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Hidden and Untreated: Ending Illinois' Silent Mental Health Crisis

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Mental Health Conditions are Common, Yet Few Get Treatment

Mental health conditions, such as depression or anxiety disorders, are more common than breast cancer or diabetes,¹ affecting over 2.5 million people across Illinois, including more than 850,000 children and young adults under the age of 25.² Yet, these conditions remain hidden and untreated for hundreds of thousands of Illinois children and adults due to stigma and a lack of access to treatment.

Most mental health conditions begin to develop in childhood and young adulthood. Half of all lifetime mental health conditions begin by the age of 14, and 75% by the age of 24.³

Medical research clearly demonstrates treatment is effective in enabling wellness and stabilizing symptoms.⁴ Treatment also has other life-long benefits, including leading to higher rates of school completion – 37% of children age 14 and older with a mental health condition drop out of school⁵ – and increased employment and higher productivity in adulthood.⁶

Illinois Mental Health Facts

- 2.5 million Illinoisans will experience a mental health condition (1 in 5)
 - 850,000 who are under age 25
- 50% of conditions manifest before age 14
- 75% manifest by age 24
- Treatment works, yet only 1/3 receive it

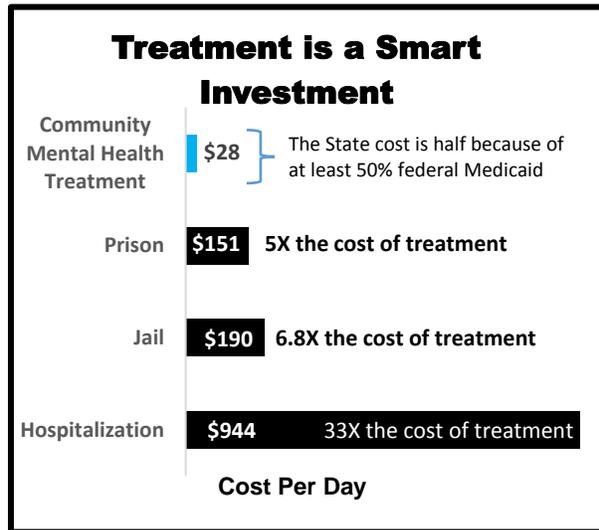
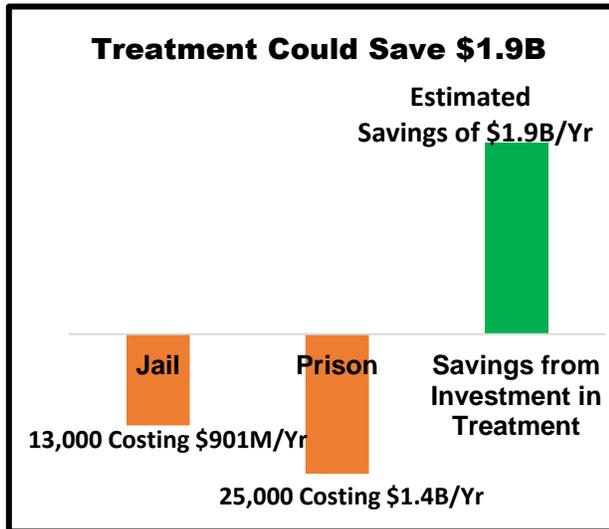
A Lack of Access to Treatment is Tragic and Costly

However, treatment is often out of reach. Only about one-third of those who need treatment receive it.⁷ This is because neither private insurance (despite federal and state parity laws) nor Medicaid treat mental health conditions like other health conditions. When mental health conditions go untreated, symptoms worsen and can become debilitating, resulting in numerous hospitalizations, erratic behavior, suicide due to untreated depression, unemployment, disability, poverty, and criminal justice involvement for low-level survival crimes. ***This downward trajectory, which often starts in childhood, is entirely preventable in the vast majority of cases, but has become the societal norm for thousands across Illinois.***⁸

