovery vision followed by the development and implementation of comprehensive educational programs, materials, and discussion groups about recovery are essential first steps toward ensuring that DMH and other state agency management and staff, community-based providers, legislators, family members, advocates, and consumers are familiarized with the latest information on recovery issues.

2. Support independent stakeholder constituency groups and strengthen consumer and family involvement in decision-making.

Illinois does not have strong, well developed and supported consumer or family groups or advocacy organizations, and thus lacks the kind of financially secure, mature and well-informed constituency organizations that make it possible for states to maximize consumer and family involvement at all levels of decision-making. Supporting these groups both financially and with technical assistance is key to developing leadership and strengthening stakeholder involvement, both of which are vital to systems change. There is a need for DMH to make a commitment to ensuring significant and meaningful consumer and family involvement at all levels of the system.

As part of this process, DMH should commit to providing support to its consumer services staff and to involving them more integrally in leadership and decision-making; their voices will be key in developing a recovery vision and strategy. An important step would be to redefine the consumer services specialist positions as civil service jobs with a consistent job description, salary and benefits across networks, to eliminate the current inequities across networks.

3. Develop a viable plan for implementing the *Olmstead* Decision

The U.S. Supreme Court's 1999 decision in the case of *Olmstead v. L.C.* held that unwarranted institutionalization of people with disabilities is a form of discrimination, and mandated that states develop and implement plans to move unnecessarily institutionalized people to the least restrictive setting possible. In 2004, the Disability Services Act was passed to create a Disability Services Plan that addresses the *Olmstead* decision and the Americans with Disabilities Act. DHS is the lead. The inappropriate institutionalization of thousands of Illinois citizens in nursing homes and IMDs is perhaps the single most significant barrier to implementing a recovery vision. As a consumer in a focus group stated, "You can't have a recovery plan without a plan to get out of the nursing home." The issue of nursing homes and IMDs is a problem of crisis proportions that needs to be addressed as quickly as possible if the people kept unnecessarily in these institutional settings are to have a chance at recovery.

4. Systematically review and address other current policies and practices that interfere with recovery

As discussed earlier in this chapter, consumers in Illinois have identified some current practices that they believe significantly impede their recovery. These include inflexible treatment and medication protocols, dependence on nursing homes, inadequate supported housing, insufficient training and employment services, and too few peer-run services.

These and other significant barriers must be addressed if a recovery-oriented system is to become possible. Many of these problems are rooted in policies and procedures that are outdated and at odds with a recovery orientation. Program history and an interest in maintaining the status quo are also at play. A very significant barrier is the negative assumptions and attitudes about people with psychiatric disabilities that are rife within the public mental health system across the nation. In many cases, it is these attitudes and assumptions, not money that is the primary obstacle to moving the system toward a recovery orientation. These problems are long-standing, complex, and it will require both a clarification of values and political will to develop a plan for reform. A willingness to listen to consumers' views and to grapple seriously with these issues is key to moving forward.

IV. GOAL: Address Mental Health with the Same Urgency as Physical Health - Financing Illinois' Public Mental Health System

The financing mechanisms used to support a state's public mental health system are governed by two sometimes competing interests: to provide access to quality services that help clients meet their goals, and to control the State's financial exposure. The optimal financing system would be one that is values-driven – that is, the financing mechanisms should facilitate rather than impede programmatic goals – and also controls costs in a responsible way. As Illinois moves toward a new fee-for-service payment model at the same time that it is making a commitment to design a more recovery-oriented system, finding a balance between the competing interests described above takes on a new urgency. While financing for a recovery-oriented system would ideally involve tailoring funding mechanisms to support recovery values, Illinois finds itself in the position of implementing a new payment model before it has reached a consensus on what a recovery-oriented system would look like.

The chapter looks at Illinois' current mental health financing package from a variety of perspectives. To illustrate the State's relative commitment to its poor and uninsured residents with mental illness, we will examine how Illinois' current public expenditures compare to those of states in its region and to other large states across the country.

The intent of this chapter is to present relevant information and options to inform stakeholders' future deliberations on maintaining or changing the design of the current system, the level of resources, which are made available to support the system, and the distribution of available resources.

Current Expenditures Supporting the Illinois Public Mental Health System

The first series of tables below shows Illinois public support for its mental health services in the context of six nearby states and seven other states commonly referred to as "large states." The expenditure data are from reports prepared by the Kaiser Family Foundation and the National Association of State Mental Health Program Directors

(NASMHPD) Research Institute, Inc. These data sources have limitations common to all aggregate data collected by state: states have different types of administrative and political organization; differing budgeting and appropriations methods; differing understandings by individuals completing surveys in each state; and missing data. While it is not possible for any survey to anticipate all of the dissimilarities among the states, these data do allow some qualified comparisons among states.

Table 1. Demographic Profile of the States

	Population (est. 2002)	Number of Medicaid enrollees – June 2003	Percentage of population enrolled in Medicaid	Percentage of population in poverty - 2003
Illinois	12,578,007	1,530,809	12.2%	12.6%
Indiana	6,157,831	736,082	12.0%	9.9%
Iowa	2,936,276	261,288	8.9%	8.9%
Michigan	10,047,938	1,310,333	13.0%	11.4%
Missouri	5,656,382	931,453	16.5%	10.7%
Ohio	11,413,894	1,565,272	13.7%	10.9%
Wisconsin	5,440,184	631,376	11.6%	9.8%
California	34,952,231	6,408,019	18.3%	13.1%
Florida	16,642,363	1,982,202	11.9%	12.7%
Massachusetts	6,423,309	913,496	14.2%	10.3%
New Jersey	8,581,768	810,151	9.4%	8.6%
New York	19,134,061	3,760,803	19.7%	14.3%
Pennsylvania	12,330,785	1,567,438	12.7%	10.5%
Texas	21,658,836	2,576,733	11.9%	17.0%
US Total	287,127,700	40,553,151	14.1%	12.5%

Illinois is the fifth most populous state and has the seventh largest number of Medicaid enrollments. It has the greatest percentage of its population in poverty among the states in its region and its percentage in poverty is about the national mean. Notably, Illinois is the only state in its region whose Medicaid enrollment as a percentage of its population is less than the percentage of its population in poverty. Among the other large states during this timeframe, only Florida and Texas have fewer persons enrolled in

Medicaid than the percent of their population “in poverty. It must be noted that recent expansions in eligibility have pushed enrollment in Illinois’ Medicaid program over two million individuals.

Table 2. General Medicaid and Mental Health Expenditure Profile

	Total Medicaid exp. - 2002 (000,000)	Total Medicaid expenditures per capita	Total Medicaid expenditures per enrollee (Annual)- 2000	Total SMHA-controlled Mental Health expenditures - 2002 (000,000)	Per Capita Mental Health expenditures - 2002	Percentage of median US per capita MH Exp	State ranking of per capita MH Exp
Illinois	\$8,976	\$714	\$3,806	\$865	\$68.79	98.20%	31
Indiana	\$4,476	\$727	\$3,905	\$427	\$69.40	99.10%	28
Iowa	\$2,603	\$887	\$4,559	\$157	\$53.45	76.30%	40
Michigan	\$7,603	\$757	\$2,571	\$916	\$91.14	130.20%	17
Missouri	\$5,442	\$962	\$3,282	\$391	\$69.10	98.70%	29
Ohio	\$9,750	\$854	\$4,966	\$699	\$61.21	87.40%	35
Wisconsin	\$4,251	\$781	\$4,657	\$493	\$90.56	129.30%	18
California	\$27,165	\$777	\$2,068	\$3,656	\$104.61	149.40%	14
Florida	\$9,978	\$600	\$3,131	\$736	\$44.24	63.20%	46
Massachusetts	\$7,909	\$1,231	\$4,862	\$690	\$107.36	153.30%	13
New Jersey	\$7,822	\$911	\$5,501	\$1,036	\$120.69	172.40%	9
New York	\$36,839	\$1,925	\$7,609	\$3,527	\$184.32	263.20%	2
Pennsylvania	\$12,214	\$991	\$3,584	\$2,053	\$166.48	237.80%	3
Texas	\$13,638	\$630	\$3,284	\$833	\$38.46	54.90%	49
US Total	\$248,723	\$866	\$3,762	\$25,166	\$87.65		
US Median					\$70.02		

This table combines data from the Kaiser Foundation and NASMHPD. It illustrates Illinois’ financial commitment to the health needs of its poorest citizens and to the mental health needs of that group, as compared to other states in its region and to large states.

In terms of overall Medicaid expenditures per enrollee, Illinois is about at the national average. The six neighboring states, on average, spend a little more per enrollee. Three of the seven large states spend more per enrollee, and four spend less. Regarding per capita public mental health expenditures (limited to those of the mental health

agency), the picture is more complex. Illinois' per capita mental health expenditures are at about the median of the six nearby states. Illinois also spends far less on per capita mental health expenditures than five of the seven large states. Compared to the nation as a whole, both Illinois' calculated expenditure rate and its rank are below the median.

	State Psych Hospitals	Community Hospitals - Inpt	All Comm Res Exp, incl IMDs	All Ambulatory Programs	All State Op Inpt, Adm + Res	Total SMHA Comm Prov Expend	Total Per Capita MH Expend	State Operated MH, Adm + Res as % of Total Exp	State Psych Hosp Exp As % of Total	All Hospital Exp as % of Total
Illinois	\$22.29	\$12.86	\$9.86	\$22.31	\$23.76	\$45.02	\$68.79	34.50%	32.40%	51.10%
Indiana	\$24.12	\$0.00	\$0.00	\$44.60	\$24.80	\$44.60	\$69.40	35.70%	34.80%	34.80%
Iowa	\$12.85	\$0.83	\$11.94	\$44.58	\$13.04	\$40.42	\$53.45	24.40%	24.00%	25.60%
Michigan	\$27.97	\$11.09	\$18.67	\$32.61	\$28.76	\$62.38	\$91.14	31.60%	30.70%	42.90%
Missouri	\$28.67	\$0.50	\$6.64	\$31.20	\$36.22	\$38.35	\$74.57	48.60%	38.50%	39.10%
Ohio	\$16.50	\$0.85	\$4.14	\$37.21	\$19.01	\$42.20	\$61.21	31.10%	26.90%	28.30%
Wisconsin	\$29.45	\$14.55	\$6.52	\$39.80	\$29.69	\$60.87	\$90.56	32.80%	32.50%	48.60%
California	\$17.91	\$8.72	\$7.71	\$69.32	\$18.86	\$85.75	\$104.61	18.00%	17.10%	25.50%
Florida	\$23.46	\$5.53	\$5.43	\$9.24	\$24.04	\$20.20	\$44.24	54.30%	53.00%	65.50%
Massachusetts	\$19.60	\$13.33	\$35.78	\$35.40	\$23.71	\$83.65	\$107.36	22.10%	18.30%	30.70%
New Jersey	\$39.35	\$19.46	\$13.24	\$47.10	\$40.89	\$79.80	\$120.69	33.90%	32.60%	48.70%
New York	\$55.02	\$26.70	\$20.70	\$74.26	\$82.00	\$102.33	\$184.32	44.50%	29.90%	44.30%
Pennsylvania	\$32.34	\$14.00	\$2.28	\$116.61	\$33.60	\$132.88	\$166.48	20.20%	19.40%	27.80%
Texas	\$15.03	\$1.51	\$0.00	\$20.63	\$16.32	\$22.14	\$38.46	42.40%	39.10%	43.00%

Table 3 shows expenditures by the program categories in which state-controlled mental health agency funds were spent, as reported to the National Association of State Mental Hygiene Directors. Missouri, Florida, New York and Texas were the only states where state-operated expenditures represented a greater percentage of overall mental health expenditures than Illinois. (Illinois, Indiana and New Jersey are about equal in the state agencies' direct share of each state's overall mental health expenditures.) However, these data are from 2002 and do not include significant reductions of state-operated hospital beds in Illinois which have occurred since. With these reductions, Illinois cut state-operated hospital operations by about 10%. This would place Illinois in the lower third of these 13 comparison states with respect to expenditures for state-operated psychiatric hospitals.

Table 4. Sources of Funds for Community Mental Health Programs– 2002

(000,000s)	State Gen Fund + State Sh of MA + Local \$	Fed Share of MA	Other	Total	Fed MA % of State, Local + Fed MA
Illinois	\$428	\$138	\$18	\$585	24.40%
Illinois - Fee-for-Serv projection	403	163			28.80%
Indiana	\$146	\$116	\$14	\$276	44.20%
Iowa	NA	NA	NA	NA	NA
Michigan	\$392	\$229	\$13	\$635	36.90%
Missouri	\$146	\$73	\$17	\$236	33.30%
Ohio	\$312	\$183	\$30	\$525	37.00%
Wisconsin	\$257	\$68	\$8	\$333	20.90%
California	\$2,055	\$869	\$107	\$3,030	29.70%
Florida	\$272	\$0	\$74	\$346	0.00%
Massachusetts	\$545	\$107	\$16	\$668	16.40%
New Jersey	\$554	\$72	\$60	\$685	11.40%
New York	\$991	\$417	\$416	\$1,823	29.60%
Pennsylvania	\$1,081	\$415	\$164	\$1,659	27.70%
Texas	\$380	\$89	\$39	\$507	18.90%

Table 4 displays Medicaid expenditures for community mental health programs in comparison states. In 2002, Illinois Medicaid participation, as measured by the federal share of Medicaid reported to NASMHPD, was nearly 25% of the total of state general payments for community mental health programs. Note that this percentage was lower than all but one of the neighboring states and three of the seven other large states. Line two of the table shows the change in the calculation when the projected \$50 million increase in gross for Illinois' community mental health programs and the commensurate decrease in State General funds is accounted for. Illinois will still, in aggregate, trail five of its six neighboring states, but will nearly match the federal Medicaid participation rate of the highest of the other large states.

These data do not compare the programs and policies underlying these expenditures. For example, this data does not include the cost of care provided in nursing

facilities funded by the Department of Public Aid, including institutions for mental disease (IMDs) which are large residential programs where a majority of residents have a psychiatric illness. Most other states do not have comparable programs.

Eligibility criteria for the Medicaid program are different in the various states. Illinois does not generally provide Medicaid coverage for single poor adults who do not meet federal disability standards. Other states do provide this coverage and have been approved to receive federal Medicaid reimbursement for some or all of them via waivers. (A basic requirement of a waiver is that the change be cost neutral to the federal government; i.e., no increase in federal Medicaid spending.) If Illinois had comparable Medicaid eligibility standards, its Medicaid participation in its community mental health program might be higher.

It is important to note that the percentage of states' Medicaid expenditures reimbursed by the Federal government, the Federal Medical Assistance Percentage ("FMAP") varies significantly among the states presented in this comparison. A state's FMAP is determined by the relative wealth of the state. Illinois has always been among the states with the lowest level of FMAP, along with Massachusetts, New Jersey, and New York. Each of these states receives federal matching funds equal to only 50% of total state expenditures. Other states in this comparison had FMAPs ranging from 51.40% to 61.06%, meaning that total expenditures represented a comparably smaller commitment of state funding.

How Community Mental Health Services Have Been and Will be Financed

The Illinois Division of Mental Health (DMH) is beginning a new era in the financing of publicly supported mental health services for individuals diagnosed with serious mental illness and other poor and uninsured individuals. In response to budgetary constraints, the Governor and State Legislature set a target for DMH to increase its anticipated Medicaid reimbursement for DMH-funded mental health programs by about \$50 million (gross, including both federal and state shares of Medicaid) over the actual Medicaid reimbursement in prior years. At the urging of providers, the State Legislature, Governor, Department of Human Services (of which DMH is a Division) and providers executed several agreements governing the circumstances of the transition from the

previous relationship between the State and State-funded mental health providers to the new relationship.

The transition activities are being planned through four subcommittees of the Strategic Restructuring Initiative (SRI), Finance, Access and Eligibility, Services and Pilot Test. The breadth of the assignments and the commitments of time and resources by state staff and state-paid consultants, provider executives and staff and consumers are testament to the general appreciation of the consequences of the changes associated with the new revenue targets.

Current Funding

Illinois' financing of DMH-supported mental health services through FY 2004 may be described primarily as grant-in-aid awards combined with fee-for-service billing for Medicaid services. The amount DMH spent on the state's funded outpatient community mental health system totaled about \$350 million for all ambulatory and residential services, including Medicaid expenditures of about \$146 million. About \$277 million of these total payments were awarded to providers in advance, as grants. As providers billed for Medicaid services, a portion of these grant funds were applied to the costs of providing Medicaid services. DMH expanded service capacity by funding providers with an additional payment equal to one-half of the value of the approved Medicaid bills.

FY 2005 Fee-for-Service Changes

Illinois' FY 2005 payment strategy, referred to as the "fee-for-service" initiative, will, when fully implemented, materially change the DMH-provider relationship and force important financial changes on provider agencies. First of all, all funding is awarded as grants, in advance of the provision of services, including the portion that is Medicaid reimbursement appropriated to DMH. Second, the plan is designed to increase revenue from federal matching funds by \$25 million. This is to be accomplished without any overall funding increase, but with an expectation that Medicaid claiming for services funded with the advance payments will grow by roughly 35%, statewide. The state will not increase total expenditures to providers, but the providers are expected to bill for

significantly more services which can be matched with federal funds. This expectation is not premised on the idea that providers are to change the types of services provided or the consumers served, only that they be more attentive to the possibilities of billing Medicaid for services delivered.

