ILLINOIS CHILDREN'S MENTAL HEALTH PARTNERSHIP
FY2017 ANNUAL REPORT TO THE GOVERNOR

ILLINOIS CHILDREN'S MENTAL HEALTH PARTNERSHIP

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Illinois Children's Mental Health Partnership
FY17 Annual Report to the Governor

Dear Governor Rauner,

On behalf of the members and partners of the Illinois Children's Mental Health Partnership (ICMHP), I am pleased to present you with our twelfth Annual Report. This report diverges significantly from previous reports. Rather than delineating the activities of ICMHP in the last year, it focuses on the current mental health needs of Illinois children. This is intended to start a discussion.

The Governor's Cabinet on Children and Youth and its departments, including Human Services, Health and Family Services, Public Health, Board of Education, Juvenile Justice, and Children and Family Services, are all engaged in activities that are central to children's health. This annual report identifies areas where the Partnership might work together with the Cabinet and these state agencies.

As noted throughout the report, the available data is disjointed, making it difficult to interpret. Also, there are multiple state plans being rolled out that affect children's mental health. Coordinating these plans through a common understanding of child development, mental health, and trauma could result in a system of care that will use our state resources more efficiently and effectively as well as improve the overall health of children and families in Illinois.

Therefore, ICMHP recommends that, in the next year, Illinois focus on (1) understanding the data; (2) building upon current children's programs to address trauma; and (3) developing a children's system of care.

ICMHP stands ready to help the state in moving this agenda forward. Thank you for your consideration.

Sincerely,
Gene Griffin, J.D., Ph.D.
Chair, ICMHP

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NOTE: The Partnership represents multiple parties and interests. Some Partnership members, such as those representing State agencies and legislators, may recuse themselves from taking official positions on public policy. Opinions taken by the Partnership as a whole do not necessarily reflect all members of the Partnership.

INTRODUCTION

This Illinois Children's Mental Health Partnership's (ICMHP) 2017 Report to the Governor offers a snapshot of the current state of children's mental health in Illinois. Its intent is to focus on current resources and offer recommendations for the future.

For this report, ICMHP did not collect original data. Rather, it surveyed its members for existing data and used national and state level reviews of children's needs and services. Given the limited information available, the picture is incomplete. Multiple publications addressed some aspects of children's mental health, but no review had the mental health of all Illinois' children as its primary focus. Hence, the continued need for this consolidation.

Though ICMHP refers to 'mental health' it is more appropriate to discuss children's 'behavioral health,' which would include 'mental health' but also issues of substance abuse and trauma. Recent advances in science and medicine argue for adopting an even more integrated, comprehensive public health approach to wellness, looking at the impact of a child's behavioral health on his or her overall health. Such a holistic approach is strength-based and family-centered. Further, child development now incorporates findings regarding brain development, genetics, and epigenetics. These advances are beyond the scope of this report but a more comprehensive public health view of the child will be incorporated into ICMHP's recommendations.

For a baseline, this report relies upon U.S. Census data as of July 1, 2016[1], which states that the overall population of Illinois is 12,801,539. Of these residents, 13% (over 1,660,000) live in poverty. Regarding race, 61.7% are White (alone, not Hispanic or Latino); 17% Hispanic (or Latino); 14.7% Black (or African American, alone); and 5.5% Asian (alone). Regarding age, 22.9% (over 2,930,000) are under 18 years old and 6% (over 768,000) are under age 5.

As with many terms, the definition of 'child' can vary, depending on the data source.[2] For some sources, childhood is defined as younger than 18. In some systems, such as child welfare, education,

or juvenile justice, while children no longer enter the system after age 18, some services may continue through age 21. The Illinois Governor's Cabinet on Children and Youth's (Children's Cabinet) vision is to ensure that all children and youth in Illinois are self-sufficient by age 25.[3] Under federal law, a child may remain on a parent's health insurance until age 26.

Thus, different data sources, even when reporting on the same health issue, may be focusing on different groups of 'children.' When referring to children's mental health in this report we will use the Partnership's current definition of birth-21. However, a re-examination of this range based on current developmental science and best practices may be warranted for future work.

This report has three main sections: **Children's Mental Health Needs, Available Mental Health Resources,** and **Recommendations.** The Needs section will describe some of the challenges in comparing data across reports and will identify current issues in mental health, substance abuse, and trauma. The Resources section will focus on children served, spending, and other relevant factors. It will also highlight some current children's mental health programs. Finally, the Recommendations section will review current executive, legislative, and judicial mental health activities and outline the Partnership's key recommendations.

CHILDREN'S MENTAL HEALTH NEEDS

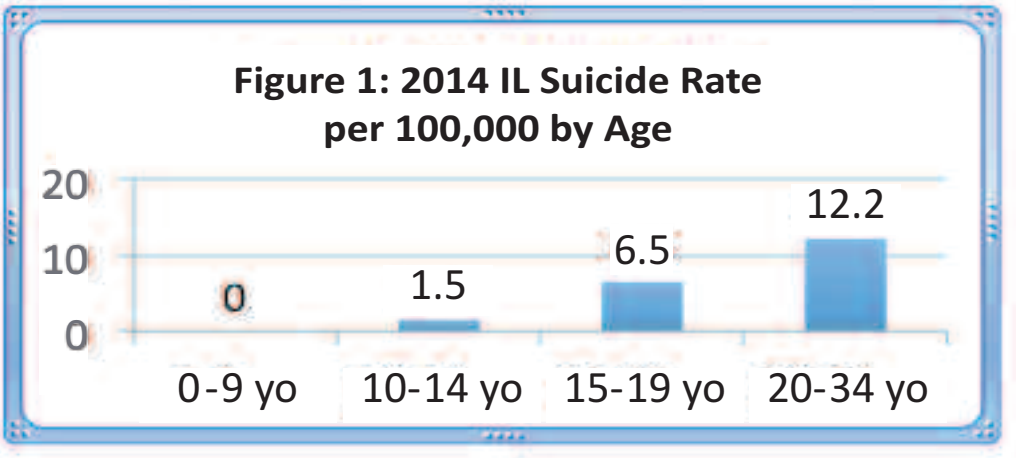
Children who experience behavioral health disorders, with proper care, can lead healthy and productive lives. Therefore, it is critical that Illinois identify, diagnose and treat those children who are experiencing behavioral health disorders. Data is needed to understand the scope of need related to children's mental health. Establishing the level of need in Illinois has become increasingly difficult, as definitions of "mental health" do not align and access to data is limited.[4] Thus, this report is an incomplete picture of the current mental health of Illinois children.

Mental Health

When ICMHP was created in 2003, the statute noted that one in 10 children in Illinois currently suffered from a mental illness severe enough to cause some level of impairment.[5] That number was based on a national estimate.[6] More current data, while varying slightly, suggest a similar percentage. For example, Mental Health America (MHA), in *Parity or Disparity: The State of Mental Health in America, 2015,* found that 9.64% of children in Illinois had "emotional, behavioral, or developmental issues[7]" while the Illinois Department of Public Health (IDPH) in its 2015 *Maternal and Child Health Data Book,* citing the same source as MHA, stated that 11% of Illinois children have a "current mental health condition."[8] This report will assume the 10% rate. Therefore, given the census data, 293,000 Illinois children are in need of mental health services.

Issue: Suicide Rate

Where MHA and IDPH agree is on the major problem of adolescent suicide. According to MHA, Illinois ranked 44th among states related to youth suicide.[9] IDPH reports that suicide is the third leading cause of death for youth aged 10 - 19 (See Figure 1).[10]



Voluntary surveys of Illinois high school students indicated that suicide attempts increased by 50% from 2007 to 2015 with 47,000 youth reporting that they attempted suicide in 2015.[11]

Table1: Illinois High School Students Self-Reports of Suicidal Thoughts and Actions 2015[12]

	Seriously Considered Attempting Suicide	Made A Suicide Plan	Attempted Suicide	Attempted Suicide and Received Treatment
All	15.9%	14.5%	9.8%	4.3%
Asian	15.1%	14.1%	6.7%	4.8%
Black	16.3%	15.9%	15.2%	7.0%
Latino/Hispanic	16.7%	15.5%	12.6%	5.3%
White	14.4%	13.2%	7.0%	3.0%
Two or More Races	12.2%	13.1%	8.9%	2.8%

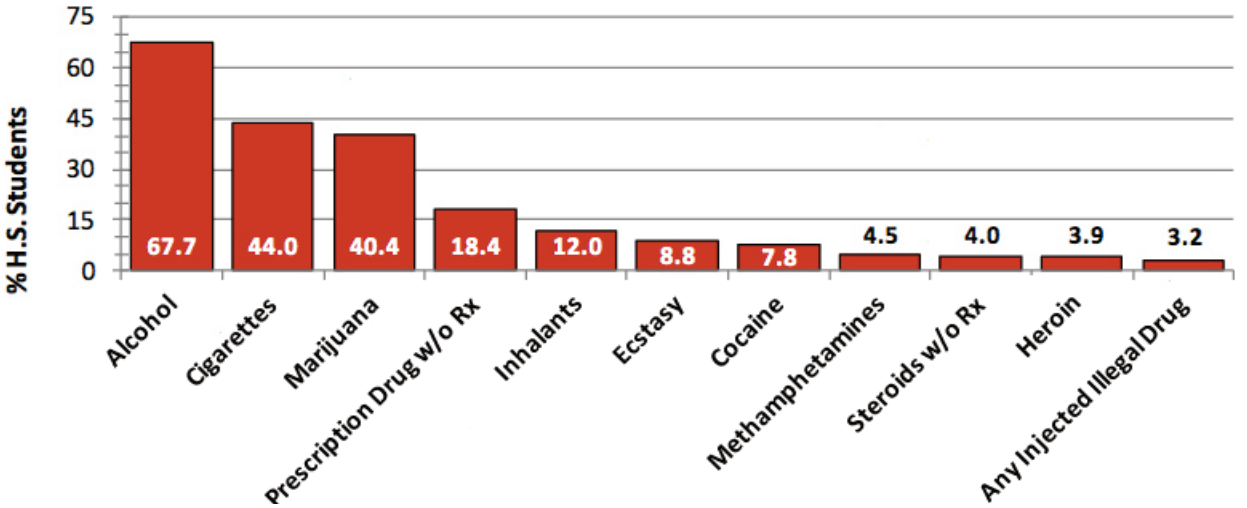
Suicide is an issue that crosses all demographics (See Table 1). High school females are more likely to attempt suicide but males are more likely to die. Risk factors for suicide attempts include feeling depressed, having a mental health diagnosis, substance abuse, and being a victim of either bullying or dating violence.

