Building a Better Mental Health System:

A Family Perspective

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Introduction

The current Michigan public mental health system is broken. It is underfunded and designed to fail. Families are on the front lines of coping with persons suffering with mental illness, and, at the same time, trying to get appropriate services from a failing system. For years, some of us have been helping each other and some of us have been advocating for change. For many people, the system has already failed. The time has come for real change.

The current system has a fatal lack of state leadership, accountability and funding. A properly transformed public system can significantly improve the management of mental illness and the quality of life of persons with mental illness and their families, and in the long term it can save lives and money. This document is about the design of an improved Michigan mental health system. All of the needed changes should be implemented to ensure that the system is driven by improving the lives of Michigan citizens.

There must be accountability to the public and assurances of quality care to minimize the impact of mental illness and provide an optimal level of quality of life through appropriate treatment and supports. An accountable system will mean some peace of mind for aging parents who fear for the welfare of their ill family member when they are gone.

This document is focused, in particular, on the needs of persons afflicted by mental illness and their families. Some adjustments may be needed to meet he needs of persons with intellectual/developmental disabilities, children with emotional disorders and persons with substance use disorders. Most of these changes should apply to the other populations as well.

Untreated Persons with Mental Illness

Based on a 2016 analysis by the National Institute of Mental Health, there are 252,133 persons with schizophrenia or bipolar disorder in Michigan, and 119,697 of these are untreated for their mental illness. For the most part, these untreated people are able to get by in spite of their illness, but among them are people at high risk of behavior that is a danger to themselves or others. This is a factor in the high prison population of persons who suffer from mental illness. More timely treatment could mitigate the risks.

In a 2010 University of Michigan study of Michigan prisoners, 20 percent of prisoners were convicted of crimes committed when they had mental health symptoms, and 63 percent of those crimes were committed by prisoners who were not receiving treatment for symptoms in prison.

The current mental health system has evolved over the last 50 years, starting with state psychiatric hospitals and federally funded community mental health centers. There has been a patchwork of changes that have been driven by political forces and questionable money-saving strategies as well as advances in medical treatment and less restrictive community care.

The system cries for major change. It must be driven the welfare of Michigan citizens and the opportunities of modern technology and advanced practices, and Michigan citizens deserve a system that delivers reliable, quality care. This document outlines needed improvements to the mental health system under the following topics:

- Governance
- Objective Oversight
- Independent Rights Enforcement
- Independent Case Managers
- Shared information Systems
- Immediate Actions

Governance

Governance is accomplished by the activities and controls of a governing body to represent the interests of the enterprise stakeholders. The governing body must ensure that the enterprise is doing the right thing and doing it well. The governing body of the Michigan mental health system is the Michigan legislature. The stakeholders are the Michigan taxpayers and, in particular, the persons in need of mental health services and their families.

For the mental health system, "doing the right thing" is providing treatment and supports suited to the condition of a person who suffers from a mental illness, serious emotional disturbance, intellectual/developmental disability or a substance use disorder. In this document, we focus on services to persons suffering from mental illness. Doing it well means providing supports and treatment efficiently, effectively and at an optimal level of care for each individual given the available resources.

The current system is inefficient and is under-funded to meet the needs of the people in need of treatment, services and supports. The legislature, by defining the mental health system appropriation, has implicitly defined an inadequate scope of services to meet the need for mental health services.

Unfortunately, the legislators do not know the scope of need for mental health services nor the extent to which that need is not met with the appropriation they adopt. Instead, the amount appropriated is a political decision based on the administration's priorities and the influence of competing interest groups. That is bad governance. In addition, the determination of who gets services and the quality of services under a limited budget is an ad hoc decision by local CMH administrators and case managers that is inconsistent across the state and varies among the persons served within each PIHP (Pre-Paid Inpatient Health Plan, i.e., Medicaid community mental health program) and its service providers.