General concerns with increasing dependence on Medicaid fee-for-service reimbursement

As one might anticipate, the three-part funding plan described above has generated significant discussion and criticism. To identify how much each provider would be expected to contribute to the statewide goal of an additional \$50 million in Medicaid billing over the fiscal year, DMH calculated Medicaid billing “targets” for each provider. These targets were based on past levels of Medicaid billing and the additional amount needed to reach the statewide goal. The Medicaid targets for individual providers agencies range from 21% to 75% of all DMH funding.

There are several dimensions to this controversy. First, it is not certain that the statewide Medicaid billing target is achievable. While earlier discussion in this section indicates that Illinois community mental health providers are billing Medicaid less than counterparts in other states, there are no data to determine if the target may be attained without significant changes in the manner in which providers do business.

Second, the increase in expected Medicaid billing by provider agencies will have an uneven impact among the agencies. Some providers have developed highly effective practices of billing Medicaid for services provided, but these providers are still expected to contribute to the statewide increase of 35%. Other providers have billed Medicaid only to a small degree or not at all, and their expected contributions to the statewide target are modest. Yet, the State is not permitted to shift funding from one provider to another. Many providers view this as unfair.

Specific risks related to service access and quality of care

Certainly, all agencies will need to be more attentive to revenue. Better revenue management by the agencies may, in fact, result in more timely review of service plans, better communication between staff and consumers and more productivity by staff,

marginally increasing service capacity in the system overall. The actual impact on consumers will depend on how the agencies respond to the new revenue targets.

Quality of care. Because the revenue targets are financial and do not address the volume or types of services delivered, agencies that cannot achieve their targets by being more attentive to the eligibility of their clients and more effectively producing claims for the current array of services delivered will have to look at other options to maximize revenue. Short-run choices on maximizing billing revenues may not be the right choices for offering consumers a comprehensive array of high-quality services.

Access to services. A key issue for consumers is whether the “fee-for-service” system will limit or eliminate access to services by consumers who are uninsured. This is certainly one possible outcome. This cannot be determined without more information about the actual distribution of utilization by Medicaid and non-Medicaid consumers, including the use of non-reimbursable services by Medicaid-enrolled consumers. After adjusting for the new revenue targets, it is likely that some providers, assuming they generally maintain their current service/procedure profile, may have to reduce their access for non-MA consumers. The systemic question is, however, whether access for these consumers is significantly reduced on a provider-specific, geographically proximate or county-wide basis. Some critics have argued that the financial expectations of “fee-for-service” quietly but definitely redefines the mission of the publicly supported mental health system to persons seriously disabled by mental illness, with space available for others so long as they are insured. Unless there is implicit willingness to forego assistance to uninsured persons with acute or less serious mental health problems, the State will have to develop some mechanism to assure that uninsured people who are in fact disabled by mental illness are triaged and assured access to services everywhere in the state.

Another important issue for consumers is how individual agencies will change their service organization and delivery. The current financing system for contract agencies essentially supports capacity; agencies have had mixed histories regarding revenue maximization. Generally, agencies have had no external pressure to demand

more service units per day per staff person; to increase their enrollment; to pay attention to the revenue profile of people they serve; or to change the service array they provide. Historically, each agency defined its own niche and performed up to its own standards, subject, of course to State regulations.

Prospectively, almost 80% of the agencies' budgets, on average, will be based on reimbursement for service units delivered. In fact, the FY 2005 revenue targets include 35 agencies whose fee-for-service reimbursement projections, including both Medicaid and non-Medicaid revenue targets exceed 85% of total contracts and 16 whose total fee-for-service revenue targets comprise more than 90% of their total contracts. When the "fee-for-service" paradigm is fully implemented, and reimbursement replaces most of agencies' cash advances, the agencies will become "revenue production-dependent". Every available moment for a clinician becomes a revenue opportunity. Among persons with disabling mental illness, consumers have different degrees of service attachment. Some become service-dependent, others are service-reluctant, often service-estranged. Missed appointments are missed revenue opportunities. Agencies may, in response, make enrollment less "voluntary" for difficult to serve consumers. Agencies, prospectively, will attempt to fill every available service "slot" with income-producing clients. Some agencies may, therefore, attempt to increase attendance, beyond what is clinically indicated, by "compliant" consumers. Such a practice will certainly reduce access to services by new, possibly less-"compliant" consumers. Research has shown that consumers are generally loyal to clinicians, irrespective of their credentials, rather than to agencies. The agencies' focus on revenue and differential reimbursement rates based upon staff credentials may result in agencies directing certain consumers to staff with certain qualifications, irrespective of consumer preference.

Although fee-for-service reimbursement encourages "competition" between providers for consumers, it is certainly not evident that there are enough mental health service choices in most counties in Illinois to assure that consumers have real, comprehensive provider options. Their only choice for many may be to take what is offered or receive, in many cases, nothing at all.

Clearly, it is not Illinois' intent that the "fee-for-service" initiative promote, even condone, provider behavior antithetical to consumer recovery. Ongoing review of

service information, anecdotal information received from consumers and on-site visits by DMH staff will identify changes in provider behavior. Strong program and “mission” leadership by DMH, abetted by an array of contractual and regulatory penalties, should help “anchor” providers within parameters of tolerable revenue-centered behaviors.

Regulation, Contracting, and Rate Setting

The final section of this chapter discusses the complex interaction of program administration by the State, rates and the means of paying providers.

Just as the broad concept of “program” reflects a series of policy and values decisions, all subsequent decisions that affect service delivery (such as target populations, payment rates, a focus on individualized plans vs. rigid program models, performance/reimbursement standards), also reflect policy and values decisions. Each implies a variety of incentives and disincentives to consumers and providers that can promote or undermine the goals of the program.

As described in the introduction to this chapter, a state’s public mental health financial strategy is governed by two sometimes competing interests: to provide access to quality services that help clients meet their goals, and to control the state’s financial exposure. The first represents the system’s contract with stakeholders, while the latter reflects political decisions about the program’s relative value among all of the state’s other voluntary and mandatory responsibilities. Simply, the state has two tools through which to explicate its two interests: regulations and contracts.

Although the SRI is currently reviewing possible changes to the mental health service taxonomy to make it more recovery-oriented, the outcome of this review is not yet clear, nor is it evident that SRI is simultaneously considering rate restructuring/rebasing. To this point in time, “fee-for-service” does not project changes to the rates currently in place.

Prospectively, the State will pay all providers at the same rates for all services for which rates have been established for all consumers, irrespective of their Medicaid status. This will be different than the contractual relationship between DMH and providers preceding fee-for-service. Although all providers historically were paid the federal share of Medicaid at common rates, the contracts did not incorporate unit cost expectations, so

it is likely that unit costs for many services varied among providers. (This will be evaluated in Navigant's study to be completed by June 30.) More than 80% of the average provider's targeted budgets will be produced by state payments paid at common rates. Assuming that unit costs do in fact vary among providers, providers will necessarily have to change the cost and/or revenue variables they control should their projections of revenue against their current service delivery array fail to meet their current contract amount. They can reduce their net unit cost, they can increase their units of service or they can reconfigure their service delivery array to generate a higher average unit reimbursement.

The other major change, already discussed, accompanying full implementation of "fee-for-service" is the change in the financial relationship between DMH and the providers. Heretofore, providers received most of their public funds in periodic advances of their contractual amounts. Advances are financially "comforting" to providers, smoothing over difficulties caused by unanticipated expenditures and/or revenue shortfalls. Prospectively, providers will be more dependent on reimbursement derived from service delivery. Providers will have greater need to accumulate "retained surpluses" to offset financial problems caused by interruptions in service delivery, linked to clinical staff vacancies, "seasonality", space "problems" like power outages, etc., or interruptions in revenue flow caused by administrative staff turnover or payment delays by the State.

Accompanying the phase-in of "Fee-for-Service" as it is now configured, the State has the opportunity to review some possible complementary options.

Program and/or Medicaid Regulatory Options

To the extent that DMH is satisfied with the current pattern(s) of service delivery among all providers across the state and concurs that full implementation is likely to change that pattern due to, at least, the factors noted above, it is faced with the choice to actively intervene to preserve the current pattern(s) or to await the development of new patterns over time. Action in either circumstance will involve changes either to program regulations, reimbursement regulations or both.

Briefly, Illinois' program regulations now establish minimum program standards and minimum staff qualifications. Reimbursement regulations generally pay based on service duration, most often in 15-minute increments, with payments generally varying based on the minimum qualifications of the staff delivering the service. There are no requirements regarding the array of staff likely to be found at any provider independent of or related to the number of clients or the mental health status engaged with the provider or receiving services on any day, week or month. Similarly, there are no standards, either programmatic or reimbursement, with regards to duration of any contact or the minimum or maximum number of contacts any consumer should have during any episode or can be reimbursed in any period with or without provisions for exceptions. Finally, the rates of payment for each procedure within each service provided by comparable staff are generally comparable, thereby offering no incentives or disincentives to offer one service or program over another to a general caseload or one or more subpopulations in a general caseload.

States' Medicaid programs may establish some limits on reimbursement apart from utilization thresholds. For example, many states limit Medicaid reimbursement for hospital-based ambulatory programs to one visit per day. New York, at least, limits the number of visits any consumer can make to one mental health provider to one per day, apart from crisis services and limits the number and types of mental health programs that can be reimbursed by Medicaid for the same consumer in the same month. In addition, New York State establishes the maximum reimbursement duration for any consumer on any day to each of its mental health services. For example, an individual clinic visit extending beyond a half-hour is reimbursed at the ½ hour fee, irrespective of its actual duration or number of staff accessed by the consumer during the visit. For some services, it further establishes the maximum number of reimbursable hours per month.

The motivations for these limits are programmatic, financial or both. In certain programs, providers may be able to retain consumers in a program many hours a day for reimbursement purposes only. By limiting the number of service units that may be billed, providers may have to serve more consumers per available service hour to maintain revenue at historic levels. System wide, this may increase the number of consumers

served within a fixed service capacity and may have an impact on consumer satisfaction/dissatisfaction or outcomes.

As many health insurers establish both credentialing and programs standards for providers who desire to be part of their approved “panel”, states can and do impose additional requirements on their Medicaid reimbursed providers of mental health services, including minimum staff complements in terms of distribution of qualifications and/or full-time versus part-time staffing; hours of operation; maximum enrollments; and staff to consumer ratios for certain services. Admission requirements or independent authorization serve give priority access to certain services for certain groups within the larger eligible population

Controlling Disbursements

The state’s control of its financial risk and the efficiency and effectiveness of its investment are more or less determined by the financing, regulatory, and reimbursement options it chooses. Most states’ Medicaid programs, including mental health services, struggle annually with the variability in disbursements linked to Medicaid enrollments, changing patterns of utilization, unexpected demand, cost pressures passed through rate adjustments, etc. In most states, contracts are the only option that has predictable costs.

Illinois’ total disbursements for ambulatory mental health services are largely controlled because almost all authorized providers of mental health services (apart from hospitals and private practitioners) are under contract with DMH. The contractual payment for these providers includes both the State share of any Medicaid-reimbursed service, and reimbursement for any other expenditure approved in the contract. With its costs successfully contained, Illinois has elected not to utilize the staffing and service prescriptions generally described above. The data presented earlier suggest that Illinois’ mental health providers have established idiosyncratic patterns of services and accessibility. In the absence of further data, it cannot be determined whether these patterns represent the most efficient and effective application of public funds for services to individuals who present for mental health services.

Reimbursement Considerations

Reimbursement methodologies, including the actual rates, are essentially decisions on incentives and/or disincentives. No methodology is values-neutral, but the consequences of any methodology necessarily involves trade-offs. Reimbursement design is inextricably linked to the program and administrative choices described above. Some methodologies for a particular service are very appropriate in one regulatory/contract environment, but would be inappropriate for the same service managed in a different regulatory/contract environment.

All of the options discussed should be mirrored in the reimbursement design and rate calculation. For example, Illinois' rates correlate with staff qualifications. Other rate structures could be developed. If the state prescribed minimum staffing standards for similarly licensed programs it might establish a single individual and single group rate for all service units irrespective of the qualifications of the staff actually delivering the service to an individual consumer. For providers delivering multiple distinct services, the state could prescribe minimum staffing patterns for each of the services nested within the single provider and again pay one rate for the service irrespective of which of the authorized staff actually delivered the procedure. In the absence of staff modeling common provider wide or service wide rates would encourage providers to develop staff complements less expensive than anticipated by the rate. (Obviously, conformance with the staffing regulations would have to be monitored in these examples apart from reviewing Medicaid claims.)

Similarly, reimbursement for some individual procedures or services could be limited to, perhaps, 15 minute or 30 minute durations, based on actual clinician-consumer time. The few visits that consume more than the reimbursed duration could be accounted for in the productivity assumptions used to develop the rates. Rates for off-site services could be adjusted for the costs of average travel time if the off-site location is incidental, or rates for off-site locations could be based on lower expected workload if off-site delivery is an integral element of the service. Clearly, this reimbursement design would be inappropriate for services that are expected to last much longer than the maximum reimbursed duration, such as day treatment or partial hospital services.

Mode of Payment

Apart from “pre-paid” health plans, notably “managed care,” Medicaid prescribes that its reimbursement be “fee-for-service,” although its regulations do not further define what constitutes the unit of service for which a fee (or rate) is paid. Illinois currently defines the unit of mental health service for reimbursement purposes as the duration of time delivering a “covered” procedure as the unit of service and pays, and proposes to continue to pay, accordingly.

In the general health care arena, most reimbursement schemes for ambulatory services pay for an individual therapeutic contact of a minimum duration or a per-minute rate, with or without a maximum per contact. (Medicare has instituted a payment per “episode of illness” for some hospital-based ambulatory services.)

For some services, the population served has unique characteristics for which non-traditional modes of reimbursement may promote program goals. Individuals using public mental health services fall into two broad groups: those whose condition is acute and incidental, and those who are disabled as a result of their psychiatric diagnoses and histories.

The two groups tend to make different decisions about the services they seek (or accept). Incidental service users tend to seek counseling and other clinic treatment services. Their goals are relief of distress that currently interferes with their ability to function at their accustomed level. Their customary service model is a model of periodic intervention or service, and dependence on the individual’s existing support system to contribute to their stabilization and recovery. Those with long-standing disabilities, on the other hand, often find it difficult to function independently in various areas of their lives for an extended period, and they sometimes need assistance to retain or regain skills that will enable them to recover and reintegrate into their communities. Their service model often includes assistance with numerous domains of independent living (including medical, psychiatric, social, educational, vocational and residential), provided by a range of professionals and paraprofessionals. These individuals may initially lack confidence that any support system will contribute to their recovery. The move to a more recovery-focused approach to this group requires a genuinely consumer-centered, individualized recovery plan based on the individual’s strengths, needs, and wishes.

For incidental users of mental health services, the typical fee-for-service reimbursement (either “per visit” or “time duration”) may be perfectly appropriate. The situations of persons with long-standing psychiatric disabilities call for exploration of other modes of payment for some services. The examples provided below are taken from the current organization of the mental health system, and do not illustrate the components of the desired recovery-oriented system. However, the reimbursement strategies described could be adapted to a revamped system that allows for more flexibility to help each consumer reach his or her recovery goals.

Targeted case management for people with psychiatric disabilities is often focused on consumers whose relationship to the service system and to various aspects of community living (work, housing, etc.) may be tenuous. One of the objectives of these programs may be to engage consumers with the service system. At any given moment, some people on a case manager’s caseload will be satisfactorily engaged, and others will not. Some individuals will be easy to find and to serve. More disengaged clients may be difficult to find; they may be homeless, in a hospital or jail, and may be resistant to contact. The reimbursement design should encourage case managers to make very necessary effort for their clients most in need, while assuring minimum, regular attention to those who are less needy.

A typical fee-for-service payment system offers the wrong incentives for this program model. With reimbursement limited to face-to-face contact time, it encourages case managers to focus their time at their desks to maximize revenue, and to spend more time with those who are easiest to serve, to the detriment of clients whose needs are more complex. Paying case managers for “duration of visit” may encourage them to evolve into “pseudo-therapists” in order to maximize their billable time for each client contact, a role generally proscribed by federal targeted case management guidelines.

Another example where fee-for-service may not be appropriate is reimbursement for rehabilitative services delivered in group residential settings. Staff often have multiple roles, including assessment, service plan development, skills teaching, and supervision. The service site is used for active programming and is also the residents’ home. The incentives inherent in fee-for-service regimens may encourage revenue maximization when, in fact, most moments in a consumer’s residence should not be

therapeutic moments. Nevertheless, agency costs accrue for each moment staff are present.

One reimbursement design that might promote the goals of these two example programs is called case payment. Applied to a case management program, a minimum number of monthly face-to-face contacts per client would be necessary to generate a fixed monthly payment. The prescribed minimum number of contacts is projected to occupy a percentage of the available work time of the case manager. Program requirements and performance measures would require case managers to use the balance of their workday to attend to additional and emergency needs of the people on their caseload.

Likewise, monthly case payments for rehabilitative services in a residential setting would balance the need to deliver services, the flexibility for the residents to be free of service expectations most of the time they are at home, and the responsibility of staff to monitor and supervise activity. As with the case management model, case payment in residences would require development of a service plan with identified needs and activities, a minimum number of rehabilitative activities monthly, etc. As with the case management model, additional oversight and quality assurance activities would be needed to ensure that the minimum expectations for reimbursement do not evolve into the *de facto* performance standard.