A lack of access to treatment is also extremely costly for Illinois taxpayers. The criminal justice system is where tens of thousands of Illinois adults and youth with treatable mental health conditions end up.⁹ A jail cell is not where anyone should go for “treatment.” Yet, over 13,000 people with an untreated mental health condition are in jails across Illinois,¹⁰ costing local taxpayers an estimated \$901 million a year.¹¹ Illinois prisons house over 25,000 people with untreated mental health conditions¹² (often for repeated low-level crimes), costing state taxpayers \$1.4 billion every year.¹³ ***In short, Illinois is facing a silent mental health crisis that has been decades in the making because treatment is inaccessible for most.***¹⁴

Investing in Treatment Could Yield State Savings of \$1.9 Billion

There is no question treatment is more cost effective than other settings, as the charts below highlight. The most intensive level of community-based mental health treatment for the most serious conditions costs an estimated \$28/day,¹⁵ half of which is federally matched through Medicaid. Additionally, costs for community-based mental health treatment are far less than incarceration. *If Illinois invested in early treatment rather than waiting until incarceration, the state could save state and local taxpayers an estimated \$1.9 billion a year.*¹⁶



Sources: Illinois Department of Human Services (treatment cost); Illinois Commission on Criminal Justice and Sentencing Reform (prison, adjusted for mental health costs during incarceration); Cook County Sheriff's Office (jail); Thresholds, *A Path Forward: Investing in the Illinois Community Mental Health System* (hospitalization cost calculated using Medicare Cost Reports; hospitalization includes emergency room and inpatient stay costs).

Medicaid, the public health care program for low-income individuals, is the primary payer of mental health treatment and the foundation of Illinois' mental health system.¹⁷ Yet, because Illinois has not adequately invested in treatment covered by Medicaid and other necessary wrap around services, mental health conditions are a primary driver of high Medicaid costs. Medicaid enrollees with mental health and substance use conditions (both of which are closely linked) make up 25% of Illinois' Medicaid population but drive 56% of the state's total Medicaid costs because the early treatment is inaccessible for many.¹⁸ Just one psychiatric hospitalization costs, on average, an estimated \$6,328 (\$944/day).¹⁹ Many hospitalizations are common without treatment. The costliest 10% of Illinois Medicaid enrollees with mental health and substance use conditions cost the state approximately \$2.5 billion annually due to preventable hospitalizations and residential treatment because community-based treatment is often out of reach.²⁰

That Lawmakers should be alarmed that Medicaid is the primary payer in Illinois of mental health treatment given that 60% of Illinoisans have private insurance coverage.²¹ If private insurance covered the right treatment approaches at the time and duration needed, hundreds of thousands of young Illinoisans could avoid disability, which would prevent a permanent, life-long move to Medicaid, or long periods of incarceration in prisons and jails, all of which are major cost drivers for Illinois.

Despite Consent Decrees, No Systemic Change Has Occurred

To date, the state has simply never funded an adequate treatment system or required private insurance companies to cover the right treatments when patients and their families need them, despite numerous consent decrees and civil rights lawsuits.²² Illinois ranks 38th nationally and near

last among Midwestern states in its investment in mental health state agency spending per capita.²³ Illinois recently divested over \$100 million in mental health funding, resulting in a statewide spike in behavioral health hospital admissions by 19% as people lost treatment.²⁴ That alone is proof that treatment works and that when it is withdrawn, a person’s condition worsens, resulting in hospitalization. The end fiscal result was more costly than the cuts, costing the state an estimated \$131 million, for a net cost increase of \$31 million.²⁵

**Illinois Spends Far Less on
Mental Health Per Capita Than Other States²⁶**

State	National Rank	State MH Agency Spending Per Capita
Similar States		
Pennsylvania	5 th	\$287
New York	6 th	\$261
Midwestern States		
Minnesota	13 th	\$178
Iowa	15 th	\$142
Michigan	18 th	\$130
Kansas	19 th	\$125
Wisconsin	22 nd	\$113
Ohio	25 th	\$100
Missouri	26 th	\$99
Nebraska	32 nd	\$90
North Dakota	34 th	\$89
South Dakota	36 th	\$84
Illinois	38 th	\$72
Indiana	40 th	\$71