IDPH has formed the Illinois Suicide Prevention Alliance[13] with other interested agencies and stakeholders and they have developed a plan for adolescent-focused suicide preventive health initiatives, including public awareness, expanded community behavioral health treatment, and tele-health efforts to better reach children and youth in rural areas.[14]

Substance Abuse

The prevalence of substance use disorders is also subject to interpretation. IDPH reports on the high percentage of Illinois high school students who have tried alcohol or illicit drugs (See Figure 2-[15] note that these categories are not mutually exclusive), noting that in 2013-14, over 88,000 Illinois adolescents reported using illicit drugs.[16] MHA, on the other hand, relies on diagnosis, citing a study indicating that 62,000 Illinois high school students meet the DSM-IV definition for Dependence or Abuse of Alcohol or Illicit Drugs.[17]

Figure 2: % of Illinois High School Students Reporting That They Have Tried Substances, 2013



CHILDREN'S MENTAL HEALTH NEEDS *cont'd.*

Issue: Opioids

Illinois, like many other states, is experiencing an opioid abuse crisis. In Illinois, 40,000 teens reported non-medical use of prescription opioids in 2013-14.[18] Since 2008, opioid overdoses have killed nearly 11,000 Illinois residents, with nearly 1,900 people dying of overdoses in 2016 alone. While only 7 youth (under age 18) died in this last year from opioid overdoses,[19] IDPH notes that "[beyond these deaths are thousands of emergency department visits, hospital stays, as well as the pain suffered by individuals, families, and communities." In fact IDPH has declared that the "opioid epidemic is the most significant public health *and* public safety crisis facing Illinois."[20]

Child Trauma

Trauma can disrupt normal child development, interfere with learning, exacerbate mental health symptoms, and lead to long-term medical health issues.[21] Currently there are no accurate estimates of the prevalence of traumatized children in Illinois.[22] Trauma can result from adverse experiences. On a positive note, due to resilience and protective factors, not all these children exposed to adverse events will become traumatized. IDPH reports a 2013 survey[23] where 1 in 7 Illinois adults say they encountered at least 4 categories of adverse experiences (ACES) prior to age 18. By definition, all these ACES happened to Illinois residents when they were children. Hispanics and Blacks reported a higher incidence (1 in 5) than Non-Hispanic Whites (1 in 8). Having so many adverse experiences places people at high risk for all the negative behavioral, medical and academic outcomes associated with trauma exposure.[24]

Several subgroups of children are at high risk for trauma. All children who have been abused and neglected or exposed to domestic violence are at risk of developing trauma-related effects. The Illinois Department of Children and Family Services (DCFS) indicated it served 21,483 distinct youth in FY17[25], which means that just in this system alone, over 21,000 children have been exposed to traumatic events and are at risk of negative behavioral, medical and academic outcomes. Similarly, youth in juvenile detention centers report a high rate of exposure to adverse events. In a study done in Cook County Juvenile Detention Center[26] over 90% of the youth reported exposure to one adverse event, with a median of six events resulting in a high risk of trauma. These numbers illustrate a clear need to incorporate trauma measures into clinical assessments and treatment of children and youth.

Issue: Exposure to Violence

One of the most prevalent adverse childhood experiences for Illinois youth is exposure to violence. This can include both community violence and domestic violence. According to the US Attorney General's Report on Children Exposed to Violence, two out of every three children "can expect to have their lives touched by violence, crime, abuse, and psychological trauma [each] year."[27] For Illinois, that would translate to over

195,000 children exposed to violence. The Illinois Criminal Justice Information Authority (ICJIA) notes that exposure to violence can result in emotional, social, and behavioral problems, with about one-third of children exposed to trauma developing posttraumatic stress disorder (PTSD).[28] In Chicago alone, since September 2011, 158 children (under 17) have been shot and killed with an additional 1,542 youth being wounded.[29] That includes the 31 homicides and 176 wounded so far this calendar year. ICJIA just received a U.S. Department of Justice Office for Victims of Crime's (OVC) Vision 21 Award, which ICJIA will use to develop a coordinated statewide plan to serve children and youth who have been directly victimized or exposed to violence in their homes, schools, or communities.[30]

Public Agencies Serving Children with Mental Health Needs

Children with mental health needs become involved in multiple systems. It is not uncommon for the same child to be served by mental health, education, and healthcare, not to mention child welfare and juvenile justice. However, Illinois agencies do not report common data identifiers. Therefore, the numbers of children served by these agencies are not mutually exclusive and cannot simply be added up. Also, ICMHP did not have access to private healthcare system data. Even though it is not possible to determine the number of unique children being served using available data it is still informative to look at some agency data to understand the scope of children's mental health needs.

Department of Healthcare and Family Services (HFS)

The Children's Mental Health Act of 2003 that created ICMHP also required the development of protocols for screening and assessing children and youth prior to any Medicaid funded inpatient hospital admission. As a result, HFS, in collaboration with the Departments of Children and Family Services (DCFS) and Human Services (DHS), developed the Screening, Assessment and Support Services (SASS) program. SASS features a centralized point of intake known as the Crisis and Referral Entry System (CARES) Line. Some of the children and youth traditionally served by the SASS program are now being served by Mobile Crisis Response (MCR) programs administered and funded by the various HFS-contracted managed care organizations.[31]

In Fiscal Year (FY) 2017, the CARES Line received in excess of 128,000 incoming calls, of which more than 122,000 were calls related to a crisis referral (crisis calls). This would mean that about 334 crisis calls were received per day in FY17. Additionally in FY2017, the SASS system enrolled more than 16,000 unique children and youth experiencing a crisis while the Mobile Crisis Reponses system responded to more than 8,000 unique children and youth experiencing a crisis. Thus, the SASS program identified 24,000 children needing mental health services.

CHILDREN'S MENTAL HEALTH NEEDS *cont'd.*

Department of Human Services, Division of Mental Health (DMH)

DMH reports that in FY17, it served 18,336 children and adolescents (through age 17) with or at risk for a mental health diagnosis. It further divides this group into those who meet the criteria for Severe Emotional Disturbances (SED).[32] This SED group constitutes two thirds of all children and adolescents served by community mental health providers and funded by DMH. In FY17 DMH estimates that it served approximately 12,200 SED children and adolescents. These numbers do not include children and adolescents who receive services through Managed Care or private insurance.

Illinois State Board of Education (ISBE)

MHA, citing 2012 data from the U.S. Department of Education, reports that 10.87% of Illinois children (20,192 students) in grades 1 - 12 are "Students Identified with Serious Emotional Disturbance" in their Individualized Education Programs (IEPs).[33] Note that the educational version of SED is a "Serious" Emotional Disturbance and its criteria focus on impaired educational performance, which results in the need for an Individualized Education Plan (IEP).[34] This is different than the SED of "Severe" emotional disturbance used by DMH, which is based on a DSM diagnosis plus functional impairment.[35] Therefore, the SED children being treated by DMH are not necessarily the same SED children with an IEP. Additionally, these education numbers do not reflect those students who have mental health concerns not deemed 'serious.'

Department of Children and Family Services (DCFS)

National research[36] finds that 61% of youth in child welfare will qualify for a diagnosis of at least one psychiatric disorder during their lifetime. Local research with DCFS youth gives a more specific finding that, at admission, over 49% of DCFS youth presented with symptoms of either mental illness or trauma.[37] Given that DCFS reported 21,483 distinct youth served in FY17[38] (19,910 in paid substitute care and 1,573 in institutions and group homes) that would mean that over 10,525 youth needed mental health services that year.

Department of Juvenile Justice (DJJ)

There are multiple data points in the juvenile justice system, each of which could present a different level of mental health need, if that issue were tracked. Many more children are arrested than actually have a case opened in juvenile court. Of the court cases, a subset will go to trial. Some of these will be found delinquent and go on probation while an even smaller subset will be sentenced to the Department of Juvenile Justice (DJJ). A 2010 survey by the Illinois Justice Criminal Information Authority (ICJIA) found that "less than 6 percent of counties in Illinois are served by probation and court services departments that use standardized mental health screening instruments, and even fewer departments used standardized mental health assessments (3 percent)."[39] Within DMH, several programs serve youth with mental health issues

in the juvenile justice system, including the Mental Health Juvenile Justice Initiative; youth found not guilty by reason of insanity; and youth found unfit to stand trial. However, current data was not available for these programs.

This ICMHP report looks at those youth ordered by the court into the custody of DJJ. In FY16, 1,152 youth went to DJJ.[40] DJJ currently reports that 44% of its youth are on some psychotropic medication and that over 95% of its residents carry at least one DSM diagnosis.[41] Therefore, 1,094 of its FY16 residents needed mental health services.

The Individual Care Grants Program (ICG)

The Individual Care Grant (ICG) program provides funding to children with a Serious Emotional Disturbance (SED) under the age of 18 to assist in obtaining the appropriate level of treatment services required to improve their condition.[42] This program was started by DMH in 1967 but moved to HFS at the beginning of this fiscal year. HFS reports that during FY17 the ICG program served 279 unique youth.

Identifying Need

At the beginning of this section it was estimated that, in Illinois, 293,000 children are in need of mental health services. Even assuming that there is no overlap among the children identified by the five public agencies above (an incorrect assumption),[43] that would still only identify 74,426 youth, or approximately 25% of those children in need. Using these estimates, that would leave the majority of Illinois children with mental health needs to be identified by other state agencies, local organizations, or the private health care system, if they are identified at all.[44]

Private Insurance

MHA reported that 97.4% of Illinois children with emotional, behavioral, or developmental issues were consistently insured in 2012, though 36.4 of these same families reported that the insurance was inadequate.[45] The MHA 2017 report finds that, of Illinois children with private insurance, 8.9% of these policies did not cover mental or emotional problems.[46]

The issues around insurance coverage and parity for mental health and substance abuse are not unique to Illinois. Little information regarding actual private health coverage in Illinois is available.[47] Currently, Illinois law does not require insurers to report usage, access, denial, or spending data for mental or behavioral health services. It is the responsibility of the Illinois Department of Insurance to protect consumers and regulate the insurance industry's market behavior.[48] HFS regulates the state's Medicaid managed care plans and is working to ensure on-par coverage levels for mental health and addiction treatment and medical conditions.[49]

AVAILABLE MENTAL HEALTH RESOURCES

Number of Children Receiving Mental Health Services

In the statute creating ICMHP, it stated that "one in 10 children in Illinois suffers from a mental illness severe enough to cause some level of impairment; yet, in any given year only about 20% of these children receive mental health services."[50] This is similar to the national estimate that about 25% of children with emotional and behavioral disorders receive specialty mental health services.[51] (Also, note that this section is focusing on 'mental health' services and does not attempt to estimate how many children receive substance abuse, trauma, or other more comprehensive public health services.)