The state's interest in predictable and controlled expenditures would require establishment of case management capacity for each agency and each case manager. Similar considerations are implicit in the approved capacity of each residence and the rehabilitative services and staff authorized for these programs. In both examples, payment models would have to accommodate the unpredictable nature of temporary absences, permanent departures, and the lag time needed to fill caseload and residential vacancies.

Another, more complex payment design would be a voluntary, mental health-only managed care plan. Participating providers would receive a monthly premium for each eligible consumer who enrolls with that provider for all of their covered mental health services (although providers could subcontract with others for some of the services). The premium may be statewide, regional or county-specific. The initial premium would be based on the historic utilization of Medicaid reimbursed services by the eligible

population. Subsequent premiums would reflect the historic service utilization by persons who actually enroll. Enrollment would be voluntary, and not all consumers using a specific provider's services would have to be managed care enrollees. (Mandatory enrollment would require a federal waiver unless included in a comprehensive managed care plan.) Payment for non-enrollees would still be fee-for-service.

For providers, managed care allows flexible assignment of staff and eliminates the need to fit all activities for all enrolled individuals into a likely outdated service taxonomy, allowing creative development of unique service options and the provision of services ineligible for Medicaid reimbursement. It also changes the economic consequences of new enrollments and disenrollments and the blend of high users and low users. For consumers, managed care can offer the possibility of a more individualized recovery plan and flexible services. For the state agency, managed care requires careful attention to the possibility that agencies might reduce capacity in order to just meet minimum consumer expectations, rather than to maximize recovery opportunities. The state would also need to monitor and respond to patterns of economically consequential disenrollments from individual agencies. To the extent that eligibility criteria, the enrollment process and rates match, the State's financial risk is limited.

Another payment design would structure rates to promote a desired program participation model. For example, mental health day treatment programs often expect that consumers participate regularly and for an extended period, but that they should not become service-dependent or be treated by providers as "income earning assets". Program designers might think it desirable for the targeted consumers to participate 2-3 times a week for 3-4 hours per day. At the same time, the State might want to preclude individual consumers from attending more often or more intensively. Duration-adjusted rates could be developed that would promote the desired model. In such a model, for instance, the per-visit rate could be reduced when an individual exceeds a certain number of visits or hours per month. By reducing the amount paid for visits that exceed the threshold, rather than imposing a fixed limit on the number of allowable visits, providers could accommodate consumers who chose to participate less frequently, and would still be reimbursed for most of their costs when individual consumers decide they want or need to use the service more frequently.

Summary

This chapter has briefly profiled the financial performance of Illinois' publicly funded mental health system and generally described the mechanisms currently employed and prospectively available to financially manage the system. The data suggests that Illinois' current mental health system is not financed comparably to the other states against which it is often measured and does not treat its similarly situated residents comparably.

The "Fee-for-Service" initiative and the associated SRI with its several committees and contracted assistance, with active participation and assistance from the state agencies, providers, consumers, other state and local government officials and advocates emphasize the common understanding that changing both the percentage of the current system supported with state general funds and the implicit performance expectations on providers, measured at least by service volume, is an important inflection point in the history of the publicly funded mental health system.

This chapter concludes not with specific recommendations for change but with observations and examples regarding some financial and financially related opportunities to change. Reimbursement methodologies should be designed and rates calculated only after program is designed and intended and unintended consequences commonly understood and approved.

V. Delivery of Culturally Competent Services

Across the nation, clear disparities exist in the availability of and access to mental health services for racial and ethnic minorities and for Americans living in underserved, rural and remote areas (Smedley, Stith, & Nelson, 2002; United States Public Health Services Office of the Surgeon General, 1998; United States Public Health Services Office of the Surgeon General, 2001). Racial and ethnic minorities have less access to services, lower likelihood of receiving needed services, greater likelihood of receiving poorer quality of care, and are under-represented in mental health research. (United States Public Health Services Office of the Surgeon General, 2001; Smedley, Stith, & Nelson, 2002) Individuals in rural and geographically remote areas have inadequate access to care, limited availability to skilled care providers, lower family incomes, and greater stigma for seeking mental health treatment. (United States Public Health Services Office of the Surgeon General, 1999)

The Final Report of the President's New Freedom Commission on Mental Health Report identified the elimination of disparities in mental health services as one of the goals of a transformed mental health system. The Commission noted that eliminating disparities requires improving access to quality care that is both culturally competent and is available in rural and geographically remote locations. (New Freedom Commission on Mental Health, 2003).

How is cultural competence defined? There are several accepted working definitions of cultural competence. However, many are derived from the work of Cross, Bazron, Dennis, and Issacs (1989), who defined cultural competence as “a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or amongst professionals and enables that system, agency, or those professional to work effectively in cross-cultural situations.” (Pg. iv). Although more research needs to be conducted with regard to the impact of cultural competence on outcomes, initial findings based on a review of literature, are indicative that services delivered in a culturally competent manner may improve treatment outcomes and reduce disparities in the provision of treatment among diverse populations (Brach and Fraser, 2000). The provision of treatment in a culturally competent manner is considered to be essential to the delivery of quality mental health care.

National Initiatives

Several recent national initiatives have focused on improving the cultural competence of mental health services. In the year 2000, the Center for Mental Health Services (CMHS) of the Substance Abuse Mental Health Services Administration (SAMHSA) published cultural competence standards for managed care mental health services for African Americans, Hispanics, Native Americans/Alaska Natives, and Asian/Pacific Islanders (Center for Mental Health Services, 2000). During the same year (2000), the Office of Minority Health of the U.S. Department of Health and Human Services published a document identifying 14 standards for culturally and linguistically appropriate services (known as the CLAS standards) in health care (Office of Minority Health, 2001).

In 2002 and 2003, the National Association of State Mental Health Program Directors (NASMHPD) and the National Technical Assistance Center for Mental Health Planning (NTAC), in consultation with the National Alliance of Multicultural Behavioral Health Associations and other stakeholders, developed a *State Mental Health Agency Cultural Competence Activities Assessment Instrument* (NASMHPD, 2004). The NASMHPD Assessment Instrument makes recommendations for state mental health agencies that are “premised on the notion that the implementation of cultural competence is not a compartmentalized, adjunct activity but that it is a critical management and quality of care concern that must permeate the entire system” (pg. 4). The instrument provides a framework for identifying the progress and action taken by state mental health authorities to move the cultural competence agenda forward. The emphasis of this approach is on answering questions such as: ‘Is progress being made to advance cultural competence, and what needs to happen at the state mental health authority level to promote and sustain cultural competence?’

Progress in Implementing Cultural Competence Initiatives in Illinois

This report focuses on the strengths and challenges of the Illinois mental health system in advancing a cultural competence agenda, and provides recommendations with regard to specific actions to further advance the agenda. The focus of this report is not

whether staff of individual agencies or state hospitals provide services in a culturally competent manner. The level of assessment required to determine whether this is occurring across the entire mental health system is beyond the scope of this report. However because culturally competent services are a part of the basic fabric of mental health services cutting across access, financing, and service delivery a special effort was undertaken to assess the efforts undertaken by the Illinois DMH to address this issue. To aid in the assessment of the Illinois DMH, specific aspects of the NASMHPD instrument were used to provide a lens through which to determine the progress of the Illinois DMH in advancing a cultural competence agenda. Many of these aspects are echoed in the recommendations of the President's New Freedom Commission Report.

Strengths in promoting cultural competence

Information gathered for this assessment was obtained from interviews across a wide variety of mental health system stakeholders as well as from a review of relevant documents. The Illinois DMH has undertaken the following efforts to promote cultural competence in the delivery of public mental health services in the state:

- (1) The DMH has created and filled a position for a coordinator of cultural competence, who is charged with the responsibility for promoting cultural competence in the state.
- (2) The DMH requires providers of mental health services (community and state hospital) to regularly report information on the race and ethnicity of persons receiving services using a standardized format. This information is submitted to the Reporting of Community Services (ROCS) Management Information System and the State Hospital Clinical Information System (CIS).
- (3) A DMH State Hospital Bilingual/Bicultural Services Committee comprised of clinical staff from Chicago Read Mental Health Center, Elgin Mental Health Center, and Chester Mental Health Center, in collaboration with the DHS Office of Hispanic and Latino Affairs (OHLA) developed a draft Mental Health Facility (SOF) Questionnaire for Limited English Proficient (LEP) Patients to collect information about the need for and the provision of services to consumers with limited English proficiency (LEP).

Also, a tracking system developed in 2003 as part of the quality improvement program is used to evaluate access to culturally appropriate services.

(4) DMH has received a SAMHSA/CMHS-funded technical assistance consultation to develop a cultural competence plan in 2003. Information gathered from a wide variety of stakeholders during the consultation and recommendations from the subsequent consultant's report were intended to help define and outline DMHs' cultural and linguistics strategic action plan.

(5) A variety of initiatives have been undertaken focusing on consumers with limited English proficiency. These include:

- Provision of special bilingual pay to approved DMH staff members who are available to serve as interpreters
- Establishment and use of the DHS Translator Bank; when these translators are not available or when there is an immediate need, the utilization of the AT&T Phone Bank which provides interpreter services
- Collaboration with the DHS Office of Hispanic/Latino Affairs subcommittee to review standards for interpreter qualifications, instruments for assessment of the competency of interpreters, and local training resources
- Participation in a DHS taskforce focusing on limited English proficient (LEP) populations to identify service gaps and policies to address the needs of this population,
- Collaboration with the DHS Limited English Proficient Populations Committee to identify the psychiatric needs of underserved bilingual populations residing in rural parts of the state
- Establishment of a committee on access and equality comprised of staff from throughout the state to identify cultural competence and health disparities for rural areas

(6) Efforts have been made to obtain external funding to promote the DMH cultural competence agenda. The Coordinator of Cultural Competence has submitted grant proposals to assist in these objectives.

- (7) The delivery of culturally competent services has been identified as a key component of the Division's 3 to 5 year strategic plan, which is in the process of development. The DMH strategic vision has as a basic tenet, the delivery of culturally competent services. The development of standards of care with guidelines for ensuring the delivery of cultural competent and linguistically appropriate mental health services has also been identified as a 2005 Block Grant Objective.
- (8) DMH has implemented the MHSIP Consumer Surveys for adults, and children/adolescents and their caregivers. The surveys contain information that can be used to develop performance measures related to cultural sensitivity and competence.

Challenges in promoting the cultural competence agenda

Based on a review of documents and discussions with DMH staff, it is clear that a great deal of work is being done in individual committees and as part of facility-based initiatives. However, most stakeholders agreed that there is a lack of follow-through or measurable outcomes resulting from these efforts. One staff member noted that a great deal of information has been gathered through many different initiatives and activities, "but what gets done is the issue. Practices have not changed."

Challenges to moving the DMH cultural competence agenda forward have been identified in various venues:

- (1) The report developed in connection with the SAMHSA/CMHS-funded technical assistance on cultural competency that Illinois received in 2003 identified system barriers to cultural competency. These barriers included: (a) vacancies in key leadership and professional programming posts; (b) a poorly designed therapeutic environment; (c) fear and poor communication between providers and patients; (d) difficulty in providing translation services; (e) lay-offs of credentialed minority professionals as a result of hospital closures; and (f) hiring delays in the recruitment of racial minorities and/or bilingual staff (Technical Assistance Report, 2003).

(2) In discussions with staff and other stakeholders during the development of this report, the lack of resources throughout the system was cited as a significant barrier to implementing practices to improve and promote cultural competency. Additional significant challenges identified included:

- There is no devoted budget to carry out activities to improve cultural competency.
- The Coordinator of Cultural Competence is also the Chief of Human Resource Development, with many competing responsibilities.
- Staffs at state-operated facilities do not reflect the race and ethnicity of the populations served. Diversity should be reflected across disciplines, including professional as well as technical staff.
- Consumers have limited access to staff members who speak languages other than English. For example, Tinley Park Mental Health Center has a high Spanish speaking population but only one Spanish-speaking staff person.
- Equal Employment Opportunity (EEO) officers in state-operated facilities do not have much authority. It was noted that by the time an EEO officer is involved, usually a candidate has already been chosen for the position, and thus the involvement is for sign off purposes.
- Staffs lack awareness regarding people from different cultural groups.
- There is a general lack of understanding about how spirituality and religion impact treatment.
- DMH has limited funding for workforce development and training. Some DMH staff noted that trainings are often didactic (e.g. they give a general overview of the role of culture in service delivery and then spend time on the health beliefs and behaviors of specific racial and ethnic groups) rather than experiential (e.g., staffs are made aware of their limitations, given knowledge and skills, and then provided with opportunities to practice what they have learned through interaction with people of different cultures). Training state hospital staff is cumbersome and expensive, since all shifts must be trained separately.

Recommendations

Although it is clear that DMH has made some strides in moving its cultural competence agenda forward, it is equally clear that these efforts need to be strengthened and additional actions undertaken. These changes can not occur overnight, however incremental implementation of these actions in a systematic way are likely to result in the attainment of DMH's goals in this area. The following actions are recommended:

(1) Promotion of Cultural Competence as a priority for the mental health service system. Cultural competence initiatives should not be a compartmentalized adjunct activity, but rather it should be a critical management and quality of care concern that permeates the entire system.

(2) Some states have found it useful to develop an Office of Cultural Competence that includes a focus on linguistic competence as well. Such a structure focuses on: (a) developing culturally and linguistically competence standards of care; (b) developing, organizing, and providing training and technical assistance within the system; (c) researching emerging trends and issues in the delivery of culturally and linguistically competent care, and incorporating the results in training efforts; and (d) monitoring and evaluating the implementation and progress towards a culturally and linguistically competent system. The establishment of an advisory committee would assist in the development of the written cultural competence plan and procedures for updating the plan, review policies, and make recommendations related to cultural competence.

Although DMH has appointed a coordinator of cultural competence, it may be useful to develop a formal structure to support the cultural competence agenda.

(3) The DMH strategic plan should include an integrated cultural competence component with objectives, strategies and implementation timetables. This plan should identify resources needed for priority activities including activities related to training, interpreter services, and specialized programs. Training for DMH state hospitals staff will need to employ innovative strategies such as utilizing Web-casts and other technologies, since training staff across three work shifts is an issue.

(4) Resources in terms of funding and staffing should be allocated to support and advance cultural competence related activities. Block Grant funds, if available could be used as a partial support for this effort.

(5) There is a need to conduct periodic multi-level organizational self-assessments to determine how well the system is doing in delivering cultural competent services. The self-assessments should include an analysis of state population and demographics, the race/ethnicity/gender of providers and their languages capacities, and a description of how the system promotes cultural competence formally and informally. Also included should be assessments of other cultural issues including gender, age, sexual orientation, and deaf and hard of hearing. Stakeholders acknowledge the difficulties DMH has experienced in recruiting and retaining staff at all levels from diverse racial and ethnic backgrounds and who speak languages other than English. The organizational self-assessment should help to identify hiring and promotion practices that promote the hiring and retention of staff from prevalent cultural groups and service users, or staff familiar with or experienced in working with these groups. It is critical to supplement the information obtained from organizational assessments with provider and consumer assessments.

(6) DMH currently collects data on characteristics and service utilization of consumers who access community-based and state hospital services. This information should be systematically and regularly reviewed to examine disparities in service. Strategies should be identified and implemented to address disparities that are identified.

(7) As noted previously, DMH utilizes a limited number of interpreters in state hospitals to assist in providing service to mental health consumers. It is recommended that information should be collected and analyzed on a periodic basis to identify the linguistic competency needs of its staff, and used to monitor and update those skills. It is recognized that it may not be possible to have a staff person available to meet all language needs, thus DMH should continue to utilize interpreter services to accommodate persons who have limited English proficiency. As recommended in the NASMHPD Assessment Instrument, however only qualified mental health interpreters should be used.

(8) DMH should continue efforts to develop system wide standards of care to address cultural competence and should develop contractual requirements to ensure that private,

community providers implement them. As previously noted, this recommendation was included in DMH's 2005 Block Grant Objectives. The current DHS Community Services Agreement for Fiscal Year 2005 includes provisions to provide equal employment opportunities. Providers are expected to be in full compliance with all laws, rules, policies, procedures and mandates specified in the Community Services Agreement, DMH Attachment B, as well as other applicable administrative rules and all reference documents however no specific cultural competence requirements are included.

(9) DMH should continue to utilize resources developed by consumers such as *The Knowledge Corner Incorporated*' spiritually based, culturally diverse training model that focuses on the issues of consumers with dual diagnoses of mental illnesses and substance abuse.

VI. DISPARITIES IN MENTAL HEALTH CARE ARE ELIMINATED

The most basic aspect of evaluating mental health service delivery involves assessing the extent to which services are accessible. A basic underlying premise of public mental health service system design is that mental health consumers and their families will have timely access to appropriate services when needed. While this is an expectation, research has shown this premise does not hold true for all members of society. Disparities in the delivery of treatment based on geography, race and ethnicity, culture and other factors are well documented. This issue has been highlighted in both the Report of the President's New Freedom Commission (2003), as well as in the U.S. Surgeon General's Report on Culture, Race and Ethnicity (2001).

The way in which mental health services are financed has also been found to impact access to services. As noted in the earlier chapter on financing in this report, an unintended consequence of converting a grant-in-aid system to one that is heavily focused on Medicaid fee-for-service may be to limit access to services for persons who are not Medicaid recipients. The fee-for-service initiative that the Illinois DMH has been engaged over the past year and a half has led to stated concerns by a range of stakeholders that the initiative may result in a reduction in access to service for these persons.

