Making the Case for Funding and Supporting Comprehensive, Evidence-Based Mental Health Services in Illinois

MAY 2015 WHITE PAPER

NAMI Chicago
Chicago's Voice on Mental Illness

EXECUTIVE SUMMARY:

NAMI Chicago is releasing this timely report on the poor system of care available to individuals living with mental illness. With this report, we look at where we are and how we can move forward in providing an evidenced-based fiscally responsible system of care for individuals impacted by mental illness. A detailed list of references, citations and data figures can be found in the full report.

How many people in Illinois are living with a mental illness?

38.5% of adults in Illinois ages 18 and older reported poor mental health (feeling very depressed and/or anxious and having to limit daily activities because of mental health problems)16.68% of Illinois adults were living with a mental illness and 3.37% of Illinois adults were living with a serious mental illness

When we apply these estimates to U.S. Census data in 2013:

- Approximately 4.96 million Illinois adults experienced poor mental health
- 2.1 million Illinois adults were living with mental illness
- 434,412 Illinois adults were living with serious mental illness

What happens if people living with mental illness have nowhere to go to get treatment?

What data demonstrates, is that when people living with serious mental illness don't receive services they often end up in in the emergency room (ER), or in jail, or experiencing homelessness. And too often, all of the above happens. Here's a snapshot of what has happened in Illinois since funding cuts took place in FY2009:

- Emergency room visits for people experiencing psychiatric crises increased by 19% between 2009 and 2012.
- Studies show that over 60% of incarcerated individuals meet diagnostic criteria for mental illness.That means that of the approximately 76,400 people who were admitted to Cook County Jail (CCJ) in 2012, 45,840 were people living with mental illness. CCJ is now considered one of, if not, the largest mental health care provider in the country. Studies show that for many people living with mental illness, the only time they get treatment is when they are in jail.
- The total number of nights spent in a shelter statewide increased from 2,000,000 in FY2011 to 3,041,000 in FY2013. The National Alliance to End Homelessness estimates that approximately 32% of the 14,144 individuals who currently experience homelessness on any given night in Illinois have a serious mental illness.

What is the state of mental health services in Illinois?

From FY2009-FY2012, Illinois cut $113.7 million in general revenue funding for mental health services. Illinois made some of the largest cuts in mental health funding nationwide during this time period. In fact, only California and New York cut more from their budgets than Illinois did.

In many cases, agencies have not been able to afford to stay open. In 2013, DMH contracted with 150 community agencies across the state to provide mental health services to adults living with mental illness. As of the spring of 2015, only 141 agencies statewide are contracted to provide these services. Providers can only afford to offer services that are Medicaid-reimbursable, and, with state Medicaid reimbursement rates remaining relatively stagnant in the past five years, many community-based providers have had to stop delivering all recovery-promoting services that are not Medicaid billable.

The community mental health system was further strained when Illinois entered into two Olmstead Consent Decrees: Williams v. Quinn and Colbert v. Quinn. These class action lawsuits mandate that people living with serious mental illness who are nursing home residents be offered the opportunity and supportive services to move out of their facilities and into their own homes in the community. While we celebrate the fact that the consent decrees help people living with serious mental illness move out of nursing homes and transition into the community, we also recognize the strain this puts on providers—and provider capacity.

Despite funding and service cuts, Illinois has continued to make a commitment to providing evidence-based practices (EBPs) that promote recovery. EBPs are services that research studies have proven to be effective in improving specific outcomes for people living with mental illness, like employment and independent living. The EBPs that the state offers include Assertive Community Treatment (ACT), the Individual Placement and Support (IPS) supported employment model, and permanent supportive housing (PSH). ACT teams provide a broad range of supportive services, such as case management and medication monitoring that help people living with mental illness stay in the community and work on their recovery goals. Research shows people living with serious mental illness who receive ACT services have fewer inpatient hospitalizations, and better housing stability, social functioning and quality of life. In FY2013, 979 individuals received ACT services from 21 ACT teams statewide represents only 1% of people living with serious mental illness who received state-funded mental health services. Moreover, the increase in the number of ACT teams from 15 teams in FY2012 to 21 teams in FY2013 was largely in response to the need to meet the requirements of the Williams v Quinn consent decree and provide ACT services to Williams Class Members.

After five years of dealing with funding cuts, eligibility restrictions and consent decrees, Illinois has a bare-bones publicly-funded mental health system. These cuts have made it impossible for service providers to build the infrastructure required to support the need of those living with mental health conditions.

Governor Rauner's proposed FY2016 budget cuts will further strain our already fragile mental health system.

The following analysis offers a number of fiscally responsible evidence based recommendations for the state to pursue. These recommendations will lessen the wasteful and ineffective spending by supporting and funding a compassionate and effective public mental health system.

The mission of the National Alliance on Mental Illness (NAMI) Chicago is to provide hope and improve the quality of life for those in the Chicago area whose lives are affected by mental illness, by providing information and referrals, education, support, advocacy, and active community outreach.

Acknowledgements and Gratitude

This White Paper was prepared by Advocates for Human Potential, Inc., under the direction of NAMI Chicago and the leadership of Alexa James, NAMI Chicago's Executive Director. We thank Benjamin Breit, Fred Friedman, Nanette Larson, Elli Montgomery, Meryl Sosa, Mark Heyrman, and Ed Stellon for their invaluable contributions and insightful reviews of this paper. AHP Authors: Susan Pickett, Ph.D., Cassondra Branderhorst, M.A., and Karina Powell, M.S.

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Making the Case for Funding and Supporting Comprehensive, Evidence-Based Mental Health Services in Illinois

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INTRODUCTION

People living with mental illness can—and do—recover and lead full, productive lives in their communities. This fact has been well-established by two decades of research and is illustrated daily by the thousands of individuals who successfully manage their illnesses and are contributing, tax-paying members of society.