Scope of services aligned to funding

The legislature, the administration and the public must be fully informed regarding the population that is expected to be served by an appropriation, and the population that is not. This information will provide accountability for appropriation decisions, define requirements for the providers of services, and establish entitlements of persons who need services. The scope of services is the basis for contracts, delivery of appropriate services and the measurement, inspection and enforcement of contracts.

The scope of services must be defined with recognition that it will have a significant effect on the efficiency and effectiveness of the system. For example, the current system is driven primarily by admission of persons in crisis. If the system intervened with persons in the early stages of their mental illness, then their illness might not become as severe, their lives might not be consumed by the illness, and they would achieve a better long-term quality of life at a lower cost to the mental health system.

The scope of services defined by the legislature should emphasize early intervention, promotion and support of recovery, minimal loss of clients to criminalization and homelessness, and the delivery of other basic services that ensure food, clothing, safe, affordable housing, socialization, transportation and person-centered planning. Funding must also reflect competitive wages for quality staffing.

A mental health appropriation must be accompanied by full public disclosure of the scope of services supported, the needs of the people that will not be helped. The assessment of needs should also identify the likely consequences of failure to help those who will be unserved.

Represent the public interest

As noted above, the legislature as governing body must be accountable to the public for their decisions regarding the funding of mental health services and their assurance that the system is doing the right thing and doing it well. Each PIHP serves a population defined as residents of a geographical area, so, for the most part,

PIHPs are not in competition to engage lower-cost recipients of services. However, if a PIHP delegates risk (i.e., managed care) to provider organizations, then a provider organization has the opportunity and incentive to compete with other providers. Additional controls, in particular, rigorous under-utilization management, are required to ensure that providers deliver adequate and appropriate services to all recipients who qualify under the specified scope of services.

Unrestricted psychiatric medications

Currently, Michigan does not restrict access to psychiatric medications. This is frequently challenged in the legislature proposing that restrictions will save money. However, the use of less effective medications would be costly both in terms of the need for more intensive services and in the effects on the quality of life of persons with mental illness and their families.

Treatment of mental illness requires particular insights and flexibility to discover the most effective medications for each individual. Recipients must not be forced to endure fail-first on inexpensive medications to qualify for appropriate medications. Use of inappropriate medications will increase the likelihood that recipients will suffer unnecessary side effects and refuse appropriate medications in the future. DNA testing should be preferred to help guide medication selection. Politics or budgets should not restrict the ability of psychiatrists to use their best judgement.

State-wide standards and protocols

It is important for consistent standards and protocols to be applied across the state. First, all citizens should have equal access to quality care regardless of where they live. Furthermore, persons with a mental illness should be able to travel or relocate within the state and be able to access consistent treatment and supports. When they travel or relocate; the funding for their services should follow them. Finally, the state should be able to analyze data about symptoms, services, medications and outcomes to gain insights on best practices. Such analyses are less effective if the data reflect different measures and protocols.

Choice of professionals and providers

The mental health system should open up choices of qualified professionals and providers. Currently, available professionals must be employees or under contract to PIHPs, their contractors or sub-contractors. This limits a recipient's choices to the network of the contract agency that provides their services.

Early intervention and outreach

Early intervention and outreach are important for engaging persons with serious mental illness in treatment to potentially limit the severity of the illness and enhance recovery. This is particularly important from a community and family perspective. However, it increases the number of persons receiving services.

When budgets are tight, curtailing early intervention and outreach, as well as activities to sustain recovery, can have an immediate effect on reducing costs but the long-term costs will be increased. The governing body must be able to recognize and correct such short-sighted savings.

Promote and sustain recovery

With appropriate treatment and supports, many persons with mental illness can experience significant improvement, reducing their dependence on mental health services and potentially becoming more productive members of society.

