Mental Health Legislation after the 2018 Election in Illinois

A Public Health Culminating Experience submitted in fulfillment of the requirements for the MPH degree

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Table of Contents

Abstract

Background and Significance

Mental health problems represent a significant and growing public health crisis in Illinois, with suicide being the 11th leading cause of death and 683,000 adults receiving mental health treatment each year.(1, 2) Following the 2018 election, the Illinois Democratic Party gained control of all three houses of government and the newly sworn-in Governor, JB Pritzker, expressed interest in following through on his campaign promises to address mental health in the state.

HB2154

The Children and Youth Mental Health Crisis Act (HB2154), signed into law in August 2019, was the most significant mental health legislative effort of the 2018-2019 legislative session. The bill created an insurance mandate that will require private insurance plans purchased by individuals and corporations to cover integrated mental health services for children and adults under the age of 26. The bill also reinvents the state's Individual Care Grant Program as the Family Support Program to better support families in paying for residential mental health treatment for those under the age of 26. Finally, the bill creates a process for redefining Medicaid billing rules to increase utilization of preventive mental health services.

Implications of Legislation for Mental Health Screening and Treatment

HB2154 grew from a collaborative effort between mental health care providers and legislators and garnered the broad support it will need for its implementation to be successful. Going forward, IL should take efforts to increase the number of mental health care providers and how many accept health insurance payments.

Background

Entering 2019, Illinois had a single, Democratic Party control of the state house, state senate, and governorship. Incoming Governor JB Pritzker expressed a particular interest in mental health policies throughout his campaign. This open policy window was embraced by legislators, activists, and organizations who were prepared to make the most of the opportunity to create lasting changes in the health of the state. Mental health has come into focus as a defining issue in public health, largely due to rising levels of substance use in the "opioid epidemic," high utilization of health services by the homeless and the severely mentally ill, and the increased incidence of major depression.(3) The focus of state legislation in Illinois became how best to improve access to mental health care. HB1254 embodied what mental health provider advocates felt were the most important and achievable regulatory measures to most quickly achieve progress in the state.

Public Health Relevance

In Illinois, suicide is the 11th leading cause of death among all ages and the 3rd leading cause of death in children.(1) With the epidemic of substance use disorders still raging, drug overdoses accounted for 2722 deaths in IL in 2018.(4) About 683,000 adults receive mental health treatment each year in Illinois, and yet the majority with mental illness still go without treatment.(2) While the major loss from mental illness is a human one, it also hinders the ability of individuals to participate in the economy. Of the adults served in Illinois's public mental health system in 2014, only 16.1% were employed, with 45% not in the labor force and 38.9% unemployed.(2) A study undertaken in 2015 showed that on a single night in January, there were 13,177 individuals who were homeless in Illinois and about 30% of those experiencing chronic

homelessness have mental health conditions.(5) Mental health problems continue to grow as both health and economic concerns, meriting significant legislative efforts.

While the burden of mental health problems continues to expand, patients often go undertreated or without treatment at all. This is even more true for younger patients and those with more serious mental health concerns. Among adults with any mental illness (AMI), 23.6% of all adults and 37.9% of adults aged 18 to 25 report having an unmet need for mental health services.(3) Among those with serious mental illness (SMI), 45.1% of all adults and 59.5% of adults aged 18 to 25 report having an unmet need for mental health services.(3) Among those with AMI and unmet care needs, 44.4% of all and 54.3% of those age 18 to 25 report not receiving any mental health services in the last year.(3) It is clear that mental health issues are central to public health and society, yet even as this becomes broadly acknowledged we have not yet sufficiently addressed the need for mental health care.

Barriers to Mental Health Care

There are many reasons why people do not receive the mental health care that they need, but people commonly deal with difficulties paying for care. Many cannot afford care, with 45.2% of adults with undertreated AMI and 54.7% of adults with undertreated SMI reporting not receiving services because they could not afford the cost of care.(3) This barrier exists for those both with and without health insurance. Among undertreated adults, 9.3% of those with AMI and 11.1% of those with SMI said that they did not receive services because their insurance did not cover any mental health services.(6) Of those with unmet needs, 13.1% of adults with AMI and 15.1% of adults with serious mental illness said that they did not receive services because even though their insurance covered mental health services, it did not pay enough for them.(6) Among those age 12 and older in need of substance use treatment but not receiving it, 32.5% did not receive

care because they had no healthcare coverage and could not afford the cost and 10.4% did not receive care because they had insurance but it did not cover treatment or the full cost of treatment.(7) Difficulties affording care is a broad issue in society that prevents people from accessing necessary mental health care.

Mental Health in Children and Young Adults

Mental health problems are common among adolescents, with 32.3% of high schoolers reporting symptoms of depression.(8) A 2017 national survey of high schoolers found that in the prior 12 months, 17.2% had seriously considered attempting suicide and 7.4% had actually attempted suicide.(8) Youth mental health problems have been increasing in prevalence recently. Since 2007, rates of depression symptoms and the rate of considering suicide have increased among high schoolers.(8) Youth in the US have required continually greater amounts of emergency department visits and hospitalizations, with a 28% overall increase in ED psychiatric visits between 2011 and 2015.(9) During 2016 – 2017 there were 39,507 ED visits in IL for children with a primary diagnosis of depression or anxiety, with one fifth of these patients being hospitalized.(10)

Despite the prevalence of mental health problems in youth, they are especially likely to go untreated. In the US, only 45% of adolescents with a psychiatric disorder were receiving treatment.(11) The majority of children in Illinois with at least one episode of major depression do not receive care, with 61.8% not receiving any mental health services.(2) Despite this, 37,107 children received mental health care in 2014 in Illinois.(2) Overall, the majority of people with mental health needs have major delays between onset of symptoms and when they first receive medical care, with median delays of at least several years.(12) These problems are exacerbated by the dependence that children have on others when it comes to gaining access to healthcare.