Nationwide, recovery is a fundamental goal of mental health services. The Substance Abuse and Mental Health Services Administration (SAMHSA) defines recovery as "a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential." Four major dimensions support recovery: home, health, purpose and community.

Health
Overcoming or managing one's symptoms or illness

Home
Having a stable and safe place to live

Purpose
Having meaningful daily activities (work, school) and the independence, income and resources to participate in society

Community
Having relationships and social networks that provide friendship and support

Recovery is self-directed, strengths-based, and, to be 100% successful, uses supportive services that help people living with mental illness manage their symptoms, live independently, and contribute to their communities. Yet in Illinois, severe budget cuts and under-funding of mental health services over the past five years have resulted in a bare-bones system that makes recovery all but a dream for many citizens.

In response to these fiscal challenges, in 2011 the Illinois State Legislature established the Mental Health Services Strategic Planning Task Force and charged this group with creating a strategic plan for providing publically-funded mental health services in Illinois. The 2013-2018 Strategic Plan outlines key goals and objectives to guide the Illinois Department of Human Services-Division of Mental Health (IDHS-DMH, referred to throughout this paper as DMH) and other state agencies that provide services to adults living with mental illness. At the heart of the Strategic Plan is this vision:

"In Illinois…all adults with a diagnosis of, or at risk for developing, a mental illness will have access to a coordinated, integrated, well-funded mental health system that promotes recovery and social inclusion through timely access to prevention, treatment and recovery support services."

As outlined in the Strategic Plan, this vision is to be realized by accessible, community-based mental health care that includes person-centered, evidence-based, recovery-promoting services.

The Strategic Plan offers a promising roadmap for mental health care. We applaud DMH, the Illinois State Legislature and other leaders for their hard work and commitment to providing recovery-promoting services in the midst of overwhelming economic and systems challenges. Yet as we reach the midpoint of the Strategic Plan's implementation, what has actually been achieved? Services continue to be under-funded and provider capacity is greatly diminished, limiting both access to and receipt of mental health care. And, as the fiscal year draws to a close here in the spring of 2015, Illinois faces more dire budget cuts that will decimate the remaining system.

In this White Paper, our goal is to answer these questions: *What's the state of our public mental health system? Is the system able to provide recovery-promoting services to Illinois residents living with mental illness? How do we move forward?* To answer these questions, we look at the current state of mental health services in Illinois, and whether and how Strategic Plan priorities related to recovery have been achieved. We examine the challenges the system has faced in the past five years and the impact inadequate funding and treatment have had on both the system and people living with mental illness. We explore why it's critical to provide evidence-based services that promote recovery, and share examples of innovative efforts currently underway in Illinois.

STRATEGIC PLAN RECOVERY-RELATED PRIORITIES

Priority 1, Goal 1: Ensure that services provided within the state are available to meet the needs of individuals with mental illness.

Priority 2, Goal 4: Ensure access to appropriate and affordable housing for adults diagnosed with mental illness.

Priority 2, Goal 5: Ensure access to opportunities for employment, with support needed to maintain employment, for adults diagnosed with mental illness.

Priority 4: Obtain and maintain financial viability for providers in a cost-effective manner to the state.

Priority 5, Goal 1: Ensure the direct and active involvement of individuals with lived experience in the planning for and provision, evaluating and monitoring of services.

We use several sources of information to answer our questions. These sources include interviews with providers and advocates, published research results, and the most recent, publically-available federal, state and local data. It's important to point out that collecting and analyzing data—especially federal and state data—is a long process, and for some information, the most-recent, reliable data available to us are two-three years old. We're not able to factually report what happened last year, or last month, because those data are still in process and haven't been released. For example, even though the Affordable Care Act (ACA) has been up and running for over a year, as Mental Health America reports, it is too soon to tell what the impact really is and has been for people living with mental illness because those data are still in-process. Along with this, it is also important to remember that we live in a fast-paced, fast-changing time: policies and budgets (including proposed budget cuts) change daily. We recognize that what we report and recommend now in May 2015 has the potential to be quickly outdated. What we report is what we know and where we are right now, and how we can use what we know at this moment to ensure that Illinois has a strong, compassionate, recovery-promoting system of care for people living with mental illness.

THE STATE OF MENTAL HEALTH AND MENTAL HEALTH SERVICES IN ILLINOIS

How many people in Illinois are living with a mental illness?

Mental illness does not discriminate: it affects people of all races and social and economic groups. Federal data show that in 2013 (the most recent year for which these data are available) 38.5% of adults in Illinois ages 18 and older reported poor mental health (feeling very depressed and/or anxious and having to limit daily activities because of mental health problems); 16.68% of Illinois adults were living with a mental illness (defined as a mental, behavioral or emotional disorder, other than a developmental or substance use disorder that was diagnosed within the past year using *Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM-IV)* criteria); and 3.37% of Illinois adults were living with a serious mental illness (a mental, behavioral or emotional disorder diagnosed within the past year using the DSM-IV that results in serious functional impairment). When we apply these estimates to U.S. Census data, in 2013:

- Approximately 4.96 million Illinois adults experienced poor mental health
- 2.1 million Illinois adults were living with mental illness
- 434,412 Illinois adults were living with serious mental illness

It's important to note that these numbers do not include co-occurring substance use disorders or medical conditions. Many people living with mental illness also are living with drug and/or alcohol problems as well as physical health problems. Given this, the number of people living with mental illness may actually be much **higher** than what is reported here. Additionally, the DSM-IV has been updated and the DSM-5 is now used to assess mental illness.

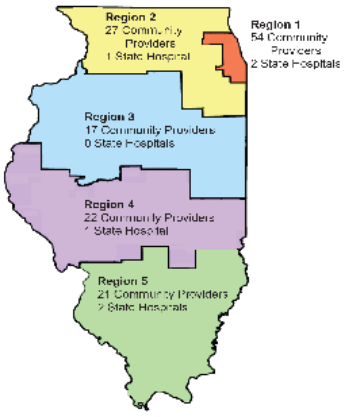
Are people in Illinois who are living with mental illness getting mental health care?