Illinois’ 1115 Medicaid Waiver Has Potential to be a Good First Step

Recognizing the need to build up the state’s public mental health and substance use system, the Rauner Administration laid out a vision for significant Medicaid investment in its recently filed 1115 Medicaid waiver application to the federal government. The waiver, in combination with several Medicaid state plan amendments, is called the Plan for Behavioral Health Transformation.²⁷ This plan includes the development of Integrated Health Homes that integrate mental health and substance use treatment and primary care, coverage of first episode psychosis treatment, crisis services for children and families, supportive housing services, and other important investments. If approved by the federal government, and ***if implemented well, the waiver has the potential to be the first major step forward in building a strong mental health system in Illinois.***

The Next Steps Needed to Build a Strong Mental Health System

The waiver is just one of many steps that are necessary to create a strong statewide mental health system. Below are Thresholds’ recommendations for the necessary investments in both the public sector and through private insurance.

We acknowledge that many of these recommendations require the state to increase funding for treatment. The cost data reported in this policy brief make it absolutely clear that this up-front investment, most of which is federally matched through Medicaid, will result in substantial, long-term

state savings by preventing unnecessary hospitalizations, criminal justice involvement, and permanent, life-long disability for thousands.

I. Focus on Early Identification and Treatment

Because most mental health conditions begin to manifest in childhood and young adulthood, that is where Illinois' system should be focused. Historically the state has focused treatment on adults with advanced mental health conditions, and slowly adapted these models to youth in very limited ways. Illinois' mental health system for children and youth is virtually non-existent. There are significant differences in how children and adults experience mental health conditions. For instance, bi-polar disorder in adults typically causes distinct periods of euphoria and depression, but for children it can cause rapidly changing mood behaviors characterized by irritability and belligerence. Moreover, children and young adults are at different life stages than adults with advanced mental health conditions. Treatment models for children and youth, therefore, should be specifically tailored to their needs. Following are recommendations for early detection and treatment:

- 1. Annual depression screening, as recommended by leading physician groups, should be incorporated into annual primary care visits at the appropriate age.** The U.S. Preventative Services Task Force and the American Academy of Pediatrics recommend annual screening for major depression beginning at age 12 *when there are adequate systems in place for follow-up treatment.*²⁸ A major impetus for this recommendation is that suicide due to untreated depression is a leading cause of death among adolescents and young adults.²⁹ ***However, the foremost challenge to implementing this best-practice is that the state has not made the public sector investments nor held private insurance accountable for coverage of treatment – there simply is not enough access to care.*** Illinois must make these investments to enable early detection. Early detection is critical to early treatment.
- 2. Create specialty care, team-based treatment models specifically tailored for adolescents and young adults with mental health needs.** The state has applied for Medicaid coverage of First Episode Psychosis treatment in its 1115 waiver, an important step forward. However, treatment models must be built for children and young adults with significant mental health needs who do not have psychosis – psychosis occurs in a very narrow band of the population (about 3.5%).³⁰ Many other states have successfully built or are in the process of building a set of specialty services for children and young adults.³¹
- 3. Require private insurance to cover the proven treatment approaches long covered by Medicaid for purposes of early treatment of significant mental health conditions.** 60% of children and young adults in Illinois have health coverage through private insurance.³² If insurance covered the right services, worsening conditions and a permanent shift to state coverage could be prevented for tens of thousands across Illinois. Medicaid provides far better treatment options for mental healthcare than private insurance (e.g., Assertive Community Treatment, Community Support Treatment, and wrap-around crisis services). Insurance plans should cover these treatment models for purposes of early treatment for youth. The insurance parity laws do not address this problem.
- 4. Maintain the Medicaid expansion under the Affordable Care Act.** Medicaid expansion enabled thousands of low-income Illinoisans with mental health conditions who are not yet disabled to have health coverage, and the potential to get early treatment. Prior to the expansion, these individuals were not eligible for Medicaid because they did not fit into the categories of people who are permitted coverage under the traditional Medicaid rules (pregnant women, children, seniors, and those who are

disabled), and private insurance coverage was out of financial reach. Without Medicaid expansion, this population will have no avenue into treatment (and their mental health condition will become exacerbated).