The process of recovery can take years. This requires an investment in future savings and quality of life. In addition, when people recover, there is a temptation of funding organizations to believe sustaining services are no longer needed and the costs can be saved. The immediate effect may be cost reduction, but the long-term effect is likely to be relapse and repeated need for intensive services, including hospitalizations, to control the illness and, hopefully, restore recovery.

Persons who do not receive appropriate services and supports to achieve and sustain a recovery are at risk of continuing to require more intensive services. Some that are poorly served will fall through the cracks and may be at risk of premature death or become involved in the criminal justice system. While this may represent a savings to the mental health system, the alternative taxpayer costs of medical care and incarceration will likely far outweigh the cost of appropriate mental health services.

The governing body must ensure that the people being served do not suffer from these false economies.

Objective Oversight

An agency that is independent of the state administration, potentially a legislative agency, is needed to ensure effective oversight of the mental health system in support of the governing body (the legislature). The primary role of this agency is objective measurement of the system and assessment of its impact on the community.

Measurement of the needs for mental health services and the specification of an appropriate scope of services for a mental health appropriation will require special skills and objectivity.

Needs assessment

The needs for mental health services must be objectively assessed, state-wide and for each PIHP service area. The analysis must identify the number of persons with needs for different levels of service and needs for supports, and it must have adjustments for services provided from other sources such as private insurance, nursing homes, and incarcerations.

This assessment must be the basis for analysis of proposed mental health appropriations. The analysis must determine the scope of services that will be supported by a given appropriation and the needs that will not be met. The scope of services must address early interventions, outreach and support for achieving and maintaining recovery. The unmet needs must be public information associated with the appropriation, and the associated scope of services is the scope of services that must be delivered by the PIHPs. The unmet needs are a primary basis for accountability of the legislators and the administration. Additional measurements will provide accountability for the quality of care, the efficiency of the system, the levels of recovery achieved and sustained, and the level of cost shifting to other sources of funding.

Qualified personnel

Personnel involved in the planning and delivery of services must be qualified and certified for their roles. Currently case managers are not specifically qualified for providing mental health services—degrees are not enough. Direct care workers generally have some training, but when fired for cause they should not get re-hired by another provider. Qualified personnel must be paid a competitive wage. The minimum should be a living wage.

Basic needs of recipients

Recipients will not recover if they don't have food, clothing and safe housing in addition to other supports for their treatment and daily living. Performance measures should ensure that basic needs are met, and appropriations should include funding to meet basic needs for persons who cannot afford them on their own.

Services transparency

Currently Michigan law provides for non-profit organizations as well as for-profit organizations to be exempt from the Freedom of Information Act (FOIA) and the Open Meetings Act. Mental health provider corporations are spending public funds and it is essential that they are transparent to public scrutiny, so they should be subject to FOIA and open meetings by contract in lieu of appropriate legislation to make FOIA and open meetings applicable.

Performance and community impact measurement

The operation of the system must be measured to determine if providers are fulfilling the scope of services specified for the appropriation and are providing quality care. In the early stages, there will be insights gained on more accurate assessment of the scope of services for a particular appropriation, and the need for measurements to more accurately reflect the performance of providers.

Measurements should also reflect the community impact of the mental health system. This may be based on surveys of landlords, employers, schools, churches, police departments and retailers who have contact with significant segments of the public and may be aware of accomplishments or failures to address persons in need of treatment.

The needs assessments and performance measures must be designed for clear and consistent assessment of doing the right thing and doing it well across the state.

Cost avoidance accounting

When an enterprise, such as the public mental health system, receives a fixed appropriation to provide services to a population, there is an inherent incentive to avoid providing services. When mental health services are not provided to persons who need them, there are other, consequential costs. The most obvious are costs of persons diverted to criminal justice, medical care (consequences of neglect or dangerous behavior) and nursing homes. There are also consequences to families that are more difficult to measure but are also important.

These costs of avoidance must be measured and reported, and should be the basis for setting objectives for improvement an possible penalties. Generally, the cost of medical care, nursing homes and incarceration will be greater than the cost or providing needed mental health services, but the costs are not incurred by the mental health system. They are nevertheless burdens on the rest of society.