Mental health treatment is extremely effective in restoring the health and well-being of people who are living with mental illness. Yet, despite national policy initiatives to improve and increase access to services - most people with mental illness do not receive treatment. Without treatment, mental illness—especially serious mental illness—can result in significant disability and decreased quality of life. Recent, publically-available data analyzed by Mental Health America indicate that in Illinois, only 42.7% of adults living with mental illness received mental health treatment. This means that less than half of the 2 million Illinois residents living with mental illness receive any mental health care.

There are many reasons why people living with mental illness don't get treatment for their mental health problems. Some of the most common barriers include mental health stigma, limited access and availability of services, and cost.

Mental health stigma. As Dr. Patrick Corrigan, an international expert on mental health stigma at the Illinois Institute of Technology, states "The prejudice and discrimination that are a part of the stigma of mental illness is an important reason why people living with mental illness don't seek treatment". Dr. Corrigan's research shows that negative public and personal perceptions about mental illness keep people from getting help for their mental health problems. When people are afraid of being labelled as dangerous, incompetent, unpredictable and to blame for their disease, they are less likely to seek treatment.

Limited service access and availability. Not knowing where to get mental health treatment or how to access services is another barrier to care. A recent report released by the National Alliance on Mental Illness (NAMI) found that many people living with mental illness experience significant problems finding mental health providers in their health plans. Not having enough providers and places that offer mental health services also are barriers to care. SAMHSA estimates that more than half of all counties nationwide have no practicing psychiatrists, psychologists, or social workers. In Illinois, since FY2009, 2 state-operated inpatient facilities, 6 City of Chicago mental health clinics, and several community mental health agencies throughout the state have closed. And for many years, there has been a shortage of psychiatrists in Illinois in rural and under-served areas. As our map above shows, there are many areas of the state where very few mental health services exist.

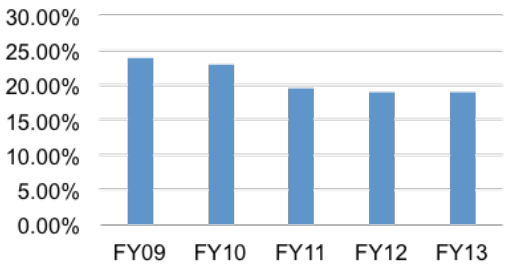


Cost of mental health care. Being able to afford and pay for mental health care is a huge obstacle to getting treatment. Studies show that 1 in 5 people with mental illness do not receive the services they want and ask for. The odds for having unmet treatment needs—not being able to get the mental health services one says that he/she wants and needs—are significantly higher for people who are uninsured and for those living with a serious mental illness. Roll and his colleagues found that nationally, rates of unmet need for mental health care increased from 4.3 million in 1997 to 7.2 million in 2011. The greatest percentage of unmet mental health treatment needs occurred among working age adults (those ages 18-64 years). Perhaps most notably, people who were uninsured had rates of unmet mental health treatment needs nearly five times higher than those who had private health insurance.

The problem is this: People living with serious mental illness have many unmet treatment needs and too often, they are not able to pay for mental health care. Since many people living with serious mental illness are low-income, under-employed or unemployed, Medicaid is their only viable source of health care coverage. While the ACA offers great promise to help people living with serious mental illness get the treatment that supports their recovery, years of budget cuts make it difficult for many states, including Illinois, to deliver on that promise. As we describe in more detail in the next section, funding cuts and stricter service eligibility requirements over the past five years have resulted in fewer Illinois residents living with serious mental illness being able to get the mental health care they want and need. Indeed, data from Illinois Executive Budgets show that the percentage of those who received publicly-funded mental health treatment who were in need of services has steadily decreased from FY2009-FY2013 from 24% to 19%.

What is the state of mental health services in Illinois and how did we get here?

Pecentage of Illinois adults living with mental illness who needed treatment that received publicly-funded mental health care



It's no big secret: From FY2009-FY2012, Illinois cut $113.7 million in general revenue funding for mental health services. Illinois made some of the largest cuts in mental health funding nationwide during this time period. In fact, only California and New York cut more from their budgets than Illinois did!

To try to make ends meet, DMH responded to these budget cuts by restricting who would be eligible for state-funded community mental health services. Beginning in FY2011, only people living with serious mental illness who are eligible for Medicaid are able to received state-funded services. These are individuals living with serious mental illness who are low-income and whose illness impairs their everyday functioning. Uninsured individuals living with serious mental illness who are not eligible for Medicaid are able to receive a time-limited, small subset of services, primarily, as the Strategic Plan notes "for little more than crisis stabilization".

The result? Fewer state-funded services are available to a fewer number of people. Providers can only afford to offer services that are Medicaid-reimbursable, and, with state Medicaid reimbursement rates remaining relatively stagnant in the past five years, many community-based providers have had to stop delivering any and all recovery-promoting services that are not Medicaid billable. Unless there is money to pay for it, services stop. Agencies have had to make hard decisions about whether to let staff go. In many cases, agencies have not been able to afford to stay open. Case in point: When the Strategic Plan was implemented in 2013, DMH contracted with 150 community agencies across the state to provide mental health services to adults living with mental illness. As of the spring of 2015, only 141 agencies statewide are contracted to provide these services.