Many children go without care because they do not have access to it. In Illinois, access issues exist for children covered by both public and private health insurance plans. Medicaid provides coverage for 3 out of every 8 children in IL, with most other children being covered through private insurance plans.(13, 14) However, the number of children without health insurance in IL is increasing – from 2.6% in 2016 to 3.4% in 2018.(15) In Illinois, 5.8% of children with private insurance still did not have coverage for mental or emotional health problems.(6) Even when care is covered it can be difficult for children to find a provider, with only 35.4% of psychiatrists accepting Medicaid nationally and this number decreasing year-by-year.(16) These gaps represent opportunities for the state legislature to ensure that families can afford mental healthcare for their children.

The Benefits of Early Diagnosis and Treatment

Children and adolescents often spend their most formative years suffering from untreated mental illnesses. This is especially problematic because repeated studies have shown that the majority of mental health disorders of all types begin before adulthood.(17) Mental health conditions rarely disappear as children get older and eventually will require intervention to ameliorate both immediate and long-term consequences. Early diagnosis and treatment in youth have demonstrated benefits across many mental health problems. Early detection and intervention for people at high risk of developing psychosis has been shown to decrease the progression to psychosis in the following year by 54%.(18) Earlier treatment initiation for youth who have developed psychosis has shown many benefits in both clinical and social outcomes.(19, 20) Early intervention programs for bipolar disorder have begun to amass evidence for their effectiveness and are continually being developed.(21) Early intervention for youth with depression, while historically under-studied, is gaining momentum and evidence.(22)

Given the benefits to mental health from early diagnosis and intervention and the prevalence and early onset of mental health problems among youth, children and young adults represent a crucial population for attempting to impact the epidemic of mental health problems in society.

Methods

In early 2019 it was apparent that a mental health legislation had significant prospects for passage in IL. Both Governor JB Pritzker and many leading legislators were interested in addressing improving mental health treatment in Illinois as a bipartisan issue. This study is based on a series of interviews with key IL health policy stakeholders. These included State Representative Robyn Gabel, with whom I discussed which public health issues were currently being worked on or were likely to be addressed by legislators at the start of 2019. Next, I held a meeting with IL health policy expert Michael Gelder, the former Senior Health Policy Advisor to Governor Pat Quinn who was a member of the Health Children and Families committee of then Governor-elect JB Pritzker's transition team. We discussed the legislative priorities of the newly sworn-in Governor Pritzker, as well as the feasibility of progressing policies in different areas. Finally, I met with Margie Schaps, the Director of the Health and Medicine Policy Research Group - a non-profit that promotes health and health equity in IL. We spoke broadly about what public health problems in IL were in the most need of legislative efforts.

Heather O'Donnell, the VP of Advocacy and Public Policy at Thresholds, one of the largest mental health service providers in IL, contributed her insights into the legislative history of HB2154, the Children and Young Adult Mental Health Crisis Act, which had recently been introduced as a bill and was later signed into law in August 2019, and spoke about its potential impact and other areas of mental health which still needed to be addressed by the legislature.

A comprehensive literature review included academic journals, news articles, and publicly accessible data sets necessary to evaluate the effectiveness of HB2154. The discussion section features future efforts that the IL state legislature can take to further improve access to mental health care.

Legislative History

The Children and Young Adult Mental Health Crisis Act originated from attempts to have private insurance plans pay for more comprehensive mental health care in Illinois. Public insurance plans have long covered evidence-based treatment models, including ACT, CST, and coordinated care for first psychotic episode. While private plans usually covered the services of hospitalizations, psychiatrists, and therapists - they did not cover most other services, like family support, care coordination, and community-based care. Representatives from medical providers and nonprofit groups spent several years meeting with representatives from health insurance companies in order to negotiate better coverage. However, these discussions continued to make little progress and coverage was not expanded.

During this same time, an advocacy coalition was built called the Healthy Minds Health Lives Coalition (HMHLC). The group was spearheaded by Thresholds, one of the largest mental health service providers and advocacy groups in Illinois. They brought together dozens of providers, community groups, and advocacy organizations to create a statewide campaign for better access to mental health services for patients. The first bill put together by the group was an amendment to the Illinois Insurance Code called the Fair Insurance Coverage for Families for Early Treatment of Serious Mental Health Conditions Act. The legislation would have amended the code to include a requirement that all insurance plans operating in Illinois used bundled payments to cover the same comprehensive mental health services that were already being

covered by public insurance plans. The bill was introduced to the house in February 2018, but was quickly met with rigorous opposition from representatives of private health insurance plans. The act never made it out of committee in order to be debated and voted on by the full house. HMHLC members realized that it might not be possible to pass a standalone insurance mandate in the face of strong insurance industry opposition.

The HMHLC recognized that there was broad appeal with legislators and incoming Governor Pritzker for measures seeking to improve youth mental health. The HMHLC decided that a broader youth mental health bill could address multiple issues while also garnering more political support than a standalone insurance mandate. They merged the previously unsuccessful insurance mandate with a revitalization of the Individual Care Grant program and a plan for changing preventative service billing requirements that had been plaguing providers. The result was a relatively comprehensive approach to improving youth access to mental health services in IL that gathered wide support among healthcare providers, advocacy groups, legislators, and the governor. It was then introduced by Representative Sara Feigenholtz in February 2019 as HB2154 shortly after Governor Pritzker and the new members of the house took office. It was also sponsored in the house by representatives Tom Demmer, Kathleen Willis, Ryan Spain, Deb Conroy, Mary Edly-Allen, Michelle Mussman, Robyn Gabel, Natalie Manley, Yehiel Kalish, Joyce Mason, and Monica Bristow. The chief senate sponsor was Heather Steans, with Linda Holmes, Melinda Bush, Christopher Belt, Julie Morrison, Laura Fine, Mattie Hunter, Ram Villivalam, Christina Castro, Jacqueline Collins, and Robert Peters also sponsoring the bill. There were 133 witness slips filed from proponents of the bill, including numerous representatives from community groups and mental health care providers. There were 4 witness slips filed from opponents of the bill, including representatives from the Illinois Chamber of

Commerce and Blue Cross Blue Shield of Illinois. Though opposition from insurance groups had defeated the previous standalone insurance mandate, it did not overcome support for this more comprehensive bill. It quickly passed the house in March 2019 with a vote of 100-0-0 and the senate in May 2019 with a vote of 44 yes's and 11 no's. It was signed into law by the governor in August and became effective January 1st, 2020.