Independent Rights Enforcement

The current system for protection of recipient rights is ineffective. People fail to submit rights complaints, grievances or Medicaid appeals because they expect the resolution would be either that their claim is not-substantiated or that they will have no meaningful remedy.

The problem is that the PIHP office of recipient rights has a conflict of interest between protecting rights of recipients and protecting the PIHP and its providers. In addition, when rights violations are substantiated, there are no remedies for the persons violated. Corrective action focuses on the lowest level person of the offending organization, and systemic/management problems are seldom addressed.

Grievances (disputes over service decisions) are also resolved within the PIHP organization with questionable objectivity.

Medicaid appeals have a similar problem. Appeals are not timely. The administrative judge has a conflict of interest as a member of the state mental health organization, there are no meaningful remedies, and the offending organization is represented by an attorney funded by mental health dollars, opposing a recipient, family or guardian. When the provider has an attorney, the PIHP should pay for an attorney for the recipient so they are on a level playing field.

An independent agency, possibly the same agency as the oversight agency, above, is needed to objectively enforce recipient rights and service disputes. This should include resolution of provider failures to comply with a treatment plan.

Monitoring and investigations

The rights enforcement agency must have responsibility and authority for monitoring mental health system sites and operations for rights violations, and for investigation of complaints.

Penalties and remedies

The rights enforcement agency must have authority to impose penalties and award remedies to the recipients. Persons being served by the mental health system cannot afford to sue for violation of their rights, and Michigan law makes it very difficult to prevail in malpractice suits. Recipients should be compensated for rights violations and treatment not suited to condition, and those responsible for a violation should receive a penalty that will function as a deterrent for them and others in the future.

Independent Case Managers

A recipient should have the option of engaging an independent case manager, but there should be a process by which all case managers are certified as qualified to provide case management services for persons served by the mental health system.

The Medicaid Provider Manual, Mental Health-Substance Abuse, Section 13, defines Targeted Case Management as follows:

> Targeted case management is a covered service that assists beneficiaries to design and implement strategies for obtaining services and supports that are goal-oriented and individualized. Services include assessment, planning, linkage, advocacy, coordination and monitoring to assist beneficiaries in gaining access to needed health and dental services, financial assistance, housing, employment, education, social services, and other services and natural supports developed through the person-centered planning process. Targeted case management is provided in a responsive, coordinated, effective and efficient manner focusing on process and outcomes. [emphasis added]

A case manager for mental health services has a much broader responsibility than the typical healthcare case manager.

Objective person-centered planning

The case manager must develop a treatment plan for services in the least restrictive environment that reflect the recipient's needs and desires. In order to be objective, a case manager must be independent of the organization that must pay for the services defined in a recipient's treatment plan. A case manager should be focused on the needs of the recipient and assurance that the recipient receives the needed services. Furthermore, the treatment plan must be meaningful, measurable and enforceable. Too many families consider treatment planning to be a meaningless exercise because their input is ignored and the plan is not implemented.

Unfortunately, budget shortages have caused many case managers to focus on cutting costs rather than the welfare of the recipient. This results in inadequate treatment plans, inadequate oversight of service delivery by the case manager, and poor response to changing recipients needs by the case manager.

Most persons served by the public mental health system have conditions that require unique plans for treatment and support services that depend on their particular affliction, the level of disability, their particular circumstances and often co-occurring conditions. In addition, a case manager is responsible for ensuring that recipients have access to needed community services and supports.

Informed choice by recipients

Case managers should ensure that recipients have informed choice of alternative services and service providers. This information should be maintained and organized to be available to all case managers and recipients of services. It is information that each PIHP should manage and make available on the internet.

Case managers should also assist a recipient in changing a provider if they are unhappy with the services. When a recipient chooses to change provider, the money must follow the recipient so that the provider departed does not gain by losing the recipient, and the receiving provider does not lose.