According to the 2015 MHA Report, 55% of Illinois children who needed mental health services were able to receive them.[52] While this sounds like a significant improvement over the original ICMHP estimate, one needs to understand the limitations of that phone survey.[53] By contrast, MHA's 2017 report finds that 64.8% of Illinois children with major depression did not receive any treatment and only 18.1% of Illinois youth with a severe depression were able to receive consistent outpatient treatment.[54] More helpful data is reported by IDPH,[55] which found that in 2013, 39,501 children and adolescents were served in the Illinois public mental health system in various capacities. This is just over 13% of the 293,000 Illinois children needing mental health services. Certainly a portion of the remaining children would have been served in the private sector.

The Illinois Department of Healthcare and Family Services (HFS), in its 2016 report on Illinois' Behavioral Health Transformation (1115 Waiver, which will be addressed in more detail in the Recommendations section below), noted that many of the Medicaid recipients (adults and children) with mental health needs "fall through the cracks: nearly a quarter of this population receives a behavioral health diagnosis in any given year but does not receive any behavioral health services, and more than 10% receive behavioral health services, largely medications, without a corresponding behavioral health diagnosis."[56] This latter group, people receiving mental health treatment even though they are not diagnosed with a mental health diagnosis, makes estimating the percent of those children with mental health needs actually receiving services even more difficult.

All these limitations aside, the fact remains that at best, based on the MHA survey, 45% of Illinois children identified as needing mental health services were not getting them. This placed Illinois 41st nationally within the survey. Further, these numbers indicate only whether a child received any treatment, not whether it was appropriate treatment or helpful. Finally, whatever the number of Illinois children actually receiving mental health services in 2012, available mental health services have declined in the last few years.

Spending on Mental Health Services[57]

Illinois' Budget Crisis

As HFS has noted, "the Illinois budget situation has exacerbated challenges in the healthcare delivery system."[58] A similar sentiment was echoed by IDPH in 2016: "Illinois' behavioral health infrastructure is in a time of major transition with budget reductions that have been ongoing for at least eight years."[59] For two fiscal years (FY15 -16) the State did not have a fully approved budget. Illinois' lengthy budget impasse and years of reductions in funding for social services has impacted access to services and supports for children and families. Mental health and substance abuse services have been particularly hard-hit, with some community behavioral health agencies forced to close their doors or consolidate. According to the United Way, 91% of over 400 social service agencies surveyed in 2016 reported cutting the number of clients served, leaving nearly 1 million clients without critical services. A third of the agencies reported closing programs, 45% laid off staff, and 49% increased waitlists for services. As of June 2016, those agencies reported taking on $37 million in debt. As late as March 2017, 69% of the agencies reported receiving no or only partial payment from the state for services delivered.[60]

In spite of the service cuts, the last several years may have seen some improvement in health care coverage. IDPH reports that there have been "shifts in incentives such as managed care expansion, new opportunities in Medicaid, increasing capacity of health departments and community health centers (including federally qualified health centers), and the population shift from uninsured to insured via the Affordable Care Act." In spite of this increased coverage IDPH recognized "that there are still barriers for vulnerable populations accessing treatment for substance abuse and mental health conditions. Unfortunately, it is unclear exactly how much behavioral health capacity is needed and whether the market will address these gaps."[61]

Agency Spending

Although it appears that significant dollars are being spent on overall health services, consistent numbers regarding children's mental health services are difficult to find, as reports look at different age groups in different years.

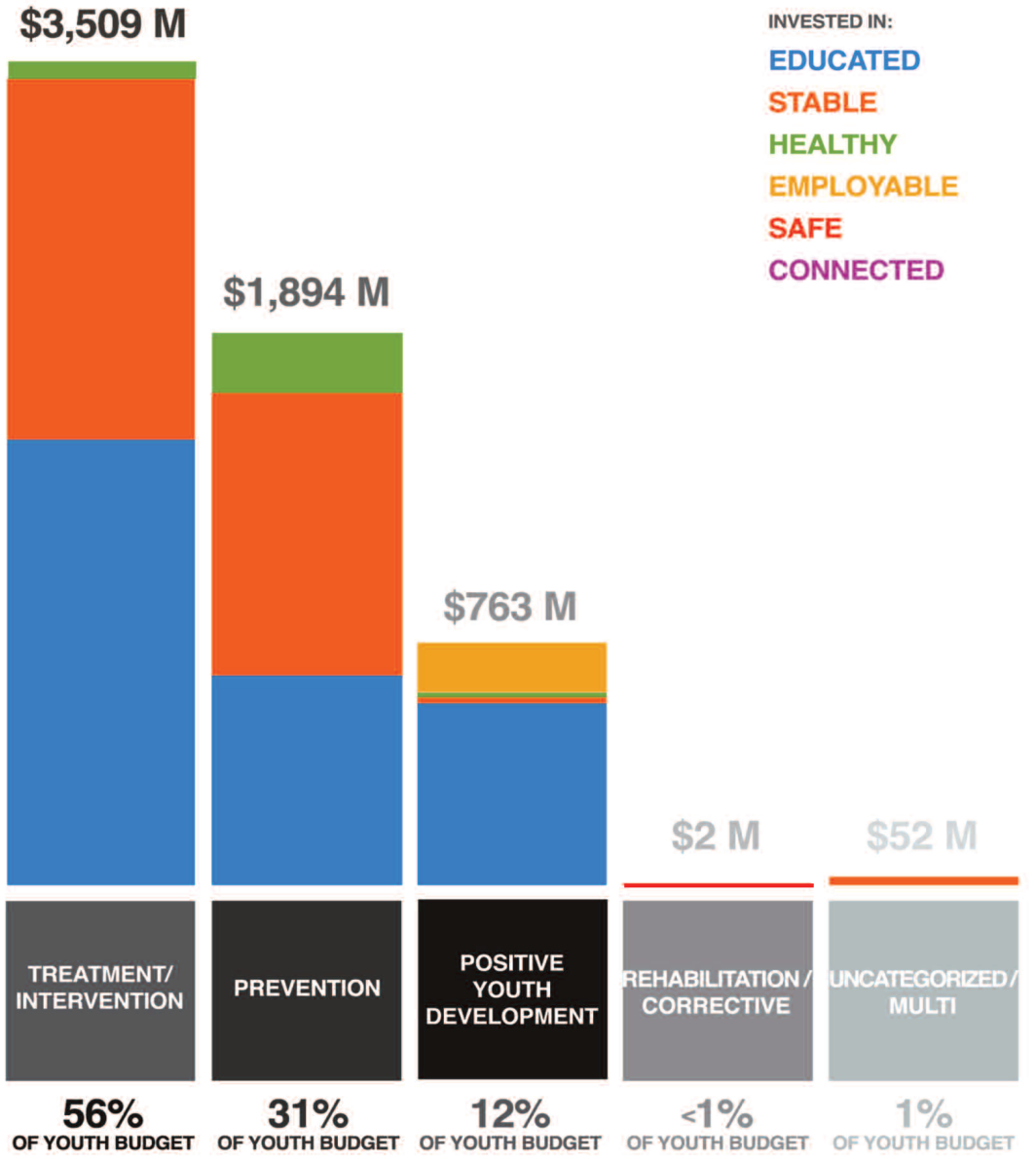
HFS pointed out in its report of FY15 spending that "Illnois is one of the largest funders of health and human services (HHS) in the country. With $32 billion spent across its HHS agencies...the State is deeply invested in the health and well-being of its 12.9 million residents and 3.2 million Medicaid members. There is an urgent need to get more from this investment."[62]

AVAILABLE MENTAL HEALTH RESOURCES *cont'd.*

Agency Spending *cont'd.*

A privately funded 2017 scan of FY15 public spending led by Children's Home and Aid estimated that $6.2 billion was invested in children and youth ages 8-25, with $3.51 billion categorized as treatment and intervention (with the majority of those funds related to education), $1.89 billion as prevention, and $763 million as positive youth development (see Figure 3). Spending was not specifically broken out by mental health services, though the report mentions that $159 million in children's mental health grants focused on stability and $59 million focused on health issues.[63]

Figure 3: FY15 Public Investments in Youth Ages 8-25 by Service Model



In FY14, ICMHP participated in a fiscal mapping process that identified $1.5 billion in spending for children's behavioral health by public child-serving systems.[64] At that time, children's behavioral health spending by agency was estimated as:

- $596,332,022, Department of Children and Family Services[65]
- $392,694,193, Illinois State Board of Education/Local School Districts[66]
- $281,328,752, Healthcare and Family Services[67]
- $151,822,227, Department of Human Services[68]
- $86,899,864, Department of Juvenile Justice[69]

This report identified heavy reliance on out-of-home services by multiple state agencies, with 46% of children's behavioral health spending associated with institutional care, including psychiatric residential treatment facilities, inpatient hospitalization, group homes, and other congregate care settings. On average, an out-of-home placement costs nearly $450 per day, and some can cost over $160,000 per year. Community-based services, which include lower-level interventions, case management, and medication costs, constituted 23% of spending on children's behavioral health. Screening, Assessment and Support Services (SASS) expenditures, including services administered through DCFS, HFS, and DHS, totaled $39 million.[70]

Federal Support

Some of the children's mental health spending by state agencies includes the support it receives from federal agencies. As such, state funding is heavily influenced by federal decisions regarding healthcare, including the Affordable Care Act, Medicaid, and its requirement for Early and Periodic Screening, Diagnostic and Treatment (EPSDT). Though a complete summary or future speculation is beyond the scope of this report, it is worth noting that all the state agencies listed above as spending money on children's mental health receive some funding from federal agencies, including the U.S. Department of Health and Human Services (HHS), the Department of Education (DOE), and the Department of Justice (DOJ). HHS is a primary funder with relevant federal dollars coming through the Substance Abuse and Mental Health Services Authority (SAMHSA), which not only funds mental health and substance abuse services but also trauma services through the National Child Traumatic Stress Network (NCTSN); the Administration on Children and Families (ACF) which funds child welfare, runaway, homeless, and Temporary Assistance for Needy Families (TANF); and Health Resources and Services Administration (HRSA). For example, HRSA funds the Maternal, Infant, Early Childhood Home Visiting (MIECHV) program, with DHS as the fiscal lead and the Governor's Office of Early Childhood Development as the programmatic lead.[71] In the last fiscal year, Illinois received over $13 million in federal funding for MIECHV.

AVAILABLE MENTAL HEALTH RESOURCES *cont'd.*

Foundation Support

Similarly, some of the children's mental health spending in Illinois comes from private foundations. Again, a complete summary is beyond the scope of this report, but different foundations directly support work in children's mental health (Illinois Children's Healthcare Foundation, ILCHF[72]), child welfare (Casey Family Programs[73]), juvenile justice (Annie E. Casey Foundation[74] and MacArthur Foundation[75]), school-based health clinics (Polk Brothers Foundation[76]) and early childhood and infant mental health (Irving Harris Foundation[77]). As an example of braided funding from multiple foundations, ICMHP is currently involved in several demonstration projects that focus on early childhood mental health consultation in early childhood and after school programs, where funders have included the Irving Harris Foundation, ILCHF, the W.C. and Jessie V. Stone Foundation[78], the McCormick Foundation[79], and the Bright Promises Foundation[80], with continued investments from additional private partners anticipated in the next several years. There is an increased interest in the private sector to invest in public-private partnerships to address children's mental health, with the hopes of leveraging resources to promote sustainable systems changes.

