IDHS
ILLINOIS DEPARTMENT OF HUMAN SERVICES

JB Pritzker, *Governor*

Dulce M. Quintero, *Secretary Designate*

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DATE: March 28, 2024

MEMORANDUM

TO: The Honorable John F. Curran, Senate Minority Leader
The Honorable Don Harmon, Senate President
The Honorable Tony McCombie, House Minority Leader
The Honorable Emanuel "Chris" Welch, Speaker of the House

FROM: Dulce Quintero
Secretary Designate
Illinois Department of Human Services

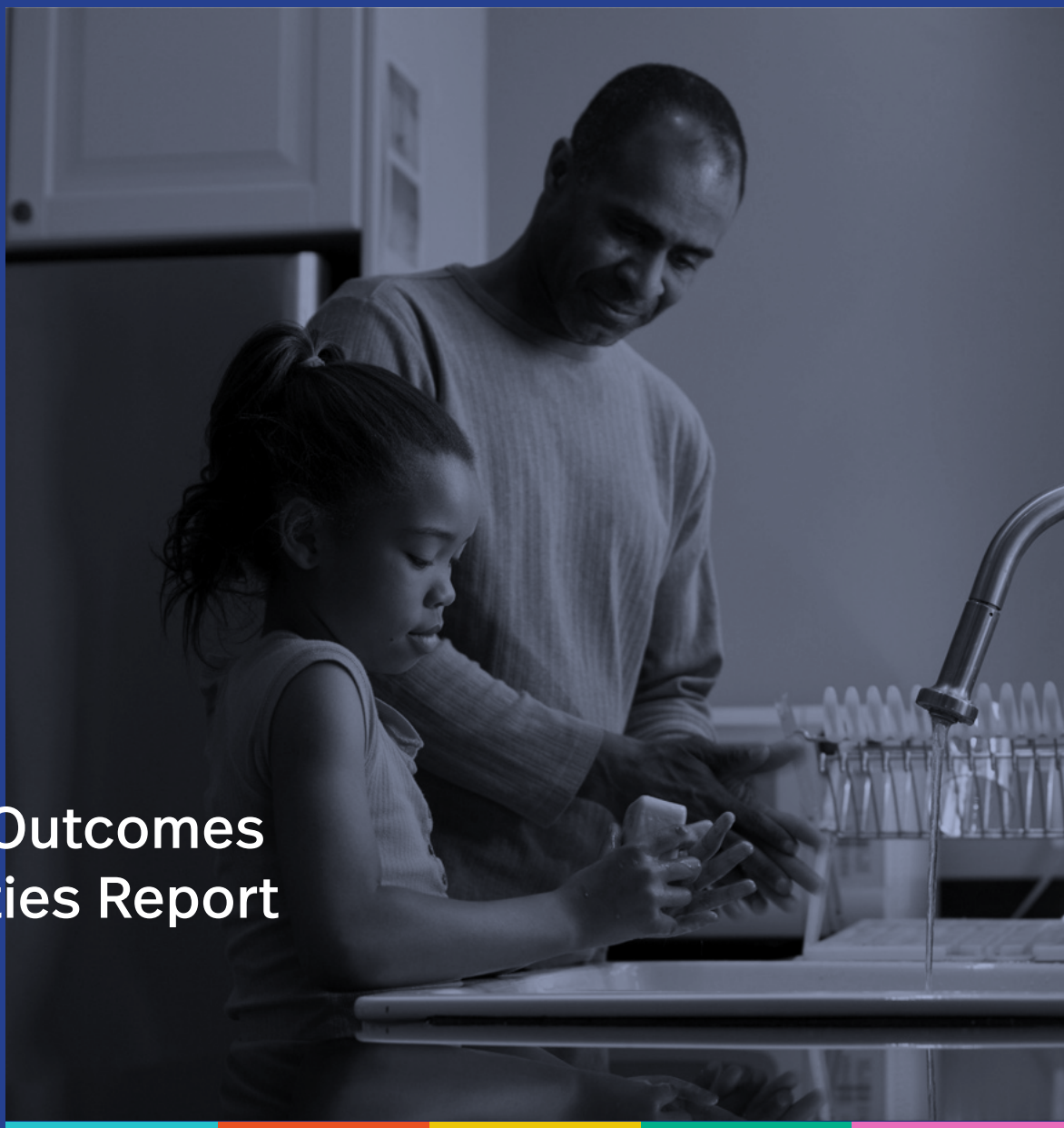
SUBJECT: **Health and Human Services Task Force Health Outcomes Disparities Report 2024**

The Illinois Department of Human Services respectfully submits the Health Outcomes Disparities Report on behalf of the Health and Human Services Task Force in order to fulfill the requirements set forth in 20 ILCS 5175.

If you have any questions or comments, please contact James Pagano, Senior Policy Advisor, at James.H.Pagano@illinois.gov.

cc: The Honorable JB Pritzker, Governor
John W. Hollman, Clerk of the House
Tim Anderson, Secretary of the Illinois Senate
Legislative Research Unit
State Government Report Center

Illinois Department of Human Services



Health Outcomes Disparities Report 2024

Executive Summary

Multiple health studies have found disparities in health outcomes and systemic inequities in access to health and human services, which contribute to Black and Brown populations having shorter life spans than White populations on average.

The Health Care and Human Service Reform Act led the Illinois Legislative Black Caucus to conclude that to improve health outcomes for Black Illinoisans, it is necessary to dramatically reform the State's health and human services system by 1) increasing access to needed healthcare and social services and 2) improving collaboration and data sharing across state agencies and other key health stakeholders. In response to this call for change, the Health and Human Services Task Force was created within the Illinois Department of Human Services (IDHS) to systematically review the State's health and human services landscape to improve health outcomes for Illinois residents.

By surveying the disparities in health outcomes across the health and human services field, this report identifies key social factors critical to improving access to the resources necessary for achieving health and well-being. Furthermore, it outlines a plan for making Illinois' care system more responsive to the needs of historically marginalized communities so that all Illinois residents have equal opportunity to realize their full human potential.

Key Findings

Many of the root causes of health disparities in Illinois stem from the challenges systems face in meeting vulnerable communities' complex and diverse health needs. The inability to adequately address these challenges perpetuates barriers that continue to thwart health, including a lack of access to high-quality health and social support services, lack of trust in systems of care, not centering the community voice in decisions, the prohibitively high cost of care, a lack of focus on prevention and wellness, the siloing and lack of collaboration across sectors and state agencies, and a lack of data and system interoperability.

It is imperative for care systems to remedy a legacy of structural racism that disenfranchised generations and created lasting mistrust. As identified in the Task Force's recommendations, remediation must be anchored in dialog and shared decision-making with communities to create conditions that will enable human flourishing.

Recommendations

The Health and Human Services Task Force developed five key recommendations for developing innovative care systems to reduce health disparities. These recommendations are intended to advise the Office of the Governor and Illinois General Assembly on how to improve interoperability and cooperation between the Medicaid program and other agencies to address a range of drivers of health and wellness, including food, housing, environment, employment, education, public support services, and costs related to better health outcomes. Recommendations may also be used to advise on public policies for better coordination of care between Federally Qualified Health Centers (FQHCs) and safety-net hospitals, educating and integrating trauma-informed approaches into state agencies and programs, and developing public policies to address gaps or deficiencies in access to education and health services, particularly in African American and minority communities.

The Task Force recognizes that the ongoing internal work within the identified agencies - including IDHS, HFS, and IDPH - was not thoroughly investigated or recognized due to time constraints. Therefore, recommendations are meant to outline a broad and systematic approach to solving identified needs and barriers in the State's care systems.

Strategic Outline for Key Recommendations

1 ADDRESS THE SIX KEY HEALTH-RELATED SOCIAL NEEDS DRIVING POOR HEALTH OUTCOMES

The State and its agencies should consider making additional investments in expanding access to:

1. Affordable housing and homelessness prevention programs
2. High-quality educational opportunities
3. Gainful employment opportunities
4. A stable and living wage
5. Safe and inviting environments (free from violence)
6. Healthy and affordable food

2 EXPAND ACCESS TO HIGH-QUALITY HEALTHCARE

The State and its agencies should build on the work already being done and consider additional investments that increase access to high-quality healthcare for areas in the state with reported limited access. Such investments could include:

- Additional funding for community health centers and other solutions that put high-quality care closer to communities in need
- Expanded access to community-based, culturally fluent supportive services such as mental healthcare and substance use disorder treatment
- Development of combined health and social services wraparound supports that focus on the whole person
- Expanded and improved care coordination and navigation services
- Implementation of telehealth services that help close the digital divide
- Decrease prohibitive out-of-pocket healthcare costs
- Address workforce gaps in the healthcare sector
- Ensure physical environments, language, and intellectual diversity are not barriers to high-quality care

3 REDUCE DISPARITIES ACROSS FIVE KEY HEALTH OUTCOMES AREAS (MATERNAL HEALTH, MENTAL HEALTH, TRAUMA, CHRONIC DISEASES, AND DISABILITY)

Additional investments by the State to improve key health outcomes could:

- Increase access to healthcare services reflective of needs in communities facing significant disease burden
- Expand access to supportive and culturally relevant services for health needs from “people who look like me” and “who I can relate to”
- Address implicit bias and racism within healthcare systems
- Address physical and intellectual disability barriers within health and social service systems
- Develop continuous funding models and sustainable solutions specific to communities in need

4 PROMOTE HEALTH EQUITY AND COMMUNITY VOICE IN HEALTH AND HUMAN SERVICES DECISION-MAKING

The State and its agencies should consider additional investments in health equity that:

- Direct resources to historically marginalized communities and those with the greatest need
- Center community voice in conversations and decisions about the state of health in the community
- Assure that community knowledge and assets are valued and an integral part of any decision or communication
- Fund more community-based and community-driven solutions organized by and taking place within BIPOC (Black, Indigenous, and People of Color) communities
- Address systemic racism and discrimination in health care and social services

5 IMPROVE HEALTH AND HUMAN SERVICES SYSTEMS IN SUPPORT OF COLLABORATIVE CARE MODELS

The State should consider additional investments in its agencies that:

- Quickly improve data sharing and system interoperability towards better customer care and service experiences
- Create a culture of sharing and collaboration across departments and agencies
- Assure state services, both in-person and online, meet the complex and multiple needs of communities

It is the shared hope of the Task Force that this report lends a sense of urgency to the vital work that must be done to realize needed changes for ensuring the well-being of Illinois and all its residents.