The Children and Young Adult Mental Health Crisis Act (HB2154)

HB2154 uses a variety of methods to increase youth access to mental health treatment services. It has three principle components: a mandate for insurance plans operating in Illinois to cover coordinated mental health care, a reform of the Individual Care Grant program, and a process for defining new Medicaid billing practices for mental health care for children without a diagnosis. Finally, it sets up a year-long public awareness campaign about the changes made in the bill. This will be led by the IL Department of Healthcare and Family Services and involve producing written materials and webinars and conducting outreach visits. The campaign with be targeted towards mental health care providers and youth service and support agencies.

Integrated Coverage Mandate

Private insurance plans in IL typically only pay for the services of psychiatrists and therapists, even though multimodal coordinated care models have been shown to be particularly effective for mental health problems. These models integrate care coordination, social support, and other services together with therapy and medication. These programs are particularly effective for children and their families dealing with early mental health disorders. Given the long delays between when youth first start experiencing symptoms and when they first receive care, it is of the utmost importance that youth receive early evidence-based treatment for mental health problems.

HB2154 requires that all insurance plans amended, delivered, issued, or renewed after December 31st, 2020 in IL cover three types of coordinated care models for children and young adults under the age of 26: coordinated care for individuals with first psychotic episode, Assertive Community Treatment (ACT), and Community Support Teams (CST). These three modes of care have long been covered by IL Medicaid, but children with private insurance have typically not had covered access to them. The law requires paying for these services via a bundled payment, meaning the insurance would pay one total price to the group – who would provide whichever types of care are most appropriate. This is in contrast to paying through a "fee for service" model, where separate fees are paid for psychiatrist, therapist, or case manager visits. This prevents insurance companies from picking and choosing which services that they would like to cover. The criteria for medical necessity of these programs will be developed by a workgroup including the Department of Human Services' Division of Mental Health, the Department of Healthcare and Family Services, and providers of these services. The Department of Insurance is required to adopt a rule that defines necessity for each of the three treatment models by June 30, 2020.

Insurer Protection

In order to assuage concerns from insurers about the costs of meeting these requirements, the bill includes a clause that if requested by an insurer, an independent analysis will be done five years after full implementation to make sure these programs have not caused more than a 1% annual rise in premium costs. This would involve hiring a group to look at how much insurance plans have spent on these services and how that has translated to higher prices being paid for insurance plans. If they have caused a greater than 1% annual increase in premiums then plans will no longer be required to pay for these integrated care models.

Coordinated Care for First Psychotic Episode

Youth with psychotic symptoms are especially likely to go untreated, even as they may be experiencing the first manifestations of a psychotic disorder. When children and adolescents have a longer delay in receiving treatment after first experiencing psychotic symptoms, they develop worse symptoms and have lower a lower level of social functioning and general quality of life.(20) Early intervention utilizing coordinated care is central to giving these youth the best possible health and life outcomes.

Coordinated care for first psychotic episode is a care model involving multiple types of providers and is started for children and young adults when they first develop psychotic symptoms (delusions, hallucinations, disorganized thinking, etc). This is based on the National Institute of Mental Health's Recovery After an Initial Schizophrenia Episode Early Treatment Program (RAISE-ETP). The early treatment program evaluated, called NAVIGATE, had the core services of a Family Education Program, Individual Resiliency Training, Supported Employment and Education, and Individualized Medication Treatment.(23) This team-based approach involves psychotherapy, medication management, family education & support, and case management. Early intervention facilities provide a kind of one-stop shopping for patients and their families, with a group providing all of these services in one place in a coordinated manner. These services would address both medical and social aspects of conditions from the first start of psychotic symptoms. HB2154 explicitly requires coverage of all of the elements of NAVIGATE except for "components of the treatment model related to education and employment support."

Assertive Community Treatment

ACT programs first developed in 1980's in the US as individuals with severe mental health disorders, historically often housed in psychiatric institutions, began to be transitioned into communities.(24) These programs offer an intensive outpatient alternative to inpatient psychiatric care, using a team-based approach that operates in communities to provide a complete set of services to individuals with mental health disorders. Their services are typically accessible 24/7 and consist of multidisciplinary care with medical providers at the core, based around enabling living in the community through managing medical problems and comorbid conditions and their impacts.(25) Along with providing medical treatment, they provide support in dealing with social needs like navigating public transport and getting groceries.(25) As an example, when observing an ACT team in another state I witnessed a social worker drive to the homes of clients and provide counseling and resources like bus tickets. The key to these services is that they are provided actively, through frequent contact with those enrolled in their programs.

Community Support Teams

CST's focus on decreasing the incidence of crisis and hospitalizations through the use of social supports and crisis management. They use teams of providers and services available 24/7 in order to build skills and facilitate family and community social supports and resources. They typically include crisis management services, such as first responders that can be called by individuals or their families to intervene and deescalate a crisis.

Family Support Program

When a child is discharged from a psychiatric hospital, they sometimes require a higher level of care and support then they can receive at home. For instance, an adolescent with severe behavioral issues may not be safe without a level of supervision which their parents can't

reasonably provide. To be safely discharged from the hospital, they should be transferred to a residential facility in their community. However, finding and getting insurance to pay for residential programs can be difficult.

Residential programs can be prohibitively expensive for families and may not always be covered by insurance. Some families face an impossible situation. They cannot keep their child at home because then the child won't have access to needed resources and may put themselves and others in danger. However, they also cannot afford to pay for the child to be in a residential program. The child often ends up repeatedly being hospitalized, as health insurance pays for inpatient treatment. Still, they neither can nor should leave the child in a hospital all of the time. Some families have to make the heart-breaking decision to resort to a "psychiatric lockout," in which they relinquish custody of their child to DCFS by leaving them indefinitely in a psychiatric hospital. Once DCFS has custody of the child, they can then pay for the needed residential care. This problem is not new or unique to IL – a study done by the US Government Accountability Office looked at 19 states and found that in 2001 over 12,700 children were placed into child welfare or juvenile justice systems in order to be able to afford mental health care.(26) In 2015, IL passed the Custody Relinquishment Prevention Act, setting up a process for intervening when families were about to relinquish custody to the state for this reason.(27) This process included state agencies identifying children at risk of a psychiatric lockout and connecting them to support services. While this may have helped, the core problem of families not being able to afford treatments continues. In IL, dozens of children still enter state custody each year because their families cannot afford mental health treatments.(28)