Other Mental Health Service Factors

Appropriate Treatment- Level of Care

An analysis of mental health service spending touches on another important issue- just because a service is provided does not mean that it is the best or most appropriate service. In fact, over-relying on high-end, institutional services can be detrimental to a child's recovery, in addition to wasting money.

HFS acknowledges both that the "Illinois behavioral health ecosystem is heavily reliant on deep-end, institutional care rather than upstream, community-based care" and that "this over-reliance on institutional care has significant implications for behavioral health members, who may experience additional stress due to removal from their communities and treatment in more restrictive institutional settings."[81] The HFS 1115 waiver outlines ways in which the State intends to address this over-reliance on institutional care and is addressed below. An appropriate children's system of care will include many levels of care, (See Table 2).[82]

Table 2: Array of Services and Support in a Children's System of Care

Non-Residential Services

- Assessment and evaluation
- Individualized "wraparound" service planning
- Intensive care management
- Outpatient therapy—individual, family, group
- Medication management
- Intensive home-based services
- School-based behavioral health services
- Substance abuse intensive outpatient services
- Day treatment
- Crisis services
- Mobile crisis repsonse
- Therapeutic behavioral aide services
- Behavior management skills training
- Therapeutic nursery/preschool

(Specific evidence-informed interventions and culture-specific interventions can be included in each type of service)

Supportive Services

- Peer youth support
- Peer family support
- Youth and family education
- Respite services
- Therapeutic mentoring
- Mental health consultation
- Supported education and employment
- Supported housing
- Transportation

ResidentialServices

- Therapeutic foster care
- Therapeutic group home care
- Residential treatment center services
- Inpatient hospital services
- Inpatient medical detoxification
- Crisis stabilization services

Services by Location

Assuming one knows the appropriate level of mental health service to seek for a child, the next step is to locate such a service. The good news here is that agencies and providers are aware of each other.

One valuable tool in the service landscape is the Illinois Department of Children and Family Service's Statewide Provider Database (SPD), which is available to most community agencies and mental health providers serving children. This database allows searches by agency, program type, population, zip code and type of funding accepted (including Medicaid, Medicare, private insurance, and free or sliding scale). The providers listed serve DCFS clients as well as community residents. As of September 2017, the SPD listed 180 agencies that provide children's mental health services, 283 that offer substance abuse treatment, 27 providers of inpatient care for adolescents, 143 crisis intervention programs, and 115 home visiting programs.[83]

However, in searching for resources, sometimes the answer is that there is no relevant provider near the child. This is certainly an issue for rural residents, particularly when it comes to community-based services.[84]

AVAILABLE MENTAL HEALTH RESOURCES *cont'd.*

Services by Location *cont'd*

Nearly 1.5 million people, or 11 percent of the state's population, live in rural areas, where they often must travel long distances to access child behavioral health services.

Douglas County, a 417-square mile jurisdiction in east central Illinois, has just one mental health provider for 19,823 residents. Eleven Illinois counties have less than one mental health professional for 2,900 residents. Ten other counties reported no mental health provider data: Calhoun, Gallatin, Greene, Hamilton, Henderson, Marshall, Pulaski, Putnam, Scott, and Stark.

In particular, there are very few psychiatrists in rural counties (see Figure 4) and even fewer child and adolescent psychiatrists in the state.

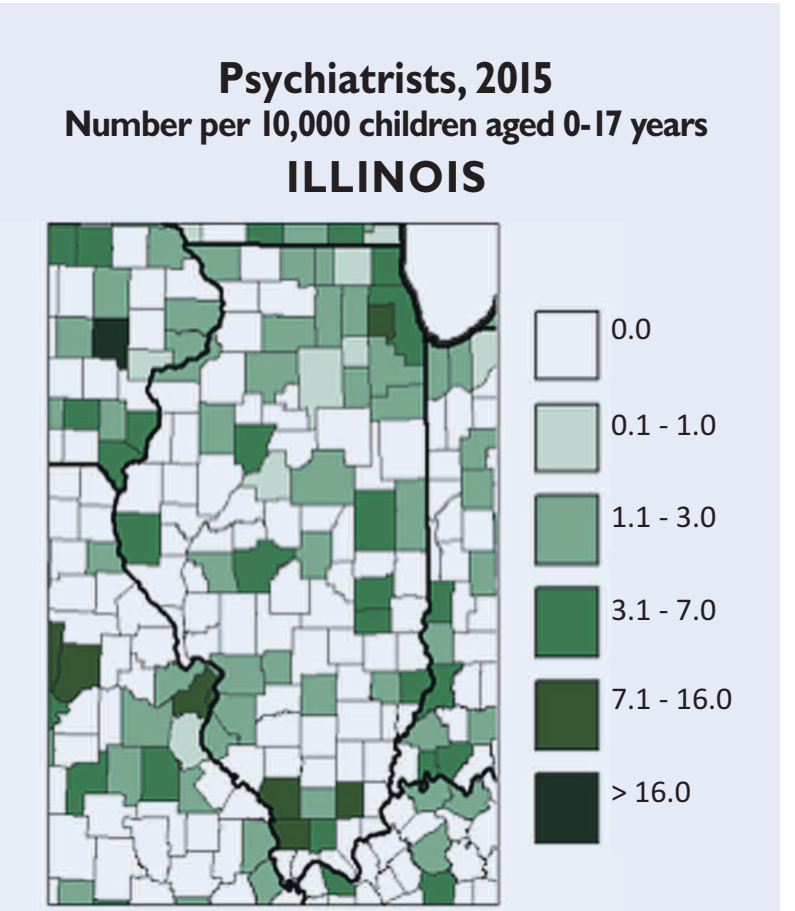


Figure 4: Psychiatric Coverage by County[85]

Equity

Taking a more comprehensive public health perspective, when considering access to services, Illinois needs to consider not only geography but also equity. Social determinants of health "are mostly responsible for health inequities," according to the World Health Organization.[86] Concentrated disadvantage is a measure of community economic and social factors, including high poverty, unemployment, percentage of households headed by single women, percentage of residents receiving public assistance, and percentage of children in the population. Living in concentrated pockets of poverty and high unemployment is associated with higher rates of crime and domestic violence and poorer health outcomes, including mental health outcomes.[87] Concentrated disadvantage has a disproportionate impact on minority children in Illinois.

Research also shows that Illinois communities of color are disproportionately impacted by violence and trauma.

Statewide, one in five Illinois children under age 18--over 580,000 children and youth--live in poverty. Alexander County, the state's southernmost county, has state's highest child poverty rate of 52 percent. Ten Illinois counties--Alexander, Cook, Kankakee, Macon, Marion, Pulaski, St. Clair, Saline, Vermillion and Winnebago--are the most disadvantaged counties in the state. (See Figure 5)

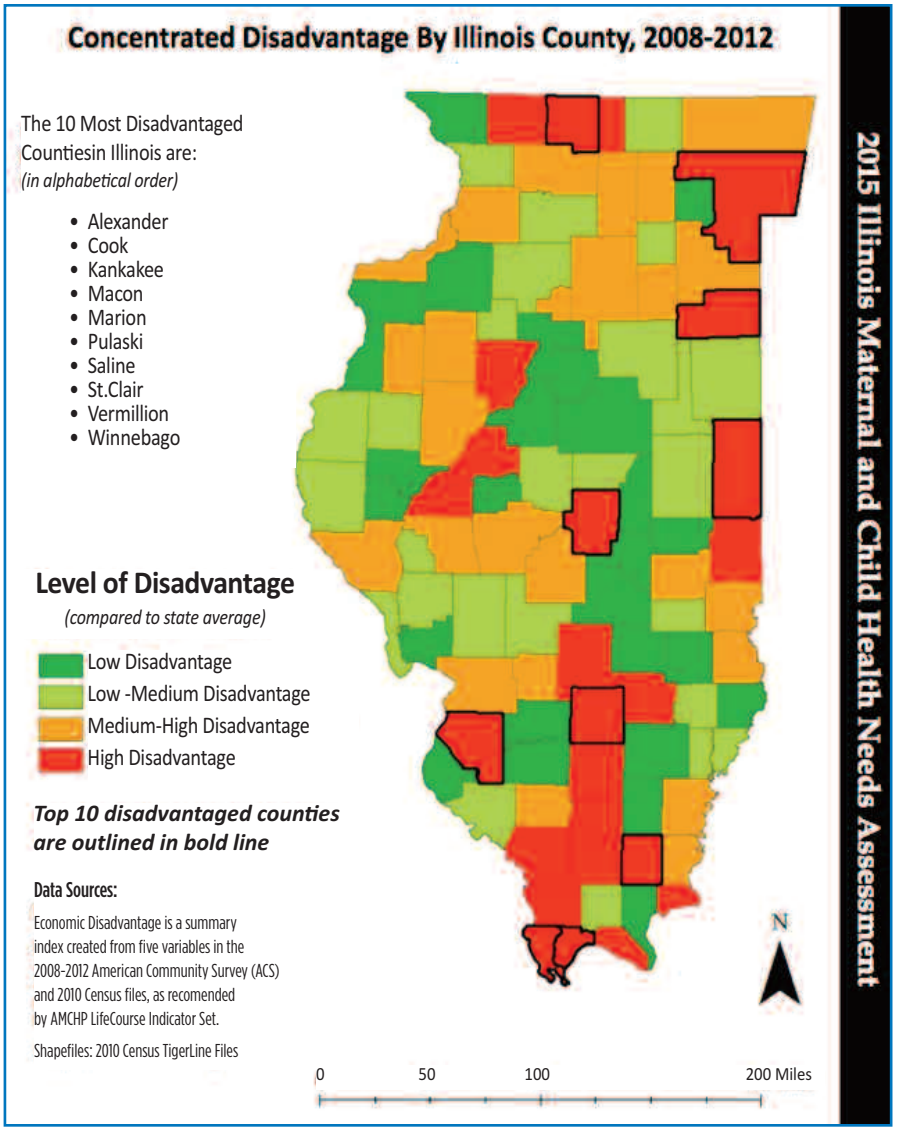


Figure 5: Concentrated Disadvantage[89]

Culture and Language

According to the US Census[90] in Illinois in 2011, 22.7% of residents five years or older spoke a language other than English at home. Within this group, over 22% reported that they did not speak English well or did not speak English at all. This would represent over 600,000 Illinois residents that might need family mental health services to be delivered in a language other than English. This is not an issue of poverty but one of culture.