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SECTION ONE

Introduction

On April 27, 2021, the Illinois General Assembly enacted Public Act 102-004, referred to as the Illinois Health Care and Human Service Reform Act. As part of the Illinois Legislative Black Caucus' healthcare pillar, this legislation is ambitious in its vision to address health inequities and obstacles by establishing new programs, increasing oversight and training, and improving transparency. The Act will expand healthcare access and equity, improve children's health, women's health, and mental health, address substance abuse, and improve quality care for all Illinois residents.

The Act cites a 2019 Rush University report that found an 11-year life expectancy gap between a Black person (71 years) from the Austin neighborhood on Chicago's West Side compared to a White person (82 years) living in downtown Chicago. It references reported disparities in health outcomes for cancer, cardiovascular disease (CVD), COVID-19, diabetes, HIV/AIDS, maternal morbidity, and a range of other health indicators. The extent of these long-known inequities led the Illinois Legislative Black Caucus to conclude that it is necessary to dramatically reform the State's health and human service system to improve health outcomes.

To this end, the Illinois Department of Human Services (IDHS) created the Health and Human Services Task Force (20 ILCS 5175) to systematically review health and human service departments and programs to improve health and human service outcomes for Illinois residents.

Co-chaired by Senator Mattie Hunter (Illinois' 3rd District) and Representative Camille Lilly (Illinois' 78th District), members of the Health and Human Services Task Force share an ambition to achieve a system in which collaboration and data sharing across state agencies and other key health stakeholders increases access to needed healthcare and social services. With shared objectives of increasing interagency interoperability and the goal of health equity, the Health and Human Services Task Force assembled members from the Department of Human Services, Department of Children and Family Services, Department of Healthcare and Family Services, Department on Aging, Department of Public Health, Department of Veterans Affairs, and Department of Insurance, along with local government stakeholders and nongovernmental partners engaged in direct human services and advocacy. Based on a review of the current health and human services landscape, using a health equity lens, members of the Task Force focused their recommendations on improving the health and well-being of its historically underserved and vulnerable populations.

Since July 2022, the Task Force has met regularly to carry out its mandate. Four subcommittees were created and focused their efforts on healthcare outcomes and reduction of healthcare disparities, health-related social needs (previously referred to as social determinants of health), workforce competency and diversity, and data sharing and collection. Work sessions facilitated by the University of Illinois Chicago (UIC) Institute for Healthcare Delivery Design identified four defining qualities of an ideal healthcare model: *people-centered, collaborative, community-anchored,* and *prevention-focused*. Defining such a model became the basis for the Task Force's five strategic areas of focus outlined in this report.

Task Force Membership

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Approach

House Bill 0158 calls for the Task Force to address health disparities, the social determinants of health, workforce, education, health equity, and the ability for agencies to work together in pursuit of healthy people and communities.

The Task Force sets forth five key decisions about its approach to meet the broad mandate:

- Develop a North Star (a vision of Illinois in which its systems achieve health equity and create conditions for human flourishing for all Illinoisans) and share this definition of health to guide the work.
- Identify system-level needs and solutions addressing ongoing health disparities.
- Utilize prior research and reports on poverty, homelessness, and other health-related social needs driving poor health outcomes among Black and Brown communities in Illinois.
- Leverage Task Force members' expertise and lived experiences to inform the understanding of the health landscape and how identified needs might be met. (Task Force member quotes gathered from one-on-one interviews are included throughout the report.)
- Task Force meetings were open to the public, with an allotment of time given during the meetings for community input.

Defining Health

The World Health Organization defines health as *"a state of complete physical, mental, and social well-being and not merely the absence of disease and infirmity."*[1]

In Illinois, many systems addressing health remain focused on treatment instead of prevention and "complete" health. In response, the Task Force aligned on a shared health definition consistent with the above definition. Task Force members agreed that a well-functioning health system should integrate services and programs across state agencies to provide equitable access to resources people need to live healthy and productive lives, including access to:

- Safe and healthy physical environments (free of violence)
- Secure, high-quality housing options
- Healthy, high-quality food
- Safe and reliable transportation
- High-quality educational opportunities
- High-quality employment opportunities and the ability to earn a living wage
- High-quality healthcare
- High-quality health insurance
- An inclusive community/society free from racism and other forms of discrimination

REORIENTING ILLINOIS HEALTH AND HUMAN SERVICES: FROM – TO DIAGRAM

To bring about substantive change in the health of all its residents, Illinois must shift from:

Defining health in terms of its physical expression…	→	to an expanded definition that includes mental, emotional, financial, and social health and well-being
Systems oriented to individuals' health…	→	to those that also support community health
Siloed service systems…	→	to collaborative and integrative ones
Focus on treatment delivery and commitment…	→	to prevention practices

02
SECTION TWO

Persistent Health Disparities Highlights Gaps Across Illinois' Health Ecosystem

Figure 30. A Strategy for Solving for Health Disparities and Achieving Individual and Community Health

To solve disparities in health outcomes and help all communities achieve whole health, the state and key health players must...

1 Improve health outcomes related to the five highest health outcomes disparities	2 Address key HRSN factors as a preventative approach to care	3 Address root causes to health and HRSN disparities across the health landscape
Maternal and Infant Health, Youth and Adult Mental Health Trauma/Adverse Childhood Experiences Chronic Diseases including Cancer Physical and Cognitive Disabilities	Healthy communities free from violence Stable and quality housing Access to high quality education Access to a stable and living income Access to high quality food, Meaningful relationships Feeling valued by your community Access to high quality healthcare Access to affordable high-quality insurance	Lack of access to high-quality health and social support services Lack of trust in systems of care Not centering the community voice in decisions Prohibitive costs of care Lack of focus on prevention and wellness Siloing and lack of collaboration across sectors and agencies Funding models that limit impact Lack of data and system interoperability

Target Audience Impacted

This report aims to provide a blueprint for achieving health equity throughout Illinois by identifying methods and responses to the needs of historically marginalized communities within Illinois' healthcare systems. A lack of investment in Illinois' Black, Brown, and rural communities has left many Illinoisans disconnected from services that impact their health outcomes. The Task Force seeks to inspire and make recommendations to build upon existing strategies to address further and take steps to rectify the inherent structural racism and other barriers of Illinois' health and human services infrastructure so that people of color, immigrants, those with disabilities, and other marginalized populations across the state have equal opportunity to realize their full human potential.

Key Health Outcomes Disparities

The Health Care and Human Service Reform Act identified key health outcome disparities across COVID-19 mortality rates, maternal and infant health, trauma and adverse childhood experience, youth and adult mental health, chronic diseases, and physical and cognitive disabilities.

LEARNING FROM COVID-19 MORTALITY

The arrival of the SARS-CoV2 virus (COVID-19) in 2020 brought wide-scale illness and death to the State of Illinois, the nation, and the world. It became evident early in the pandemic in Illinois and across the country that the devastations of COVID-19 affected racial and ethnic groups in far greater numbers than White counterparts. In 2020, Black people represented 30% of Chicago's population but accounted for a disproportionate 60% of COVID-19 deaths in the city that year[2]. Though this stark statistic has declined, racial disparity in COVID-19 mortality persists. As of January 2023, Black Chicagoans accounted for 41.8% of all deaths from COVID-19 in comparison with 29.2% Latino/a/x and 23.7% White Chicagoans.[3]

Multiple drivers accounted for differences seen in mortality, many rooted in longstanding structural racism. Living in crowded and poorly ventilated housing and using public transportation were major disease factors that spread disproportionately, affecting low-income communities. Higher rates of preexisting chronic conditions like high blood pressure and diabetes in Black populations also contributed to higher rates of mortality. The prevalence of such conditions is attributable significantly to social and economic factors such as lack of access to healthy food or safe neighborhoods where a person can walk and exercise.

Difficulty accessing health care and not having health insurance or only limited coverage became another barrier to marginalized Illinois residents getting needed care during the pandemic. In response, the Illinois Department of Healthcare and Family Services (HFS) sought and received federal approval to implement the COVID-19 Uninsured group, a partial benefit Medicaid eligibility group that covered COVID-19 testing, specimen collection, vaccine administration, monoclonal antibody treatment and administration, and oral antivirals without premiums or co-pays and regardless of income level. Additionally, Illinois became the first state in the nation to provide health coverage for low-income seniors, regardless of immigration status. HFS implemented the Health Benefits for Immigrant Seniors program in December 2020 to provide Medicaid-like health coverage for noncitizens aged 65 and older who are ineligible for Medicaid solely because of their immigration status. Health Benefits for Immigrant Adults, an expansion of this program, was implemented in 2021 for noncitizens ages 42 and older.

These measures eased some of the economic disparity that contributed to increased mortality in Black and Brown communities during the pandemic. However, many low-income Illinois residents - who often hold jobs without health insurance –still faced increased risk of infection as they worked "essential" jobs.

> *"I don't think there [are] adequate resources, and I think as a result of the pandemic it has gotten worse"*
> *NAMI CHICAGO FOCUS GROUP PARTICIPANT*

Stark outcome disparities in the early phase of the pandemic made apparent the high cost of structural racism and the perpetuated health inequities. Urgent plans attempted to address these issues.

- In 2020, Chicago Mayor Lori Lightfoot established the Racial Equity Rapid Response Team (RERRT) to develop hyperlocal, data-informed, and community-driven strategies to slow the spread of COVID-19 and improve health outcomes among communities most heavily impacted
- Governor Pritzker's Office developed the Pandemic Health Navigator Program (PHNP), launched in partnership with the Illinois Public Health Association (IPHA), the Illinois Primary Health Care Association (IPHCA), and the OSF Healthcare System. The program integrates community health centers, community-based organizations, and public health partners to coordinate available resources for Illinois regions that the COVID-19 pandemic has most impacted
- Illinois Department of Public Health (IDPH) leveraged detailed state-level data tracking to monitor the disease and worked closely with local public health authorities to address their needs

These approaches indicate ways in which the State might address other longstanding and systemic outcomes inequities in Black and Brown communities. Developing similar hyperlocal, data-informed, and community-driven strategies for the entire State is critical to addressing the other pronounced health disparities in Illinois discussed in this report.