Many children end up staying in the hospital longer than they need to because they are waiting for a program to be found and covered. This problem exists even for children in the care

of DCFS, who pays for residential treatment. In 2015, IL lawmakers commissioned an audit which led to the creation of a database by DCFS meant to track this problem among children in the custody of DCFS, who represent a fraction of the total number of children likely affected. Between 2015 and 2017, IL spent nearly seven million dollars on psychiatric hospitalizations beyond medical necessity for children in the custody of DCFS.(29) During this same time period, almost 30% of the 6000 hospitalized children in DCFS's care were held beyond medical necessity.(29) These stays can become extensive, with 80% of these children being held for ten or more days beyond necessity and more than 40% for a month or longer.(29) These numbers account only for children in the care of DCFS and there are likely many more youth affected by this issue. Though it is difficult to exactly measure the wider scope of the difficulties in discharging youth to appropriate care, it is clear that more programs need to be developed and covered for youth in need of residential care.

The Individual Care Grant Program

The Individual Care Grant Program (ICG) was initially established in 1969 to provide grants to Illinois families needing financial support to pay for residential mental health treatment for their children. It was originally run by the IL Department of Human Services, Mental Health Division. While it played an important role supporting families, repeated state budget cuts to the Mental Health Division made the program difficult to sustain. As a result, the program had to create increasingly strict requirements for families applying for grants. As less and less families were able to access the support they needed, advocates successfully pushed for the program to be moved to the IL Department of Healthcare and Family Services in 2015. However, it still remained difficult to apply to and few families had access to it. The program needed to be revitalized, with a simpler and less stringent set of requirements and more public awareness.

Under HB2154, the Individual Care Grant Program will be transformed and renamed the Family Support Program (FSP). Individuals under the age of 26 will be eligible for the program upon their 3rd hospitalization for psychiatric treatment within a 12-mo period. DHFS will lead a work group including DCFS and youth and young adult residential treatment providers to create a plan for developing residential programs for youth and young adults with high-acuity mental health concerns. They will then use collected data from the last five years on hospitalization beyond medical necessity to estimate and report to the General Assembly the number of residential treatment beds needed in each region of IL. Then residential programs will be developed for children and young adults in this group with high-acuity needs to transition them out of the hospital, with up to 12% of the FSP budget to be used to fund the program. A community-based supportive housing model with integrated intensive mental health services will also be developed for individuals age 18-25 years old, with up to 25% of the FSP budget to be used to fund it.

The Department of Healthcare and Family Services will seek input from a working group of psychiatric hospitals, FSP providers, family support organizations, the Community and Residential Services Authority - a statewide association representing youth health programs, and foster care advocates. They will use this input to develop a clear process for identifying people under the age of 26 upon first and subsequent psychiatric hospitalizations, then educating and connecting them and their families to resources through FSP. When a patient under the age of 26 has a second psychiatric hospitalization, the hospital will be responsible for notifying the patient and/or their family about FSP before discharge. To address psychiatric lockouts, hospitals will be responsible for educating youth and their families about FSP and connecting them to an FSP coordinator before referring the youth to DCFS for being left in a psychiatric hospital beyond

medical necessity. The Department of Health and Family Services will also develop a guide for families about the resources available to help pay for care, including FSP, and make it available on the department's website.

Coverage Without a Mental Health Diagnosis

The national Medicaid & CHIP programs require that covered children have access to Early & Periodic Screening, Diagnostic, and Treatment Services for mental health disorders. This includes early treatment for children who have symptoms but do not meet criteria for a full psychiatric diagnosis. Illinois meets this requirement by allowing providers to bill Medicaid for mental health services provided to children who need them but don't have a diagnosis. However, it requires that providers assign a potential future diagnose and designate services as preventative for that diagnosis. For instance, a child suffering from feelings of unmanageable sadness may not meet criteria for diagnosis of a depressive disorder. However, they still may need treatment such as therapy. For that therapist to receive Medicaid compensation for this therapy, they would have to indicate a depressive disorder which the therapy was trying to prevent. Many providers are understandably hesitant to associate a child with a diagnosis in their medical record that is not appropriate. As another example, an adolescent might be suffering from paranoia. For Medicaid to cover their treatment, a provider might need to indicate that it is meant to help prevent or mitigate future schizophrenia development. This associates an inappropriate diagnosis with them which can be highly stigmatizing. Furthermore, there is large overlap between some mental disorders and variability in how they develop, so a given symptom does not necessarily indicate a specific future diagnosis. The requirement severely limits billing for services, preventing mental health professionals from providing care to youth who do not fit a particular diagnosis, who often are presenting with symptoms for the first time.

HB2154 requires that the Department of Healthcare and Family Services convene a working group with children's mental health providers to design a minimally-burdensome approach for providers to bill for services for individuals under 21 years old with mental health needs but no diagnosis. The group will need to meet at least four times prior to finalizing a solution. The new billing method will remove the current Medicaid billing requirement that a diagnosis be listed for prevention in undiagnosed youth. Any necessary Title XIX State Plan amendments or administrative rule changes will be submitted within one year of the effective date of the bill.

Discussion: Evaluating the Bills Strengths and Weaknesses

The Children and Young Adult Mental Health Crisis Act takes many needed steps towards improving access to care for those under the age of 26. The effects of this bill will depend on how many people it affects and how great of an impact it will have on their health.

Integrated Care Insurance Coverage Mandate and the Limitations under ERISA

Coordinated multi-disciplinary care programs such as those in HB2154 have long been covered by public insurance programs in IL and many other states, but are rarely covered by private insurance programs. With this bill, Illinois will become the first state to require that private insurance programs cover these programs for adults under the age of 26. Since Medicaid/CHIP plans in IL already cover these services, the change in requirements will affect plans purchased by individuals and employer-provided plans. These make about 65% of the 4.2 million people in IL under the age of 26 with health insurance.(30) Private insurance plans purchased by individuals provide coverage for 179,941 children - about 5.9% of those in IL with private insurance.(30) Though specific estimates do not exist for the number of young adults under the age of 26 with such plans, when included they likely increase the number of people

under the age of 26 with individually purchased plans to over 200,000. All of these individuals' plans will be affect by the requirements in the bill.