5. **Implement, monitor, and enforce the federal and state mental health and substance use parity laws.** There is a complete lack of transparency in whether or not the state is reviewing private insurance behavior related to the parity laws and whether insurance companies are in compliance. When private insurance limits coverage for mental health treatment, tens of thousands of young Illinoisans move to Medicaid permanently upon disability.
6. **Strengthen medical education on the treatment of mental health and substance use conditions for medical students and through continuing medical education for practicing physicians.** One-third of patients seeking treatment for their mental health condition receive treatment solely through their primary care physician.³³ Given the high prevalence of mental health conditions and the mental health workforce shortage,³⁴ it is critical that primary care doctors and other physicians have strong training on recognizing the signs and symptoms of a mental health condition and have the understanding and comfort level to discuss treatment options with patients. While the integration of primary care and mental health and substance use treatment is in the forefront for many providers, not all primary care practices will be integrated with a mental health provider, and it is critical that all primary care physicians are armed with a robust level of knowledge and training on early, effective treatment.
7. **Creation of trauma-informed care pilots in neighborhoods across the state that are experiencing extremely high violence rates could prevent life-long mental health conditions.** Data supports that repeated exposure to violence can have a profound negative and lasting impact on mental health.³⁵

II. Build Treatment Access through Medicaid Rate Reform and Other Investments

Illinois does not have enough access to mental healthcare because the state has never adequately paid for it through the Medicaid program, which is the foundation of the public mental healthcare system.³⁶ Reimbursement rates that do not cover costs limit capacity and do not allow for expanding access to services. As noted above, Illinois' lack of capacity and inability to expand services is a key reason the state has such a high number of individuals in the justice system who have a mental health condition.

While Illinois' 1115 waiver states that Integrated Health Homes will help drive down costs through better care coordination, there is simply no new service capacity for actual care/treatment of these individuals. The result will be care coordination to nowhere unless there is a commensurate investment in growing the treatment sector. To grow treatment capacity across the state, we recommend the following:

1. **Make the mental health Medicaid “temporary rate add-on payments” permanent.** In 2016, following a major mental health grant cut, Illinois implemented a new plan that provided Medicaid rate add-on payments for certain community mental health services to help address the funding cuts. These add-on payments are set to expire in June of 2018 and will only be renewed quarterly thereafter. This is simply not a stable reimbursement source for providers. The rate add-on has the potential to grow access to certain treatment services if it were made permanent.
2. **All other Medicaid reimbursement rates for community mental health and substance use treatment and for psychiatry must be adjusted upwards to cover costs and allow for service expansion to grow access to treatment.** According to a recent study,

Illinois needs to increase most community mental health Medicaid rates by 16% simply to keep pace with inflation from when the rates were established 10 years ago.³⁷ Psychiatry rates cover less than 50% of costs,³⁸ making it difficult to increase the number of psychiatrists in the Medicaid program. Community substance use treatment rates need to be adjusted upward by 27% just to keep pace with inflation since they were put in place.³⁹ Between 40-50% of individuals with a significant mental health need also have a substance use condition.⁴⁰ Effective treatment requires treatment of both conditions. ***There is simply no other way to expand access to treatment to the thousands across Illinois who need it – current rates do not allow for growth of services.***