> *"We need to look at what we did for COVID, how we used Care Navigators to reach all these people, and we need to do that for all these other health issues."*
> *TASK FORCE MEMBER*

MATERNAL AND INFANT HEALTH

Maternal Morbidity and Mortality. The Eunice Kennedy Shriver National Institute of Child Health and Human Development describes maternal morbidity as "any short- or long-term health problems that result from being pregnant and giving birth" and maternal mortality as "the death of a woman from complications of pregnancy or childbirth that occur during the pregnancy or within 6 weeks after the pregnancy ends.[3]"

The United States is the only industrialized country in the world with a rising maternal mortality rate, which is now higher than it was at the end of the twentieth century. The National Center for Health Statistics Maternal Mortality Rates in the United States (2021) reported that the maternal mortality rates for Black women were 2.6 times the rate for White women.[4] Across the country and within Illinois, deaths of pregnant women or within one year of pregnancy remain unacceptably high. The Illinois Department of Public Health (IDPH) in its Illinois Maternal Morbidity and Mortality Report (2016-2017)[2] included the following key findings:

- 34% of women who died while pregnant or within one year of pregnancy died from a cause related to pregnancy
- The leading cause of pregnancy-related death was mental health conditions, including substance use disorders, which comprised 40% of pregnancy-related deaths. The next three most common causes of pregnancy-related death were pre-existing chronic medical conditions that were exacerbated by pregnancy, hemorrhage, and hypertensive disorders of pregnancy
- Black women were about three times as likely to die from a pregnancy-related condition as White women
- Hispanic women had rates of severe maternal morbidity that were approximately 20% higher than White women
- Black women were more likely to die from pregnancy-related medical conditions, while White women were more likely to die from pregnancy-related mental health conditions
- One-third of pregnancy-related deaths occurred more than two months after pregnancy
- 83% of the pregnancy-related deaths were potentially preventable

Figure 2. Top Four Underlying Cause of Death Categories for Pregnancy-Related Deaths, Illinois 2016-2017

Cause of Death Category	Number of pregnancy-related deaths	Percent of pregnancy-related deaths
Mental Health Conditions*	24	40%
Pre-existing Chronic Medical Condition**	5	8%
Hemorrhage	5	8%
Hypertensive Disorders of Pregnancy	5	8%

Due to rounding, percentages in this figure do not add up to 100%
Image: Illinois Maternal Morbidity and Mortality Report 2016-2017

> *"I mean, I just recently saw some literature about [it] - It's definitive, it's not anybody's talking point any longer that Black women have disproportionately high numbers of infant mortality, death, and adverse outcomes."*
>
> *TASK FORCE MEMBER*

The Pritzker Administration and Illinois legislature are taking action to address these alarming disparities.

In April 2021, Illinois became the first state in the country to receive approval for federal matching dollars to provide full-benefit Medicaid coverage for 12 months postpartum with continuous eligibility

- In fall 2021, Illinois became the first state in the country to provide this coverage regardless of immigration status with a federal match

Acknowledging that providing coverage alone is not a silver bullet, the Illinois HFS and IDPH maternal health teams applied for, and were one of eight states selected for, a National Academy for State Health Policy & Maternal Health Policy Improvement Academy

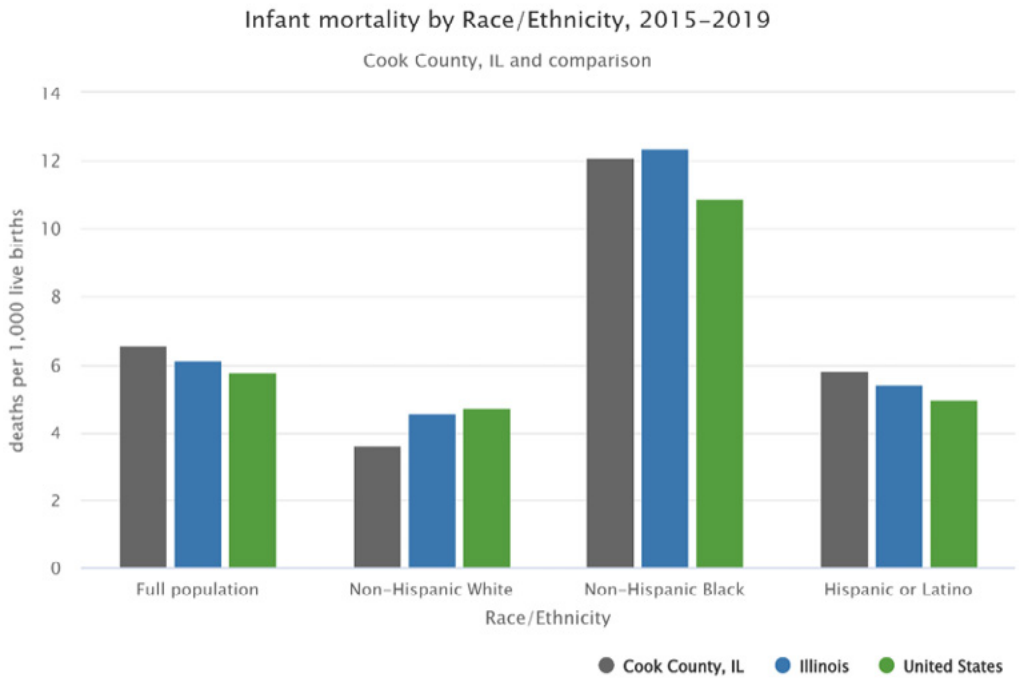
- The HFS and IDPH teams have worked together to identify and implement changes to reduce health disparities and improve health outcomes for birthing people in Illinois. HFS added 1) a second-covered Medicaid preventive postpartum visit (one at 0-3 weeks postpartum and one at 4-12 weeks postpartum) in alignment with an American College of Obstetricians and Gynecologists (ACOG) recommendation (and is working to implement provider bonus payments when preventive postpartum care is provided within the ACOG recommended windows); 2) increased prenatal and postpartum rates effective January 1, 2023, and then increased prenatal, postpartum, and labor and delivery rates further to 80% of Medicare within the FY24 budget to increase timely access; and 3) broke out the maternal child health Medicaid managed care quality measure results by race, ethnicity, and disproportionately impacted area (DIA) zip codes

Beyond physical and psychological factors driving high rates of maternal mortality in Black women, social and structural issues add to reported disparities. Several obstetric units were either temporarily or permanently closed on Chicago's majority Black South Side due to economic reasons in 2019 and after the arrival of the COVID-19 pandemic in 2020. Closures of the obstetric units on the South Side left only three remaining birthing hospitals to serve Chicago's largest geographic area, whereas the city's other two areas - the North and West Sides - are served by six obstetric units each. The reduction or lack of perinatal resources close to where pregnant women live could put them at risk for increases in maternal mortality.

The April 2021 Illinois Maternal Morbidity and Mortality Report stated that while maternal health is complex and multi-faceted, "it is important to recognize how systematic racism such as redlining policies has negatively impacted communities of color by creating barriers to health, and how

Figure 3. Infant Mortality Rates in the US Compared to Illinois and Cook County, IL. 2015-2019

Image: 2019 Alliance for Health Equity Community Health Needs Assessment



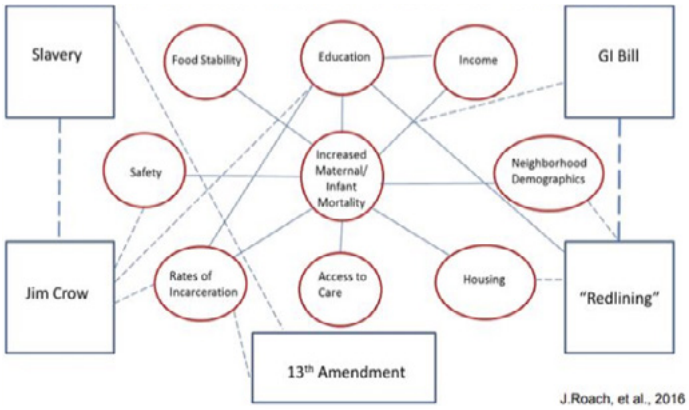
these barriers directly influence a woman's ability to have a healthy pregnancy." The report cites a study in Chicago that found redlined Black-majority communities had higher preterm birth rates than Black-majority communities that were not redlined. It has been written that continuing to frame maternal mortality rates as "health disparities" implies that the concern is a matter of differences in outcomes and not structural racism[1]. However, an emerging body of evidence underscores the role of structural racism in maternal health outcomes. Women who experience racism and discrimination in their prior encounters with the medical system may avoid seeking necessary prenatal care. As a result, women with pre-existing conditions go unrecognized or untreated and then find themselves at increased risk during pregnancy. The Illinois Department of Public Health concludes that addressing such social and structural barriers is essential to ensure equitable care for women.

To address some of these issues, HFS is working to implement new provider types and covered services within the Medicaid program, including doulas, certified professional midwives, home visitors, and community health workers. Additionally, HFS is funding Healthcare Transformation Collaboratives (HTC) that are testing new ways for providers and community-based organizations to work together to address social and structural barriers to health in their communities. Some of the HTCs are focused on improving maternal health, and all HTCs include community health workers in their initiatives to help connect Medicaid customers to services.

The HFS 1115 Healthcare Transformation waiver also seeks to bring federal Medicaid matching dollars to Illinois to test Medicaid coverage of Health Related Social Needs (HRSN) benefits, including housing support, nutrition services, and more. HFS selected the access to timely prenatal and postpartum care quality (HEDIS PPC) measures as the state's Performance Improvement Project (PIP). The PPC measure results are broken out by race, gender, and DIA zip code, and the PIP requires Medicaid Managed Care Organizations (MCOs) to identify a disparity gap within the PPC measure's results and test interventions to close it. As part of the PIP initiative, one MCO partnered with a Cook County Health ambulatory clinic for rapid turnaround on initial visits, and another MCO created a workgroup that included both MCO staff and healthcare providers to work together to improve outcomes. Medicaid MCOs have also created farmers' markets in some zip codes to support access to healthy food.

> *"The people we're talking about, they're middle or upper class. They've had all the childbirth and prenatal care that they can get. One of them was a physician that died. We're talking about racism here; we're talking about racial discrimination. We have the implicit bias that needs to be included, and we need to get the minds of these physicians that are just letting things go."*
>
> *TASK FORCE MEMBER*

Figure 4. ROOT Web of Causation – Structural and Social Determinant's Impact on Health



ROOTT Theoretical Framework. 15 This figure depicts the theoretical framework developed by ROOTT 15 used to identify structural and social determinants of maternal and infant mortality in the United States. Structural determinants are those depicted in boxes connected by dashed lines, which in turn shape the distribution of social determinants (those depicted in circles and connected by solid lines). The multiple and interconnected pathways between structural and social determinants lead to increased maternal and infant mortality rates and socially defined inequities in these outcomes. ROOTT, Restoring Our Own Through Transformation.