The recommendations of the President's New Freedom Commission specifically include a goal of eliminating racial and ethnic disparities in the receipt of mental health care. The commission further notes that there is a need to improve access to quality mental health care in rural and geographically remote services.

This section of the report focuses on determining whether there are differences in access to mental health services in Illinois based on where a person resides (geography), their race/ethnicity, age and gender. Of equal importance, is the status of the Illinois mental health system in adoption and implementation of treatments and practices that have been shown to lead to positive outcomes for consumers when implemented with fidelity to the treatment model. While there is recognition that the implementation of these practices is complex, involving an investment of resources in the areas of training and workforce development, as well as the adoption of new approaches to financing and

service delivery, consumers deserve access to the latest state-of-the art treatments. Recommendations are provided based on the results of the analysis.

Access to DMH Funded Services by Geographic Area

There are a variety of performance measures that have been used historically to assess access to mental health services. This includes the use of service utilization or penetration rates, and direct reports from consumers through the use of consumer perception of care surveys. This latter approach was used for the Field Test Evaluation of the DMH Fee-for-service initiative. This analysis utilizes service utilization rates by county as a measure of access. Although it is recognized that the Illinois mental health service delivery system is not organized around county-based services, employing this method of analysis provides an appropriate strategy for determining whether persons have equal access regardless of where they live in the state.

The source of the data used for the analysis was consumer level service information submitted directly to DMH via the Reporting of Community Services (ROCS) system by community agencies that contract with the DMH. The number of hours of service was obtained for each person receiving community-based services purchased by the DHS Division of Mental Health in fiscal year 2004. This information was partitioned by the county in which each consumer resided and then aggregated for each county. Because counties differ substantially in population size across the state, it was necessary to create a measure that takes this into account.

Service utilization rates for each county were created by dividing the total number of service hours received by service recipients residing in the county by the number of persons residing in the county. Finally the rates were adjusted to reflect service utilization per 1,000 population. This represents a reasonable approach to constructing a rate in the absence of an estimate of the prevalence rate of mental illnesses in each county. The data was further partitioned by type of service utilized, so that it was possible to not only look at amount of service received by persons living in any county within the state, but to also look at the type of service received. Services were grouped into six broad categories:

- Psychiatrist services
- Outpatient services
- Crisis-Emergency services

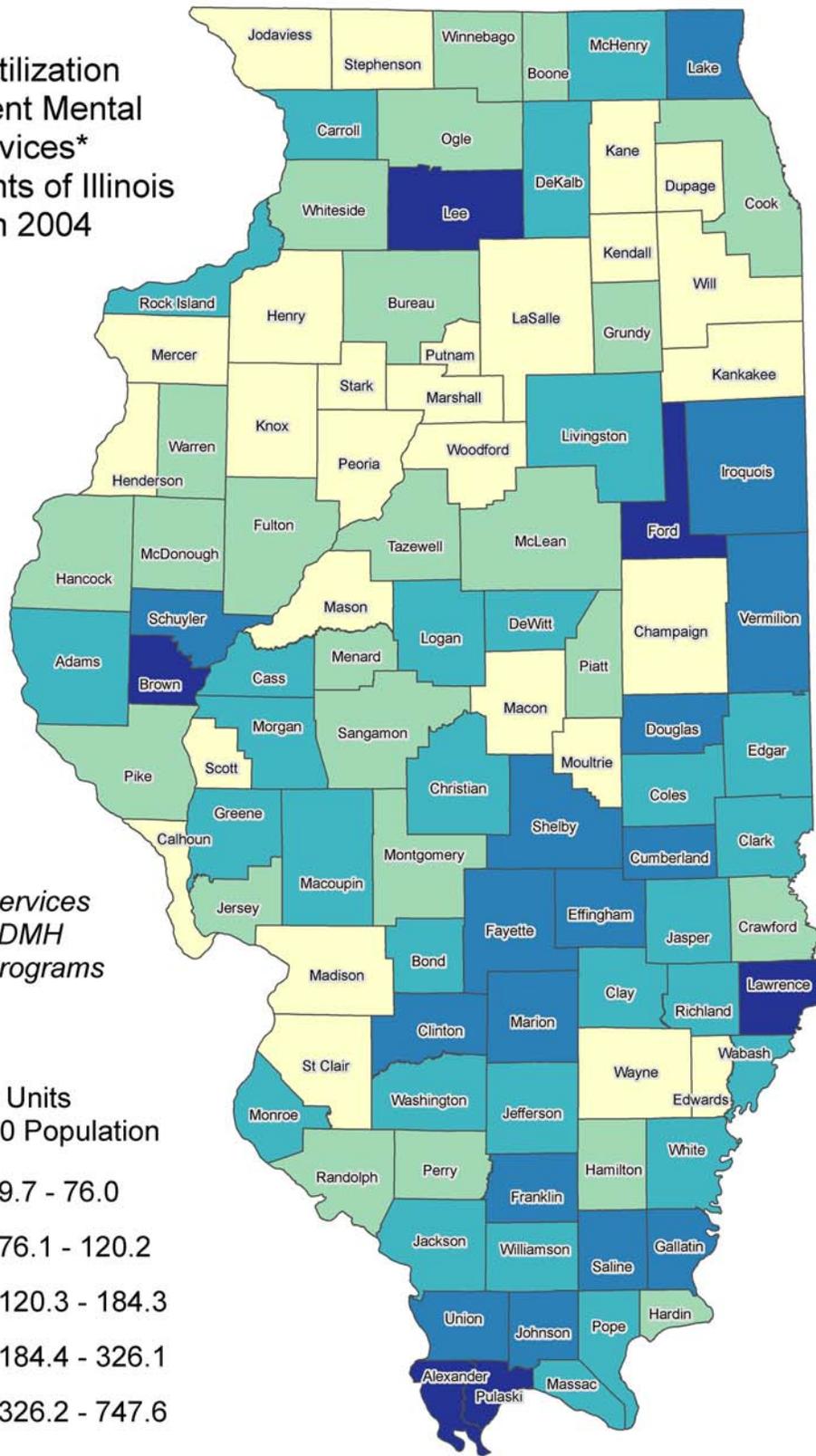
- Case Management services
- Rehabilitation services
- Residential services

Findings. The results of this analysis are indicative that there is wide variability in service utilization across counties and across all six service categories. Service utilization rates for outpatient services per 1000 population across the state ranged from a low of 9.7 hours to a high of 747.6 hours. These results are presented in the thematic map that follows. For purposes of the display, service utilization rates have been classified into five groupings representing rates from low to high service utilization. The counties with the lowest utilization rates are shown as white. Those with the highest utilization rates are shown in black. The counties that are in between are in shades of gray with higher rates of utilization represented in increasingly darker shades of gray. Twenty-seven (27) counties fell in the lowest utilization rate range of 9.7 to 76 hours; 24 counties fell in the 76.1 to 120.2 hours; 29 counties fell in the range between 120.3 to 184 hours, 16 counties fell in the 184 to 326 hour range and 5 counties fell in the range of 326 hours to 747. Similar patterns of variability in service utilization rates were found for the other categories of service into which the data were partitioned.

The next map shows the rates of utilization of emergency/crisis services. For this category of service, the counties with the lowest rates of utilization range from 0 to 3.5 hours of service per 1000 population. There are 39 counties in this group, all shown in white. There are only three counties in the highest utilization group, which ranges from 45.5 to 100.4 units of services per 1000 population. What is important to note is the great variation in rates. The county that is at the low end (45.5 per 1000 population) of the highest utilization group, has a rate that is approximately eight times greater than the county that is at the high end (5.6 per 1000 population) of the lowest utilization group. The counties that are in the higher groupings typically have utilization rates that are several times higher than the rates of the lower groupings.

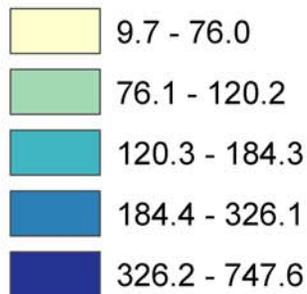
Another finding that emerges is the variation in the type of services that are utilized within each county. For example, Champaign County is in the second highest utilization grouping for crisis-emergency services, in the middle category for psychiatric and residential services, in the second lowest category for case management services, and

Rates of Utilization
of Outpatient Mental
Health Services*
by Residents of Illinois
Counties in 2004

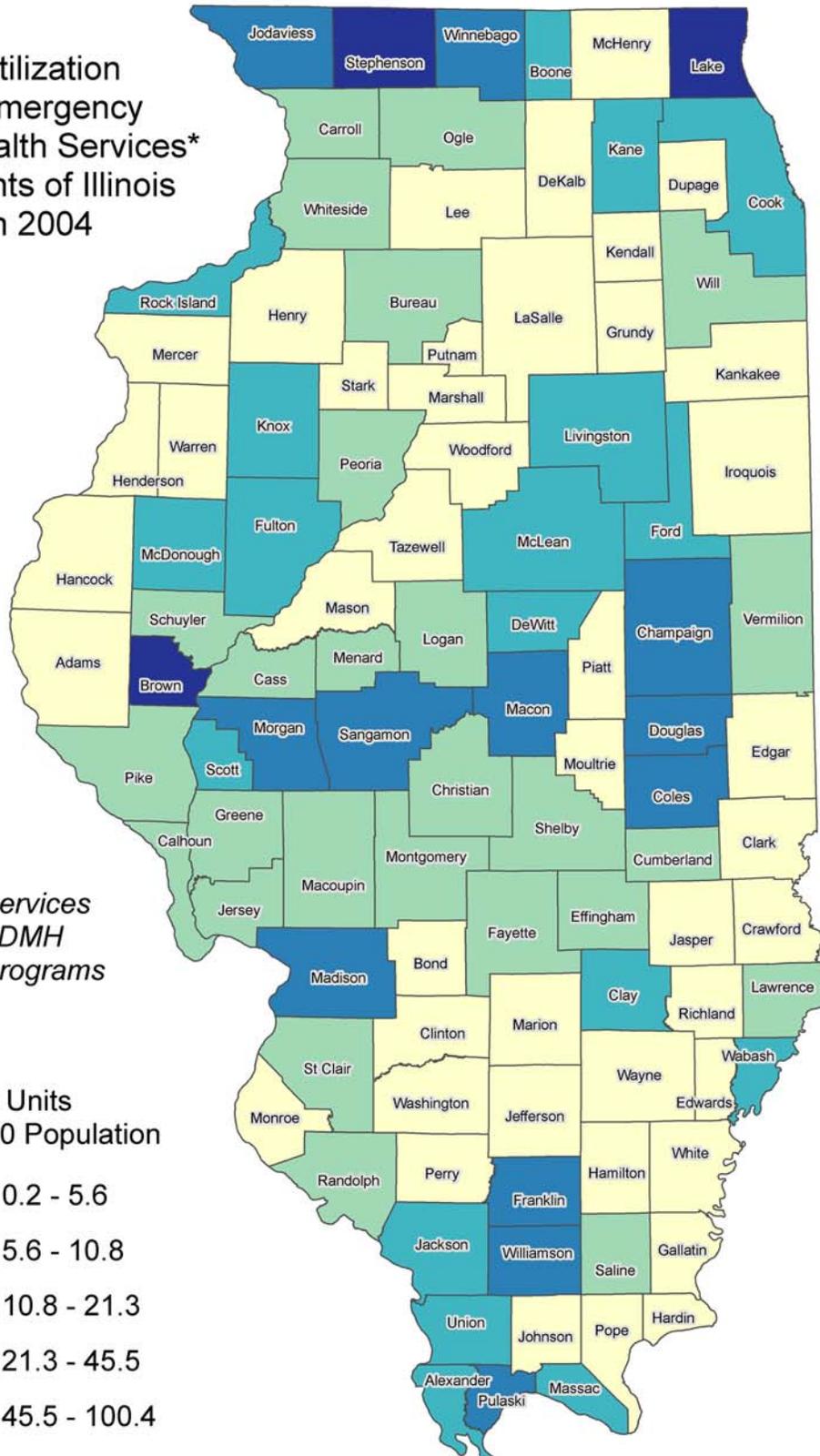


*Limited to services
provided by DMH
contracted programs

Service Units
per 1000 Population

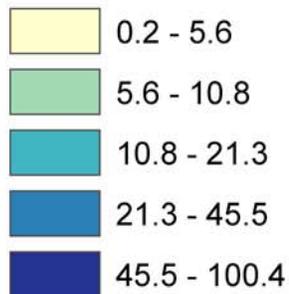


Rates of Utilization
of Crisis-Emergency
Mental Health Services*
by Residents of Illinois
Counties in 2004



**Limited to services
provided by DMH
contracted programs*

Service Units
per 1000 Population



in the lowest category for outpatient and rehabilitation services. Other counties show a very different ordering of rates of service utilization.

During the focus groups conducted with stakeholders to gather information used for this report, a perception stated by a number of participants was that Interstate 80 is the dividing line between greater and lesser availability of services, with more services available north of Interstate 80. One finding of interest derived from this analysis is that the perception of stakeholders was not confirmed. Cook County, in particular, was in the county groupings at the lower end of the range of utilization rates.

How do we interpret these significant differences in utilization rates? Although it is recognized that historical funding patterns and policies influence the type of services that are provided in a geographic area, the variability in the amount and type of services that are accessible to consumers by the county in which they reside is nevertheless striking. The available service capacity in the highest counties is significantly greater than in the lowest counties. The major alternative explanation for these observed differences is that the need is much greater in the counties that show the highest rates of utilization. However, while there are surely some differences in need that are not accounted for by our rate model, it is difficult to believe that these entirely explain the disparities. Historic differences in allocation of funding to support increases in services are likely to be the best explanation for these current differences in access.

Access to Mental Health Services by Population

In looking at access to service by population characteristics, a similar approach to the one described above was undertaken. However, rather than examining categories of service, overall service utilization rates for specific population groups were obtained and compared to determine the extent to which they were representative of the state population. Thus, this analysis focused on determining whether there are differences in service utilization patterns by persons of different races, age groups and gender by comparing the percentage of persons in each population group receiving services with the percentage of persons in each population group residing in the state.

Table 7-1, which is displayed below, compares the percentage of persons served in 2004 by community agencies contracted by DMH to provide mental health services to

the statewide population by race and ethnicity. [Not included in the table are persons served in general hospital psychiatric inpatient and outpatient services and persons served in nursing facilities.] The table indicates that African-American persons are enrolled in mental health services at about twice the rate that would be predicted from their representation in the population alone. All other groups are underrepresented among persons served.

Table 7-1. Percentage of persons enrolled in mental health programs for racial and ethnic groupings compared to the State population.

Measure of Access	Racial and Ethnic Groupings (Known)				
	African-American	Asian	Hispanic	Caucasian	Other
State population	1,856,152	419,916	1,530,262	8,424,140	34,827
Mental Health Service Recipients	47,433	1,701	14,580	89,493	538
Percent State Population	15.0%	3.4%	12.3%	67.8%	.28%
Percent Persons Receiving Mental Health	30.9%	1.1%	9.5%	58.2%	.35%
Percentage Differences	+15.1%	-2.3%	-2.8%	-9.6%	+.07%

*Note: Table excludes persons for whom race/ethnicity was not known.

Data Source: Illinois DMH ROCS for 2004.

General population source: www.state.il.us/agency/idol/wm/2002/BOOK02/Chpt102.htm

Service Utilization Rate Adjusted by Ethnicity. Table 7.2 provides the service utilization rate per 1,000 population adjusted by ethnicity. Note that even when utilization rates are adjusted in this manner, nearly twice as many African-Americans are seen for treatment than are persons of Hispanic descent and Caucasians. A similar relationship is observed between Caucasians and persons of Hispanic descent and Asians.

**Table 7.2 Utilization Rate Per 1,000 Adjusted by Ethnicity – Fiscal Year 2004
Persons Receiving Services from DMH Funded Community Agencies**

<i>Race/Ethnicity</i>	<i>Penetration Rate</i>
African-Americans	25.6
Asians	4.0
Hispanic/Latinos	9.5
Caucasians	10.6
Other	15.4
Total Population	12.5

Gender. Table 7-3 provides a comparison of the percentage of persons served in 2004 by agencies contracted by DMH to provide mental health services to the statewide population by gender. The table indicates women that are enrolled in mental health services at slightly higher rate (54%) than would be predicted from their representation in the population alone (51%).

Table 7-3. Percentage of persons enrolled in mental health programs by gender groupings compared to the State population.

Measure of Access	Gender	
	Male	Female
State population	6,080,336	6,338,957
Mental Health enrollments	80,683	91,039
Percent State Population	49%	51%
Percent Mental Health enrollments	46%	54%

General population source: www.state.il.us/agency/idol/wm/2002/BOOK02/Chpt102.htm
Enrollment data: Illinois Mental Health Block Grant Reporting

Age. Table 7-4 compares the percentage of persons served in 2004 by agencies contracted by DMH to provide mental health services to the statewide population by gender. The table indicates that persons aged 18-64 are enrolled in mental health services at significantly higher rate (74.3%) than would be predicted from their representation in the population alone (61.8%). Persons over the age of 65 are very significantly underrepresented. Children and adolescents are also underrepresented, but not to the same extent.

Table 7-4. Percentage of persons enrolled in mental health programs by age groupings compared to the State population

Measure of Access	Age Groupings		
	0-17	18-64	65 and over
State population	3,245,451	7,673,817	1,500,025
Mental Health enrollments	36,412	126,290	7,010
Percent State Population	26.1%	61.8%	12.1%
Pct. Mental Health enrollments	21.4%	74.3%	4.1%
Percentage Differences	-4.7%	+12.5%	-8.0%

General population source: www.state.il.us/agency/idol/wm/2002/BOOK02/Chpt102.htm

Source of mental health enrollments is Illinois DMH ROCS for 2004.