However, the requirements will not apply to many of the health plans of the 56% of IL children who are covered by employer plans.(31) This is because the Employee Retirement Income Security Act of 1974 (ERISA) sets limitations on state regulation of employer health insurance plans. ERISA provides federal uniform regulations on pensions and employee benefit programs. This law allows federal regulations to apply to all health insurance plans obtained through employers, which provide coverage for 54% of people in IL.(14) This law allows federal laws and requirements to pre-empt, or override, any state-level regulations.

There are two broad categories of employer-provided health insurance plans. The first is one in which employers pay premiums to an independent insurance group. That insurance group becomes the insurer, making them responsible for payments on claims made for services, medications, technology, etc. As an example, let us imagine that I work for Company X and am enrolled in the insurance plan they provide for their employees. I contribute $200 a month towards my premium, which is combined with the rest of the premium paid by Company X. This is paid to an insurance company who runs the insurance plan. If I am hospitalized for a few days and the hospital submits a claim for $10,000, this claim goes to the insurance company and they pay their portion of the claim.

The second category of plans are "self-insured," in which the employer themselves acts as the insurer. In these plans, the employer is responsible for claims payments. Complicating this situation is that many companies with this second type of plan still hire an insurer to manage the plan for them. However, while the management may be done by another organization, the employer is still responsible for all claims. If I have this type of plan, then my monthly $200 is

added to a pool of money contributed to and kept by Company X. The claim for my hospital bill will then be sent to Company X, who will be responsible for their portion from this pool of money. If they contract an insurance company to manage the plan then that company will process the claim, but Company X will still be responsible for payment. This second type of plan offers several advantages to employers, including the ability to customize plans to fit their workforce. In addition, they keep the pool of money used to pay out claims can add to the pool through investing this money. Furthermore, these types of plans are not subject to taxes on premiums which some states impose on health insurance plans.

This distinction between the two types of plans may not make a lot of difference to employees on an everyday basis, however it makes a world of difference in how they can be regulated. The first type of plan, in which the employer purchases insurance from an insurance company for employees, can be regulated by state laws. This stems from interpretation of ERISA the Supreme Court 1985 Metropolitan Life v. Massachusetts, which allowed Massachusetts to set requirements for the health insurance plans sold to employers by insurance companies.(32)

However, ERISA prevents state regulations from affecting any employer health insurance plan which is self-insured by the employer. This exemption has been upheld in court cases where the right of states to place requirements on such self-funded ERISA plans has been challenged. For example, in 2016 the US Supreme Court sided in favor of exempting such plans from a Vermont law which required plans to report to a state-wide claims database.(33) In Illinois, 35.7% of employers offer these self-insured plans, slightly less than the national average of 38.7%.(34) However, they employ a large percent of employees because companies with more employees are much more likely to offer these plans, ranging from only 5.6% of IL employers with less than 100 employees to 84.5% of employers with 500+ employees offering them.(34) In

2018, 58.7% of IL employees enrolled in health insurance through their employers were enrolled in a self-insured plan.(34) In IL, there were about 2.5 million children and young adults under the age of 25 who were covered by an employer-based insurance.(35) If we assume that these young enrollees are distributed roughly proportional to the distribution of employees among types of health plan, then we can estimate that about 1 million people under the age of 25 in IL are enrolled in health employee health plans which are not self-insured. As such, these individuals would have their plans affected by the HB 2154.

This reveals a major limitation of the bill – that the remaining 1.5 million youth covered by self-insured plans will not have their plans affected. However, this is not due to any given problem with the bill and would be unavoidable in any current state-level attempts to regulate private insurance plans. In total, we can estimate that at least 1.2 million individuals in IL are currently enrolled in health insurance plans which will be affect by the new coverage requirements of HB2154. These 1.2 million young people in IL will benefit from the coverage of integrated mental health care services which have proven effectiveness – coordinated care for first episode of psychosis, ACT, CST.

Coordinated Care for First Episode of Psychosis

Analyses of the coordinated care for first episode of psychosis programs developed through the RAISE-ETP program have shown very positive results when compared to usual community treatment.(19) The average age of participants in NAVIGATE was 23, well within the age range of those who will be affected by HB2154.(19) Those enrolled were more consistently involved in treatment - remaining in treatment for a median 6 months longer and using more outpatient mental health services than those receiving traditional care.(19) The NAVIGATE program also created clinically and statistically significantly greater improvements

in quality of life.(19) Furthermore, the program demonstrated reductions in inpatient treatment time and improved school and work participation.(19) Of particular importance is that these programs improved symptoms when compared to traditional care, meaning that the coordination and extra services included in NAVIGATE improved both social and psychiatric components of psychosis.(19) These effects were significantly moderated by the duration of untreated psychosis, such that those who went less than 74 weeks between symptom onset and beginning treatment had the greatest improvements in symptoms and quality of life.(19) This further strengthens the argument for the benefits of HB2154, which seeks to reduce barriers to care and get youth into comprehensive treatment earlier after they first experience symptoms.

Despite reducing inpatient hospital stays, the NAVIGATE program is likely somewhat more expensive to administer than traditional care in the short-term. Six months of NAVIGATE costs about $1100 more per patient than traditional care.(36) This cost difference is increased to about $1800 if you include the cost of training staff in the new intervention, spread over the first two years of implementation.(36) These differences are attributed to greater patient engagement in treatment and the use of better treatments. For instance, over one third of the increased cost came from higher medication costs, largely driven by the usage of second-generation antipsychotics with better side effect profiles than the first-generation antipsychotics prescribed in the more traditional treatment groups.(36). However, the NAVIGATE program is actually more cost effective, with a greater benefit derived from each dollar spent, than traditional programs because the improved outcomes greatly outweigh the increased program costs.(36)

One weakness of HB2154 is that it specifically excludes requiring coverage of components of NAVIGATE related to education and employment support. The NAVIGATE trial results can only truly be extrapolated to programs that contain all of the same components.