Image: 2019 Alliance for Health Equity Community Health Needs Assessment

> *"I believe African American women have a disproportionately high amount of infant mortality because they're walking into pregnancy with pre-existing conditions that are unmet. Because they [the pre-existing conditions] weren't met, because they didn't have health care. It is such a cycle and [...] where do we short circuit the cycle?"*
>
> *TASK FORCE MEMBER*

Infant Mortality. The Centers for Disease Control and Prevention defines infant mortality as *"the death of an infant before their first birthday.*[3]*"*

The most current available data from the Organization for Cooperation and Development ranks the United States 33 out of the 38 countries that report infant mortality. Racial disparity in infant mortality is pronounced across Illinois and the nation. Infants born to Black women are 2.5 times more likely to die before their first birthday than infants born to White women[3]. Leading causes of infant death in Illinois include prematurity and fetal malnutrition, birth defects, sudden unexpected infant death (SUID), and pregnancy and delivery complications. Among the leading causes of death, the largest racial/ethnic disparity occurs in SUID deaths and prematurity/malnutrition deaths, where infants born to Black/African American women are, respectively, six times and three times as likely to die than as infants born to White women[9].

It is estimated that between 15% and 20% of Black mothers in Chicago have low birth-weight babies, one of the leading

causes of Black infant death. This statistic rivals some of the poorest nations in the world, including Ethiopia at (20%), Chad (20%), Nigeria (15%), and Benin (15%).[3] In Illinois, Black infants die at rates twice as high as their White and Hispanic counterparts and three times higher in Cook County and Chicago[10].

Many of these noted infant mortality factors can be addressed through a more intense focus on maternal health through the duration of a pregnancy and are already being addressed in the Illinois Medicaid initiatives noted above in the Maternal Morbidity and Mortality section, which include focusing on improving access to timely prenatal care, new community provider types supporting birthing people, the Healthcare Transformation Collaboratives, and 1115 waivers to provide HRSN benefits.

Figure 5. 2019 Infant Mortality in Illinois by County of Residence

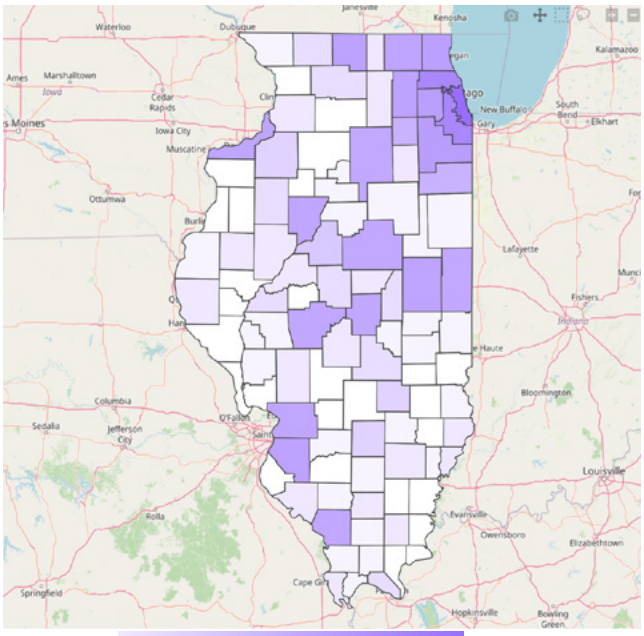


Image: Infant Mortality Statistics[11]

TRAUMA AND ADVERSE CHILDHOOD EXPERIENCES

Trauma. Trauma is perpetuating harm to Black and Brown communities across Illinois. The Illinois State Board of Education (ISBE) reports that large numbers of Illinois students have experienced trauma that can lead to behavioral or academic problems.[12] The Centers for Disease Control and Prevention defines trauma as "a physical, cognitive, and emotional response caused by a traumatic event, series of events, or set of circumstances that is experienced as harmful or life-threatening. Trauma can have lasting effects, particularly if untreated."[13]

Trauma can be caused by a range of experiences, including racism, discrimination, historical oppression, poverty, homelessness, or experiences with violence and drug overdose. Situations that may be traumatic include but are not limited to abuse, abandonment, death of a loved one, a serious accident, witnessing violence, being bullied, incarceration of a loved one, and life-threatening situations. Trauma thrives in an environment of high social vulnerability where people do not have access to life-saving social services like housing and food and is seen at incredibly high rates in areas of high social vulnerability and violence. Emerging research has documented relationships among exposure to traumatic events that can result in impaired neurodevelopmental and immune system responses as well as subsequent health risk behaviors that can result in chronic physical or behavioral health disorders.

Trauma also impacts communities. Community trauma, or collective trauma, is "*an aggregate of trauma experienced by community members or an event that impacts a few people but has structural and social traumatic consequences.*"[14] "The symptoms of community trauma are the product of decades of economic, political and social isolation, a lack of investment in economic development and for the maintenance and improvement in the built environment, the loss of social capital with the flight of middle-class families, and the concentration of poverty and exposures to high levels of violence."[15]

> *"I read books dealing with trauma, and so the children [would] begin to start talking about, "My brother died, and I saw him in the street." Now, I could be sympathetic and empathetic, but I don't know how to deal with trauma!"*
>
> *TASK FORCE MEMBER*

Adverse Childhood Experiences (ACEs). The Centers for Disease Control and Prevention defines adverse childhood experiences, or ACEs, as "potentially traumatic events that occur in childhood (0-17 years)."[16] ACEs are linked to chronic health problems, mental illness, and substance use problems seen in adolescence and adulthood and can impact a person's ability to thrive.

Examples of ACEs include:
- Experiencing violence, abuse, or neglect
- Witnessing violence in the home or community
- Having a family member attempt or die by suicide

Also included in ACEs are aspects of the child's environment that can undermine their sense of safety, stability, and bonding, such as growing up in a household with:
- Substance use
- Mental health issues
- Instability due to parental separation or household members being in jail or prison

In Illinois, 18.5% of young Black adults experienced four or more different types of ACEs compared to 13.7% experienced by their White counterparts.[17] Research indicates that youth with four or more ACEs are at three times the risk for depression.

When addressing ACEs and suspected cases of physical abuse, social service agencies, and providers may take action to remove the child from the home environment. Though well-intentioned, the action may, for some children, also be traumatic. Implementing trauma-informed training programs within social service agencies and community-based providers can help minimize such possibilities.

The Task Force urges Illinois' entire health and human services system to adopt trauma-informed care practices to gain proficiency in recognizing and treating trauma in those it serves. Illinois must do more to address the root causes of trauma and develop programs and services to attend to them proactively.

HFS introduced the Violence Prevention Community Support Team (VP-CST) into the Medicaid service array effective May 1, 2022. VP-CST is a specialized model of team-based mental health care that delivers culturally responsive, evidence-informed trauma recovery services and support to Medicaid-eligible children and adults who have been exposed to firearm violence. Additionally, HFS requests expenditure authority through an 1115 demonstration waiver to bring additional activities to local communities to support and expand the violence prevention work resulting from the Reimagine Public Safety Activity (RPSA) in Illinois. HFS is proposing actions such as evidence-based coaching programs that will assist youth and young adults to identify job and career options and provide resiliency training.

> *"Is there some way that we can partner with hospitals even if they just came and had a little healing circle once a week with my kids?" Because they keep living with this trauma, and never dealing with it, it's going to affect them."*
>
> *TASK FORCE MEMBER*

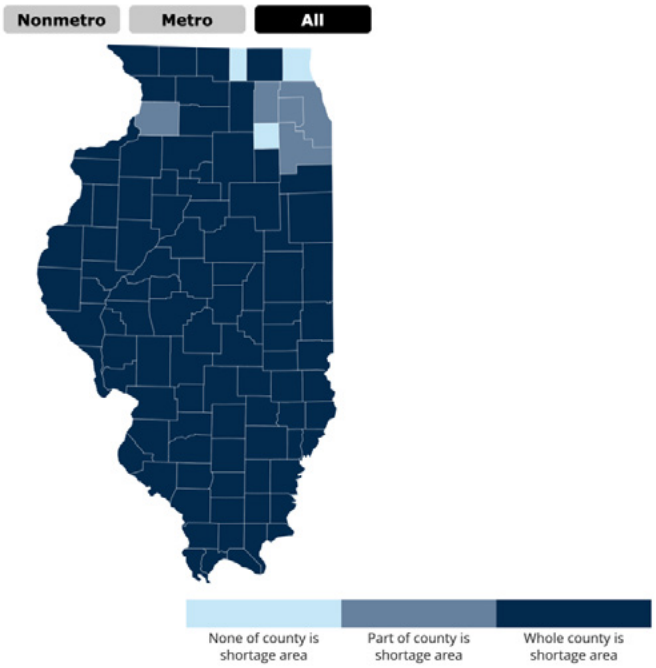
> *"Trauma doesn't just actualize physically; trauma could also come from lack of housing, food insecurity."*
>
> *TASK FORCE MEMBER*

YOUTH AND ADULT MENTAL HEALTH

The Centers for Disease Control and Prevention define mental health as *"including a person's emotional, psychological, and social well-being."*[18]

Mental health affects how a person thinks, feels, and acts and can determine their ability to handle stress, relate to others, and make healthy choices. Mental health is important at every stage of life, from childhood and adolescence through adulthood. "*For example, depression increases the risk for many types of physical health problems, particularly long-lasting conditions like diabetes, heart disease, and stroke. In the U.S., more than 1 in 5 adults live with a mental illness, and 1 in 5 youth (ages 13-18), either currently or at some point during their life, have had a seriously debilitating mental illness*"[18].

Figure 6. Health Professional Shortage Areas: Mental Health, by County, 2022 - Illinois



Source: data.HRSA.gov, November 2022.

According to the Substance Abuse and Mental Health Services Administration (SAMHSA), the agency within the U.S. Department of Health and Human Services that leads public health efforts to advance the behavioral health of the nation, rates of behavioral health disorders among different racial groups do not significantly differ, *"but Blacks and Latinos have substantially lower access to mental health and substance-use treatment services."*[19] Consequently, *"Blacks and Latinos with mental health and substance- use disorders are more likely to be incarcerated and experience homelessness than the general population"*[19].