Limitations of the Analysis

An important limitation of this analysis is that it only includes services provided by agencies that receive grants from DMH. The services include both Medicaid and non-Medicaid funded services. This analysis does not include services provided by agencies that do not receive grants from DMH. Of particular importance are inpatient and

outpatient services provided by general hospitals and residential services provided by nursing facilities. The resources or the time was not available to permit a complete analysis. Described below are the strengths, challenges and several recommendations related to system access. The section following this discussion focuses on access to evidence-based practice (EBPs).

Strengths of the Illinois Mental Health System with regard to Monitoring Access

- (1) DMH currently has the detailed data available to permit systematic analyses related to geographic access of DMH-funded mental health services for the majority of the population for whom it purchases services. As demonstrated above, data also exists to determine disparities in access for racial/ethnic populations, as well as by gender and age. Although the current analysis could not focus on other variables in relation to access such as diagnosis, severity of illness etc. the data is available.
- (2) DMH has implemented the Adult MHSIP Consumer Survey and the Youth and Caregiver Surveys. Each survey provides a means of calculating indicators that can be used monitoring consumer perception of service access.

Challenges to eliminating disparities

- (1) The DMH does not have ready access to information from other state agencies that provide or purchase mental health services on behalf of residents of Illinois.
- (2) Private hospitals and other private providers in Illinois also deliver mental health services. DMH does not obtain data routinely for these systems, thus again, the ability to determine access, or even to track continuity of care does not currently exist.
- (3) A state initiative implemented in the last year to expand the Screening Assessment and Support Services (SASS) program for children and adolescents has resulted in the loss of data for the DMH population. The new SASS initiative pools dollars from DMH, the Department of Children

and Family Services (DCFS—the Illinois Child Welfare Agency) and the State Medicaid Agency to pay for services. Service providers who previously submitted ROCS data to DMH for this population no longer do so, and there have been delays in accessing this important data.

- (4) The current analysis focused only on the population receiving services. Methodologies should be used to determine access for persons in need of service, but who are not currently receiving services. This data is not currently available.

Recommendations:

- (1) **Geographic Gaps in Services:** Based on the analyses described above, the greatest disparities in access to DMH funded services are geographic. There are wide variations in amount and type of service utilization, and thus access to these services across the State. This analysis should be repeated and strengthened by incorporating access to inpatient and outpatient programs based in general hospitals, as well as State facility utilization. Prevalence rates for each county should be developed and employed in the denominator, rather than population. Finally maps showing rates of utilization of individuals or episodes of care and by total expenditures should be developed, in addition to the rates of utilization of units of service that we have presented.

Once complete rates have been developed, then DMH must turn its attention to addressing the largest disparities. We assume that there will be wide variations in utilization of inpatient care, as there are for other services. Areas with high inpatient utilization should be a focus of concern, particularly the development of community programs that will reduce this costly service. In addition, DMH networks should examine how resources are currently employed by the type of service provided, particularly why some communities have relatively low rates of access to particular services. These may be evidence of unmet needs and discussion among consumers; family and providers should be initiated to examine whether resources should be allocated in a different way or whether

certain programs should be a priority for new resources. DMH should also consider whether there should be minimum, expected rates of utilization by communities and take appropriate steps to target communities with lower than expected rates for changing access to services.

- (2) While the disparities among other population groups were not as large as the geographic disparities, DMH should consider whether children and older adults particularly have adequate access to services. For children, DMH should probably take into consideration services offered through DCFS contracts, as well as its own grants.
- (3) Analyses such as the one described above, should be routinely conducted and use to inform planning efforts.
- (4) Although it is not perfect, the analysis that was performed provides baseline information that can be used to determine how access to services changes as the DMH fee-for-service initiative is implemented. DMH should undertake additional recommended analyses.

Access to State of the Art Treatments (Evidence-Based, Best and Promising Practices)

Despite the fact that research has documented the effectiveness of a limited number of treatments and services, the extent to which these treatments are used in the mental health field is extremely limited. Information regarding this body of research and the treatments or evidence-based practices has been broadly disseminated, but not adopted. This gap between research and practice has been referred to as the *science to service gap*. A number of reasons for this gap have been identified, including: (1) a need to re-engineer the human services workforce to help them develop the skills and knowledge needed to provide evidence-based treatments; (2) the lack of policies and financing strategies required to support adoption and implementation; (3) a lack of awareness by the public that such treatments exist; (4) continued focus on financing and provision of treatments that have been historically provided despite the fact that some treatments have been shown to be more efficacious. However, just as medical treatment

for physical illnesses rely on the use of state-of-the-art approaches; so then should mental health treatment.

State mental health agencies across the United States have begun partnering with local stakeholders and providers to begin incremental implementation of evidence-based practices. Yet, it is a daunting challenge given the system and organizational changes that must occur. Implementation requires sustained commitment of mental health leadership and the building of consensus with mental health stakeholders to adopt such practices. The development of new financing strategies to support these approaches is critical. The Report of the President’s New Freedom Commission notes that “mental health system transformation, hinges in part, on better balancing fiscal resources to support using proven, evidence-based practices.

The Federal Substance Abuse and Mental Health Services Administration (SAMHSA, USDHHS) has identified six model mental health programs as “evidence-based practices” (EBP’s) and has developed toolkits and grant programs to support their implementation. These are each briefly reviewed here, including the status of their implementation in the public mental health system in Illinois. For each program model there are guidelines for what constitutes “fidelity” to the model—that is, what elements must be included for a program to be considered as a faithful implementation of the model. Some programs (e.g., Assertive Community Treatment) were adopted in many public systems more than ten years ago; however, the program “label” does not necessarily assure that the actual program follows the model and states rarely assess the fidelity of implementation.

Assertive Community Treatment (ACT) is designed to help people stay out of the hospital and to develop skills for living in the community, so that their mental illness is not the driving force in their lives. Assertive community treatment offers services that are customized to the individual needs of the consumer, delivered by a team of practitioners, and available 24 hours a day, seven days per week. Illinois has been a leader in implementing and funding ACT. There are currently 47 ACT programs funded to provide these services throughout the state. The DMH worked with Dr. Gary Bond to develop and customize ACT services for Illinois in the early 1990’s. A fidelity instrument was used to help agencies and DMH measure progress in implementation of

the model. An evaluation was also performed to determine the success of the model in achieving the outcome of reduction in hospitalizations. As ACT became more integrated into the Illinois service delivery system, staff of DMH networks were charged with annual monitoring of ACT programs, and network staff took on the charge of prior approval before enrollment of consumers in the ACT program. However, with the reduction of DMH staff due to early retirement and attrition, in the past few years, the ability to monitor ACT fidelity at has been curtailed. Efforts are currently underway to assess fidelity of the ACT programs that are being funded.

Integrated Dual Diagnosis Treatment (IDDT) is a program model for people who have co-occurring disorders of mental illnesses and substance abuse addiction. The integrated dual diagnosis treatment approach helps people recover by offering both mental health and substance abuse services at the same time and in one setting. Prevalence rates for people with serious mental illnesses and substance abuse addiction has been found to be as high 50%; ensuring that this state-of-the-art treatment is available is critical. The need to focus on the provision of IDDT was identified by a number of stakeholders who were interviewed for this report.

The DMH has worked collaboratively with the DHS Division of Alcoholism and Substance Abuse (DASA) for a number of years to fund what are referred to as MISA--- mental illness and substance abuse services. Six MISA consortiums comprised of mental health and substance abuse providers have been established in diverse geographical areas around the state, with the goal of coordinating treatment for persons with co-occurring disorders. Some providers such as the Human Services Center in Peoria have also focused resources on developing and implementing co-occurring treatment and have received National recognition for this effort. The work undertaken by the MISA consortiums, in collaboration with DMH and DASA, has helped advance treatment for persons with co-occurring disorders. While the MISA model is similar to the IDDT model, however, there are differences. Thus an effort is being undertaken to begin implementation of the IDDT. Three current initiatives relate to this effort. In 2003, Illinois received a three-year grant from the SAMHSA Center for Mental Health Services to support the implementation and evaluation of the IDDT model in two geographically diverse areas. Eighteen agencies are enrolled in this pilot program. This project provides

an opportunity to (1) determine the effectiveness of the use of the model with ethnically and racially diverse populations, which has been recommended by the President's Commission on Mental Health; and (2) to determine the kinds of policies and financing strategies that need to be adopted to supported implementation of this EBP. This project is timely in that the fee-for-service initiative in which DMH is engaged may provide an opportunity to develop funding strategies to support the implementation and sustenance of the IDDT model. It is also expected that the learnings gained from this project can be used to develop strategies for expanding the use of the model throughout the state.

A second initiative that relates to adoption of the IDDT model in Illinois, is the participation of DMH and DASA in the SAMHSA CMHS sponsored and funded Co-occurring Disorder Policy Academy. Staffs from both agencies, as well as staff from the State Medicaid agency and consumers, have participated in strategic planning efforts geared toward meeting the treatment needs of persons with co-occurring disorders.

Finally, treatment of co-occurring mental illness and substance abuse disorders is an important goal that has been incorporated in the DMH strategic planning process.

Supported Employment (SE) is a well-defined approach to helping people with mental illnesses find and keep competitive employment within their communities. Services include assisting individuals in finding work; assessing individuals' skills, attitudes, behaviors, and interest relevant to work; providing vocational rehabilitation and/or other training; and providing work opportunities. Supported employment programs are staffed by employment specialists who have frequent meetings with treatment providers to integrate supported employment with mental health services. DMH and DRS have recently received a grant from the Robert Wood Johnson Foundation to develop and pilot supported employment in limited areas of the state.

Family Psychoeducation is a program for teaching consumers and family members about major mental illness. The goal is to teach both groups about what to expect and how to respond to the signs and symptoms of mental illness, as well as treatment. The model involves the establishment of a partnership among consumers, families and supporters, and practitioners. Several years ago, Illinois provided widespread training to community

providers and staff of DMH state hospitals in the Psychoeducation model, however the model has not been adopted across the state. Efforts are currently underway to identify opportunities to work with mental health system stakeholders to build consensus regarding the use of the model. DMH has also provided support/funding to the Illinois Alliance for the Mentally Ill to educate its members in the *Family to Family* peer training model developed by Joyce Borland. This model provides information and resources to people with family members who have mental illnesses that are geared toward better preparing them to understand and interact with the person in their life who is mentally ill.

Medication Management Approaches in Psychiatry focuses on using medication in a systematic and effective way, as part of the overall treatment for severe mental illness. The ultimate goal is to ensure that medications are prescribed in a way that supports a person's recovery efforts. Although the model is not widespread in Illinois, it has been implemented in two areas of the state as pilot projects ---Peoria and at the Elgin Mental Health Center. The learnings from these implementations have been used to initiate another project in Springfield Illinois at DMHs' McFarland State Hospital.

Illness Management and Recovery strongly emphasizes helping people to set and pursue personal goals and to implement action strategies in their everyday lives. Illinois has not adopted the SAMHSA model. However, it has chosen to train consumers in the Wellness, Recovery Action Program (WRAP) model developed by Mary Ann Copeland (see Chapter 4 above).

Supported Housing (SH) is a program designed to assist individuals in finding and maintaining appropriate, normal housing arrangements. It is not part of the original six SAMHSA endorsed program models. However, SAMHSA has sponsored research on this program and is currently sponsoring the development of a toolkit for implementation. While this program idea has been widely adopted elsewhere, Illinois has not adopted the program model. Supported housing may provide an alternative to residential services for adults with serious mental illness currently residing in nursing facilities.

Strengths of the Illinois Service Delivery System with Regard to Adoption of EBPs

As can be inferred from the sections above, the Illinois DMH has had some limited success with regard to evidence-based practices, but it has far to go in this arena, as do many other states across the country.

- (1) The DMH Fee-for-Service Initiative incorporates a focus on the development of services that support recovery. EBPs support recovery efforts of consumers.
- (2) Several years ago, the DMH convened a taskforce of a wide range of stakeholders to build consensus regarding the implementation of evidence-based practices. Although a plan was initially developed to move forward, reductions in staff and other priorities have intervened. There is however, awareness that there is a need to move toward the implementation of EBPs. This awareness is reflected in the DMH strategic vision and strategic plan development process. Of note also, is that implementation of EBPs was a strong theme that emerged from the interviews and focus groups conducted with stakeholders to gather information for this report.
- (3) The adoption of ACT more than ten years ago initially put Illinois in the forefront of implementing EBPs. However, since that point in time, the momentum has greatly slowed. Some bright spots include recent grant funding secured to implement and evaluate IDDT and supported employment (SE) pilots, as well as the work initiated in the area of Medication Management in three areas of the state. Additionally the collaboration of DMH and DASA on the MISA Consortia and the Co-occurring Disorder Policy Academy, and the collaboration of DMH and DRS in the supported employment area bode well for continued efforts in these areas if nurtured.
- (4) The change in financing strategies required by the DMH fee-for-service initiative provides an opportunity to determine how to address critical funding issues associated with the adoption of EBPs.

Challenges to adopting EBPs

- (1) As noted above, the adoption of evidence-based and promising practices has been slow in Illinois. The ability to monitor the fidelity of implementation to

EBP program models is critical, however in recent years DMH has not had the staff or resources to monitor fidelity of the one statewide EBP---ACT that has been implemented.

- (2) Other than ACT, the remaining EBPs are either just getting started or have yet to be initiated. With the current focus on shifting the mental health system financing from grant-based to fee-for-service, it is difficult to see how this will change significantly in the next year or two. With many providers focused on their economic health, it is unlikely that they will have the resources to make significant changes in their program. Moreover, it is not clear whether the reimbursement system will support the ongoing costs of these programs.
- (3) The implementation of EBPs requires organizational commitment in terms of developing and implementing policy and financing strategies. Although DMH has prioritized the implementation of EBPs in its strategic planning process, this will only be realized by developing specific strategies for monitoring and evaluating the implementation process. Implementation of EBPs will not be cost-neutral. However, when EBPs are implemented they are cost-effective.
- (4) Finally, DMH is challenged to initiate major training efforts and to offer technical assistance with its current administrative staff.

Recommendations

- (1) The implementation of EBPs is in a developmental state in many states across the country. Just as it would be difficult to implement the six EBPs described above simultaneously, it is difficult to implement EBPs statewide simultaneously. As noted above, DMH has initiated efforts to implement, through pilots, several EBPs. Most of the pilots however, are dependent on non-State funding. The learnings from these efforts should be reviewed and used as a basis to expand implementation across the state. However at the same time, DMH should determine which practices should be a priority of

statewide adoption and what funding strategies are needed to support implementation.

- (2) Planning for the assessment of the fidelity of ACT services to the program model is underway, however this evaluation needs to become, once again, part of the routine monitoring associated with the delivery of services.
- (3) DMH will need to develop a long-range plan for the sustainability and expansion of the adoption of IDDT and SE models.
- (4) In other areas in which the DMH or individual providers have adopted models that are different than those SAMHSA recommends (*i.e.*, family Psychoeducation, illness management and recovery) an analysis of the differences should be undertaken and decisions made about which model is most appropriate to support.
- (5) Finally, the role of nursing facilities and other institutional models in relation to the DMH service system should be reviewed in light of the shift of many states to the adoption of the EBP of Supported Housing. The likely impact of the *Olmstead Decision* will be to develop alternative residential models in less restrictive settings than that currently available in congregate institutional settings. DMH will need to collaborate with the State Medicaid and Public Health agencies to move this agenda forward.

VII. GOAL: Technology is used to access mental health care and information

John is 38 years old. He has spent most of the past twenty years of his life in the public mental health system with repeated hospitalizations, outpatient therapy, and various day programs. For the past three years John had been living with a roommate in a licensed apartment under the supervision of a residential services provider. Six months ago John moved to his own apartment. John is still receiving disability payments and his case manager checks in with him once or twice a month. But John is clearly moving on with his life. He has a part-time job, and he is far less dependent on mental health services than he once was.

Mary is 46 years old. She also has been in the public mental health system since she was a young adult. For the past few years Mary had been entirely independent of public services and supports. She had a well-paying, full-time job and an active social life. One year ago Mary had a major relapse. She was hospitalized three times within a few months; she lost her apartment. She is now living in a supervised community residence and not doing very well.

Is the experience of John or Mary more typical? If you listen to the defenders of the system, John's experience is more and more common. The system is working better everyday, and the only problem with the expenditure of public funds is that there are not enough of them. Others will argue that major relapses like Mary's are a frequent occurrence, and that the system has never worked very well--that it is marked by incompetence, an absence of caring, even fraud. Who is right? How effective is the system in helping people recover from serious mental illness. It is impossible to say with any credibility because the evidence is mostly anecdotal. We do not currently have outcome data that would enable us to know where the system is working and where it is not.

John and Mary are real people, but they are not statistics. No one keeps tabs on the outcomes of mental health services except in special research studies. The major changes in John and Mary's lives described above are not known to any statistical system in the state where they live. But they ought to be if the state is to evaluate the benefits, as

well as the costs, of publicly funded services. Obtaining appropriate outcome data is within reach with the investment of marginal additional resources.