Returning to the DCFS Statewide Provider Database discussed above, it lists over 260 providers/locations in Illinois that offer some mental health services in Spanish, 35 in Polish, and 44 in other languages. It is unclear whether this is sufficient to meet the need.

AVAILABLE MENTAL HEALTH RESOURCES *cont'd.*

Outcomes- Do Children Get Healthier?

All of the data presented thus far regarding services for children with mental health needs- spending, level of care, location, equity, and culture- still do not address the most fundamental question- once identified and served, do children get healthier? Answering this question requires looking at outcomes. This also goes beyond diagnosis and focuses much more on whether there is a change in a child's functioning, level of development, and overall health.

Illinois agencies understand the importance of measuring outcomes.[91] Many programs require that providers report outcome data. However, in researching this report, ICMHP staff could not identify any system-wide reports regarding relevant outcomes for children with mental health needs. To better understand the effectiveness of children's mental health services it is essential to report such findings in the future.

Highlighting Some Children's Mental Health Programs and Initiatives

While Illinois' fiscal struggles have resulted in fewer resources available than in the past, there is a strong community of providers and child-serving systems that are dedicated to doing whatever they can to assist children with mental health needs. There are also many excellent programs and initiatives in Illinois. The following are a few programs and initiatives in Illinois worth noting from this last year:

Illinois Children's Healthcare Foundation Grants

Illinois Children's Healthcare Foundation offered four community Children's Mental Health Initiative grants to integrate mental health care into schools and primary health settings. In Quincy, the grant funds assessment of each child for behavioral health needs at the start of each school year, marking a cultural shift in which behavioral health is viewed more like vision and dental care. A Social Emotional Coach aids teachers and school support staff. In addition, a community clinic collaborates to offer care from multiple disciplines including mental health, speech, and physical therapy. http://www.ilchf.org/

Mental Health Consultation Initiative

The Mental Health Consultation Initiative (MHCI) is a mental health consultation project set to implement, evaluate, and build a sustainable Infant/Early Childhood Mental Health Consultation system in Illinois. The pilot of the Mental Health Consultation Initiative, a project led by ICMHP with public and private collaboration, will offer mental health consultation at early childhood sites in and around Chicago and Peoria. Consultants are experts in infant and early childhood social and emotional development who provide coaching and support to caregivers and teachers. The consultation pilot will occur in three systems: Illinois Department of

Human Services-funded home visiting, Illinois Department of Human Services-funded center-based child care, and the Illinois State Board of Education's Prevention Initiative and Preschool For All programs. In addition, a parallel project with the Illinois Department of Public Health is planned. http://icmhp.org/icmhp-in-action/projects/mentalhealthconsultationinitiative/

HFS Specialized Family Support Program

HFS initiated the Specialized Family Support Program (SFSP), a 90-day crisis stabilization program that offers multi-agency supports for youth who cannot return home for safety reasons after discharge from inpatient psychiatric care or other intensive treatment. SFSP is a collaborative effort between HFS, DCFS, DHS, DJJ, IDPH, and ISBE. https://www.illinois.gov/hfs/MedicalProviders/behavioral/sass/Pages/sfsp.aspx

DJJ Re-entry Programs

IDJJ continued its efforts to reduce the incarceration of low-risk youth and add supports to help youths return successfully to their communities after incarceration. An average of 384 youths were held in IDJJ facilities in FY17, less than a quarter of the number incarcerated in 2003. DJJ's Aftercare program, which offers links to substance abuse and mental health treatment, mentoring, education and job training program, served 528 youths for an average of 12 months. https://www.illinois.gov/idjj/SiteAssets/Pages/Data-and-Reports/Public%20Monthly%20Report%20-%20May%202017.pdf

Juvenile Justice Collaborative Project

Strengthening Chicago's Youth, a violence prevention initiative at the Ann & Robert H. Lurie Children's Hospital of Chicago, together with Cook County Juvenile Probation Department, Treatment Alternatives for Safe Communities, Illinois Collaboration on Youth, and 10 community-based service providers launched the Juvenile Justice Collaborative project, a pilot that offers intensive supports to divert youths in high-crime communities from the juvenile justice system. Caseworkers assess risk, needs, and strengths for each youth and work with families, schools, and community providers to ensure there are no avoidable barriers to accessing services. The pilot served 44 youths between January and June. Nearly half of participants are female.https://www.luriechildrens.org/en-us/news events/Pages/pilot _program_to_help_curb_ chicago_ youth_violence_425.aspx

AVAILABLE MENTAL HEALTH RESOURCES *cont'd.*

School-Based Health Centers

School-based health clinics are increasingly seen as a promising practice to promote access to mental health services for children and youth. The School Health Program at the Illinois Department of Public Health monitors 66 certified school health centers. These centers work to improve the physical and emotional health of school aged children and youth, and can provide a service array that includes behavioral health services.[92] These health centers not only help to provide services to the children in their care, but can be a mechanism to create trauma-informed schools. The UIC Office of Community Engagement (OCEANHP) School Health Centers are an example of ways to think innovatively about school health centers as a major component of a child's mental health and well-being. They have incorporated trauma training for all staff members, and have incorporated trauma into the differential diagnosis list for each child seen. Additionally, they have creatively engaged parents, school staff, and community members around the promotion of trauma-informed approaches, and continue to think innovatively about ways to promote child and youth wellbeing.[93] School-health centers provide a promising opportunity to expand access to trauma-informed behavioral health services.

RECOMMENDATIONS

State Executive Plans

There are several current state plans that are relevant to children's mental health. In some cases, ICMHP has taken the lead on developing the children's mental health recommendations while, in other instances it has participated on committees or submitted comments.

ICMHP Strategic Plan

The Partnership developed its own Children's Mental Health Plan in 2005 and is required to "submit an annual report to the Governor on the progress of Plan implementation and recommendations for revisions in the Plan.[94]" In 2012, ICMHP updated the original plan to focus on ten priorities.[95] These recommendations remain relevant and were integrated into other state initiatives.

For example, ICMHP convened the Children's Behavioral Health Integration Initiative Committee (CBHII), which included DHS/DMH, DCFS, HFS, and DJJ. In 2015, the committee issued both a list of service descriptors (for wraparound; parent and youth peer services; parent support and training; intensive in-home services; respite services, in-home and out-of-home; mobile crisis response and stabilization services; residential crisis stabilization; therapeutic mentoring; and transition Services) and a Report on Early Intervention for Children and Youth with Emergent Social, Emotional, or Mental Health Concerns.[96]

IDPH, State Health Improvement Plan (SHIP)

ICMHP participated as a team member in developing the 2016 IDPH State Health Improvement Plan (SHIP), titled "Healthy Illinois 2021.[97]" All three of its priorities: behavioral health, chronic disease (including childhood obesity), and maternal and child health; include important child issues and begin to bring together the more comprehensive public health approach that is needed in addressing children's mental health needs.

RECOMMENDATIONS *cont'd.*

Illinois' Health and Human Services Transformation Strategy

Concepts from these CBHII and SHIP reports were incorporated into the state's Health and Human Services Transformation Strategy. This state plan includes input from thirteen state agencies, departments, and offices. The 2016 plan focuses on behavioral health for both adults and children. The pillars of the strategy include[98]

a. Prevention and population health
b. Pay for value, quality and outcomes
c. Institutional to community care
d. Education and self-sufficiency
e. Data integration and predictive analytics

The strategy includes identifying a wide range of funding resources, including Medicaid.[99]

HFS' Behavioral Health Transformation

1115 Demonstration Waiver

In 2016 HFS applied to the federal government for an 1115 waiver,[100] which is a contract between the state and federal government wherein the federal government waives some federal Medicaid requirements and authorizes the state to create specific demonstration projects that will be paid for through Medicaid funds. The projects must be 'budget neutral' to the state's federal Medicaid claims. ICMHP was one of the many stakeholders that submitted comments and testimony during the drafting process.[101]

The HFS waiver focuses on integrating behavioral health (mental health and substance abuse) with physical health service delivery.[102] Built around ten initiatives (see Figure 6) relevant child mental health portions of the waiver include infant / early childhood mental health initiatives (consultation and home visiting); intensive in-home services; respite care; crisis beds; DJJ transition services; and workforce development.

Mental Health Rule Reform

In addition to the 1115 Waiver, state leaders from HFS and DHS have been working together to reform administrative rules related to mental health billing and access. Under the auspices of DHS, Rule 132 is being revamped with the goal of reducing the administrative burden on community mental health providers and expanding service availability. Under HFS, Rule 140 will also reduce the administrative burden, as well as allow increased flexibility for providers who may not meet the requirements of a community mental health center to be able to bill under Medicaid. These reforms will allow for the needed flexibility and innovation for children's mental health, including the expansion of strategies such as school-based health centers and telehealth.

Figure 6: Ten Initiatives of HFS' behavioral health strategy

RECOMMENDATIONS *cont'd.*

Legislature and Courts

While ICMHP has been most involved with the Executive branch, it has also responded to opportunities with the legislative and judicial branches of government.

Committee / Task Force

This year the Illinois House of Representatives has formed a Committee on Mental Health. It recently held joint hearings with the House Committee on School Curriculum and Policies. ICMHP submitted comments and members testified at the Joint School Mental Health Hearing.[103] Among other issues, the Partnership endorsed strategies such as the continued development of trauma-informed schools, communities, and courts; earlier and better access to mental health services through increased and improved mental health screening and referral procedures; and, continued support for comprehensive, coordinated approaches to support children birth through college and their families through innovations such as school/community partnerships, mental health consultation, and tele-health.

In addition, the legislature created the Illinois Mental Health Opportunities For Youth Diversion Task Force.[104] Similar to ICMHP in membership design, it is tasked with developing an action plan for state and local law enforcement to divert youth that need mental health treatment away from the justice system and over to appropriate health care settings.