SAMHSA also reports that while Blacks have similar rates of opioid misuse as the general population, in recent years, they have experienced the greatest increase in the rate of overdose deaths from non-methadone synthetic opioids. In Chicago, a research-based consultancy named Ujima conducted a study and found that 66% of young Black and Brown men report facing challenges with their mental health, with 55% of them considering professional counseling if given the chance.[20] Yet, these groups are less likely to receive appropriate care for reasons of cost, insurance, and availability. The above statistics highlight a pronounced need that is going unmet. This situation warrants a cohesive campaign and needed changes to the State's care systems to address this critical matter.

"The Kaiser Family Foundation estimates that only 23.3% of Illinoisans' mental health needs can be met with its current workforce."[21] Inadequate workforce capacity has contributed to a statewide crisis in behavioral health access. Presently, it can take up to 6 months to be seen by a psychiatrist. In other

cases, services are unavailable because vacancies for needed social workers and other behavioral health professionals have gone unfilled. The issue is particularly acute in less densely populated parts of the state. *"93.7% of Illinois' rural hospitals are in designated mental health shortage areas"*[21].

Similarly, appropriate high-quality mental health care for children, adolescents, and young adults is severely limited despite continually rising rates of depression, anxiety, suicide attempts, and other mental health conditions among this demographic.[22] According to the Behavioral Health Workforce Education Center Task Force Report, *"Half of all lifetime cases of mental illness begin by age 14, but the average delay in receiving diagnosis and treatment is 8 to 10 years,* and *"Shortages of behavioral health professionals with these specific skills interfere with access to effective infant and early childhood mental health care."*[23]

In March of 2022, Governor Pritzker launched the State of Illinois Overdose Action Plan,[24] a comprehensive, equity-centric outline for combating the opioid epidemic, and he named David T. Jones, the State's Associate Secretary for Behavioral Health at the Illinois Department of Human Services, to be known as the Chief Behavioral Health Officer (CBHO). The CBHO seeks to transform how Illinois supports mental, emotional, and overall behavioral health wellness for everyone.

Figure 7. Correlation Between Self-reported Poor Mental Health and Poor Self-reported Physical Health in the United States, 2019
Image: 2019 Alliance for Health Equity Community Health Needs Assessment

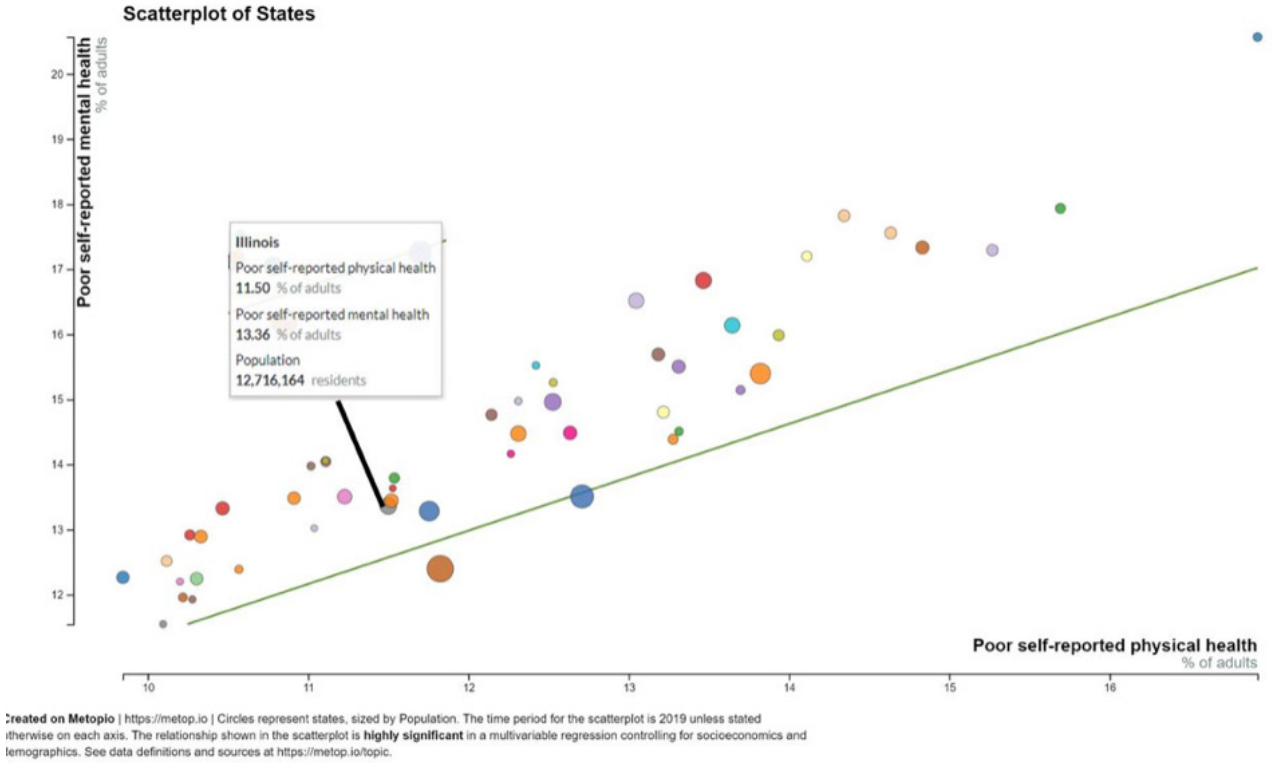


Figure 8. Self-reported Depression Among Youth in Illinois
Youth Risk Behavior Surveillance System (YRBSS), 2007-2019
Image: 2019 Alliance for Health Equity Community Health Needs Assessment

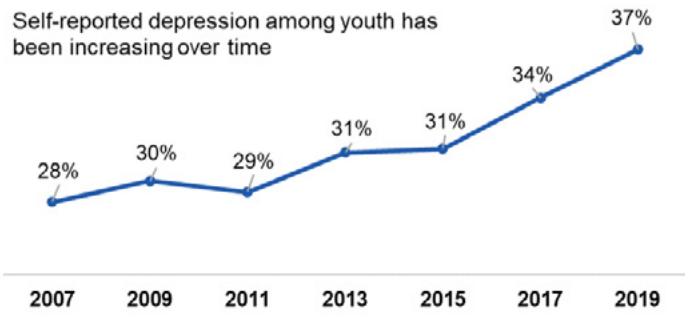
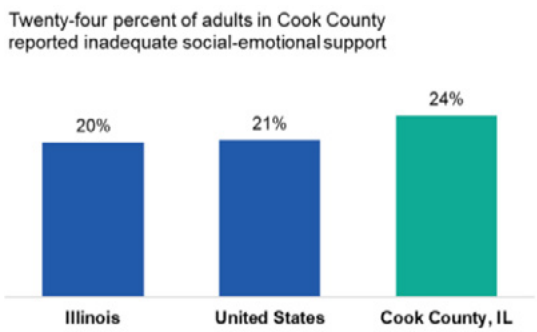


Figure 9. Percentage of Resident Adults Aged 18 and Older Who Report Inadequate Social and Emotional Support, Cook County, Illinois
Behavior Risk Factor Surveillance System (BRFSS), 2006-2012
Image: 2019 Alliance for Health Equity Community Health Needs Assessment



On February 24th, 2023, Governor JB Pritzker released a new report[25] from the Children's Behavioral Health Transformation Initiative[26] to address the specific need for Youth Mental Health. This initiative looks to redesign the delivery of behavioral health services for Illinois youth. A total of $10 million is being invested in a two-year expansion of Comprehensive Community Based Youth Services for youth aged 11 to 17 who are at risk of involvement in the child welfare system or the juvenile justice system. This funding will better equip these organizations to provide 24/7 services to youth – including assessments, crisis stabilization, and housing – while assisting the critical work of Department of Children and Family Services (DCFS) staff.

HFS also invests in enhancing services available to children and families with complex behavioral health needs by implementing Pathways to Success services and supports. These include specialized care coordination, Intensive Home-Based Services, Family Peer Support, Therapeutic Mentoring, Respite, and Individual / Therapeutic Support Services. HFS is establishing a statewide network of specialized Care Coordination and Support Organizations that will provide enhanced care coordination, Mobile Crisis Response, and additional providers offering the other Pathways to Success services. HFS has budgeted $100 million for the first year of the program. Investment is anticipated to increase in coming years as more providers are established and more youth are eligible for the Pathways to Success services and supports.

The continued lack of access to mental health providers in rural areas and low-income communities for youth and adults represents a major obstacle to achieving better health outcomes for all Illinoisans. The Task Force, therefore, recommends making it a top priority. In addition to providers, there is a critical need to create additional supplemental mental support (e.g Community Health Workers and Peer Advocates) to combat lengthy times to appointments with therapists, psychologists, and psychiatrists.

> *"[A] barrier is good insurance that allows people to access mental health services regularly alongside a steady income that covers copays."*
>
> *UCAN FOCUS GROUP PARTICIPANT-2019 COMMUNITY HEALTH NEEDS ASSESSMENT (CHNA)*

> *"A lot of people just don't have the luxuries I do [...] I have a client here now who came in, and he was suicidal, and he ended up in a hospital for a period of time. They released him back to us and said: "You know he needs to set up time with the psychiatrist." The only psychiatrist we could get was a telehealth [appointment] out of Chicago, and they said that would be about four months."*
>
> *TASK FORCE MEMBER*

SUBSTANCE USE DISORDERS

The Centers for Disease Control and Prevention (CDC) defines substance use disorders (SUD) as *"treatable, chronic diseases characterized by a problematic pattern of use of a substance or substances leading to impairments in health, social function, and control over substance use. It is a cluster of cognitive, behavioral, and physiological symptoms indicating that the individual continues using the substance despite harmful consequences."*[27] The CDC also states, *"SUDs can range in severity from mild to severe and can affect people of any race, gender, income levels, or social class."* [27]

The United States is experiencing an opioid epidemic. Drug overdoses are *"the leading cause of death nationwide for people under the age of 50"*[23]. The highest number of overdose fatalities ever recorded in a 12-month period occurred in 2021. This increase began before the COVID-19 pandemic but accelerated throughout 2020 and 2021[7]. According to the 2021 National Survey on Drug Use and Health (NSDUH) published by SAMHSA, the percentage of people aged 12 or older with an SUD was highest among young adults aged 18 to 25 (25.6% or 8.6 million people), followed by adults aged 26 or older (16.1% or 35.5 million people), then by adolescents aged 12 to 17 (8.5% or 2.2 million people).[28]