Research has demonstrated that mental health services can assist most individuals with a serious mental illness to overcome their illness and lead productive lives. But they only make a difference if quality services are delivered. For many years government has relied primarily upon limited, statistical information regarding level of effort (*e.g.*, units of services, expenditures) and indirect measures of quality (*e.g.*, minimum licensing and accreditation standards) in order to monitor the mental healthcare industry. Some states have been more successful in implementing systems to monitor performance and outcomes, but most have not. In the absence of the systematic collection of this information, we don't if quality services, or for that matter effective services are being provided. The focus on services that support recovery also supports monitoring of outcomes. An investment in assessing performance outcomes is long overdue.

Outcomes cannot be reliably predicted for every individual. The fact that one individual has fewer hospitalizations, is better able to live independently, shows improvements in relationships with friends and family, and enters the job market, while another does not, often cannot be attributed to a provider or a system of care. However, outcomes for a group of individuals within one geographic area or one managed care plan can be reliably compared to outcomes for other groups served in other areas or by other plans. Establishing credible information to compare performance is a primary task of mental health statistics.

In the absence of clear information about performance, systems tend to keep doing what they have been doing, whether it is working or not. The principal catalysts for change are the rare, but frightening, instances of violence or negligence that receive public attention, and intermittent new discoveries from the research community. If individuals are to receive the best care and if systems are to achieve the best possible client outcomes given available knowledge, then there must be statistical information regarding comparative performance. Without information that is updated regularly and

publicly available, there can be no external impetus for providers to improve and no accountability to the public.

Defining Accountability

This chapter will focus on the uses of information technology (IT) to support management information needs or accountability. Accountability is often expressed as a goal of government programs, but support for resources to assure the availability of information required to support this goal often take a back seat to other priorities. In general, when resources are scarce—as they typically are in public mental health—the first priority for funding is on services. Of course, there is no point in allocating resources to accountability in the absence of services. However, there is also a point where it is negligent to spend resources on services without the capacity to evaluate what is being delivered and whether the anticipated benefits are actually occurring. This chapter begins with a brief introduction to the functions of IT and then moves on to a discussion of the uses of IT for internal accountability.

For most organizations, the first priority for IT is the support of administration. By administration we mean the “business needs” of the organization, including billing for services and tracking accounts receivable, payment of expenditures (e.g., payroll, invoices), and managing personnel operations. Historically the first IT systems replaced paper systems that were designed to support these functions. For state mental health authorities some of these functions are done “in-house” while others are hosted by another state agency. IT may also be employed to support program operations. This can include maintaining part or all of patient medical records, as well as employing technology to support assessment and treatment interventions. These functions will not be explored here.

Management information can serve a number of needs at the state, area, agency and program levels. These can be grouped into two major areas, external and internal reporting. External reporting covers information that is provided to external authorities. For DMH, this can include the Governor or administrative agencies, the Legislature, the Courts, the Federal government, interested constituencies, and the general public. Under

most circumstances the needs for information of these groups can be met if there is adequate information available for internal management. So we will focus our attention on these needs.

Broadly speaking, internal information can serve three functions: quality management, risk management, and change management. Each of these will be briefly discussed below.

Quality management: Under quality management, we group three important domains: access to care, appropriateness of care, and outcomes of care. These domains were defined in the SAMHSA-sponsored MHSIP Consumer-Oriented Mental Health Report Card that is discussed further below.

Risk management: Risk management is similar to quality, covering the same domains. However, risk points very directly to problems that must receive special attention. For example, indicators of the use of seclusion and restraint are intended for risk management. Higher than expected rates of seclusion and restraint may be an indication of difficulties in the management of inpatient care and should trigger a focused review of treatment practices where they are identified.

Change management: Change management typically focuses on the implementation of a specific new initiative, for example, the introduction of an evidence-based practice.

What to Measure?

Although the broad objectives of designing performance management systems for mental health services are reasonably clear, the devil is in the details. A state mental health authority must determine to what it is willing and able to hold itself and its providers accountable. Fortunately there are some good answers to these questions. Beginning in the 1970's Pennsylvania developed a performance management system for its county-led community mental programs. A few other states followed, but the greatest breakthrough occurred with the development of the SAMHSA/CMHS-sponsored Consumer-oriented Mental Health Report Card ten years ago. The task force appointed to design the report card recognized the importance of a design that formally incorporated the following elements:

1. Values. The report card was based upon a well-articulated set of values for the public mental health system. These were represented as specific "concerns" within each of the major, report card domains (Access, Appropriateness, Outcome, and Health Promotion/Prevention). Each concern identifies a significant goal of mental health services (*e.g.*, Service recipients experience increased independent functioning). Twenty-six mental health system goals provided the basis for rating performance; the largest number of goals (13) are in the outcome domain.

2. Specificity. For each of the twenty-six concerns, there were between one and four performance indicators to assess how well the system was managing in that goal area. Recommended measures were presented for each, individual performance indicator. The measures include standardized instruments where the task force judged that these were appropriate and new measures in areas where there were no existing measures to rely upon.

3. Sources of Data. The design of the report card required multiple sources of data to construct performance indicators. Most prominent among these was the report of service recipients themselves on their care and treatment outcomes. Clinician assessments, enrollment-encounter data, medical records, and financial information were all also incorporated into the design.

4. Population Sensitivity. The task force recognized the fact that different populations were served. While the primary focus was on assessing performance of systems serving persons who were seriously mentally ill, the task force identified the subset of performance indicators that applied to other adults and children and to persons with substance abuse problems. Subsequent additions also identified specific performance indicators for seriously emotionally disturbed children and adolescents.

The domains and indicators of the original report card are outlined below:

- I. Access to Care
 - o Utilization rates including dropout rates by race/ethnicity

- o Expenditure rates
 - o Consumer ratings
 - Timely contact
 - Ease of access (location, parking)
 - Able to obtain services I needed
 - Cultural sensitivity
 - Cost not an obstacle
- II. Appropriateness of Care
- o Continuity of care
 - Inpatient follow-up
 - Emergency follow-up
 - Change in primary therapist
 - o Consumer ratings
 - Active participation in treatment planning
 - Able to ask questions
 - Not penalized for complaints
 - Staff believe I can grow, change, recover
 - Staff encourage me to take responsibility
 - Staff knowledgeable and competent
 - o Consumers involved in planning, delivery and evaluation of services
 - o Best practice guidelines
 - o Global Satisfaction
- III. Outcomes
- o Linkage to health care
 - Rate of physical examinations
 - Mortality rates of recipients 35-50
 - o Minimize iatrogenic effects
 - Annual AIMS
(Abnormal Involuntary Movement Scale)
 - o Consumer-rated symptom distress (SCL-15)
 - Nervousness or shakiness inside
 - Spells of terror or panic
 - Heavy feelings in arms or legs
 - Feeling of worthlessness
 - Feeling blue
 - o Consumer-rated sense of personhood
(Rosenberg Self-esteem)
 - Able to do things as well as most other people
 - Do not have much to be proud of
 - Satisfied with myself
 - o Clinical rated Alcohol-Substance Abuse
 - o Consumer-reported changes (SF-36)
 - Cut down on work

- Accomplished less than you would like
- Didn't do work as carefully as usual
- Interference with social activities
- Involvement in competitive employment
- Involvement in volunteer activities
- Living in owned/leased residence
- Involvement in self-help group
- Read information about MH treatment

Within a year of dissemination of the MHSIP Report Card, a toolkit on report card design and implementation was developed by the Evaluation Center at Human Services Research Institute (HSRI) and made available to support implementation efforts within the states. Additionally, HSRI offered consultation to states to help implement the Report Card.

The MHSIP Report Card has had a wide influence upon state mental health authorities, as well as on SAMHSA, the sponsoring agency. Public mental health systems in most states adopted the report card design in part or in whole. The most frequently adopted element is of the consumer survey, although it is not unusual for states to make additions to this instrument. The report card also influenced the development of the reporting requirements for the Federal Mental Health Block Grant, which have evolved in the past five years. In fact, several key Block Grant indicators are directly derived from the Report Card.

The design of the report card continues to evolve. SAMHSA/CMHS has sponsored a new taskforce to review and update the original design based on findings and experiences of people working in the field during the last nine years. A new, draft report card design will be circulated to states at the upcoming CMHS National Mental Health Planning and Statistics Conference later this month (May, 2005).

Challenges to Performance Measurement/Report Card Implementation

Implementation of mental health performance indicators is not a simple matter. There are many constraints on state mental health authorities that may make it difficult to undertake this successfully. While the provider community is often verbally supportive of the need to be accountable, there are also sources of resistance. Concerns will be raised about whether the data are accurate and reliable, whether findings reflect the “fact”

that some programs serve more difficult clients than others, whether the most fitting indicators have been selected, and other potential questions about the fairness of the system. The costs of design, implementation, and maintenance may be another barrier, particularly in a system that devotes as little resources to administration and management as Illinois. In order to overcome these obstacles, there must be both a clear plan for development and a commitment to see it through.

Consensus on design: State mental health authorities are appropriately reluctant to determine the design of performance management systems without first providing the opportunity for all stakeholders to have input into the process. It is necessary to involve all constituencies in a process in which they have the opportunity to offer ideas and to provide feedback on design decisions. This includes all elements of the design, including the conceptual and operational definition of indicators, the methods of data collection, including the costs and risks that may be borne by providers and clients, and the intended uses of the data, including reporting.

Costs of data collection: Most public systems already collect some data as a part of their administrative systems, particularly reimbursement systems that can provide information to construct indicators of access and appropriateness. The major add-on costs are those that are associated with the collection of survey data from consumer and/staff. Since these data are rarely collected at every encounter, decisions must be made with respect to the frequency within which data will or can be collected and the most efficient methods for doing so.

Costs of analysis and reporting: When systems are designed, it is not unusual for the details of reporting to be set aside until data are actually available. This will cause major problems for two reasons. First, the uses of data, as represented in planned reports, are the major benefit of a system. Those benefits should be articulated in detail as a part of the design process. Second, the costs of undertaking analysis and producing reports are often not estimated. There is an assumption that once the data become available, that will take care of itself. That rarely happens. More commonly data sit in boxes or in electronic files waiting to be processed and analyzed. When the data are ignored, then compliance with data collection begins to erode and the system will gradually deteriorate to the point where people begin asking why this effort was initiated in the first place.

Strengths of The Illinois Mental Health System – Information Technology and Accountability

- (1) The Illinois Division of Mental Health has the ROCS client information system. This system has been successfully employed to create claims for Medicaid and to track non-Medicaid services provided to individuals who are seen by contractual providers. The system is also capable of providing performance information about access to mental health services. Service utilization rate has been generated annually as part of DMH reporting under the SAMHSA CMHS funded Data Infrastructure Grants for the past five years. Although this data has been shared with the Mental Health Planning and Advisory Council, as well as DMH managers, it has not been used for decision-making purposes.
- (2) DMH has also begun collecting MHSIP Consumer Survey data for a stratified (representative) sample of consumers, but this has been a somewhat difficult and labor intensive endeavor. DMH has also been involved in pilot-testing several measures from the new MHSIP Quality Report. There have also been other recent efforts to develop ongoing evaluation information about the performance of the system. However, with the significant loss of administrative resources, DMH is no longer able to move these efforts ahead.
- (3) DMH has been, and continues to receive Data Infrastructure Grants (DIGs) from SAMHSA CMHS that are focused on performance measurement. SAMHSA has awarded DIGs to forty-nine states and territories. Performance measures are developed, operationally defined and tested in collaboration with SAMHSA CMHS, the states and territories and the National Association of State Mental Health Program Directors Research Institute (NRI). This is one of the primary benefits of participation in the DIGs.

- (4) DMH has a history and experience in collecting and disseminating information on performance measures—though they have been primarily process oriented.
- (5) The use of data to support management, decision-making, and planning has been articulated by DMH Executive Staff as a strategic goal for the mental health service delivery system.

Challenges to the use of technology to improve mental health services

- (1) Although much information is gathered it is difficult to get data in a timely manner for decision-making and planning purposes.
- (2) The ROCS system needs to be reconfigured to collect performance and outcome data across time. Although information is available that could be used to assess outcomes this data is currently only collected at one point in time.
- (3) IT needs to be updated to support the timely generation of information that is needed to support fee-for-service financing. Currently there are delays in creating and generating reports that are needed to monitor provider and system performance in a fee-for-service environment.
- (4) There is a perception by stakeholders that although lots of data is collected and submitted through the ROCS system, it is not used to support planning and decision-making.

Recommendations

DMH stands at a crossroads. Shortcomings with the primary, existing community information systems have been recognized and discussions about redesign have taken place. However, those discussions could go in either to two directions. One direction would be to entirely eliminate data collection by DMH. As the mental health system moves in the direction of paying for services largely on a fee for service basis, there will be considerable pressure to limit data collection to the State's Medicaid Management Information System, an administrative system. Thus the available data would be limited to reporting on indicators of access, a few indicators of appropriateness, and one or two outcome indicators. This is the path of least resistance, but will provide a very weak system for accountability at best. Should this occur, DMH will be in a difficult position

to demonstrate the benefits of its programs within the State; to have data that will provide a rationale, empirical basis for planning and evaluation of programs, and to meet its external reporting obligations to the Federal government under the Mental Health Block Grant program. This direction is not the approach recommended for DMH for all these reasons.

The alternative direction is to redesign the system so that a full range of access, appropriateness, and outcome indicators could be collected and produced, which would make the system fully accountable. As suggested earlier, this second path would require more resources to implement than a system that is primarily designed to assure reimbursement of paid claims for services. Yet it is essential if DMH is to have available data on the performance of the system overall, as well as for the networks or subgeographic areas within the networks and for individual programs. More importantly, it is necessary for DMH to be accountable for service delivery, and purchasing and financing public mental health services on behalf of the citizens in Illinois.

DMH must begin the process of designing and implementing a new client information system that will serve both its administrative and management information needs. The models and examples for how to do this, as well as technical assistance, are widely available. The knowledge and experience for how to undertake this effort are already present in the Division. What are lacking are the resources necessary to initiate and achieve this important goal.

Appendix A

Service Utilization Thematic Maps

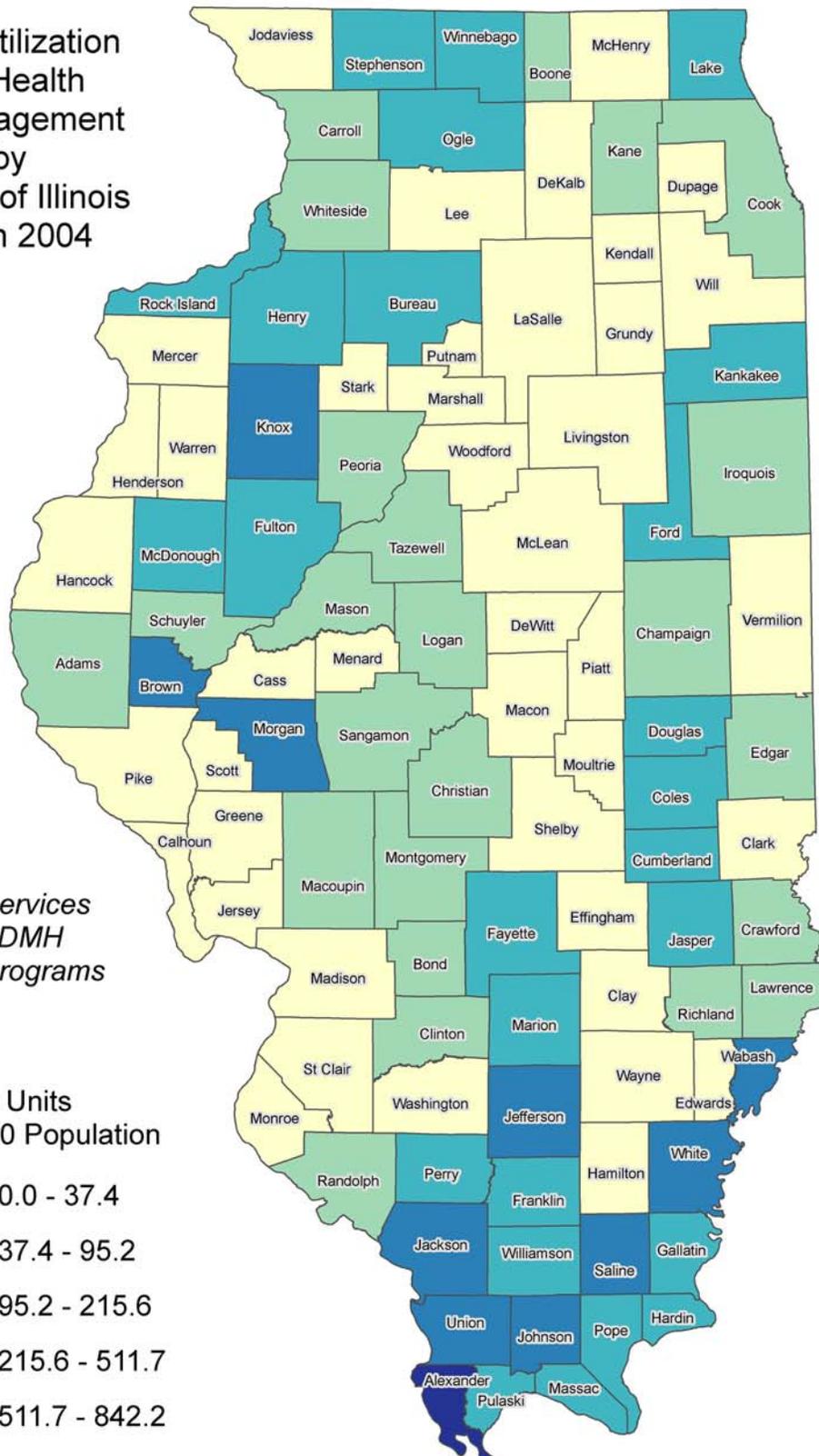
Case Management Services

Psychiatrist Services

Rehabilitation Services

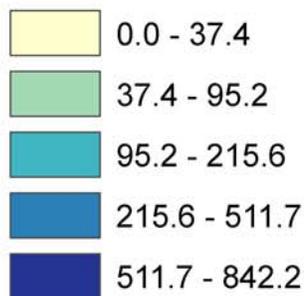
Residential Services

Rates of Utilization
of Mental Health
Case Management
Services* by
Residents of Illinois
Counties in 2004