3. **Allow psychologists, advance practice nurses (APNs), and social workers to practice telehealth.** There is a very real psychiatrist shortage in Illinois and throughout the country.⁴¹ Illinois must maximize the entire mental health professional field to meet the state's needs. Under current law, only physicians are permitted to do telehealth. In addition, prices for telehealth are being driven by market forces – it can be far more expensive than delivering the service in person, making it cost-prohibitive for many community providers. Providers simply cannot afford the increased costs of telehealth without adequate reimbursement (which must reflect market realities).
4. **Illinois should request federal approval to develop a pay-for-performance Medicaid payment model for community mental health services based on achieving good health outcomes rather than maintaining the fee-for-services system (*which continues to be the foundational payment structure even under managed care*).** While Illinois has shifted to Medicaid managed care, the existing federal and state fee-for-service rules for mental health service delivery are still in existence. This payment structure continues to incentivize volume rather than outcomes-based care, and hampers providers, prohibiting the delivery of many of the services that would drive better health outcomes and lower state costs.
5. **Enable affordable housing for high Medicaid and justice system utilizers with significant mental health conditions through the use of rental subsidies.** For those disabled by their mental health condition, finding affordable housing is one of the biggest challenges to recovery and stability. Supplemental Security Income (SSI) is typically the only source of income for these individuals, which is a maximum of \$735 a month.⁴² Many people have to spend 70% or more of their income on rent, resulting in frequent homelessness. The state should use rental subsidies, as many states do,⁴³ for high Medicaid and justice system utilizers with mental health conditions. Currently, Illinois uses rental subsidies for deinstitutionalization. The state should also use them to *prevent* high-cost settings. A rental subsidy plus treatment costs approximately \$20,000 a year⁴⁴ compared to being housed in an Illinois Department of Corrections facility for \$37,000 a year.⁴⁵ Further, just five hospitalizations cost the state approximately \$30,000.⁴⁶ Housing plus treatment makes far more fiscal sense.

III. Create a Full, Integrated Continuum of Care from Childhood through Adulthood

1. **In-home wrap around services should be covered through both Medicaid and private insurance for children and families experiencing a mental health crisis.** "Crisis" should be defined broadly and should enable services *before* a hospitalization or law enforcement response is required, which is what the system should help to prevent. Wrap-around services such as peer coaching, family peer support for parents who are overwhelmed, supported education to help a child stay engaged in school and on the path to graduation, and employment are critical to stabilizing a mental health crisis.
2. **Justice diversion programs for youth and adults will direct individuals into treatment rather than into juvenile detention, jails, and prisons.** Service capacity

throughout the treatment sector will need to increase (through adequate rates) to achieve effective diversion – the treatment sector is at capacity due to funding constraints.

3. **Medicaid and private insurance coverage of substance use treatment that is delivered out in the community (in the person’s everyday environment) rather than limited to a clinic or residential setting could prevent relapse.** The model would be similar to mental health treatment models such as Assertive Community Treatment and Community Support Treatment. There is little step-down substance use treatment available in Illinois following residential treatment, making relapse a stronger likelihood upon returning to the individual’s everyday environment.
4. **Allow for Medicaid and private insurance coverage of longer hospital in-patient stays for someone experiencing a mental health crisis.** The average length of stay for a psychiatric hospitalization in Illinois is 6.7 days. Many stays are shorter – two or three days. This is not long enough to stabilize an episode of psychosis. As a result, the person is often re-hospitalized because their condition was not stabilized.
5. **Incentivize the use of long-acting injectable antipsychotic medications and remove barriers to their use (prior authorization) when a person with a serious mental health condition chooses this option to enable better medication compliance.** Long-acting injectable antipsychotics are often denied by Medicaid health plans and by private insurance companies when a patient is willing to take this type of medication. Lack of medication adherence is a common reason for the exacerbation of symptoms, hospitalization, and criminal justice involvement. Long-acting injectable antipsychotics could greatly improve adherence and diversion from higher-cost settings.
6. **Allow Medicaid coverage for transportation in rural areas both to a hospital upon a mental health crisis and upon return home.** In rural parts of the state, providers are spread across larger geographic areas making access to care difficult.
7. **Leverage school-based mental health clinics for children experiencing a mental health challenge, and increase partnerships between schools, universities, and community-based treatment providers to enable better access to care.**

IV. Grow the Mental Health Treatment Workforce

Illinois has 126 mental health workforce shortages across the state.⁴⁷ We recommend the following to incentivize mental health professionals to locate in shortage areas:

1. **Provide enhanced rates for targeted mental health professionals that locate in areas with mental health workforce shortages.**
2. **Provide incentives such as student loan repayment programs for certain mental health professionals to grow the workforce across Illinois.**
3. **Increase peer support opportunities for youth for purposes of youth programing.**

Conclusion

Illinois can no longer afford to let its silent mental health epidemic continue. It is costing thousands of lives across the state and billions in taxpayer dollars. The state must take the necessary steps, many of which are outlined above, to build a strong mental health and substance use treatment system in both the public sector and for those with private insurance.