Figure 10. Deaths Per 100,000 Residents Due to Drug Poisoning (Such As Overdose), Whether Accidental or Intentional in Illinois

Chicago Department of Public Health (Epidemiology Department: Chicago community area level), National Vital Statistics System-Mortality (NVSS-M) (CDC Wonder), 2016-2020

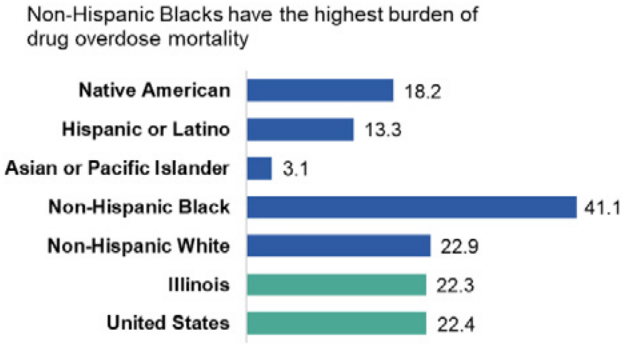


Image: 2019 Alliance for Health Equity Community Health Needs Assessment

The opioid epidemic is one of the most significant public health and public safety crises facing Illinois. More than 3,000 people died of overdoses in the State in 2021. *"The highest number of opioid fatalities in 2021 occurred in non-Hispanic White individuals (1,468), while the highest age-adjusted fatality rate was among non-Hispanic Blacks (60.8 per 100,000)"*, making it three times greater than that of non-Hispanic White individuals.[29] (Age-adjustment is a technique in which datasets with different ages undergo a statistical process to be compared in terms of health outcomes or disease rates.) During this same period, thousands of non-fatal overdoses led to emergency department visits, hospital stays, and negative impacts on individuals, families, and communities.

On March 21, 2022, Governor Pritzker announced the launch of The Statewide Overdose Action Plan (SOAP)[30], a strategic framework for moving toward the goal of reducing overdose deaths in Illinois. The plan recognizes that the overdose crisis has disproportionately impacted racial and ethnic minority communities and faces greater difficulties than White communities accessing opioid use disorder (OUD)/ SUD treatment and recovery support services. The action plan cites Illinois Department of Public Health data showing that while opioid overdose deaths among non-Hispanic White residents in Illinois decreased by 6.5% in 2018, deaths among non-Hispanic Black residents increased by 9.1%.[31] In 2020, non-Hispanic Black people were more than twice as likely to die from any drug overdose than non-Hispanic Whites[29]. It is worth quoting the plan at length to demonstrate the central importance of addressing racial and social disparities in the overdose crisis.

"To save lives, we must address the social inequities that underlie the racial disparities in overdose deaths. While social equity is one of the five categories that form the basis of the 2022 SOAP, it is also the lens through which we implement initiatives and assess our progress. This includes acknowledging the role of structural racism and social determinants of health and ensuring that every priority and recommended initiative takes these factors into consideration. It also includes actively involving people of color in developing and implementing recommended initiatives, as emphasized in the working social equity statement developed by the Council's Opioid Social Equity (OSE) Committee:

We recognize that communities have experienced structural racism, stigma and other systems of oppression and built strong, social, human, and cultural capital to manage racism and inequity. This capital must be the foundation of our efforts to redress health and social inequities. This means meeting people where they are, asking, listening to and using their definitions of justice and fairness, and ensuring that people who are impacted by a problem are involved in the decision-making and are part of the solution. Everyone should have a fair opportunity to attain their full health potential, and no one should be disadvantaged from achieving this potential. This includes addressing social, geographical, and structural determinants of health; focusing on humanistic, person-centered care; and developing just policies"[30].

> *"I think because we, as a society, put our dollars where our biases are [...] But -- and I am saying this as a society, 'I can't see or understand a person with addiction. I can blame the person with addiction...I can say, well, you shouldn't have used drugs.'"*
>
> *TASK FORCE MEMBER*

HFS implemented a $4.5 million grant from the federal Centers for Medicare & Medicaid Services (CMS) for the Illinois SUPPORT Act: Section 1003 Demonstration Project to Increase Substance Use Provider Capacity. Awarded in September 2019, the original planning grant focused on increasing provider capacity and patient access to office-based medication-assisted treatment (MAT) for Medicaid-eligible individuals as part of a comprehensive, public health approach to addressing the opioid crisis. To accomplish the goal of improving treatment capacity, HFS partnered with Cook County Health (CCH) and Southern Illinois Health (SIH) to complete activities under the grant, including a data-driven needs assessment for substance use disorder and opioid use disorder, increased training for MAT providers; expanded technical assistance for providers through in-person and web-based platforms; and improved accuracy of information collected for providers certified to prescribe MAT.

In August 2021, Illinois applied to CMS for and was one of five states awarded a 36-month post-planning demonstration grant. During the demonstration, Illinois will be eligible for enhanced FMAP of up to 80% for all eligible MAT services and treatments provided to Medicaid customers.

CHRONIC DISEASES

Chronic diseases[32] such as heart disease[33], cancer[34], and diabetes[35] are the leading causes of death and disability in the United States and leading drivers of the nation's $4.1 trillion in annual healthcare costs.[36] They are conditions that, in many cases, can be prevented through a healthy diet, regular physical activity, and avoidance of tobacco products. However, a healthy diet and regular physical activity can be more difficult to integrate into daily life if communities lack access to fresh food and neighborhoods are unsafe. The influence of environmental, social, economic, and psychological factors on chronic diseases cannot be minimized. Healthcare systems must recognize the unequal barriers different populations encounter when attempting to manage and prevent chronic diseases. Consideration of the conditions in which people reside needs to be reflected in new approaches to helping underserved populations achieve health.

Cancer, diabetes, heart disease, stroke, Alzheimer's disease, and pulmonary conditions account for the majority of the ten leading causes of death in Illinois, which make up approximately half of all deaths in a given year. The *January 2020 Health Disparities Report for Illinois and Illinois Counties 2020* found that Non-Hispanic Blacks had the highest age-adjusted death rate in three disease categories, all of which are chronic diseases *"The diabetes rate is nearly double for Blacks compared to any other race and ethnic category," and "nearly 15% of all Blacks had been told they had diabetes in 2015, compared to 10% of Whites"*[17].

Figure 11. Mortality Rates Per 100,000 Population in Chicago, Illinois (2015-2019)

Chicago Department of Public Health, Chicago Health Atlas. From Illinois Department of Public Health, Death Certificate Data Files

	2015	2016	2017	2018	2019	2020
Diabetes-related	64.6	63.4	59.5	59.7	58.8	155.3
Stroke	45.4	46.0	51.7	50.9	52.3	60.0
Cancer	190.4	185.9	179.2	175.6	177.6	173.8
Heart disease	207.4	207.1	201.3	208.5	208.4	229.4

Image: 2019 Alliance for Health Equity Community Health Needs Assessment

Figure 12. Mortality Trends in Suburban Cook County (2013-2017)

Illinois Department of Public Health, Division of Vital Records, 2013-2017

	2012	2013	2014	2015	2016	2017
Diabetes-related	49.8	44.2	50.4	48.8	39.4	40.0
Stroke	36.3	33.4	36.9	36.7	35.6	40.3
Cancer	173.6	168.9	168.1	168.9	161.2	163.3
Heart disease	165.0	164.0	164.8	164.4	149.5	158.9

Image: 2019 Alliance for Health Equity Community Health Needs Assessment

Solving the complex issues of chronic disease requires a coordinated effort across State of Illinois agencies, programs, and services to make individual and community health a top priority and not just a responsibility of hospitals. The American Cancer Society estimates that 191 Black Illinoisans will die of cancer compared to 152 white Illinoisans per 100,000 deaths.[37] Black women have disproportionate incidences of breast cancer diagnoses compared to White women, and prostate cancer diagnoses in Black men are 2.5 times higher than that of white men[16]. At a national level, Black Americans are about 20% more likely to get colorectal cancer and about 40% more likely to die from it than most other groups.[38]

Black Illinoisans experience greater barriers to cancer prevention, detection, treatment, and survival than their White counterparts. Factors making it more difficult to get such resources are low-paying jobs, lack of or low-quality health insurance, limited or no access to healthy and affordable foods, low-quality education and housing, unreliable public transportation, and unsafe environments. The Task Force believes there must be an increased focus on access to and education around preventative services as well as a concerted effort by the medical community to build trust with Black and Brown communities.

> *"Cancer screenings, colon cancer, breast cancer. These are the things that are affecting marginalized communities. We're seeing a great deal of that coming in through the emergency rooms now after three years of people taking a hiatus from seeing their primary care physicians. This was always a problem, though, even for those who didn't have access, so even it's magnified now."*
>
> *TASK FORCE MEMBER*

In response to identified health outcomes disparities, Public Acts 101-650 and Public Acts 101-0655 created the Illinois Department of Healthcare and Family Services (HFS) Hospital and Healthcare Transformation Program, otherwise known as Healthcare Transformation Collaboratives (HTC). The HTC program is designed to encourage collaborations of healthcare providers and community partners to improve healthcare outcomes, reduce healthcare disparities, and realign resources in distressed communities throughout Illinois. In particular, the program seeks to increase access to community-based services, preventive care, obstetric care, chronic disease management, and specialty care and address the social determinants of health in communities. Through HTCs, HFS is funding partnerships that reimagine the way healthcare is provided in communities by linking healthcare systems more tightly with community resources that address social determinants of health to meet the needs of residents more holistically and reduce inequities in healthcare delivery. These projects align with and use HFS Quality Pillars addressing Maternal and Child Health, Adult Behavioral Health, Child Behavioral Health, Equity, and Community-Based Services and Supports.

Figure 13. The Four Domains of Chronic Disease Prevention

The four domains of chronic disease prevention

1. Epidemiology and surveillance: to monitor trends and track progress.
2. Environmental approaches: to promote health and support healthy behaviors.
3. Health care system interventions: to improve the effective delivery and use of clinical and other high-value preventive services.
4. Community-clinical linkages: connections between community and clinical sectors to improve population health.

The four domains focus on strategies that:

- Collectively address the behaviors and other risk factors that can cause chronic diseases;
- Work to simultaneously prevent and control multiple diseases and conditions;
- Reach more people by strengthening systems and environments to support health; and
- Link community and health care efforts to prevent and control disease.