The mental health system took another hit when Illinois entered into two *Olmstead* Consent Decrees: *Williams v. Quinn* and *Colbert v. Quinn*. These class action lawsuits mandate that people living with serious mental illness who are nursing home residents be offered the opportunity and supportive services to move out of their facilities and into their own homes in the community. As a result, DMH must provide community-based mental health services and permanent supportive housing to approximately 11,300 Class Members. But, because of budget cuts, in order to meet these requirements, DMH has had to further restrict some state-funded services to Class Members only. For example, the state's Permanent Supportive Housing Bridge Subsidy program, which provides rental assistance to act as a "bridge" between the time when a person is ready to move into his/her own apartment and the time when he/she can obtain a permanent rental subsidy, currently is available only to Class Members. So, while we celebrate the fact that the consent decrees help people living with serious mental illness move out of nursing homes and transition into the community, we also recognize the strain this puts on providers—and provider capacity.

Finally, another impact on the mental health care system that has mixed results is the Save Medicaid Access and Resources Together (SMART) Act of 2012. The negatives: The SMART Act provides that whenever a Medicaid recipient needs more than four prescription medications in any month, those additional medications are subject to a very burdensome prior authorization process. This provision particularly harms people with serious, chronic mental illnesses because, in addition to the medications they may be taking for their mental illness, many have co-occurring non-psychiatric conditions for which medications are essential. Additionally, the recipient cannot her/himself initiate the prior authorization process but must rely on her/his physician. Because Medicaid reimbursement rates are so low, many physicians are reluctant or unwilling to undertake the time consuming Medicaid authorization process. Moreover, while advocates were successful in 2014 in carving out anti-psychotic medications from the 4-drug restriction, the restriction remains for anti-depressants and all other psychotropic medication. Finally, the Governor's proposed budget for FY2016, if adopted, would further burden individuals living with mental illness by once again eliminating the anti-psychotic carve out. The SMART Act thus makes it difficult, if not impossible, for people living with mental illness to pay for all of their medications. And when they stop their medications, people living with serious mental illness are at greater risk for crises and ER visits. The positives: The SMART Act expanded the state's Integrated Care Program for people with chronic health conditions. This means that the many people living with mental illness who also have medical problems like diabetes and hypertension now have access to coordinated mental health and medical care.

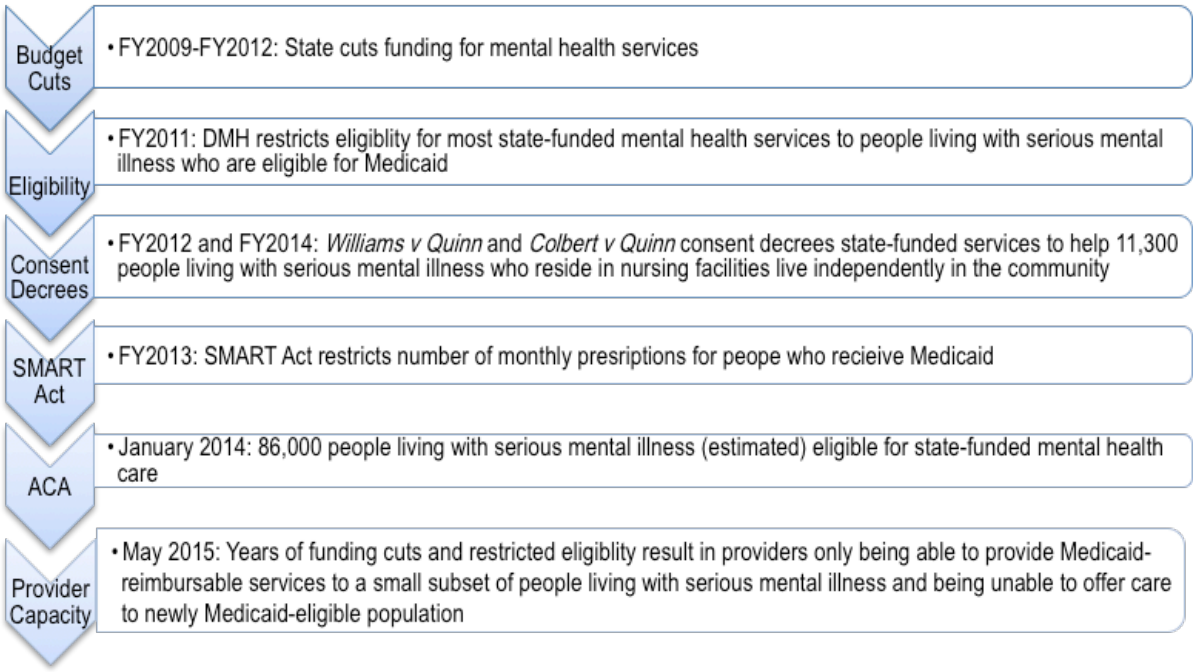
What's the impact of the ACA? Shouldn't the ACA be able to fix the system?

The ACA should fix all of this, right? After all, under the ACA, people living with mental illness are able to purchase health care coverage through the Insurance Marketplace Exchange. The strict disability requirements for Medicaid have gone away, so more people who are low-income and living with mental illness now qualify for Medicaid. Illinois is a Medicaid expansion state, and, while all of the data aren't available yet, 2011 estimates by the National Association for State Mental Health Program Directors (NASMHPD) suggest that nearly 86,000 of the uninsured individuals in Illinois who are living with mental illness will become eligible for coverage—and treatment—as a result of the ACA.

So, under the ACA, Illinois should be able to provide Medicaid-funded mental health services to more people living with mental illness, right? Wrong. As Ed Stellon, the Interim Executive Director for Heartland Health Outreach explains, with the ACA, there are now two groups of Medicaid-eligible people living with serious mental illness. The first group—Group 1—is people living with serious mental illness who have been Medicaid-eligible since before the ACA was implemented. Group 1 individuals are people living with serious mental illness who have been the most disabled by their illness and who need the intensive set of services that DMH has funded since FY2011. The second group—Group 2—is people living with mental illness who are now eligible for Medicaid under the ACA. These mostly younger, newly-diagnosed individuals often have mental health conditions that do not need the same intensive level of care. Group 2 people need a range of recovery-promoting services that will help them quickly return to their lives in the community.