Endnotes

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- ⁴ See Shannon, B.D. *Paving the Path to Parity in Health Insurance Coverage for Mental Illness: New Law or Merely Good Intentions*, 68 U. Colo. L. Rev. 63, 65-67 (1997) (no biomedical justification exist for differentiating serious mental illness from other serious and potentially chronic disorders).
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- ⁸ The Atlantic, *America's Largest Mental Health Hospital is a Jail*, June 8, 2015.
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- ¹⁰ National Institute of Corrections, *Corrections by State: Illinois* (2013 data shows 20,600 jail inmates across Illinois); U.S. Department of Justice, *Bureau of Justice Statistic Special Report, Mental Health Problems of Prison and Jail Inmates* (64% of jail inmates have a mental health problem).
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- ¹⁴ See, Kaiser Family Foundation, *Learning from History: Deinstitutionalization of People with Mental Illness as a Precursor to Long Term Care Reform*, July 2007.
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- ¹⁸ Illinois Department of Healthcare and Family Services, 1115 Waiver Application, October 2016, <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/il-il-behave-health-transform-pa.pdf>.
- ¹⁹ Thresholds, *The Path Forward: Investing in the Illinois Community Mental Health System*, November 2013 (using Illinois Hospital Association data and Medicare cost report data).
- ²⁰ Illinois Department of Healthcare and Family Services, 1115 Waiver Application, October 2016.
- ²¹ Kaiser Family Foundation, State Health Facts, *Health Insurance Coverage of the Total Population*, 2015 (using U.S. Census Bureau data).
- ²² The state is subject to two deinstitutionalization consent decrees, the *Williams* and *Colbert* consent decrees. Another civil rights lawsuit is pending for children with mental health conditions (*N.B. vs. Norwood*).
- ²³ Kaiser Family Foundation, State Health Facts, *State Mental Health Agency Per Capita Mental Health Service Expenditures*, (2013 data).
- ²⁴ Thresholds, *The Path Forward: Investing in the Illinois Community Mental Health System*, November 2013.
- ²⁵ *Id.*
- ²⁶ Kaiser Family Foundation, State Health Facts, *State Mental Health Agency Per Capita Mental Health Service Expenditures*, (2013 data).
- ²⁷ Illinois Department of Healthcare and Family Services, 1115 Waiver Application, October 2016.
- ²⁸ See U.S. Preventative Services Task Force, Summary of Recommendations <https://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/depression-in-children-and-adolescents-screening>; American Academy of Pediatrics, https://www.aap.org/en-us/documents/periodicity_schedule.pdf.
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- ³⁴ Kaiser Family Foundation, State Health Facts, *Mental Health Care Professional Shortage Areas*, 2016.
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- ⁴³ Technical Assistance Collaborative, *State Funded Housing Assistance Programs*, April 2014.
- ⁴⁴ Illinois Department of Human Services, Division of Mental Health.
- ⁴⁵ Illinois State Commission on Criminal Justice and Sentencing Reform, *Initial Report*, July 1, 2015 (annual cost of an inmate in IDOC is \$37,102).
- ⁴⁶ Thresholds, *The Path Forward: Investing in the Illinois Community Mental Health System*, November 2013 (using Illinois Hospital Association data and Medicare cost report data, one psychiatric hospitalizations cost \$6,000 on average).
- ⁴⁷ Kaiser Family Foundation, State Health Facts, *Mental Health Care Professional Shortage Areas*, 2016.