Legislation

In addition to reaching a compromise on public school funding, the state also passed several pieces of legislation relevant to children's mental health, including:

a. Public Act 99-0927 (SB565), Social and Emotional Screening in Schools, which requires age-appropriate social emotional screening in order to identify potential mental health problems among school-age children, and early intervention when needs are identified.

b. Public Act 100-0105 (HB2663), Preventing Preschool Expulsions, which protects against preventable expulsion and suspension in publicly-funded early childhood settings and addresses the high rates of Pre-K expulsion and suspension in Illinois, particularly for minority children and boys.

c. Public Act 100—0387 (HB3213), Restores the Child Care Assistance Program (CCAP), which restores and adds eligibility under the Child Care Assistance Program.

d. Public Act 100-0196 (HB3709), Increases the number of counseling sessions available to minors under the age of 17 from 5-8, and allows a provider to provide more than 8 sessions without parental consent if in the minor's best interest and parental notification would be detrimental to the minor's well-being

At the federal level, US Senator Richard Durbin and US Representative Danny Davis introduced S774 and HR1757, The Trauma Informed Care for Children and Families Act, legislation designed to support children traumatized by community violence. Several ICMHP members advised on drafting of the bill, including testifying at a congressional hearing and commenting on the drafts.[105]

Court Cases / Consent Decrees / Settlement

Illinois state courts did not appear to issue any major opinions this year regarding children's mental health. The most significant mental health related litigation consisted of social service agencies suing the state, unsuccessfully attempting to recover funds owed to them.[106]

The federal courts are still involved in several class action lawsuits and consent decrees with Illinois child-serving state agencies. Each of these included the need to address children's mental health issues.

a. BH v Sheldon[107]- involves DCFS since 1988 with a current focus on developing an implementation plan to address the lack of community mental health services and overreliance on institutional care.

b. RJ v Jones[108]- involves DJJ in a 2012 consent decree and 2014 remedial plan. It has resulted in improved mental health services as well as changes in policies regarding handcuffs and solitary confinement.

c. NB v Norwood[109]- involves HFS in a 2011 class action. Addressing the Early and Periodic Screening, Diagnostic, and Treatment ("EPSDT") requirement of the Medicaid Act, a proposed settlement would grant children access to a continuum of behavioral health services, including home- and community-based services.

RECOMMENDATIONS *cont'd.*

ICMHP Recommendations

Given the current state of children's mental health care in Illinois, ICMHP recommends that, in the next year, the state should focus on:

Understanding the Data: Illinois does not have good estimates of children's mental health needs, the number of children receiving appropriate services, the funds being spent, or whether children's mental health actually improves. In many cases the data exists but was not accessible to ICMHP. In particular, the Partnership needs more access to managed care and private insurance information. ICMHP can work with the State to continue its current efforts to better organize and share data. The Partnership should be tasked with providing recommendations on data points that would be valuable in reference to children's behavioral health, such as whether child and family health is improving.

Building Upon Current Children's Programs to Address Trauma: Illinois has done good work in addressing some aspects of children's mental health. For example, programs addressing early childhood, mental health consultation, and social and emotional learning have had some success and funding should continue. There are also other acute issues that need to be addressed. Child trauma and exposure to violence are broad-reaching and can have a devastating impact on children, families, and communities. ICMHP should be assigned to work on a systems review and needs assessment that would identify the state and local programs that need to become trauma-informed through training and planning. Additionally, the Partnership should identify existing program models of training, promotion, prevention, and treatment that have been successful and provide leadership in the systems building process.

Developing a Children's System of Care: Over a billion dollars is being spent on children's mental health services in Illinois. Managed care is shifting the focus of reimbursement based on services provided to a deeper focus on quality services and supports. Plans are being developed at the state executive, legislative, and judicial levels, as well as by private agencies and foundations, that will affect children's mental health, but no one has taken a comprehensive look at the collective impact. ICMHP should be assigned to develop a crosswalk of the plans and funding specifically in relation to children's mental health. Then, using the data, the Partnership can identify next steps to developing a children's system of care that includes mental health, substance abuse, trauma, healthcare, education, child welfare, juvenile justice, and domestic and community violence. The various state agencies need to coordinate their plans through common terms and a common understanding of child development in order to develop a system of care

that will use Illinois' resources more efficiently and effectively. We ask the Governor to utilize the public/private partnership available through the Illinois Children's Mental Health Partnership to provide the support needed to create a collective approach to better integrate the cross-systems work.

Conclusions

The Illinois Children's Mental Health Partnership was created by statue to develop and monitor a Children's Mental Health Implementation Plan that would provide comprehensive, coordinated mental health prevention, early intervention, and treatment services for children. This report is taking a new look at the issues. The Partnership estimates that there are approximately 293,000 children in Illinois whose functioning is impaired by mental health issues. Fewer than half of these children are identified by public agencies and many of the rest go untreated. Illinois has had some significant losses to its mental health infrastructure, but also has made some gains that can be maintained and/or built upon. The state needs to better understand available data and incorporate new clinical research around issues such as trauma. There are some good children's mental health resources available and state plans that will affect future support. Coordinating the various state plans through a comprehensive public health approach can result in a more efficient and effective system of care that will improve the health of children and families in Illinois. The ICMHP is a mechanism that can continue to help the State to meet these goals, and stands ready to help the state in moving this agenda forward.

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ENDNOTES

[1] https://www.census.gov/quickfacts/IL.

[2] e.g. The Illinois Department of Public Health (IDPH) 2015 Report, The Illinois Maternal and Child Health Databook 2015, at http://www.dph.illinois.gov/sites/default/files/publications/publications-owh-il-title-v2015-databook-042816.pdf estimated that in 2014, 23.5% of Illinois residents were under 18 while the Illinois Department of Healthcare and Family Services (IL HFS) reports data from services offered to children 3 to 21 years old.

[3] https://www.illinois.gov/gov/children/Pages/About.aspx.

[4] For example, state agency infrastructures do not support data sharing.

[5] Over a lifetime, the estimate for mental illness will go up to one in five. https://www.nimh.nih.gov/health/statistics/prevalence/any-disorder-among-children.shtml See the Illinois Children's Mental Health Act, Public Act 93-0495, states "WHEREAS, One in 10 children in Illinois suffers from a mental illness severe enough to cause some level of impairment; yet, in any given year only about 20% of these children receive mental health services;"

[6] That estimate was from Huang, L., Stroul, B., Friedman, R., Mrazek, P., Friesen, B., Pires, S., and Mayberg, S. (2005) Transforming Mental Health Care for Children and Their Families. . . *American Psychologist,* 60,(6), p615-627, which explains that "Recent studies indicate an alarmingly high prevalence rate, with approximately 1 in 5 children having a diagnosable mental disorder and 1 in 10 youths having a serious emotional or behavioral disorder that is severe enough to cause substantial impairment in functioning at home, at school, or in the community... In conjunction with this prevalence rate, there is an extremely high level of unmet need. It is estimated that about 75% of children with emotional and behavioral disorders do not receive specialty mental health services (p.615)." See also, the report of New Freedom Commission on Mental Health. (2003). *Achieving the promise: Transforming mental health care in America. Final report* (DHHS Pub. No. SMA-03-3832). Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration. http://govinfo.library.unt.edu/mentalhealthcommission/reports/reports.htm, which states that "In any given year, about 5% to 7% of adults have a serious mental illness, according to several nationally representative studies.1-3 A similar percentage of children — about 5% to 9% — have a serious emotional disturbance. (p.2)

[7] Mental Health America, Parity or Disparity: The State of Mental Health in America 2015. https://www.mentalhealthamerica.net/sites/default/files/Parity%20or%20Disparity%202015%20Report.pdf. This report is relying on data from The National Survey of Children's Health, 2011-12.

ENDNOTES *cont'd.*

[8] See IDPH, Databook at footnote 2. This report is relying on data from the National Survey of Children's Health 2011-12. It is worth noting that this survey only asked parents about whether their children had been diagnosed with any of seven conditions: Anxiety, Attention Deficit (Hyperactivity) Disorder (ADD/ADHD), Autism Spectrum disorders (ASD), a behavior or conduct disorder, depression, developmental delay, or Tourette syndrome. This underlying 2011-12 study found that older children were more likely to have a mental health condition and that Hispanic children were less likely to have a mental health condition than white or black children. It did not find sex or family income differences. Unfortunately, that the same source, in its earlier 2007 survey reported that, in Illinois, there was a higher prevalence rate for 6-11 year olds than for 12-17 year olds; for males than females (12.5 vs. 6.6%); and for the poorer families. All these findings differ from the later survey.

[9] See MHA, Parity or Disparity at footnote 7. This report is relying on data from Youth Risk Behavior Survey, 2010-12. That survey is conducted in selected high schools with participation by students being optional.

[10] See Suicidal Behavior Among Illinois Youth 2015, Illinois Department of Public Health, at http://www.dph.illinois.gov/sites/default/files/publications/publicationsowhfsyouth-suicide-fact-sheet.pdf citing data from Illinois Death Certificates for Illinois residents, 2000-2015. Figure 1 is from IDPH Health Data, Core Indicators, 09/12/16, p.31 retrieved from http://www.idph.state.il.us/ship/icc/documents/Data-Book-final-091216.pdf

[11] IDPH, Suicidal Behavior Among Illinois Youth 2015,at footnote 10, citing the *Illinois Youth Risk Behavior Survey* (YRBS), 2007-2015.

[12] Source: Center for Disease Control and Prevention, Illinois High School Youth Risk Behavior Survey, 2015, https://nccd.cdc.gov/youthonline/app/Results.aspx?LID=IL.

[13] See http://dph.illinois.gov/content/illinois-suicide-prevention-alliance

[14] See also, the IDPH State Health Improvement Plan, http://www.idph.state.il.us/ship/icc/documents/SHIP-FINAL.pdf Goal 3, Reduce deaths due to behavioral health crises, at p.43.

[15] IDPH, Databook, at footnote 2, page 63. This reports data from the Youth Risk Behavior Surveillance System, an optional survey done in high schools.

[16] See also, IDPH, State of Illinois Opioid Action Plan, http://dph.illinois.gov/sites/default/files/publications/Illinois-Opioid-Action-Plan-Sept-6-2017-FINAL.pdf at p. 17

[17] See MHA, Parity or Disparity at footnote 7. These alternate approaches do not directly contradict each other but do lead to a focus on different groups and numbers.

[18] See IDPH, Opioid Action Plan, at footnote 16, at p. 17, citing Substance Abuse and Mental Health Services Administration. (2015). Behavioral Health Barometer: Illinois, 2015 .

[19] See http://www.dph.illinois.gov/sites/default/files/publications/Drug-Overdose-Deaths-October2017.pdf

[20] See IDPH, Opioid Action Plan, at footnote 16, p.3

[21] See the Illinois ACEs Response Collaborative, at http://www.hmprg.org/Programs/IL+ACE+Response+Collaborative; and ICTC White Paper at http://www.voices4kids.org/wp-content/uploads/2013/04/ICTC-White-Paper-120110.pdf;

[22] In part, this is because it is a relatively new field of study. It is also confounded by the already complicated issue of differential diagnosis, as trauma symptoms often overlap with symptoms of mental illness. Griffin, G., McClelland, G., Holzberg, M., Stolbach, B., Maj, N., & Kisiel, C. (2012) Addressing the Impact of Trauma before Diagnosing Mental Illness in Child Welfare. Child Welfare, 90, 69 – 89.

[23] IDPH, Health Data: Core Indicators Report, http://www.idph.state.il.us/ship/icc/documents/Data-Book-final-091216.pdf at p.27

[24] See Illinois ACES Respons Collaborative and ICTC White Paper at footnote 21;

[25] email to ICMHP from Dr. Kim Mann, DCFS, on 09/22/17 reporting data as of 09/20/17; also see Illinois DCFS, Executive Statistical Summary, Data as of July 31, 2017, at https://www.illinois.gov/dcfs/aboutus/newsandreports/Documents/ExecStat.pdf .