Residential placements

Housing is a basic need that must be addressed if a person is to receive treatment and achieve a successful recovery. Generally it is a responsibility of the case manager to link the recipient to housing or residential services when needed. This requires special knowledge and significant effort that is better pursued by specialists. A PIHP or other housing agency should maintain the information and provide the identification of possible residential placements.

In addition, the mental health system must take a more substantial role in funding housing since recipients typically cannot afford safe housing that is located with reasonable access to transportation and other business and recreational facilities.

Direct care problem resolution

Recipients are generally dependent on the case manager to obtain services and resolve problems. A case manager should monitor the services delivered under a treatment plan and ensure that problems are identified and resolved. The case manager has a continuing responsibility to ensure that the recipient receives treatment suited to condition, that workers are qualified and appropriate, that adjustments are made as the recipient's condition changes and that direct care services are compliant with the treatment plan. The case manager must work with the independent rights enforcement agency to resolve problems quickly.

Promote and sustain individual recovery

The case manager should set appropriate goals and monitor progress to promote a recipient's recovery and to sustain that recovery with appropriate supports. This requires an initial investment in more intense services to support recovery. The more intensive services may be needed for months or years to reach the potential level of recovery, and then there must be continuing supports to sustain the recovery with occasional periods of more intensive services if the recipient suffers a relapse.

Shared Information Systems

Currently, each PIHP and many providers have independent information systems. This results in duplication of costs for development and maintenance of the systems, more risk of exposure and other security and operational problems, and incompatibility of information. Shared systems reduce costs, improve the ability to exchange information, improve the ability to introduce new capabilities, and provide consistent interfaces for providers that serve multiple catchment areas.

Consistent records and measures

Consistent records and measures are essential to support consistent reporting and analyses. Analyses include measures of performance, assessment of needs, utilization management and recognition of trends and best practices.

Analysis of treatment and outcomes

Sharable recipient records support identification of preferred treatment and supports to achieve desired outcomes as well as identification of recipients whose treatment and supports should be reviewed for application of best practices.

Providers share early advances

Shared systems enable improvements to be developed once for all and continuously improved for all. This economy of scale can greatly improve timely implementation of new technology to improve service timeliness, effectiveness and efficiency.

One system for multi-payer providers

Some providers serve multiple PIHPs that currently have different systems. A single group home may have recipients of more than one PIHP. As a result, their employees must interact with two or more different systems as they provide services to different recipients. Each of these systems will have different user-identities and passwords, different displays and data entry requirements. In addition, this encourages each provider to develop and maintain their own systems, duplicating the systems of other providers and increasing administrative costs. Shared systems will simplify the reporting and record keeping, and reduce administrative costs.

Freedom of recipient travel and relocation

Recipients of services should be able to receive consistent services as they travel or relocate across the state. With shared systems, the practices should be compatible and their records should be portable to support their needs wherever they are.

Immediate Action for an Improved Mental Health System

The following changes should be undertaken immediately to improve the current mental health system. These changes are essential for any future mental health system.

Clarification of legislature governance role

The role of the legislature as the governing body must be clarified along with the obligation of the administration to support and respond to needs for improvement identified by the legislature. The assessments of need, the scope of services associated with an appropriation, and the unfunded needs must be public knowledge.

Legislative oversight agency

An independent, legislative oversight agency must be formed and funded to support mental health system governance. The efforts of this agency support the governing body to monitor, measure and determine if the system is doing the right thing and doing it well.

Appropriations aligned to scope of services

An assessment of the overall needs for mental health services in the state provides the basis for determination of the unmet needs for a particular scope of services determined for a proposed appropriation. This assessment of unmet needs is essential for informed decision-making by legislators.