Here's the problem: For the past five years, Illinois' public mental health system has focused on providing services to Group 1. As a result, it's unable to provide less intensive services to Group 2. Along with this, because of consent decree requirements, intensive services are prioritized for Class Members, so there is little or no capacity to develop less intensive services for Group 2. As Mr. Stellon told us, the current system is one that focuses on chronic care management for people who are living with severe, disabling mental illnesses. It doesn't address early intervention that might help Group 2 recover and avoid long-term disability. Without these less intensive, recovery-promoting services, Mr. Stellon predicts that Group 2 will remain untreated and be forced onto a trajectory that, ultimately, turns them into Group 1: people living with chronic, long-term disabling serious mental illness. Another way to think of it is like this: The system can treat pneumonia but can't treat the common cold, so you have to wait until your cold turns into pneumonia before you can get treatment.

To sum it all up, the story is this. After five years of dealing with funding cuts, eligibility restrictions and consent decrees, Illinois has a bare-bones publicly-funded mental health system. It's great that the ACA helps more people living with mental illness pay for services, but today's providers just don't have infrastructure to serve them. They don't have the staff, the funding, and the less intensive services that these newly Medicaid-eligible Group 2 people need. In fact, many providers are encouraging and referring newly Medicaid-eligible individuals to private providers who accept Medicaid. **The promise of the ACA is not so promising without providers to deliver services!**



What happens if people living with mental illness have nowhere to go to get treatment?

Without community care—without those services and supports that help them recover—people living with mental illness who don't have insurance, don't get treatment and their illnesses get worse. When that happens, people living with mental illness end up in in the emergency room (ER), or in jail, or on the streets with no place to live. And too often, all of the above happens. Here's a snapshot of what has happened in Illinois since funding cuts took place in FY2009:

- Emergency room visits for people experiencing psychiatric crises increased by 19% between 2009 and 2012.
- Studies show that over 60% of incarcerated individuals meet diagnostic criteria for mental illness. That means that of the approximately 76,400 people who were admitted to Cook County Jail (CCJ) in 2012, 45,840 were people living with mental illness. It is thus little surprise that, following national trends, many of the jails and prisons in Illinois have become de facto mental health treatment centers. CCJ is now considered one of, if not, the largest mental health care provider in the country. In fact, studies show that for many people living with mental illness, the only time they get treatment is when they are in jail.
- The total number of nights spent in a shelter statewide increased from 2,000,000 in FY2011 to 3,041,000 in FY2013. The National Alliance to End Homelessness estimates that approximately 32% of the 14,144 individuals who currently experience homelessness on any given night in Illinois have a serious mental illness.

There are three related problems here. First, numerous studies show ERs and jails are more expensive than community treatment. Second, a vicious cycle gets created involving jails, homelessness, and ER use. People leaving jail who are living with mental illness have very few, if any, housing options. They often leave the jail and immediately become homeless. Once on the street, they don't have access to and/or don't seek services, and their mental health problems get worse. Then one of two things is likely to happen: they get arrested and end up back in jail, or they end up in the ER. At the ER, because there are so few housing options and hospitals don't want to force them back on the streets, people experiencing homelessness who are living with serious mental illness get referred to expensive nursing home care. Many do not need such an intensive, expensive level of care: they need the recovery-promoting combination of community care and supported housing shown to successfully help remove this population from homelessness. Third, none of these are ideal treatment methods or outcomes for people living with mental illness. Their treatment options and outcomes shouldn't be ERs, jails, living on the street or in nursing homes. Instead, it should be a compassionate, comprehensive system of care that provides the effective treatment that breaks this cycle and makes these options the outcomes of last resort for people living with mental illness.

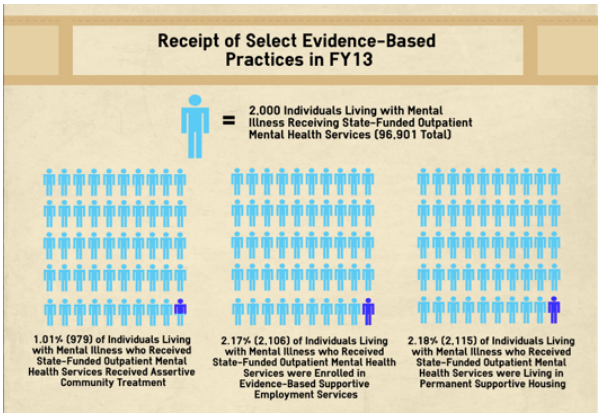
EVIDENCE-BASED, RECOVERY-PROMOTING PRACTICES

Is the mental health system providing evidence-based services that promote recovery?

Despite funding and service cuts, Illinois has continued to make a commitment to providing evidence-based practices (EBPs) that promote recovery. EBPs are services that research studies have proven to be effective in improving specific outcomes for people living with mental illness, like employment and independent living. The EBPs that the state offers include Assertive Community Treatment (ACT), the Individual Placement and Support (IPS) supported employment model, and permanent supportive housing (PSH). ACT teams provide a broad range of supportive services, such as case management and medication monitoring that help people living with mental illness stay in the community and work on their recovery goals. Research shows people living with serious mental illness who receive ACT services have fewer inpatient hospitalizations, and better housing stability, social functioning and quality of life. In FY2013, 979 individuals received ACT services from 21 ACT teams statewide. However, as our chart below shows, **this represents only 1% of people living with serious mental illness who received state-funded mental health services.** Moreover, the increase in the number of ACT teams from 15 teams in FY2012 to 21 teams in FY2013 was largely in response to the need to meet the requirements of the *Williams v Quinn* consent decree and provide ACT services to Williams Class Members.