[26] Abram KM, Teplin LA, Charles DR, Longworth SL, McClelland GM, and Dulcan MK. (2004). Posttraumatic Stress Disorder and Trauma in Youth in Juvenile Detention, 61 Arch Gen Psychiatry. 61(4):403-10.

[27] Defending Childhood: Report of the Attorney General's National Task Force on Children Exposed to Violence, 2012 at https://www.justice.gov/defendingchildhood/cev-rpt-full.pdf

[28] See ICJIA, Addressing Child Exposure to Violence, at http://www.icjia.state.il.us/articles/addressing-child-exposure-to-violence.

[29] http://apps.chicagotribune.com/news/local/young_victims/ data reported as of 10/22/17

[30] http://www.icjia.state.il.us/news/icjia-receives-federal-award-to-improve-illinois-service-collaboration-for-child-and-youth-victims-of-violence

[31] Email to ICMHP from Shawn Cole, HFS on 10/4/17, "The SASS program model is built upon the core values and principles of systems of care which calls for an organized service system that emphasizes comprehensive, individualized, and culturally competent services provided in the least restrictive environment. The model calls for the full involvement of families in treatment and planning, interagency collaboration, a strengths-based approach, and care coordination at the community level to address children's needs.

Since July 1, 2004, the SASS program has operated as a single, Statewide system serving children and youth who are experiencing a mental health crisis and whose care requires public funding from HFS, DCFS, or DHS. SASS operates 24 hours a day, 7 days a week for Illinois children and is responsible for: providing crisis

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intervention services; facilitating inpatient psychiatric hospitalization, when clinically appropriate; and providing case management and treatment services following a crisis event. SASS features a centralized point of intake known as the Crisis and Referral Entry System (CARES) Line. The CARES Line receives referrals for children and youth in crisis, determines whether the level of acuity meets the threshold of crisis, and refers the call to the most appropriate community resource, which may include the dispatch of a SASS crisis responder.

As the State's Medicaid infrastructure continues to transform through the operation of HFS-contracted managed care entities, the State's approach to crisis response began to evolve. Many of the children and youth traditionally served by the SASS program are now being served by Mobile Crisis Response (MCR) programs administered and funded by the various HFS-contracted managed care organizations (MCOs). MCR continues to feature centralized intake via the CARES Line and access to face-to-face crisis intervention services. The Departments actively work with HFS-contracted managed care entities to ensure continuity and coordination across the two crisis response systems."

[32] Email to ICMHP from Lisa Betz, IL DHS/DMH on 10/24/17. This is the number of children and adolescents with public funding that flows through DMH. The DMH child and adolescent population does not receive a Serious Mental Illness (SMI) diagnosis that adults receive. DMH does not use the terms interchangeably as they have different criteria and diagnosis that are more age and developmentally appropriate.

[33] MHA report, at footnote 7, p. 34

[34] See MHA report, at footnote 7, p. 53. "Under IDEA regulation, Serious Emotional Disturbance is identified as a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance: (A) An inability to learn that cannot be explained by intellectual, sensory, or health factors. (B) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers. (C) Inappropriate types of behavior or feelings under normal circumstances. (D) A general pervasive mood of unhappiness or depression. (E) A tendency to develop physical symptoms or fears associated with personal or school problems. Emotional disturbance includes schizophrenia. The term does not apply to children who are socially maladjusted, unless it is determined that they have an emotional disturbance under paragraph (c)(4)(i) of this section."

[35] See IL DHS/DMH criteria for SED at http://www.dhs.state.il.us/page.aspx?item=36189

[36] McMillen, J. C., Zima, B. T., Scott, L. D., Auslander, W. F., Munson, M. R., Ollie, M. T., & Spitznagel, E. L. (2005). The prevalence of psychiatric disorders among older youths in the foster care system. Journal of the American Academy of Child and Adolescent Psychiatry, 44, 88– 95.

[37] See Griffin, et al. (2012) at footnote 22.

[38] See p. 21 of DCFS Executive Statistical Summary, footnote 25.

[39] Illinois Criminal Justice Information Authority, Mental health screening and assessment in the Illinois juvenile justice system, March 2010, p. 39. http://www.icjia.state.il.us/assets/pdf/ResearchReports/Mental%20health%20screening%20and%20the%20juvenile%20justice%20system.pdf

[40] See IL Department of Juvenile Justice, Summary of State Fiscal Year 2016 Admissions to the Illinois Department of Juvenile Justice Facilities. https://www.illinois.gov/idjj/SiteAssets/Pages/Data-and-Reports/Summary%20of%20State%20Fiscal%20Year%202016%20Admissions%20to%20the%20Illinois%20Department%20of%20Juvenile%20Justice%20Facilities.pdf

[41] Cited in IL Healthcare and Family Services, Illinois' Behavioral Health Transformation: Section 1115 Demonstration Waiver, p.40. https://www.illinois.gov/hfs/SiteCollectionDocuments/1115%20Waiver%20for%20CMS%20Submission_final.pdf

[42] See https://www.illinois.gov/hfs/MedicalProviders/behavioral/Pages/icg.aspx. Additionally, HFS reports that HFS finalized the transition of the Individual Care Grant (ICG) program from the Illinois Department of Human Services – Division of Mental Health (DHS-DMH) in response to Public Act 99-0479. Tightening the link between ICG and SASS, the Department updated SASS contracts to ensure provider activities were fully supporting the updated ICG program. Moreover, on July 1, 2016, HFS transitioned all administrative duties and functions to in-house staff and resources. In this transition, HFS gained a first-hand understanding of the operational challenges facing the ICG program and began to systematically introduce operational efficiencies to improve care and access to services. The lessons learned during this period lead to the development of the proposed Title 89 Illinois Administrative Code, Part 139 – HFS' re-visioning of the ICG program. Email to ICMHP from Shawn Cole, footnote 31.

[43] The agencies data is not even from the same years.

[44] In researching this report, ICMHP staff was not able to obtain sufficient data to determine a more accurate number of children with mental health needs. See footnote 6, which reported that nationally "it is estimated that about 75% of children with emotional and behavioral disorders do not receive specialty mental health services."

[45] MHA Report at footnote 7, p. 52. Children with an ongoing EBD who have insurance coverage (Denominator), that report inadequate insurance (Numerator), defined as not meeting one or more of the following: 1) usually/always meets child's needs, 2) usually/always allow child to see needed provider, 3) out-of-pocket costs are usually/always reasonable or has no out-of-pocket costs. Data survey year 2011-2012.

[46] MHA Report at footnote 7.

[47] Illinois Providers Report Barriers to Mental Health and Addiction Coverage for Their Patients, Issue Brief, September 2017. http://www.hmprg.org/assets/root/PDFs/2017/IL%20MHSUD%20Coverage%20Provider%20 Survey%20Report%20Final.pdf

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[48] See the Department of Insurance mission statement at http://insurance.illinois.gov/Consumer/TriFold/DOIBrochureEnglish.pdf

[49] http://www.chicagotribune.com/business/ct-biz-insurers-deny-mental-health-coverage-0921-story.html

[50] See footnote 5.

[51] See Huang, et al., footnote 6, which explains that "Recent studies indicate an alarmingly high prevalence rate, with approximately 1 in 5 children having a diagnosable mental disorder and 1 in 10 youths having a serious emotional or behavioral disorder that is severe enough to cause substantial impairment in functioning at home, at school, or in the community... In conjunction with this prevalence rate, there is an extremely high level of unmet need. It is estimated that about 75% of children with emotional and behavioral disorders do not receive specialty mental health services (p.615)."

[52] MHA Report at footnote 7, p.33

[53] MHA is reporting a random telephone survey conducted in 2011-12 that asked a parent whether a child had "any kind of emotional, developmental, or behavioral problem for which [he/she] needs treatment or counseling." If the parent said 'yes' they asked if the child actually received treatment in the last twelve months. The 55% indicates the percentage of parents who answered yes to the second question related to the receipt of services. The MHA report does not tell us what percentage of Illinois children were identified by the first question as having a mental health problem. As with the preceding section, ICMHP is unable to determine how many children were actually identified as needing mental health services. Therefore, the value of the 55% conclusion is significantly lessened by the methodology. See MHA Report, footnote, 7, at p.52- The two survey questions used were K2- Q22- Does [SC] have any kind of emotional, developmental, or behavioral problem for which [he/she] needs treatment or counseling? K4- Q22- Mental health professionals include psychiatrists, psychologists, psychiatric nurses, and clinical social workers. During the past 12 months, has [CHILD'S NAME] received any treatment or counseling from a mental health professional?

[54] MHA Report, footnote 7, at pp. 29-30.

[55] See the IDPH State Health Improvement Plan at footnote 14, at p. 37

[56] See the 1115 Demonstration Waiver, footnote 41, at p.15, which is based on State Fiscal Year 2015 Illinois DHFS claims data.

[57] Note that the listed sources of funding for children's mental health services do not include estimates of spending from private insurance. Thus, ICMHP is only able to discuss how much public sector money is spent on mental health services for Illinois children

[58] See the 1115 Demonstration Waiver, footnote 41 at p. 9.

[59] See the IDPH State Health Improvement Plan at footnote 14, at p. 38

[60] See The United Way of Illinois Post-Stop Gap Funding Survey at https://uw-mc.org/wp-content/uploads/2017/04/Full-United-Way-of-Illinois-Survey-Results.pdf

[61] See the IDPH State Health Improvement Plan at footnote 14, at p. 38

[62] See the 1115 Demonstration Waiver, footnote 41 at p.4

[63] 2017 A Fiscal Scan of Illinois Public Investments in Children and Youth, Ages 8-25, Children's Home and Aid by by Children's Home + Aid and partners including United Way of Illinois, The Federation for Community Schools, and The Shriver Center. The scan focused only on those investments that were directly invested. It did not include other spending, such as Medicaid, General Service Administration dollars from ISBE's budget, funding of facilities, or any federal funding that didn't flow through the state. See https://www.children-shomeandaid.org/wp-content/uploads/2017/05/Fiscal-Scan-Print-Proof-ACPPI-logo.pdf

[64] Illinois Fiscal Mapping draft report, 2015; ICMHP participated in the 2014 GOHIT process included development of a comprehensive fiscal map that identified $1.5 billion in spending for children's behavioral health by public child-serving systems in FY14. The document attempted to identify investment by multiple agencies, including education, child welfare, Medicaid, mental health, and juvenile justice. The scan report took a conservative approach to spending estimates and stated, "the figure of $1.5 billion has the potential to be highly under-representative of the actual public spending on services." Of the $1.5 billion in children's behavioral health spending in FY 14, the report identified spending by state agencies as well as 708/Community Mental Health Boards that levy taxes or allot funds for children's services. (Note: A number of children's behavioral health programs and services that were administered by other state agencies in FY14 are now administrated by the Illinois Department of Healthcare and Family Services.)