Implementing employment services similar to those used in Navigate without the rest of the program has been shown to be effective in improving work-related outcomes.(37) While similar studies have not been done looking at isolated education services, it can be reasoned that such programs would be effective in educational outcomes.(23) While NAVIGATE showed impressive outcomes in both educational and vocational outcomes among participants, we cannot know whether these outcomes will be retained without inclusion of employment and educational services. However, it is likely that the programs covered by HB2154 will be still be highly effective overall for quality of life and symptom management, even if work and school outcomes are not as robust as those in the NAVIGATE trial.

Assertive Community Treatment

ACT programs have long been used and known to be effective in adult populations and the majority of European nations already guarantee coverage for all adults.(38) While research on the use of ACT programs in youth has not been as extensive, it has been equally promising and has so far shown results similar to those seen in adult populations. Studies have shown that ACT programs for youth markedly reduce the severity of psychiatric symptoms such as psychotic symptoms, suicidality, self-harm, and emotional problems.(39) Furthermore, studies have demonstrated significantly improved school attendance and general functioning.(39) Youth treated through ACT programs spend much less time in the hospital, with less frequent and shorter admissions.(39) ACT programs have the potential to provide serious benefits to youth enrolled in them. The ACT programs included in HB2154 contain all of the core components of validated ACT programs, so individuals who receive care covered because of HB2154 will likely derive similar benefits. Finally, ACT programs are more cost-effective than long-term

hospitalization and usually create no net added costs because they result in major reductions in how many days people are hospitalized.(40)

Community Support Teams

There are multiple components to the CST programs to be implemented in the bill, with varying levels of positive evidence demonstrating their effectiveness. One component of the programs will involve family education, training, and support. Generally, the evidence is greatest for team- or clinician-led family support programs for youth with mental health, with evidence that such programs have mild to moderate improvements in family and child functioning and mental health compared to traditional care.(41) Numerous systematic reviews have also shown the effectiveness of counseling services such as those to be included CST in youth with diverse mental health needs.(42) Studies have also shown the cost-effectiveness of community crisis intervention services and their effectiveness in improving patient outcomes.(43) Several reviews have demonstrated benefits of community-based interventions in this population that are set up similarly to the type of CST programs that are included in HB2154.(42) Overall, the CST programs to be implemented under this bill have the potential to have positive impacts on the lives of children enrolled in them, ranging for symptom management to improved social functioning.

Family Support Program

The success of the FSP program will depend on the effectiveness of the residential programs paid for and how effectively youth are connected to its services. DHFS will be required to create a process for identifying youth upon first psychiatric hospitalization and providing them with FSP education. The process for doing so will be developed through a working group outlined in HB2154 to include medical providers, service providers, and child advocates.

HB2154 makes hospitals responsible for educating young patients and their families upon their second and subsequent psychiatric hospitalizations about FSP programs. Furthermore, hospitals are required to perform this education and connect them to an FSP coordinator before referring to DCFS for a psychiatric lockout, aligning their requirements with those of state agencies under the Custody Relinquishment Prevention Act. It will be difficult for the state to enforce hospital compliance with these requirements. However, hospitals are likely to comply because having families work with FSP should be no more burdensome than working through a DCFS lockout process and doing so would reduce the amount of time that they have to keep children hospitalized beyond medical necessity. These processes have the potential to greatly reduce the number of psychiatric lockouts in IL, preventing dozens of youth from being separated from their families every year.

If the FSP residential programs are successful, they also have the potential to significantly reduce youth and young adults being hospitalized beyond medical necessity. With thousands of children each year being held unnecessarily, most for at least 10 days, this means that thousands of children may be able to receive appropriate care.(29) Along with receiving appropriate care, they will be able to retain a larger degree of normalcy and social integration and will be able to continue their education and not fall behind peers due to the limited educational resources available in hospitals. This will also reduce expenditures for care by cutting down on the millions of dollars spent each year by the state on youth psychiatric hospitalizations beyond medical necessity.(29)

The Future of Residential Programs

To be successful in improving health and social outcomes, HB2154's push for residential programs requires three things. The programs will need to be accessible to families, have enough

beds to meet needs, and provide effective treatment. If the education and service coordination proposals in the bill are carried out successfully, patients and families should be able to apply for FSP support. Given the newly simplified requirements, and as long as funding is sufficient, support for residential programs will be made available to most of those who need them under the age of 26 upon their 3rd psychiatric hospitalization within one year.

However, as more youth and their families are able to afford proper treatment, the demand for residential programs will increase. The limited number of beds in these programs is already a major driver of youth being hospitalized beyond medical necessity.(29) This is made clear by the thousands of children in DCFS custody hospitalized beyond medical necessity each year, despite having coverage for residential programs. Thus, the demand already outstrips the supply of beds. While the increased demand alone may lead to organizations creating more programs and expanding the capacity of existing programs, excess demand has not lead to sufficient programs so far. Under HB2154, DHFS will use current rates of hospitalization beyond necessity to determine the number of beds which are needed and lead a working group to develop these beds. The success of this effort will depend on many factors, including reimbursement rates, the availability of providers and staff, and the ability to find facility locations in communities. While the DHFS workgroup tasked with developing capacity includes important stakeholders, it remains to be seen how successful their efforts will be.

Finally, the residential treatments and supportive housing programs developed under HB2154 will need to be effective in treating children and young adults. In adults, studies have repeatedly demonstrated that residential treatment programs are as clinically effective or more than inpatient psychiatric hospitalization for appropriate patients.(44) In addition, residential programs broadly have higher levels of patient satisfaction.(44) Long-term healthcare costs are

also lower for appropriate patients who receive residential treatment.(44) Children and adolescents have been shown to derive sustained benefits from residential treatment.(45) The success of these programs is improved by using holistic and multi-model treatment models as well as parental involvement when possible.(45) Therefore, children will benefit even more from these programs if their parents are able to maintain custody and involvement in their care through FSP support preventing the need for psychiatric lockouts. Overall, the programs developed from HB2154 have the potential to offer more effective residential treatment for children and young adults as long as oversite is appropriately carried out by DHFS.