Illinois offers Individual Placement and Support, an EBP-supported employment model that provides people living with serious mental illness the integrated mental health and vocational services they need to find, get and stay employed. An employment specialist helps people living with serious mental illness find jobs that match their work goals, and provides on-the-job supports as needed. What's most important about IPS is that it helps people living with mental illness get competitive jobs—jobs that are open to **anyone** regardless of whether they are living with a mental illness or not. Research shows that IPS increases competitive employment rates for people living with serious mental illness: It helps them find and keep real-world jobs. IPS also improves participants' quality of life, and helps them better manage their symptoms. In Illinois, IPS is funded via a braided funding model between DMH and the Department of Rehabilitation Services (DRS). Slightly more than 2,000 people living with serious mental illness statewide received IPS in FY2013. IPS services helped 476 of these individuals find and obtain competitive employment. While this is impressive, the percentage of people living with serious mental illness who received IPS is very small—only 2% of all people who received publicly-funded mental health services in FY2013.

Permanent supportive housing provides people who are living with serious mental illness the supportive services they need to live independently in the community. The logic of PSH is simple: Without a home, it's hard to take care of yourself and achieve your recovery goals. PSH helps people living with serious mental illness find permanent housing in neighborhoods of their choosing, and offers flexible, voluntary services that help participants stay in their homes. Studies show that in addition to removing people living with serious mental illness from homelessness, PSH significantly reduces their ER visits, inpatient hospitalizations and shelter use. FY2013 data show that 2,115 people who were living with mental illness received PSH. It's important to note that, similar to IPS, only 2% of people who received publicly-funded mental health services in FY2013 received PSH.



OTHER RECOVERY INITIATIVES LED BY RSS INCLUDE:

- Monthly statewide Recovery and Empowerment calls
- Annual statewide Recovery Conferences
- Treatment Recovery Philosophy and Policy (TRPP)—a new initiative launched in March 2015 in state-operated hospitals that includes mandatory recovery training and annual recovery competency reviews for all employees

In addition to EBPs, what else is the mental health system doing to promote recovery?

The work that DMH's Office of Recovery Support Services (RSS) is doing to help people living with mental illness with their recovery is impressive. With very limited funding, RSS spearheads several recovery initiatives statewide, many of which emphasize the importance of peer support. Peer

support—the practical, emotional and social support that people with lived experience of mental illness provide to other people living with mental illness—is a powerful recovery-promoting tool. Having "walked the walk", peer support providers know first-hand what it's like to struggle with a mental illness. Research shows that peer support programs help people living with mental illness learn and use skills and resources that help them manage their symptoms, develop positive relationships with friends and family, and identify and achieve life goals. We applaud DMH for their leadership in this area. We highlight two key DMH-RSS initiatives:

- **Wellness Recovery Action Planning (WRAP®) Facilitator Training:** A recently-recognized EBP, WRAP® is a multi-week program led by trained facilitators who are people with lived experience of mental illness. WRAP® teaches people living with mental illness how to identify and use illness self-management resources and skills that help them stay well and promote their recovery. Studies show that WRAP® improves participants' quality of life and reduces their psychiatric symptoms. RSS provides annual WRAP® facilitator training and has trained over 400 people living with mental illness how to deliver WRAP® statewide since 2002. WRAP® facilitators are paid positions, providing people living with mental illness a valuable employment experience. The community support services WRAP facilitators provide are Medicaid-reimbursable making WRAP® an affordable program for many agencies.
- **Certified Recovery Support Specialist (CRSS) Credentialing:** The CRSS is a credential for professionals with lived experience of mental illness who provide peer support to other people living with mental illness. CRSS professionals are employed specifically to use their personal recovery experiences to help others in their own recovery journeys, and help the system become recovery-promoting and responsive. Every year, RSS offers annual CRSS competency training at three sites across the state. In 2014, RSS trained 350 CRSSs. Like WRAP®, CRSSs are paid professionals and provides people living with mental illness real employment opportunities. CRSSs may bill at the Mental Health Professional level for community support, psychosocial rehabilitation and other Medicaid-reimbursable services. They are valued among mental health staff for their positive impact and unique ability to connect with people who are living with mental illness and be living role models of recovery.

SERVICE INNOVATIONS

DMH is also to be applauded for its work with its contracted providers to offer new, innovative services to people living with mental illness. As an example, we highlight Advocate Illinois Masonic Hospital's Medically Integrated Crisis Community Support (MICCS) Team. MICCS was created in the spring of 2014, in part, with funding from DMH, to reduce unnecessary ER visits. The MICCS team includes social workers, a CRSS, a psychiatric nurse, a psychiatrist, and a bilingual case manager. When people living with mental illness are in crisis and come to the ER, the Advocate Illinois Masonic's Electronic Medical Record "flags" them and contacts the MICCS team. The team meets these people in crisis, helps with discharge and treatment planning and stays connected with them once they are back in the community to help intercept future ER visits. MICCS is a strategic extension of the long-standing ER-Crisis Service at Advocate Illinois Masonic Medical Center, a Level 1 Trauma Center and Chicago Police Department drop-off site for three police districts. Here are two examples of MICCS success stories:

- John is in his mid-50s and has a history of schizoaffective disorder, alcohol abuse, and long-term homelessness. From January 1, 2013 through mid-June 2014, he had 81 ER visits at Advocate Illinois Masonic, 2 of which required a medical admission. The cost for the Advocate Illinois Masonic care alone at that time was $155,794.
  Results: As a result of MICCS team interventions, John has:
  - → had only 3 ER visits in the past nine months
  - → agreed to have a representative payee; he is able to fund his basic needs
  - → applied for training at a local animal shelter where he is now a regular volunteer. He has a CTA pass, stable housing, and is compliant with medication for psychiatric and physical needs.