(Centers for Disease Control and Prevention, 2017)

PHYSICAL AND COGNITIVE DISABILITIES*

*Note: The language of this title is used to attempt to abridge the categorization of the vast range of people with disabilities for the sake of simplicity in the report and is not meant to exclude any person or type of disability identity. The State and this Task Force recognize that there are many types of differentiated physical, visual, auditory, developmental, learning, intellectual, and other disability identities that the health and social services landscape should address.

Disability constitutes the largest underserved population in America (1 in 5 individuals) and intersects with all historically disadvantaged and underrepresented racial and ethnic groups. The prevalence of disability varies across racial and ethnic groups and is widespread. In the U.S., nearly 3.5 million African American adults have a disability (13.5 % of African Americans have disabilities compared to 10.5 % for all races). Americans with disabilities are disproportionately

poor, rural, and members of racial and ethnic minority groups and thus face amplified disparities on multiple fronts. African American adults with disabilities are (when compared to all other adults with disabilities) 22% less likely to be employed, 44% more likely to experience poverty, and 84% more likely to lack adequate housing.[39]

Higher rates of functional impairment in activities of daily living (ADLs) and instrumental ADLs (IADLs) impede the ability to live independently, participate in the workforce, and require increased assistance. Consequently, many disabled individuals rely on a patchwork of safety-net programs to meet their needs. For these reasons, individuals with disabilities must have a seat at the table to address these disparities in their full complexity, and the State's health systems must do more to support the improvement of care for people with disabilities.[40]

> *"I think there's also a need to push for more disaggregated research on different communities. There may be some existing research on disability, on different marginalized communities, on African-American communities, on Asian communities. But disability under the umbrella of disability is a lot of different disability groups; there are some that have gotten more research, others that don't."*
>
> *TASK FORCE MEMBER*

Living with a disability dramatically affects one's health outcomes. According to a 2015 paper from the Ohio Disability and Health Program, *"numbers fail to show the enormous health disparity amplifying phenomenon that individuals from minority racial/ethnic groups who also have disabilities confront."* The HHS Advisory Committee on Minority Health has described living as a member of a racial or ethnic minority group with a disability as a *"double burden"* due to the added socio-political challenges encountered. As powerfully stated by researchers from the Advisory Committee, the *"omission of disability as a critical category in discussions of intersectionality [with race and ethnicity] has disastrous and sometimes deadly consequences for disabled people of color caught at the violent interstices of multiple differences."* Many Americans with disabilities endure serious health disparities and unmet service needs and face potential severe financial distress.[41]

Individuals with disabilities are less likely to have a usual source of care and receive needed primary and specialty care. Many physicians lack training and ability and report being uncomfortable treating this population. Medical spaces designed without these patients in mind make it difficult for them to disrobe and get on and off examination tables. Medicaid and Medicare recipients with disabilities often encounter providers unwilling to treat them due to low payment rates and related administrative challenges and end up referring them to emergency departments to treat non-urgent and preventable conditions[40].

More information can be found in the Illinois Disability and Health Action Plan 2012-2017.[42]

> *"Especially during moments of crisis like, like in the past couple years with the pandemic, there is a lot of information around the vaccine and testing and all that stuff. A lot of folks in the disability community did not have access; did not learn about those services. Or if they found their local vaccine testing site when they showed up, realized, oh, it's inaccessible, and that is a failure on whoever designed it because the ADA (American Disabilities Act) has been around for 31 years."*
>
> *TASK FORCE MEMBER*

> *" I think there is -- there's also like existing stigma and maybe also -- a lack of understanding of disability and accessibility. I think most people have a basic understanding of what accessibility is, but I think generally, society's understanding of accessibility think it is limited to like physical things, like is the door wide enough? Is there an elevator [and] escalator?"*
>
> *TASK FORCE MEMBER*

> *"Remind them [the task force] to consider multicultural, multilingual disability access issues. Being part of several organizations and nonprofits over the years on disability and accessibility things as well as, you know, even in other immigrant communities, those considerations are not often talked about. Sometimes they are, but they're not often talked about as part of routine practice."*
>
> *TASK FORCE MEMBER*

> *"I'm on another committee, and one of the things that they look at is called career pathways, and that's the thing the feds are kind of going to, and so they were like. 'Well, we got to bring in people with disabilities, the youth, and then people [that] are incarcerated, and we've got to put them on these career pathways.' I'm like, 'Well, that's fine, but not everybody learns that way.' The thing that I kind of challenge them with is if you want to include people with disabilities, you have to include all people with disabilities."*
>
> *TASK FORCE MEMBER*

Disparities in Health-Related Social Needs

It is well established that communities in Illinois with the highest rates of poverty and social vulnerability experience worse health. Communities need access to resources and services that enable them to achieve health. This report section outlines the social needs of Illinois' most vulnerable communities. Solutions for these needs will enable Illinois residents to achieve health and thrive.

"Improving health outcomes for these diseases and conditions can only be achieved if social determinants of health (health-related social needs) are addressed as part of healthcare delivery."

ILLINOIS DEPARTMENT OF HEALTHCARE AND FAMILY SERVICES & UNIVERSITY OF ILLINOIS AT CHICAGO, 2021

ACCESS TO AN INCLUSIVE COMMUNITY/SOCIETY FREE FROM RACISM AND DISCRIMINATION

Racism is a pervasive disease and societal force that affects education, healthcare, social services, criminal justice, affordable housing, environmental justice, and employment. The State of Illinois and health and social service institutions must continue to recognize ways systemic racism has created barriers to care for Black and Brown communities and must do more to eradicate racism across the entire ecosystem. Recognition and acknowledgment must extend to calling out racism in health and human services experiences.

A literature review of implicit racial and ethnic bias amongst medical professionals in 2015 concluded moderate levels among most medical professionals with negative consequences for patients, including strained patient relationships and worse health outcomes.[43] In 1998, research found that Black Americans received less health care than their White counterparts because doctors treated patients differently based on their race[37]. Additional studies conducted during the last three decades find that many health inequities are attributable to structural and systemic racism. It is, therefore, critical for medical professionals, especially those involved in maternal and infant care, to be trained to recognize and address implicit racial and ethnic biases. Beyond provider and service level issues, health systems and state agencies must speak to and remedy legacies of disinvestment and discriminatory practices. Brought about in part because of the disparities in mortality seen during the COVID-19 pandemic, the Illinois Legislature declared racism a public health crisis in a House Resolution on April 22, 2021. The declaration acknowledges its negative effects on health services and public health outcomes.[44]

Figure 14. Community Survey Responses – Needed Improvements

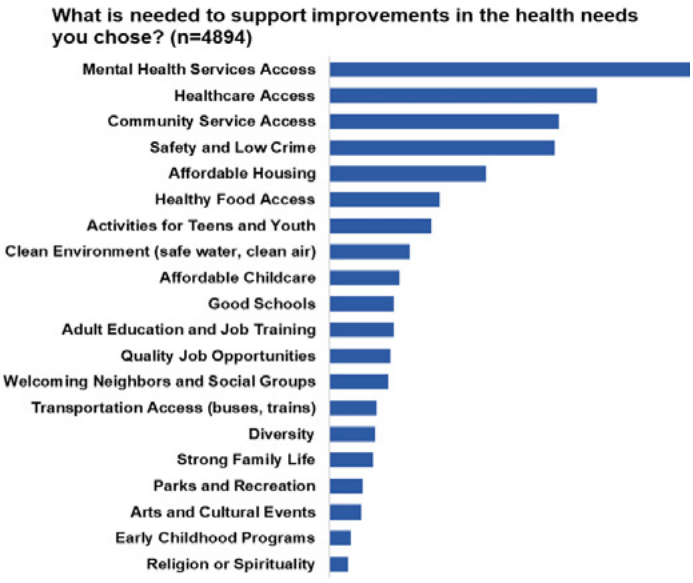


Image: 2019 Alliance for Health Equity Community Health Needs Assessment

Figure 16. Levels of Racism

INDIVIDUAL-LEVEL RACISM

INTERNALIZED RACISM lies within individuals.

These are our private beliefs and biases about race and racism, influenced by our culture. Internalized racism can take many different forms including racial prejudice toward other people of a different race; internalized oppression, the negative beliefs about oneself by people of color; or internalized privilege, beliefs about superiority or entitlement by white people. An example is a belief that you or others are more or less intelligent, or beautiful, because of your race.

INTERPERSONAL RACISM occurs between individuals.

These are biases that occur when individuals interact with others and their private racial beliefs affect their public interactions. Examples include racial slurs, bigotry, hate crimes, and racial violence.

SYSTEMIC-LEVEL RACISM

INSTITUTIONAL RACISM occurs within institutions and systems of power.

It is the unfair policies and discriminatory practices of particular institutions (schools, workplaces, etc.) that routinely produce racially inequitable outcomes for people of color and advantages for white people. Individuals within institutions take on the power of the institution when they reinforce racial inequities. An example is a school system that concentrates people of color in the most overcrowded schools, the least-challenging classes, and the least-qualified teachers, resulting in higher dropout rates and disciplinary rates compared with that of white students.

STRUCTURAL RACISM is racial bias among institutions and across society.

It involves the cumulative and compounding effects of an array of societal factors including the history, culture, ideology, and interactions of institutions and policies that systematically privilege white people and disadvantage people of color. An example is the overwhelming number of depictions of people of color as criminals in mainstream media, which can influence how various institutions and individuals treat people of color with suspicion when they are shopping, traveling, or seeking housing and employment – all of which can result in discriminatory treatment and unequal outcomes.