Coverage without diagnosis

Early treatment at the outset of symptoms has been shown to be highly effective for youth with many types of mental health needs.(46) For instance, earlier care intervention for youth first experiencing a psychotic episode has demonstrated improved outcomes in every measurable category – from improved symptoms to greater work and school involvement and less hospitalizations.(20, 47) Given that the rules affected by HB2154 apply to children covered by Medicaid, it would likely be burdensome for patients and their families to pay for services out-of-pocket – as would be required now if care was desired without being associated with a reimbursable diagnosis. By creating a way for providers to bill for services without attaching a potential diagnosis, HB2154 will likely make providers more apt to provide this type of care.

HB2154 requires that DHFS convenes a working group together with children's mental health providers to create a plan for a new billing method which is practical and does not deter clinicians from delivering services. One limitation of the effect of this new rule will be that it applies only to Medicaid. Medicaid provides coverage for 3 out of every 8 children in IL, meaning a new billing rule would apply to the insurance plans of almost 1.1 million children plus

those enrolled between the ages of 18 and 20.(13) However, with only 35.4% of psychiatrists accepting Medicaid nationally and this number decreasing each year – children with Medicaid may still not have access to services billed as preventive.(16) The new billing rules will not apply to the plans of other children – those with employer-provided plans, self-purchased plans, or no insurance coverage. These plans are variable in their coverage of and billing requirements for services provided to youth without a diagnosis and may not ensure access to these vital services.

Future directions

The Children and Young Adult Mental Health Crisis Act takes many needed steps towards addressing some of the issues in mental health in IL. However, the programs and coverage protections in the bill apply only to those under the age of 26. While this is a particularly high-risk group where early intervention can provide life-long benefits, similar legislative rules and programs should be developed for older adults. It is important that adults with private insurance also have access to the kinds of integrated services covered by IL Medicaid. Going forward, there are many other barriers to mental health care that state policy-makers have the opportunity to target. The most urgent of these barriers limit the effectiveness of all efforts to improve care access, including HB2154. Two of these issues are particularly pressing and represent opportunities for IL policymakers: the shortage of mental health care providers and providers not accepting insurance. If there are not providers available and accepting the insurance of a patient, they will not have reasonable access to care regardless of what their insurance or state programs cover.

Mental Health Provider Shortages

There is a major shortage of mental health care providers in IL that has the potential to limit the positive impact of HB2154 and future efforts to target mental health in both children and adults. Even if services are covered, there needs to be enough trained providers working to meet patient needs. This problem is not unique to IL - between 2003 and 2013, the number of practicing psychiatrists in the United States actually declined, despite the number of other types of physicians increasing.(48) The rate of psychiatrists leaving the workforce is outpacing those entering. This is despite a steady rise in the number of medical students going into psychiatry, with first year US psychiatry residents increasing by 5.3% from 2010 to 2015.(49)

This has contributed to a significant shortage of psychiatrists across the US.(50) In Illinois, 4.8 million people live in areas with a shortage of psychiatrists, defined as having a ratio of residents to providers greater than 30,000:1 in most areas and 20,000:1 in areas with very high need.(50) The Kaiser Family Foundation estimates that IL would need 215 more psychiatrists distributed appropriately in these areas to end these shortages.(50) Nurse practitioners, who are also able to prescribe psychiatric medications, have shortages far too severe to make up for a lack of psychiatrists.(51) Similar shortages have been demonstrated in non-prescribing providers, such as psychologists.(51) Most areas of the East North Central region of the US, which includes IL, have shortages of all types of mental health providers, with the lack of providers being most stark in rural areas.(51)

The current shortage in mental health providers means that patients must wait longer and travel further to access care. A study in Ohio found that adolescents need to wait a median 50 days before the soonest available psychiatrist appointment.(52) This number was higher for those with Medicaid, at a median 55.5 days compared to 47.3 days for those with private insurance

coverage.(52) Another study of five major US cities found that despite 78% providers' offices answering a first phone call, appointments for youth with psychiatric concerns could only be made with 40% of pediatric generalists and 17% of child and adolescent psychiatrists.(53) This was partially driven by limited capacity, as 22% of the generalists and 26% of the psychiatrists who researchers could not schedule an appointment with were not accepting any new patients.(53) Wait times for appointments were much shorter for primary care pediatricians, with an average wait of 12.7 compared to 42.9 days.(53) Overall, 34% of US patients receiving mental health care have difficulty finding a therapist and 33% have difficulty finding a mental health prescriber, compared to just 9% of patients trying to find a primary care physician.(54) Providers not accepting new patients was identified as a barrier for 55% of those with difficulty finding a psychiatrist and 45% of those with difficulty finding a therapist.(54)

There is no one simple solution to the shortage of mental health care providers, but there are multiple effective strategies which can be pursued. The National Council for Behavioral Health recommends a solution with multiple components: workforce development, more efficient service delivery, less burdensome regulations and confidentiality restrictions, implementing innovative care models, and adequate reimbursement for psychiatric services.(55) Some of these efforts are best addressed by the federal government and professional organizations, but several areas can be targeted through state policies.

Workforce Development

Many aspects of workforce development are beyond the control of states. For instance, the most effective way to increase the number of medical students who choose to apply for psychiatry residency programs is through high-quality psychiatry training and experiences in medical school.(56) Furthermore, states have little say in Medicare rules and funding, which

supports the majority of graduate medical education (GME) – the residency programs that train physicians after they leave medical school. However, state Medicaid programs have played increasingly larger roles in funding GME programs. In 2018, IL Medicaid contributed the 14th highest amount of any state to funding graduate medical education (GME) programs – at 108.5 million dollars.(57) IL has 42 teaching hospitals - the 8th highest number of any state.(57) IL is currently the only state in the country to make direct payments to teaching hospitals and include GME payments in MCO rates.(57) Increasing the number of psychiatry residents being trained in IL should directly translate to more practicing psychiatrists in the state. Nearly half of the physicians that graduate IL GME programs stay to practice medicine in the state, which is more than the national state median of 44.9%.(58) Going forward, policymakers can consider increasing the amount of funding directed at GME psychiatry residency programs in order to increase the number of psychiatrists trained and working in IL.