- Jane is 55 years old and has a history of bipolar disorder and alcohol abuse. She used to come to the Advocate Illinois Masonic ER 1-3 times per day. Jane is well known to many Chicago ERs, fire fighters and police officers. At Advocate Illinois Masonic alone she had a total of 741 visits to the ER since 2006. The cost of her care at Illinois Masonic was $2,613,230.
  Results: As a result of MICCS team interventions, Jane has:

  → had only 6 ER visits in a 6 month interval

  → been placed in supportive permanent housing through MICCS' partnership with Heartland Alliance

  → experienced nearly 6 months of sobriety

Another innovative program that is not funded by DMH but one we want to recognize is Cook County Jail's partnership with Cook County Health & Hospitals System (CCHHS) and Treatment Alternatives for Safe Communities (TASC) to help jail detainees enroll in Medicaid. Studies show that mental health and substance use treatment helps break the jail → no community treatment → return to jail cycle for people living with mental illness. But until the ACA, most people living with mental illness who are involved in the criminal justice system haven't been eligible for Medicaid and haven't been able to afford treatment. So beginning in April 2013 Cook County Jail, CCHHS and TASC began screening individuals as they entered the jail and helping eligible individuals apply for Medicaid. As of April 16, 2015:

- 186,328 individuals have been screened for Medicaid eligibility
- 23,248 individuals started the Medicaid application process
- 14,663 individuals submitted Medicaid applications
- 10,717 individuals now have Medicaid insurance cards because they started an application in Cook County Jail

Two important points: 1) Enrolling people in Medicaid is **not** Cook County Jail's responsibility. The Cook County Sherriff's Office took it upon itself to partner with TASC because they a) it recognized that having Medicaid and access to behavioral health care can break the jail-recidivism cycle and b) no other system was doing this targeted enrollment for this specific population. 2) It is too early to tell whether enrollment results in service use. These studies are underway and data aren't yet available.

NEW CHALLENGE: GOVERNOR RAUNER'S PROPOSED FY2016 BUDGET

Governor Rauner's proposed FY2016 budget cuts will further strain our already fragile mental health system. The proposed $1.5 billion cut to Medicaid—the largest source of funding for mental health services in Illinois—will further decimate the system and be devastating to people living with mental illness, including the thousands who are newly-eligible for Medicaid under the ACA. The governor's proposed cuts includes the $27 million cut to services that completely eliminates the Psychiatric Leadership Capacity Grant, the program that enables community mental health agencies to hire psychiatrists who can't afford the low Medicaid reimbursement rates that haven't been raised since 1996. This cut, along with proposed changes to the SMART Act to include psychotropic medications in the four-medications-per-month limitation, will make it even harder for people living with mental illness to get their medications. Other proposed mental health cuts include a $5.5 million cut to state psychiatric hospital services, and an $18.5 million cut to care coordination services.

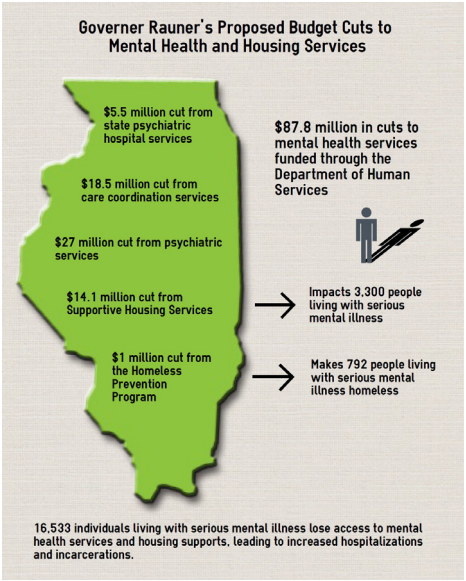
Affordable housing options for people living with mental illness are in short supply, and if Governor Rauner's proposed cuts to housing services go through, housing options will dwindle down to next to nothing. The proposed $14.1 million cut to Supportive Housing Services means that 10,311 households—3,330 of whom are estimated to have at least one household member living with a mental illness—that were just recently housed will lose services and be at increased risk of experiencing homeless once again. If the $1 million cut to the Homeless Prevention Program is enacted, 2,474 individuals—792 of whom are estimated to be living with mental illness—will lose services and supports that help them live independently in the community. In all, nearly 4,100 people living with mental illness will be at increased risk for homelessness if these cuts to housing supports take place.

The take home message is this: If Governor Rauner's proposed budget cuts go through an estimated 16,533 individuals living with serious mental illness will lose psychiatry, care coordination, evidence-based mental health services and housing supports. Just as other studies have shown **the loss of these community-based services will result in greater ER use and incarcerations at costs to the state that are much higher than the costs of the services Governor Rauner wants to cut.**

CONCLUSIONS AND RECOMMENDATIONS: HOW DO WE MOVE FORWARD?

The Illinois public mental health system has weathered many blows in the past five years. Governor Rauner's proposed cuts only add to the feeling that mental health care—and those living with mental illness—are not a health care priority. Where is the promised parity?

Yet despite the storms, DMH has continued to strive to provide recovery-promoting services to people living with mental illness. We summarize the progress made toward the Strategic Plan priorities and goals outlined in our Introduction and make the following recommendations.



Goal: Ensure that services provided within the state are available to meet the needs of individuals with mental illness. The majority of people in Illinois who are living with serious mental illness aren't receiving the services they want and need. Illinois' fiscal crisis, service eligibility requirements and consent decrees have all decreased provider capacity, leaving us with a mental health system that mostly serves only those who are most severely disabled by mental illness.

Recommendation: Echoing Fred Friedman, Head Organizer of Next Steps, "Anyone can get sick, and anyone can get better with the right supports". Both Mr. Friedman and Mr. Stellon noted that the current system's focus on illness, rather than wellness, leaves out a broad array of services that can help ensure that people receive early intervention and supportive treatment that remove them from a trajectory of long-term disability. To paraphrase these key informants, we don't need to provide more services, we need to provide the right kinds of services that support recovery and that move the system from volume to value, and from treatment to prevention. EBPs such as ACT, IPS and PSH are effective services that help people manage their illnesses and become active members of their communities. Yet only 1%-2% of Illinois citizens living with serious mental illness who receive publicly-funded mental health services receive these EBPs. Funding and provider capacity need to be increased so that these recovery-promoting services are available to everyone.