[65] DCFS, which is charged with protecting children and strengthening families, spent an estimated $596 million of a total $12 billion FY14 budget on children with behavioral health needs. Of the total, $262.2 million was eligible for federal claiming, including Medicaid matching. Behavioral health spending included substitute care for 14,931 children and youth, at a cost of $477.6 million in state funds. Approximately 86 percent of these youth were placed in foster care, at an average cost of $19,700 per child annually. Nine percent, or 1,297 children and youth, were placed in institutional or group homes, at an average cost of $116,000 per child annually. In addition, DCFS spent $62.4 million for behavioral health services including Children's Advocacy Centers, counseling, substance abuse treatment, advocacy/mentoring, and post adoption supports.

More recent data from DCFS offers a partial, updated picture from FY17, with approximately $18.4 million for mental health services that were billable to Medicaid (with Institutions and Group homes make up 76% of those costs at 14 million). The Department also expended $8,000,000 for Intensive Placement Stabilization Services (IPS), serving approximately 1,600 clients over the course of the year. The IPS program is a

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community-based system of care that provides an array of critical, intensive, in-home therapeutic interventions to clients for whom DCFS is legally responsible with trauma reactions, emotional and behavioral problems, and who are at risk of losing their current placement/living situations and their families. In FY17, The Department expended $383,000 for Substance Abuse Services for Youth and $4,600,000 for Youth and Families. Since this report is structured differently than the ICMHP report from FY14, the numbers are not directly comparable. See Footnote 25.

[66] The Illinois State Board of Education (ISBE) and local school districts served 23,347 students ages 3 to 21 who were identified as having a primary or secondary emotional disability at a cost of at least $392.7 million in 2013-14. These students made up 8 percent of the 289,887 students receiving special education services. ISBE's Special Education Expenditures Receipts Report dated May 2015 calculated $4.9 billion on children in special education. The GOHIT draft fiscal map calculated that, based on the percentage of students with emotional disabilities in the special education pupil population, spending for these students would total approximately $392 million. However, since students with emotional disabilities make up an estimated 45 percent of all students in residential placement, spending for students with behavioral health disabilities is likely higher. See Illinois State Board of Education Special Education Expenditures and Receipts Report, May 1, 2017 at https://www.isbe.net/Documents/sped-annual-16.pdf.

[67] HFS, the agency responsible for overall administration of the Illinois Medicaid Program, also maintains other state and federal children's medical programs under the Illinois All Kids Program. In FY14, HFS spent $281 million in children's behavioral health services, including $144 million for inpatient psychiatric hospitalization, $71.7 million for psychotropic medications, and $27.3 million for crisis services funded through the Screening, Assessment and Support Services (SASS) program. (Total SASS expenditures, including services administered through DCFS, HFS, and the Department of Human Services, totaled $39 million in FY14.)

[68] In FY14, DHS administered a range of human and social services organized under five divisions, Developmental Disabilities, Mental Health, Alcohol and Substance Abuse, Rehabilitation Services, and Community Services. All divisions administered multiple programs serving children with mental health or substance abuse service needs, spending a total of $151.8 million on children with behavioral health needs. See footnote 31.

[69] DJJ, the agency responsible for administering Illinois' state juvenile correction system, spent an estimated $87 million for services and activities related to behavioral health problems in FY14. DJJ's mission is to enhance public safety and promote positive youth outcomes by providing strength-based, individual services to children in a safe learning and treatment environment, so that they can successfully return to their communities. DJJ held on average 850 youth in six secure facilities around the state and was responsible for 1,300 youth in parole/aftercare in FY14. See footnote 40.

[70] See footnote 64

[71] See https://www.illinois.gov/gov/OECD/Pages/MIECHVP.aspx

[72] See http://www.ilchf.org

[73] See https://www.casey.org

[74] See http://www.aecf.org

[75] https://www.macfound.org

[76] http://www.polkbrosfdn.org

[77] See https://www.facebook.com/Irving-Harris-Foundation-143810959105428/

[78] http://www.wcstonefnd.org

[79] https://www.mccormickfoundation.org

[80] http://www.brightpromises.org

[81] See the 1115 Demonstration Waiver, footnote 41 at pp. 9 - 10 Approximately 40% of Illinois Medicaid behavioral health spend is dedicated to inpatient or residential care and utilization of state psychiatric hospitals per 1,000 residents is 44% higher than the national average. This stands in sharp contrast to utilization of lower-cost community care facilities, which is less than half the national average."

[82] See Wotring, J., & Stroul, B. (2011). Issue Brief: The intersect of health reform and systems of care for children's behavioral health care . Washington, DC: Georgetown University Center for Child and Human Development, National Technical Center for Children's Mental Health.
https://gucchdtacenter.georgetown.edu/publications/SOC_Brief_Series1_BL.pdf

[83] For more information re the Statewide Provider Database, see https://prd.illinoisoutcomes.dcfs.illinois.gov Other estimates place home visiting programs funded by ISBE or DHS at 250-300 programs.
http://asthvi.org/wp-content/uploads/2016/11/Illinois-Fact-Sheet-11.22.16.pdf

[84] See Behavioral Health Service Providers by County, 2015, Centers for Disease Control at https://www.cdc.gov/ncbddd/adhd/stateprofiles-providers/illinois/index.html; also keep in mind that state Medicaid funding does not transfer across state lines, so border counties may not benefit from closer out-of-state services.

[85] See https://www.cdc.gov/ncbddd/adhd/stateprofiles-providers/illinois/index.html Regarding psychiatry, Some of the absence can be dealt with through tele-psychiatry, the use of nurse practitioners, or consultation with and training of family physicians. Illinois passed legislation in 2014, allowing for psychologists to be trained to prescribe some psychotropic medications. However, that law does not permit these psychologists to prescribe for children.

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[86] See http://www.who.int/social_determinants/sdh_definition/en/. For Illinois, also see Cycle of Risk: The Intersection of Poverty, Violence and Trauma Report on Illinois Poverty, March 2017, Heartland Institute at https://www.issuelab.org/resource/cycle-of-risk-the-intersection-of-poverty-violence-and-trauma-2.html

[87] Mental health was the leading cause of hospitalizations for all Chicago children ages 10 to 14 in 2014, and the second leading cause of hospitalization for those ages 5 to 9 and ages 15 to 19. The highest mental health hospitalization risks were for youths 15 to 19 years old living in zip code areas with a low Child Opportunity Index (COI), a measure of community social factors including educational, health/environmental, and economic opportunities. Children in very low and low COI zip code areas lack access or experience barriers to physical and behavioral health care. See Community Needs Assessment, 2016, Ann & Robert Lurie Children's Hospital of Chicago at https://www.luriechildrens.org/en-us/community/community-health-needs-assessment/Documents/chna-2016.pdf

[88] Over 50% of the population in very low COI areas is African American; 75 percent of the population in very high COI areas is white. See Lurie study, at footnote 82. Two out of five African-American children and one in four Latino children live in poverty, compared to one in ten Caucasian children. Illinois communities of color also are disproportionately impacted by violence and trauma. African-Americans males ages 15 to 24 comprise just 1 percent of the Illinois population, but accounted for 27 percent of homicide victims in 2015. See Cycle report, at footnote 87

[89] See IDPH, Databook at footnote 2, p.75

[90] See https://www.census.gov/prod/2013pubs/acs-22.pdf, Table 4.

[91] See, for example, the 1115 Demonstration Waiver, footnote 41.

[92] See http://dph.illinois.gov/topics-services/life-stages-populations/maternal-child-family-health-services/school-health

[93] Email from Dr. Audrey Stillerman, Medical Director School Health Centers, UI Hospital and Health Sciences System to ICMHP, 11/20/17

[94] Illinois Public Act 93-0495 (5) (c)

[95] See http://icmhp.org/wordpress/wp-content/uploads/2016/01/2012_ICMHP_Full_Annual_Report_FINAL.pdf The recommendations are to (1) Increase public awareness and understanding of children's mental health needs; (2) Promote collaborations and culturally inclusive partnerships; (3) Increase mental health promotion, prevention, early intervention, and treatment services; (4) Promote ongoing family/consumer and youth involvement; (5) Advocate for improved public policies; (6) Promote sustainable mental health consultation efforts; (7) Institutionalize effective social and emotional learning strategies; (8) Improve models for residential and alternative community

services; (9) Promote evidence-informed practice models and technical assistance; (10) Implement strategies that enhance the workforce.

[96] See ICMHP Annual Report for 2015 at http://icmhp.org/wordpress/wp-content/uploads/2016/01/FINAL-FY-15-ICMHP-Annual-Report-9-28-15.pdf

[97] See the IDPH State Health Improvement Plan, http://www.idph.state.il.us/ship/icc/, at footnote 14

[98] See Health and Human Services Transformation Town Hall, Chicago, Illinois, June 22, 2016 at https://www.illinois.gov/sites/hhstransformation/overview/Documents/HHST-Chicago-TH-PP-Public.pdf

[99] See also Stroul, B., Pires, S., Boyce, S., Krivelyova, A., & Walrath, C. (2014). Return on investment in systems of care for children with behavioral health challenges. Washington, DC: Georgetown University Center for Child and Human Development, National Technical Assistance Center for Children's Mental Health. https://gucchdtacenter.georgetown.edu/publications/Return_onInvestment_inSOCsReport6-15-14.pdf

[100] See, HFS' 1115 Demonstration Waiver, footnote 41.

[101] ICMHP testified at a public hearing on September 9, 2016 and submitted written comments on September 30, 2016.

[102] See, HFS' 1115 Demonstration Waiver, footnote 41. The waiver did not specifically address trauma though HFS acknowledged many comments about it and replied that services would be trauma-informed. Specifically, in comments on p. 134, HFS responded "The State recognizes the importance of addressing trauma, adverse childhood experiences, and the impact of violence as well as the importance of providing transitional services for transition-age youth. Services in the waiver as well as services rolled out through SPAs (e.g., IHHs) aim to take a person-centered, trauma-informed approach to care to address these issues."

[103] Comments were submitted on September 29, 2017. Mike Kelly, Ph.D., co-chair of ICMHP's School Age Committee testified on behalf of the Partnership on October 2nd.

[104] Several ICMHP members commented on drafts and Colleen Cicchetti spoke at the press conference. http://www.acesconnection.com/blog/legislation-to-be-introduced-soon-in-us-house-and-senate-to-address-trauma

[105] Several ICMHP members commented on drafts and Colleen Cicchetti testified at...

[106] See http://www.paynowillinois.org

[107] https://www.aclu-il.org/en/cases/bh-v-sheldon

[108] https://www.aclu-il.org/en/cases/rj-v-jones

[109] https://www.illinois.gov/hfs/info/legal/Pages/N.B.vNorwood.aspx


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