IL can also make efforts to fund education programs for non-physician prescribers. IL does not currently have any psychiatry PA residency programs in the state, and the state could consider collaborating with a teaching hospital to provide funding for setting up such a program. In 2017, IL became one of only a couple states to allow psychologists to prescribe medications, by allowing clinical psychologists who have completed advanced training and education in psychopharmacology to prescribe psychiatric medications to non-pregnant adults between the ages of 18 and 65. Policymakers could take further steps to increase the number of clinical psychologists able to prescribe by funding further training programs. IL can also utilize its National Health Service Corps State Loan Repayment Program, a collaboration between state and federal government to provide educational loan forgiveness to physicians, nurse practitioners, physician assistants, and dentists working in primary care – defined as family

medicine, general internal medicine, general pediatrics, OBGYN, dentistry, and psychiatry. IL can consider adding targeted funds to this program and increasing the number of accepted practitioners in psychiatry.

Telepsychiatry, in which psychiatric services are delivered remotely, typically over video call, has the potential to help fill gaps in mental health care access through providing flexible working environments for professionals and improving delivery of services to rural locations. IL Medicaid has reimbursed for telepsychiatry – psychiatric services delivered remotely, typically over video call – being provided by psychiatrists since 2010. SB3049 was passed in 2018, requiring that Medicaid also reimburse for telepsychiatry services provided by clinical psychologists, clinical social workers, psychiatric APN's, and other authorized mental and behavioral health professionals. However, IL private insurance plans are not required to cover telepsychiatry. Future state legislation could be aimed at requiring that private plans operating in IL cover telepsychiatry services. Like the requirements in HB2154, such a requirement could be set for individually purchased plans and employer plans that are not self-insured.

Providers not Accepting Insurance

Patients face further difficulties in accessing mental health care providers because of difficulties finding providers that accept their insurance. Many providers do not accept public or private insurance, a problem which has become increasingly prevalent. With less and less psychiatrists accepting insurance payments each year, 40% of practicing psychiatrists now do not accept any form on insurance.(55) The situation is even more dire for patients covered by Medicaid, with the number of psychiatrists in the US working with public sector and insured patients decreasing by 10% from 2003 to 2013.(55) Patients often must see providers out-of-network, with 28% of patients seeing a therapist out-of-network and 21% seeing a prescribing

psychiatric clinician out-of-network, compared to only 3% seeing a primary care doctor out of network.(54) Out-of-pocket costs for are often significant, with per-visit costs of over $50 for 38% of patients seeing a therapist and 37% of those seeing a prescriber.(54) Of patients receiving mental health care who had difficulty finding providers, providers not accepting their insurance plan was reported as a barrier for 56% of those seeking a psychiatrist and 11% of those seeking a therapist.(54)

Mental Health Care Reimbursement Rates

While there are numerous factors affecting the rate of mental health providers not accepting insurance payments, low reimbursement rates for mental health services have undoubtedly been a principle driver. All areas of mental health care have long been underfunded compared to other areas of health care.(59) A survey of community behavioral health organization members of the National Council State Association found that 75% of these organizations actually lose money through providing psychiatric services.(55) Inpatient psychiatric service reimbursement rates have historically not covered the full cost to hospitals of providing them, leading to difficulties recruiting and retaining psychiatrists and continual closing of psychiatric units.(55) Among the 30 medical specialties, psychiatrists have the third lowest rates of compensation.(59)

Since the 2018 election, IL has taken some steps to increase Medicaid reimbursement rates of mental health services. On June 5, 2019, Public Act 101-0007 became law, defining appropriations from the state's General Revenue Fund to the Governor's Office of Management and Budget. Included in the appropriations were funds to increase Medicaid reimbursement rates for mental health services by 2.5%. However, IL will need to take further steps to improve Medicaid reimbursement rates for behavioral health services in order to ensure that those with

Medicaid have access to care. IL policymakers can also consider increasing reimbursement rates for primary care physicians, who provide many mental health services and help compensate for the shortage of psychiatrists. The increases in primary care service Medicaid reimbursement rates mandated by the Affordable Care Act created improvements in mental health outcomes for enrollees through increased primary care usage.(60) This supports the potential for improving mental health services through increasing primary care reimbursement rates as well. Increasing Medicaid reimbursement rates has the potential lead to many more clinicians accepting Medicaid payments, but this may require significant investments on the part of the state.

Conclusion

The Illinois state legislature and governor's office have taken major steps towards improving access to mental health care for residents since the 2018 election. The Children and Young Adult Mental Health Crisis Act is well-designed to have a major impact in the lives of children and young adults with mental health problems in IL through improving access to evidence-based treatments. It was created through a provider-led collaboration with policymakers after a previous failed attempt to pass an insurance mandate bill. This offers a valuable lesson to those seeking to pass state regulations on private health insurance plans. While one approach to designing public policy says that a smaller bill will have less detractors and be easier to pass, the inverse can hold true as well. While regulations alone might be blocked by insurance industry pressure, package bills that include more popular and emotionally salient features may have enough support to overcome industry opposition.

Given the longitudinal nature of mental health concerns, it is likely that the benefits of HB2154 will extend out to affected children and adults for many years. As outlined above, the success of the program rests on how it is implemented. The large amount of political and

institutional support for the bill among government agencies and healthcare providers increases the likelihood of its successful implementation. The ability of this and future legislation to improve access to mental health services depends on having enough total service providers and enough providers that accept insurance payments. IL should proactively work to improve access through funding the training and retention of providers and increase Medicaid reimbursement rates, among other efforts. The 2018 election created an incredible opportunity for IL to continue to use collaborative efforts to change the landscape of mental health care for the better. It is now up to us to use this opportunity.

Communication of Results

The results of this research are being shared with all of the stakeholders and experts interviewed during the process of writing it, including members of the Health Minds Healthy Lives Coalition. Furthermore, an academic article based on the analysis of the Children and Young Adult Mental Health Crisis Act has been submitted to the *Journal of Health Politics, Policy, and Law* and is awaiting review. I am planning to write newpaper editorials and policy briefs about issues in mental health in IL which I explored in the Future Directions section of this work. These will be written in ordinary language to explain topics that may not be well known or understood by the public.

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