Goal: Ensure access to appropriate and affordable housing for adults with mental illness. In FY2013, only 2% of people living with mental illness who received publicly-funded mental health care received PSH services. Currently, these services are available only to consent decree Class Members.

Recommendation: Nationally, efforts are in place to include PSH as a Medicaid-reimbursable service. Additionally, we know that PSH successfully helps people keep their homes and reduces costs to other systems:

- → Utah adopted a 10 year plan to end homelessness in 2005 that included PSH. Nearly a decade later, in early 2014 this state reported a 72% decrease in homelessness. It cut costs to its medical and justice systems by more than half—from $19,000 per person per year to less than $8,000 per person per year.
- → Florida reported in 2014 that the costs of leaving a person homeless cost its healthcare and justice systems $31,000 per person per year, while the cost of PSH was $10,000 per person per year.
- → In North Carolina, one PSH apartment building that housed 85 people who had been chronically homeless saved $1.8 million in health care costs. Residents' ER visits and arrests each decreased by 78%.

The costs of leaving people living with mental illness homeless are greater than the costs of PSH. We recommend increased funding for PSH so it's available to all who need it (not just Class Members) and so we can truly end chronic homelessness in Illinois.

Goal: Ensure access to opportunities for employment, with supports needed to maintain employment, for adults diagnosed with mental illness. Similar to PSH, in FY2013, only 2% of people living with mental illness who received publicly-funded services received IPS. Mr. Friedman shared with us that it's estimated that 60% of people living with mental illness who are receiving publicly-funded services would like IPS.

Recommendation: In 2014, Illinois received a 5-year grant from SAMHSA to enhance and expand IPS statewide. DMH and DRS are to be commended for this, and hopefully, as a result of this grant, competitive employment rates for people

living with serious mental illness in Illinois will increase. But the SAMHSA's grant primary focus is only on two pilot sites in Chicago, and additional efforts are needed to ensure that IPS is actually expanded and sustained statewide. Similar to PSH, there are national calls to make IPS a Medicaid-reimbursable service. We also encourage the state to incentivize companies to partner with supported employment programs and create more competitive jobs for people living with mental illness. As Mr. Friedman so eloquently describes it, employment is a "no brainer". When people living with mental illness work, they pay taxes and financially contribute to society—and the state's coffers.

Goal: Obtain and maintain financial viability for providers in a cost-effective manner to the state. When the Strategic Plan was implemented, DMH contracted with 150 providers. It now contracts with 141 and impending budget cuts have placed more community providers at risk for closure.

Recommendation: In addition to restoring and increasing the DMH FY2016 budget, we recommend the following cost-effective measures.

- → **Increase Medicaid reimbursement rates.** Medicaid reimbursement rates for psychiatry and other mental health services have been flat for years. This makes it practically impossible for many mental health professionals to be able to afford to provide services to people living with mental illness who are receiving publicly-funded care. Increasing Medicaid reimbursement rates ensures that people living with mental illness have better access to the high-quality care these professionals provide.
- → **Expand tele-psychiatry.** For ERs and community mental health agencies that don't have their own psychiatrists, tele-psychiatry provides virtual HIPAA-approved access to these professionals. It's a Medicaid-reimbursable, cost-effective service that helps rural and under-served areas provide effective psychiatric consultation and medication monitoring. Yet only a few areas downstate and a few urban community mental health agencies are currently using tele-psychiatry.

Goal: Ensure the direct and active involvement of individuals with lived experience in the planning for and provision, evaluating and monitoring of services. The Office of Recovery Support Services continues to do commendable work in meeting this goal. Its efforts ensure that people with lived experience of mental illness are trained and paid to provide a range of recovery services.

Recommendation: RSS is doing great work, but there is more that can be done to fight mental health stigma, offer peer support, and increase the involvement of people living with mental illness in recovery efforts throughout the system.

- → **Fund and promote programs that fight mental health stigma.** As we've discussed, mental health stigma is a huge barrier to people seeking mental health treatment. DMH currently supports "Say It Out Loud", a multi-year campaign that seeks to promote good mental health for all Illinois citizens, reduce stigma, and build more support services for people with mental illness. NAMI Chicago is partnering with Dr. Corrigan to provide "Coming Out Proud", a three-session group program run by pairs of trained leaders who are people with lived experience of mental illness. This program effectively reduces mental illness self-stigma. Participants have improved self-esteem and confidence, and feel more empowered to pursue their life goals.
- → **Make WRAP®, peer support programs, and CRSS-provided services more widely-available.** Research shows that peer support and peer support programs like WRAP® help people manage their mental illness and set and achieve personal recovery goals. Illinois has over 400 trained WRAP® facilitators, but few are actually delivering WRAP® on a consistent basis. Some of this is a training issue: RSS currently only provides one WRAP® facilitator training a year, and it's only in a select region of the state. But another barrier to providing WRAP® is organizational culture: not all community mental health agencies value peer support and thus don't think it's important to provide WRAP® or other peer support services. The same is true for CRSSs: if an agency doesn't value peer support, and doesn't think that a peer specialist is needed or adds anything to its services, it won't hire a CRSS.

As we have discussed throughout this White Paper, with the right supports, people living with serious mental illness can and do recover. These community-based resources that enhance strengths and wellness are cost-effective measures that remove people from long-term illness and disability. By investing in comprehensive community mental health care, Illinois is best positioned to meet the goals of its Strategic Plan and help people living with mental illness become full, participating, productive members of society. Investing in effective, compassionate, community-based care is the right thing to do.

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