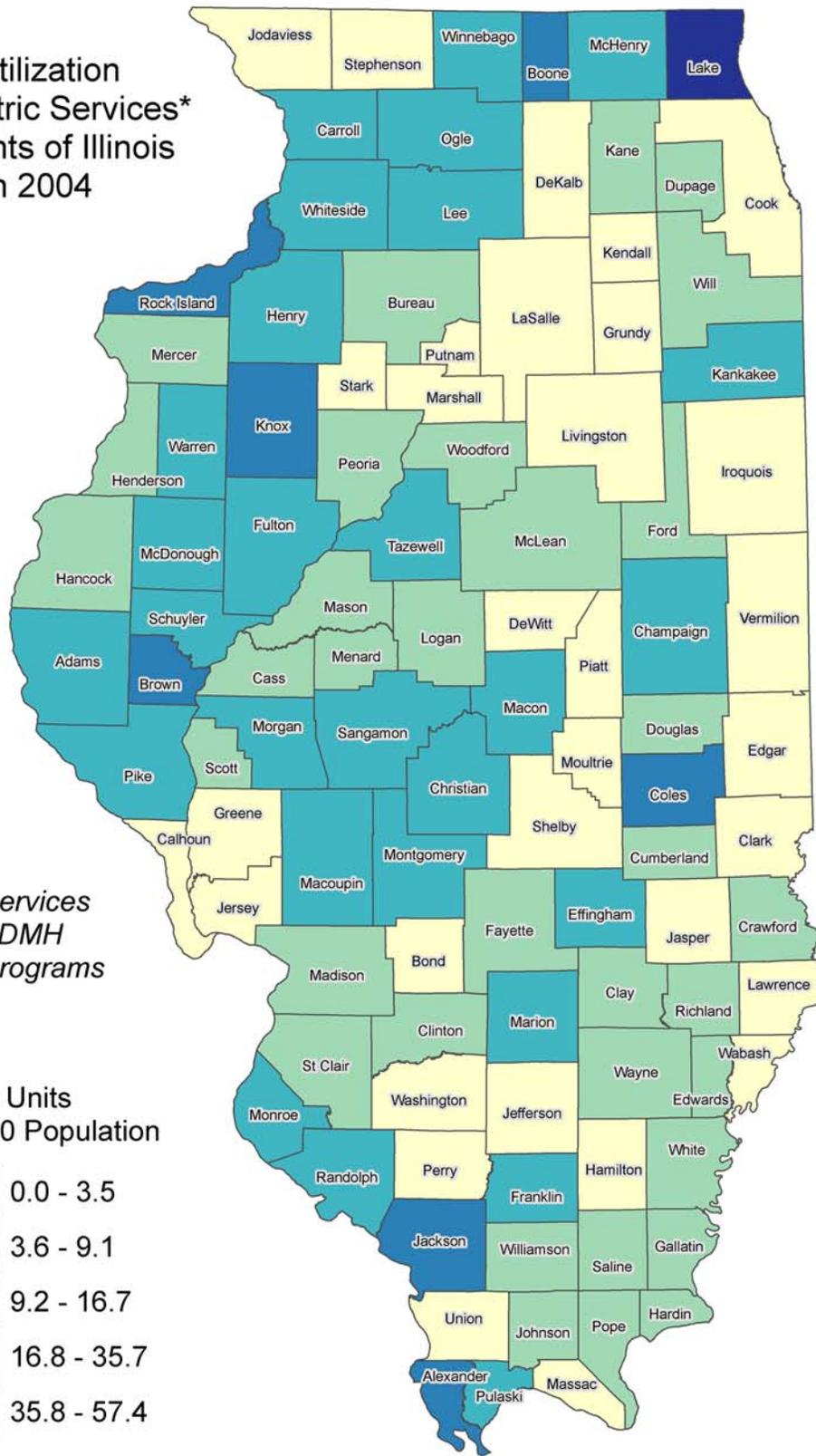


**Limited to services
provided by DMH
contracted programs*

Service Units
per 1000 Population

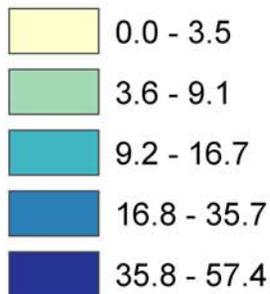


Rates of Utilization
of Psychiatric Services*
by Residents of Illinois
Counties in 2004

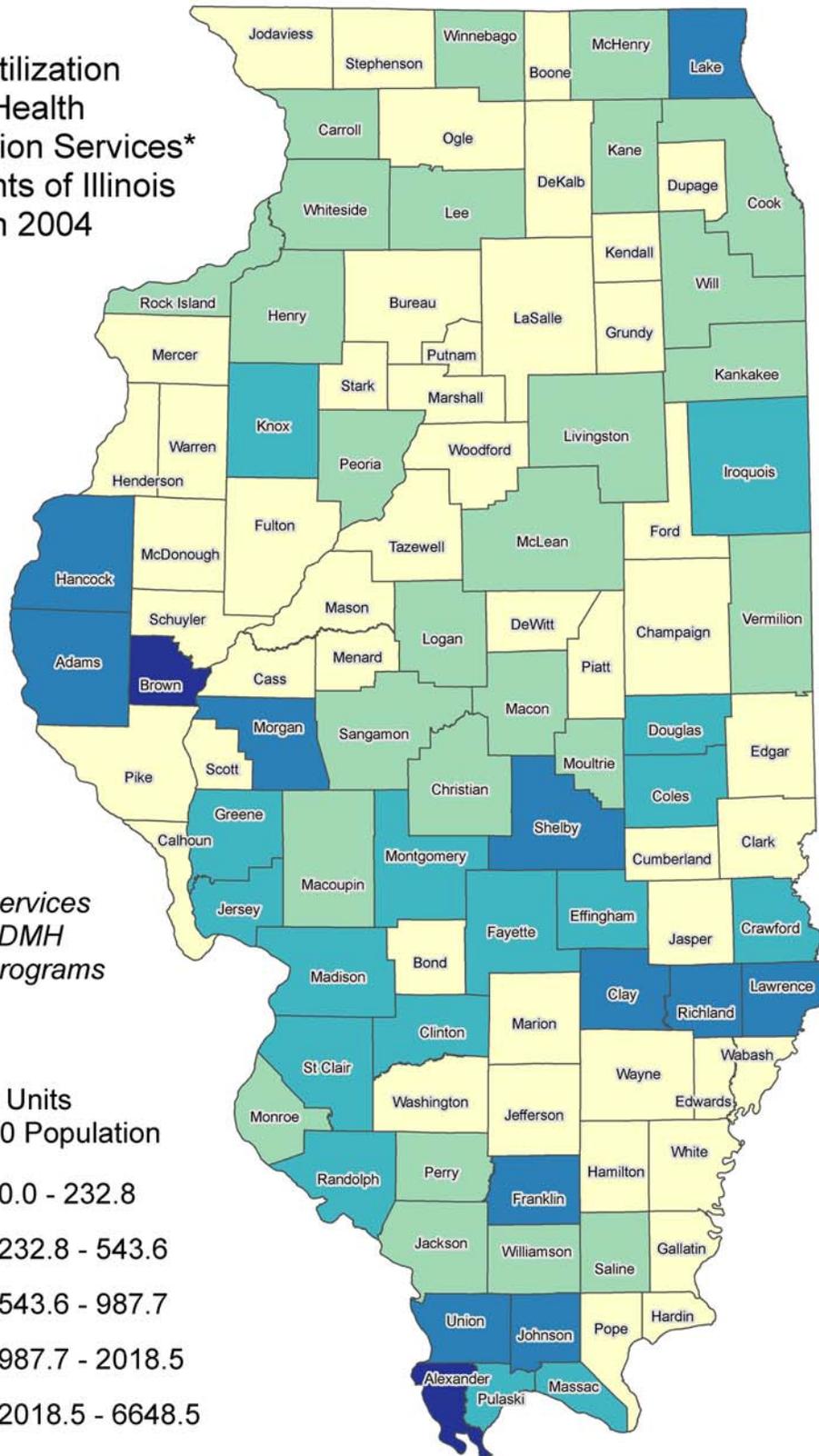


*Limited to services
provided by DMH
contracted programs

Service Units
per 1000 Population

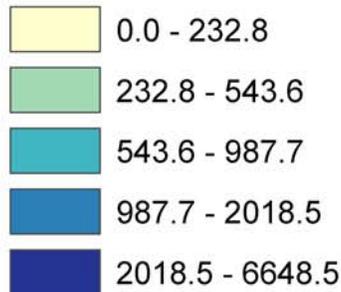


Rates of Utilization
of Mental Health
Rehabilitation Services*
by Residents of Illinois
Counties in 2004



*Limited to services
provided by DMH
contracted programs

Service Units
per 1000 Population



Appendix B
History of the Illinois Public Mental Health System

HISTORY OF THE PUBLIC MENTAL HEALTH SYSTEM

In order to understand the challenges currently faced by the public mental health system, both in the State of Illinois and nationally, it is often helpful to examine the system's history. Over the past 150 years, changing theories about the nature of mental illness and resulting changes in treatment methods, combined with powerful social forces, have acted to continually re-shape the nature of public mental health policy and services. These changes have resulted in what Morrissey and Goldman (1984) identified as four cycles of reform, which occurred from the mid-19th - late 20th century: moral treatment, the mental hygiene movement, community mental health, and community support. Each reform arose because of unanticipated problems resulting from the implementation of the previous reform, and each was based upon a new theoretical approach, the addition of new treatments or services, and a new type of facility or locus of services. These cycles of reform were driven not only by new developments in psychiatric thinking, but were also influenced by the social, political, economic and demographic forces of the time. Ultimately, Goldman (2002) believes, each cycle of reform was eventually unsuccessful "because of the failure of the treatment technologies to prevent further patient chronicity or to achieve sustained recovery." As the public mental health system faces the 21st century, new reforms focused squarely on promoting sustained recovery are being proposed across the country (National Association of State Mental Health Program Directors, 2004).

Until the mid-19th century, State governments had little or no involvement in the treatment of people considered mad. In the early 19th century, Illinois was still a frontier, and people deemed mentally ill were primarily cared for by their families. In 1839, the Illinois legislature authorized the establishment of publicly funded county poorhouses; mentally disturbed people were often sent to these institutions, where they received only minimal custodial care in often inhumane conditions (Mehr 2002). They were also vulnerable to victimization by the other inmates, including debtors, petty criminals, and destitute people with no means of support.

The first cycle of reform began in the mid-19th century, when social reformers, primarily educated upper-class women, lobbied in statehouses across the country for the

establishment of publicly funded asylums. These crusading women, many of whom were also abolitionists, exposed the often wretched conditions in local poorhouses and championed a philosophy of care called moral treatment, founded by English Quakers. Moral treatment offered a regimen which hoped to cure people newly diagnosed by providing humane care, a safe haven from the stresses of life, and work and instruction in small, rural asylums. The noted social reformer Dorothea Dix was a major force in the effort to establish state-supported asylums. Active as a young woman in educational reform efforts, Dix experienced a breakdown in 1836 at the age of 34. Rather than send her to a private asylum, her physician prescribed a trip to Europe. Staying with family friends in England, Dix met William Tuke and his family, Quakers who ran the York Retreat, where moral treatment was first introduced, and was impressed by their practices. Returning to the U.S., Dix became a passionate proponent of moral treatment and the responsibility of states to provide humane treatment for their citizens with mental disorders. She recruited other social reformers to her cause, and criss-crossed the country speaking at public forums and to state legislatures. The persistence of Dix and her band of reformers paid off, as state after state enacted legislation in the 1840s and 1850s to establish state-operated mental asylums. While moral treatment had its own set of ethical problems - its essential goal was to re-socialize people into acceptable middle-class behavior so that they could be returned to the workforce (Scull, 1990), and a modicum of fear was considered to be therapeutic (Mehr, 2002) - it replaced brutal abuse and neglect in county poorhouses, and patients were adequately housed and well-fed.

In conjunction with a prominent group of Illinois citizens from the Jacksonville area, Dorothea Dix played a major role in the establishment of the first state-supported mental asylum in Illinois (Mehr, 2002). Joseph King, a Jacksonville businessman and a member of a local committee to establish a state asylum, chanced to meet Dix on a steamboat journey in 1846, and asked for her assistance in promoting the cause. Dix spent the summer of 1846 on a whirlwind fact-finding tour of Illinois almshouses and jails, documenting the deplorable conditions in which mentally disturbed people were kept. In January 1847, she delivered a speech in Springfield vividly describing the horrors of the poorhouses, and by March of that year, the legislature had passed and the

governor signed into law an act establishing the Illinois State Hospital for the Insane in Jacksonville.

Construction began shortly thereafter, and the hospital opened and received its first patients from county poorhouses in 1851. The physical plant was not finished until after the Civil War, and the hospital was frequently over-crowded in the intervening years, resulting in some patients being periodically returned to the almshouses. Like many of the nation's new asylums, the hospital at Jacksonville was an example of Kirkbride architecture, a plan for hospitals named for Dr. Thomas Kirkbride, who promoted it as the ideal form for an asylum. Kirkbride facilities were located in bucolic settings near good water, were built of brick and stone to minimize fire hazards, and were constructed to provide good ventilation. The asylum was arranged with a large, imposing center section for administration, surrounded on both sides by successive wings that were set back from the one before. Patients thought most likely to recover were housed on wards nearest to the administration section, while patients considered hopeless lived in the far reaches of the building. This is the origin of the term "back wards."

A pioneering ex-patient advocate, Elizabeth Parsons Ware Packard, was an inmate at the State Hospital in Jacksonville from 1860-1863, and her subsequent writing and reform activities resulted in significant changes in mental health law in 25 states (Mehr, 2002). Packard, committed to the hospital by her husband because she had what he considered strange religious beliefs, was a sharp observer of life on the wards. After her release from the hospital (she was found "not insane" by a jury), Packard wrote several illustrated books describing demeaning and abusive practices in the asylum. Her exposés resulted in state investigations and a change in the Illinois commitment law to require a jury trial. She was an opponent of forced treatment, and often found herself on the opposite side of mental health issues from Dorothea Dix. Dix worked to defeat one of Packard's proposals, a federal law to allow inmates of mental asylums free access to the U.S. mail.

The latter half of the 19th century saw increasing industrialization and the arrival of immigrants in the U.S. After the Civil War, there were large influxes of new patients, many of them combat veterans; the nation's state hospital census more than doubled between 1860 and 1870, from 8,500 to 18,000, and by 1900, there were almost 150,000

patients in state hospitals across the country (Mehr, 2002). Ethnic tensions resulting from immigration and the northward migration of freed slaves, the urbanization of poverty, a rise in the number of people mentally disabled by tertiary syphilis, and other social and economic factors increased the rate of people deemed mentally ill. Across the nation, asylums were constructed at an increasing pace to keep up with the perceived demands for more capacity.

In 1869, the Illinois legislature authorized construction of two new hospitals, one in the northern part of the state (the Northern Illinois Asylum for the Insane in Elgin, IL) for people expected to recover, and one in the south (the Illinois Southern Asylum for the Insane in Anna, IL), for so-called “chronic cases.” By 1877, yet another facility, Illinois Eastern Hospital was under construction just outside the city of Kankakee. Unlike the three older state hospitals, Eastern Hospital was not built according to the Kirkbride style described above, but was built in the cottage style. This new design for mental hospitals was organized not around one massive central building with enormous wards, but had many smaller detached buildings in which patients lived. The intention was to make the environment more homelike, but as Thomas Kirkbride complained, “It is no cottage when 100 people live in it”(Mehr, 2002).

The principles of moral treatment, which relied on well-staffed retreats which allowed patients the opportunity for study and reflection, fell into disuse, as State asylums admitted increasing numbers of people deemed incurable. Funding for staff and operations did not keep pace with admissions and new construction, and conditions in state-run facilities quickly deteriorated. The optimism of the mid-19th century, when state hospital superintendents boasted that they could cure 80% of people in their care, was replaced by despair. By the turn of the 20th century, the role of state asylums had become primarily custodial care and perceived protection of the community, with treatment of only secondary importance. Most patients worked at the facility, whether on the farm, in the kitchen or laundry, or in cobblers’ and tailors’ shops. While this commitment to patient work was a hold-over from the days of moral treatment, its purpose was only partially therapeutic, for the hospitals had grown to become large, self-sustaining communities that were dependent on unpaid patient labor for their survival.