For a mental health system appropriation, the legislature must define a scope of services that is expected to be fulfilled with the specified funding. Fulfillment of the scope of services is an objective to be evaluated for identification of performance failures and to improve future alignment of the scope of services with the appropriation. The unmet needs and performance against the defined scope of services must be public knowledge for accountability of the legislature and the administration.

Independent Rights Enforcement agency

An independent rights enforcement agency must be established and funded to investigate and resolve complaints and disputes, to monitor system performance for systemic problems, and to impose penalties and remedies as incentives and to compensate recipients for violations of their rights. Each PIHP may continue to have an office of recipient rights to work with the independent rights enforcement agency, but the agency should ensure more timely and effective corrective action.

Early intervention

Early intervention is important, not only to reduce the severity and long-term intensity of care of persons with mental illness, but also for reducing the risk that persons in the early stages will exhibit dangerous behavior and become involved in the criminal justice system or die. Early intervention should include children identified as at risk in schools.

Certified case managers and direct care workers

Case managers and direct care workers must be screened and trained to meet mental health care requirements. Certification will establish qualification and will prevent disqualified personnel from getting a job with another provider.

Living wage for direct care workers

Current wages for direct care workers are unconscionable. They are responsible for the safety and quality of life of vulnerable citizens. The wages cannot attract people with the necessary level of capabilities, providers cannot compete against easier jobs with retail and fast-food employers, and workers often need to work multiple jobs thus making them less capable of providing quality care.

Priority to achieve and sustain recovery

Many persons with a serious mental illness can experience significant recovery if they receive intensive, responsive and caring services to support their recovery. The need for these intense services may diminish over months or years before savings can be realized, but the savings may be realized for the rest of a lifetime.

FOIA and Open Meetings

Services of providers are paid for with taxpayer dollars. Most providers receive most of their income from the mental health system. They are currently exempt from FOIA and open meetings under Michigan law. They must be accountable to the public for their use of taxpayer money. They should be subject to FOIA and open meetings for the segment of their business that is funded by taxpayer dollars from any source.

Accounting for cost shifting

Mechanisms must be developed to identify and measure where providers are saving money or other burdens by shifting responsibility and cost to other resources, particularly where the other resources are funded by other government departments or agencies and thus represent a different, and often greater cost to taxpayers. This includes costs of persons with mental illness hospitalized, in nursing homes, and in jails and prisons.

Access to independent case managers

Independent case managers are essential for objective treatment planning and oversight. They must be compensated for reasonable efforts that reflect the needs and circumstances of individual recipients. They must be certified to be knowledgeable and capable of functioning as mental health case managers, but they must not be subjected to conflicts of interest of the financial managers or providers of direct care services.

Ensure safe, affordable housing

Housing is essential as a foundation for quality care and recovery. Persons with serious mental illness cannot afford safe, habitable housing located near transportation, retail stores and recreational facilities. Services and funding should be developed to ensure that safe, affordable housing is available. Each PIHP should take responsibility for availability of safe, affordable, appropriately located housing, including group home placements, either as an internal department or through contracting with a specialized agency.

Ensure access to transportation

Few persons with mental illness are able to drive or afford a car. This is a major handicap to living in Michigan. People need transportation for medical care, for shopping, for recreation and potentially for employment or

volunteer activities. If possible, recipients should either be located where they can access public transportation and individual means of transportation should be available as needed. The mode of transportation should accommodate their disability that may limit their planning, attention and patience, and makes them uncomfortable with unfamiliar people and situations.

Shared information systems

PIHPs should organize a joint task force to identify the best features of their current systems, and define requirements for improved capture and sharing of information and measurements of performance. They should consider compatible common systems for providers thus reducing their administrative overhead. The requirements analysis should avoid technical detail or selection of specific technical products. This should then form the basis for development of a state-wide system with shared software. The task force should then explore outsourcing options for implementation of state-wide mental health information services. This should establish both improved capabilities and lower cost.

Alliance for the Mentally Ill of Oakland County

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