During this period, states began to consolidate their authority for mental health care. In Illinois, the State Board of Public Charities was created in 1869 and given oversight and monitoring responsibilities for state hospitals and other public institutions. In 1875, with all three mental asylums open, a policy decision was made to divide the state into three catchment areas and to rename the asylums as hospitals. Further consolidation of state authority was accomplished by the Complete State Care Act of 1907, which authorized the transfer to state hospitals of all “mentally ill paupers” still kept in county poorhouses, and allowed the state to take over administration of the Cook County Insane Asylum and convert it to a state hospital (Mehr, 2002). In 1909, the Illinois legislature again re-organized the administration of public institutions in the state, including mental hospitals. The State Board of Charities was replaced by a Charities Commission, which had oversight of all state-run institutions. State hospitals had been run by boards of trustees; these were replaced by Boards of Administration, which appointed managerial staff at the institutions. This structure was to remain in place until the Department of Mental Health was established in 1961.

The second cycle of reform, dubbed the “mental hygiene movement,” began in the 1890s. The term “mental hygiene,” which sounds peculiar to modern ears, was defined by Isaac Ray, a founder of the American Psychiatric Association, as “the art of preserving the mind against all incidents and influences calculated to deteriorate its qualities, impair its energies, or derange its movements. The management of the bodily powers in regard to exercise, rest, food, clothing and climate, the laws of breeding, the government of the passions, the sympathy with current emotions and opinions, the discipline of the intellect—all these come within the province of mental hygiene.” This definition has unfortunate references to eugenics, a now-discredited pseudo-science popular in the early years of the 20th century. Eugenics taught that “defective” people, such as mental patients, should be prevented from reproducing, and eugenics ideas were rife within the mental hygiene movement. These ideas, which began in England and were widely popularized in America, were put to grisly use by the Nazis a few decades later.

Oddly, the mental hygiene movement was championed by people like Clifford Beers, a young businessman and Yale graduate who had been hospitalized in 1900 after a

failed suicide attempt. He began his career as a mental health reformer by exposing the inhumane conditions to which he had been subjected in his 1908 book, *A Mind That Found Itself*, offering passionate arguments for extending the rights of mental patients. The influential psychiatrist Adolph Meyer, a eugenicist who worked at the Illinois Eastern Hospital for the Insane in Kankakee in the 1890s, helped Beers edit his book. He was also responsible for getting Beers to tone down his criticism of asylums and the psychiatric profession, steering him instead toward a program to help prevent mental health problems. Beers, Meyer, and other colleagues founded the National Mental Hygiene Committee (now the National Mental Health Association) in 1909. In 1913, Beers founded the first outpatient psychiatric clinic in the U.S., and promoted innovations such as occupational therapy and hospital aftercare. Professional standards of care were considered an important development, and staff training programs were widely instituted in state facilities and the techniques of social work was adopted.

The mixed legacy of the mental hygiene movement did nothing to contain the pressure for continued hospital bed growth, which remained unchecked. The state hospital system expanded tremendously in the early 20th century, but care remained primarily custodial. As the century progressed, state hospitals grew even larger and were even more poorly funded. First the Depression, and later World War II, diverted both attention and funding from these institutions, which became increasingly over-crowded. By 1947, the Illinois state mental hospital census reached 42,000 in a system designed for 28,000. Patients were basically warehoused, and were given little hope of recovery. In the 1930s and 40s, virtually the only treatments offered by state hospitals were insulin coma, metrazol coma, electro-convulsive treatments, and lobotomy, all of which significantly and irreversibly altered the brain (Whitaker, 2000). The goal of these interventions was not healing, but control, which was highly valued in over-crowded, under-staffed institutions. The third cycle of reform had its beginnings in the mid-1950s, as policy and legislation began a shift from hospital-based treatment toward a community-based system of care. After World War II, several exposes of appalling conditions in state hospitals, including a photo essay in *Life* magazine by Albert Miesel (1946), and a book by journalist Albert Deutsch (1948) entitled *The Shame of the States*, brought public scrutiny to the field. Miesel described and photographed patients in

deplorable conditions, such as people strapped into chairs on wards infested with rats; he described these people as “guiltless patient-prisoners.” These exposes prompted investigative committees at the state and national levels, a number of which recommended downsizing state hospital systems and providing more treatment in community settings. While the introduction of psychiatric drugs in the mid-1950s is often viewed as the impetus for the deinstitutionalization of mental patients in the 1960s and 70s, this policy had its roots in public reactions to the scandals and exposes of the mid-late 1940s.

Still, the introduction of psychiatric drugs in the mid-1950s did have profound changes on public mental health policy. The first such drug, chlorpromazine, was introduced in the United States in 1954 by Smith, Kline and French as Thorazine. While the drug was later hailed as an anti-psychotic agent, it was initially seen by psychiatrists as a pharmacological substitute for lobotomy. (Lehmann, 1954). The rise in the number and availability of psychiatric drugs corresponded with a shift in the thinking of the psychiatric establishment about the etiology of mental illness. Rejecting the psychological explanations that were the underpinning of psychoanalysis, psychiatry in the last quarter of the 20th century came to believe that mental illnesses were brain diseases caused by genetic factors and manifest as “chemical imbalances” in the brain.

The introduction of psychotropic drugs created a climate for change, but the provision of mental health treatment in the community rather than in institutions became a national goal in 1963 when President John F. Kennedy proposed – and Congress enacted – the Community Mental Health Construction (CMHC) act. The legislation reflected Kennedy’s concern over poor conditions in mental hospitals and the nation’s limited ability to provide community-based services. Despite the push for reform in the mid-1950s, state institutions were still essentially custodial facilities: treatment programs were limited, wards over-crowded, few recreational and social activities were available to patients, and individual privacy was lacking. State mental hospitals were under-funded, resulting in staff shortages and run-down facilities.

In Illinois, the new-found federal interest in mental health was preceded by two years with the administration of Governor Otto Kerner. Like Kennedy, Kerner had a relative who was a psychiatric patient, and he became a strong supporter of community-

based reforms and increased funding. In 1961, the Department of Public Welfare was split, with 81% of its resources going to the new Department of Mental Health. Francis Gerty, M.D., a past president of the American Psychiatric Association and chair of the Department of Psychiatry at the University of Illinois School of Medicine, was appointed as the department's first commissioner, and embarked on a re-organization of the state mental health system that had some similarities with the 1963 federal reforms, but in other regards was unique.

Through the CMHC Act, Kennedy sought to change the locus of services by promoting the development of a range of community-based services. The goal was to enable people with the most serious disabilities to remain in or return to their communities and to live as independently as possible. States were given a limited role in the design of community-based systems; local Community Mental Health Centers (CMHCs) were funded directly by the federal government under the National Institute of Mental Health.

Commissioner Gerty's reorganization, which was actually begun before the federal legislation was enacted, in some ways anticipated the local nature of the CMHCs. His plan was to develop what were termed Zone Centers, state-run centers offering crisis, acute inpatient and outpatient services, each located centrally in a geographic zone to be no more than 90 minutes from any community within the zone. While this "90 minute" goal was never reached in many parts of the state, seven Zone Centers were constructed across the state between 1963 and 1968, funded by a bond act promoted by Governor Kerner and passed in 1961.

The Zone Centers were conceptualized as the hub of service delivery for their geographic areas. They were to be built near to general hospitals and close to the older state hospitals, which would serve as a backup, although it was intended that all of these older state hospitals would eventually close. The Centers were not seen as necessarily providing all mental health services needing by zone residents, but rather as an example of what quality community-based services should and could be. They were also conceived of as focal points for community education, and they were to promote the development of additional mental health services within each zone. Existing state hospitals were expected, before closing, to restructure care and treatment, and then the

Zone Centers, seen as 'state of the art,' were expected to recruit, select and retain professional staff that could be utilized for, and contribute to, mental health services throughout the zone. (Vyverberg, 2005). But there was some friction between the new, well-funded Zone Centers and the old, under-funded State Hospitals, both for fiscal and philosophical reasons. In 1975, both the Zone Centers and the State Hospitals were re-named Mental Health Centers (Mehr, 2002).

The plans for the Centers to serve as geographical hubs for a community-based system were not fully realized across the state. As federally funded CMHCs opened their doors in various parts of Illinois, they grew and developed separate from the Zone Centers, in some areas becoming essentially parallel systems. This relationship changed over time in some parts of the state. By the mid 1980s, in many parts of the state outside of Chicago, the CMHCs and other community providers became the gatekeepers for the Mental Health Centers; they were required to assess all possible community alternatives before a person could be considered for hospitalization at one of the Centers. While it was intended that this same service delivery expectation existed for Chicago, it was not fully implemented. As Goldman (1999) and Rosenheck (2000) point out, despite the fact that the CMHC Act had promised to relieve the social burden of caring for people with serious disabilities, the lack of state involvement often resulted in local CMHCs focusing their services on people with mental health problems who were not seriously disabled; community staff often viewed people with serious disabilities as the responsibility of the state system. Funding for the CMHCs never kept pace with Kennedy's original vision, performance objectives were never defined, and the program never reached its ambitious goal of establishing hundreds of CMHCs across the country.

During the 1960s and into the 1970s, other state and federal initiatives continued to nudge the mental health system away from its reliance on institutional care. Title XIX of the Social Security Act, enacted in 1965, established the Medicare and Medicaid programs, which funded outpatient mental health services as well as general medical care for low-income citizens. The federal Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) program provided people with psychiatric disabilities with a subsistence income, which for the first time provided the financial means for many people to leave the institutions. But the income provided was not

sufficient for most people to live on their own; many people leaving institutions at this time ended up in congregate living facilities or single-room occupancy housing. They were out of the hospital, but not really part of their communities.

An instructive example of how these national developments affected a local community was what occurred along one Chicago lakefront neighborhood in the 1960s. After World War II, several large old resort hotels on the lakefront were turned into single-room occupancy (SRO) housing, mainly for newly arrived immigrants. By the 1960s, these properties became run-down and started to empty out. As deinstitutionalization progressed, many people discharged from the nearby state hospitals relocated to this neighborhood. DMH contracted with hotel owners to turn the old hotels and SROs into halfway houses, where discharged state hospital patients were provided with rooms and meals, but not mental health services. By late 1960s, there was a community backlash against the halfway houses; many residents were disturbed by the fact that there were a growing number of former patients in their neighborhood. Some residents simply wanted these individuals moved out, while others wanted to ensure that services were provided for them. A compromise was reached in the community that resulted in the creation of an organization called Community Counseling Centers of Chicago, which applied to become a federally funded CMHC, and opened its doors in 1972. Eventually, many of the halfway houses became licensed as nursing homes, where the former state hospital patients continued to live. About 15,000 people with psychiatric disabilities currently live in nursing homes in Illinois, a pressing issue that is still unresolved.

These new federal entitlements coincided with the rise of mental health legal advocacy initiatives inspired by the African-American Civil Rights Movement. A more active judiciary began to heed the arguments of patients' rights attorneys who challenged the manner in which states treated their citizens diagnosed with mental illness. Across the country, advocates challenged the civil commitment process. Court decisions created the constitutionally based doctrines of the right to treatment (as opposed to custodial care), and the right to be treated in the least restrictive environment. In many states, the use of involuntary treatment was limited through court decisions and statutory change,

and the census of state hospitals began to go down for the first time since they were created more than 100 years earlier.

But still, the forces that resulted in what came to be known as “deinstitutionalization” – psychotropic drugs, CMHC development, federal entitlement programs and civil rights advocacy – were not sufficient in themselves to ensure that people with long institutional histories could successfully re-integrate into their communities, as described in the example from Chicago’s lakefront, above. Income, mental health treatment, and segregated housing did not provide enough support for people who had become dependent upon an institution for all their needs. Sufficient funding did not follow discharged patients into the community, and negative public stereotypes of mental patients were not sufficiently addressed. These factors combined to make deinstitutionalization an apparent failure in the view of many (Scull 1990).

By the mid-1970s, some states criticized the failure of the CMHC Act and subsequent federal policies to meet the promise of community-based care for the group of people who Goldman (1999) refers to as “the least well off.” In a review of the CMHC program, the federal General Accounting Office concurred, noting that the federal government has not kept the focus of mental health policy on people with the most serious disabilities, and criticizing them for not doing enough to help hospitalized people return to the community. In response, the National Institute of Mental Health (NIMH), created the Community Support Program (CSP) in the late 1970s (Turner and TenHoor, 1978), resulting in the fourth cycle of reform.

Moving beyond the goal of the CMHC Act to provide community-based mental health services, CSP was built on the recognition that people with long-term psychiatric disabilities needed access to a wide variety of support services, not just mental health treatment, in order to live successfully in the community. CSP encouraged the development of networks providing access to a range of services including health care, social services, housing, and transportation; these were to be coordinated on the individual level by case managers. Many States responded positively to this new federal priority, and many new ideas circulated. But as Scull (1990) points out, despite the fact that CSP was touted as a major initiative to address the problems of rapid

deinstitutionalization in which money did not follow the patients, NIMH spent only \$34.4 million in seven years throughout the entire nation to implement the program.

While the implementation of CSP brought new ideas, if not much money, to the community care system in many localities, changing political, economic, and social factors in the 1980s created challenging new situations. The Carter Administration attempted to strengthen the federal role with the passage of the Mental Health Systems Act in 1980. This act was subsequently repealed in 1981 at the urging of the Reagan Administration, and replaced with the Alcohol Drug Abuse and Mental health block grant funding mechanism, which significantly reduced the federal role. Block grant funding consolidated all federal funds for these programs into a single grant, while reducing the overall funding level of the program by 37%. The mental health block grant was administered by the states, which were not required to fund the same agencies that the Federal government had funded under the CMHC program.

In a cost-containment measure in the early 1980s, the federal government speeded up the review of millions of SSDI and SSI cases. There was a significant failure of due process in this review, and many individuals who were later determined to be eligible lost their basic means of support. People with psychiatric diagnoses were disproportionately among those whose cases were reviewed, and thousands had their benefits inappropriately terminated, seriously threatening their ability to live in the community. This problem was further complicated by decreases in federal funding for low-income housing and other generic social services.

In Illinois, the 1970s and 80s saw continued reductions in the state hospital census and the closure of some state hospitals. The census had fallen from about 36,000 in 1960, to under 18,000 by 1970 (Mehr, 2002). Peoria State Hospital, plagued by a deteriorating physical plant and several highly publicized patient deaths, closed in 1973. This was followed by four more closures during the 1980s, which were primarily prompted by state budget shortfalls. After the Zone Centers were re-named Mental Health Centers in 1975, they essentially became inpatient facilities. However, one aspect of the original Zone Center idea was coordination of services within a geographic area, and this idea led to the gradual creation of a regional administrative system. In the early 1980s, what was viewed by some as a top-heavy Regional administrative structure was

essentially dismantled. Unfortunately, little of the money saved by any of these reductions was used to provide community-based services for those who were discharged.

Nationally, by 1990, it had become obvious that this fourth cycle of reform had not been sufficient to fix the long-standing problems of the public mental health system in the U.S. At the same time, there was a widespread feeling that the entire health care system in the U.S. was in disarray. The existing health care system was seen as inadequate to meet people's needs, while at the same time being too expensive. In 1992, the incoming Clinton Administration placed a new emphasis on health care reform, but much of the initial enthusiasm for this process soon became mired in political wrangling. No sweeping mental health care reform measures were instituted on a national level, but the intertwined issues of benefits reform and managed care dominated national mental health policy discussions during much of the 1990s. The 1990s also saw the creation of offices of consumer affairs in more than 50% of the nation's state mental health agencies, including Illinois. The idea behind these offices, which were headed and staffed by people with psychiatric histories, was to ensure that consumers were involved in all aspects of planning, policy development, program development, and other agency operations, and to promote a recovery-oriented reform agenda.

With the turn of the 21st century, two new, and sometimes competing, mental health reform ideas gained prominence. The first is "evidence-based practices (EBPs)," defined by Sackett and colleagues (1996) as the integration of "individual clinical expertise with the best available external clinical evidence from systematic research." The Center for Mental Health Services has identified and promoted six specific evidence-based practices: Assertive Community Treatment, medication management, family psycho-education, illness management; integrated substance abuse and mental health treatment, and supported employment (CMHS, 2003).

The second new approach is the idea that recovery is possible for most people diagnosed with serious mental illness, and that service systems need to be restructured so that they begin to enhance, rather than curtail, people's opportunities for recovery. Anthony and colleagues (2003) point to the difficulty of integrating the current narrow definition of EBPs with the idea of recovery-oriented systems change. They find that

“much of the existing, published EBP research was conceived without an understanding of the recovery vision and/or implemented prior to the emergence of the recovery vision. Thus, the system planning implications of current, published, EBP research is deficient in speaking to a system built on a recovery philosophy and mission.” A pressing issue facing state mental health authorities is to broaden the concept of evidence-based practice to incorporate values that promote recovery.

The Lessons of History

What lessons can we draw from this brief review of the history of public mental health in Illinois and the nation? Howard Goldman (2002) believes that the cycles of reform that he and Morrissey identified in 1984 were all failures. Goldman attributes this to the insufficiency of the treatment modalities developed during each cycle of reform, which he believes were just not good enough to promote sustained recovery. Another interpretation might be that the reforms of the past 150 years have each been based on the needs of the system, not on the needs of people who receive services. Each cycle of reform was designed around new institutions or new service models that were defined by the treatment ideas, financing limitations and administrative convenience of staff and managers, and patients were expected to accommodate themselves to the demands of the program. The public mental health system has never accommodated the self-defined desires and needs of consumers. If state mental health authorities across the country are serious about developing recovery-oriented systems, they need to take their lead from people who receive services. History has shown that systems built to meet the needs of institutions, staff and administrators have not been successful. It is time for the system to accommodate itself to the expressed needs of consumers, not the other way around.

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