(Race Forward, 2014)

ACCESS TO SECURE, HIGH-QUALITY HOUSING OPTIONS

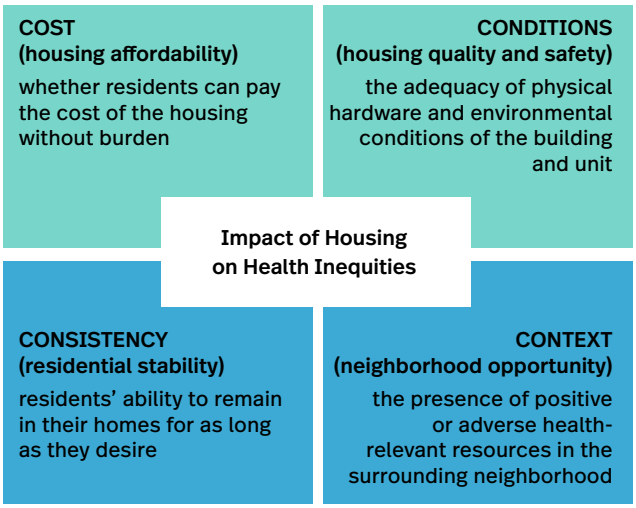
Being unhoused has massive impacts on the health and well-being of families nationwide. The unhoused or housing-unstabled often have complex health and social service needs, which require a network of cohesive and coordinated health and social services to support life-saving housing programs. People in need of housing often come from hospitals, shelters, or the justice system. All these systems and service providers require tools and processes that work together seamlessly to reduce stress and promote stability.

Statistics show that children experiencing homelessness are more likely to develop various physical and mental health-related problems. Mental health issues arising from homelessness may take the form of anxiety, depression, and suicidal thoughts. Homelessness may also worsen pre-existing conditions or create new ones. Maintaining a healthy diet, getting enough rest, and recuperating from injury and illness is almost impossible when living on the streets or in shelters.

A shortage of affordable rental homes in Illinois available to extremely low-income (ELI) households, whose incomes are at or below the poverty guideline or 30% of their area median income (AMI), contributes to poor health outcomes. Extremely low-income households spend more than half their income on housing and *"are more likely than other renters to sacrifice healthy food and healthcare to pay the rent."*[45] *"In Illinois, 32% of children live in households with a high housing cost burden, and 19% live in poverty."*[46] Though not included in this report's recommendations, Illinois can affect change by confronting substandard housing, enforcing housing guidelines and codes, implementing "Healthy Homes" programs to improve indoor environmental quality, assessing housing conditions, and advocating for healthy, affordable housing.

In 2021, the Governor issued an executive order[47] to fight homelessness in Illinois and, among other key initiatives, developed the Illinois Interagency Task Force on Homelessness. This Task Force developed a June 2022 Home Illinois report that lays out a plan to prevent and end homelessness through coordinating State of Illinois agency strategies and investments and partnering with the community to build a strong safety net and permanent housing for Illinoisans facing homelessness and housing insecurity. Five themes emerged as the plan's pillars: Racial Equity, Building Affordable and Permanent Supportive Housing, Bolstering the Safety Net, Securing Financial Stability, and Closing the Mortality Gap. A foundational goal of the plan is ending the racial disparity that exists in homelessness. The recommended solutions in that report outline needed changes to state agencies to address homelessness. The most recent State FY24 budget provides an $85 million increase in funding to support homelessness prevention, affordable housing, outreach, and other programs to reduce homelessness outlined in the Home Illinois report.

Figure 17. Four Pillars of housing's impact on health inequities
(Adapted from Swope & Hernández, 2019; Taylor 2018).



> *"Housing is not just a secondary focus. It is a primary focus of any report or any policy or a program operation, moving forward."*
> TASK FORCE MEMBER

> *"I mean, the other day with the kid that was suicidal -- his dad won't let him come home. His mom is in a mental institution, and you know he's been here. We've now got him a job, but we can't find him a place to live. Our funder says he's just been here too long, and he needs to leave. I said, 'Well, where is he going to go?' Their answer was, 'I guess he'll be homeless,' and I'm like, 'no, I'm not putting him out on the street; that doesn't make any sense.'"*
> TASK FORCE MEMBER

ACCESS TO A SAFE AND HEALTHY PHYSICAL ENVIRONMENT (FREE FROM VIOLENCE)

Traumatic stress experienced in communities due to street violence, domestic and child abuse, unemployment, and racial discrimination is linked with increased rates of anxiety, depression, and poorer health. Illinois has an ongoing public health epidemic of firearm violence concentrated in certain neighborhoods in particular municipalities. Chronic exposure to violence leads individuals to engage in behavior as part of a cycle of community violence, trauma, and retaliation that substantially increases their own risk of violent injury or reinjury. This violence is carried out among a small number of individuals, usually teens and young adults living in these areas. These same people face chronic exposure to the risk of violence and related trauma as well as criminal legal system involvement. People who are chronically exposed to the risk of firearm violence victimization are substantially more likely to be violently injured or violently injure another person.[48]

In Illinois, 1 in 4 Black or Hispanic children live in unsafe communities.[49] Rates of trauma related to violence are disproportionately seen in Black and Brown communities.[50] Living in a safe community free from violence and ongoing crime reduces incidents of trauma, reduces the likelihood of adverse childhood experiences, and positively impacts health outcomes. A study of young adults who were victims of violent injuries as children found significantly higher levels of post-traumatic stress disorder (PTSD) in this group than in the general population. Ten (41.7%) of these respondents screened positive for probable PTSD, significantly higher than the 6.8% of the general population that is typically diagnosed with PTSD.[51]

Figure 18. Homicide Morality per 100,000 in Chicago and Suburban Cook County, Illinois (Illinois Department of Public Health, Death Certificate Data Files)

	Chicago (2020) Rate per 100,000	Suburban Cook County (2016) Rate per 100,000
Overall	23.5	5.4
Non-Hispanic White	1.6	1.4
Non-Hispanic Black	67.3	20.4
Asian or Pacific Islander	2.6	Not available
Hispanic or Latino	13.6	3.4

Physical health, achieved through safe and well-kept sidewalks and access to parks or areas to run, walk, or play, is severely limited by living in unsafe areas that are not routinely maintained. The health benefits of a simple daily walk on life expectancy and overall health are well documented. Research shows that all levels of walking, even levels below the recommended guidelines, were associated with lower mortality risk. Participants who walked less than two hours per week had a lower death risk than those without activity. Those who got in one to two times the recommended level of physical activity just by walking had a 20% lower mortality risk.[53]

Many Illinoisans cannot meet this activity level because of where they live. An absence of safe recreational and green spaces and crumbling infrastructure (sidewalks, streetlights, and streets) limit communities' abilities to stay healthy. In February 2022, the Governor and the Illinois Department of Human Services (IDHS) announced[59] the first of three Notice of Funding Opportunities (NOFOs) for eligible organizations to apply for over $150 million in state funding to further violence prevention efforts. The first round of funding includes more than $50 million for violence prevention services in Chicago, including street-based violence interruption work and victim services. Subsequent funding rounds for statewide youth development and high-risk youth intervention programs will open later this month. The grants are made possible through the Reimagine Public Safety Act (RPSA), which aims to address the root causes of firearm violence in Illinois through targeted, integrated behavioral health services, access to economic opportunities, and violence interruption and prevention programs. Since his first year in office, Governor Pritzker has more than doubled the funding for violence interruption, diversion, and youth employment programs to $517 million. To provide communities with the resources they need to uplift residents, the Governor's proposed fiscal year 2023 budget increases that figure to $832 million.

In spring 2022, HFS introduced the Violence Prevention Community Support Team (VP-CST) service to help Medicaid customers who have chronic exposure to firearm violence. This model of mental healthcare combines professional counseling with peer support and links to needed services, ensuring interventions are both holistic and tailored to the specific trauma that each person has experienced. The interventions help customers develop functional, interpersonal, and community coping skills while fostering greater stability in the broader community. To date, four community mental healthcare providers have enrolled to deliver these services, and a new law is likely to increase the number of participating organizations.

"I live on a front street, and I'd like to be able to walk. But we need sidewalks to do that, and we need to get rid of all the stray dogs around here. Right now, we have to walk in the dirt or on the road and take the chance of getting hit by a car."

EAST ST. LOUIS TRANSFORMATION REPORT, CENTREVILLE RESIDENT

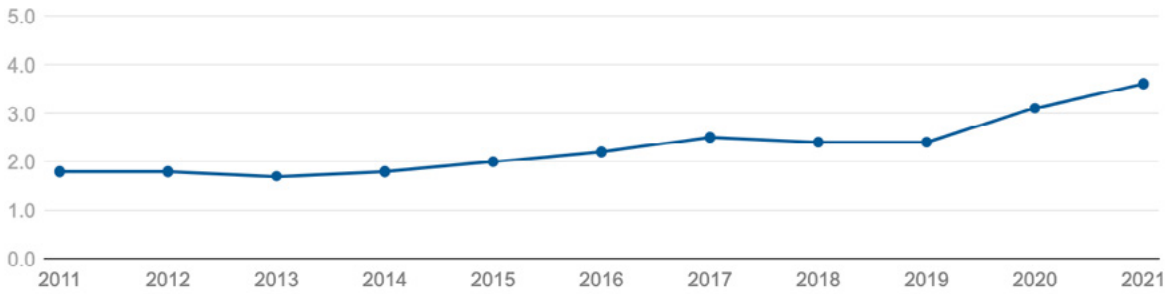
"I just know that it's a tough thing to see social [and] emotional like not seeing grass cut plays to your physical and emotional place of your emotional and your social health. You know, those types of things weigh on you."

TASK FORCE MEMBER

Figure 19. Firearm-Related Deaths per 1000,000 Children and Adolescents, 2011-2021

The impact of gun violence on children and adolescents[52]

Image: https://www.kff.org/other/issue-brief/the-impact-of-gun-violence-on-children-and-adolescents/



NOTE: Rates from 2021 reflect provisional data. Rates are per 100,000 children and adolescents ages 17 and below. Causes of death attributable to firearm mortality include ICD-10 Codes W32-W34, X72-X74, X93-X95, Y22-Y24, and Y35.0.
SOURCE: KFF analysis of CDC Wonder, 2011-2020, and CDC Wonder Provisional Mortality Statistics, 2021, Online Databases • PNG

KFF

The state needs to recognize the physical and mental toll living in unsafe and neglected areas has on residents across the state and work to address the areas most in need.

ACCESS TO HIGH-QUALITY HEALTHCARE

Access to comprehensive, quality healthcare services is critical to achieving greater health equity in Illinois. Barriers to needed health care services include lack of availability in a neighborhood or community, high cost, and lack of insurance coverage. These barriers can lead to delays in receiving appropriate care, inability to get preventative services, potentially avoidable hospitalizations, and preventable early death. Increasing access to health services is an important step toward reducing health disparities.

According to the Illinois Center for Rural Health, over 1.4 million people, or about 11% of the population of Illinois, live in rural health professional shortage areas (HPSAs).[55] The IDPH 2021 State Health Assessment identified more than 100 HPSAs, with around 60% in rural areas and 40% in urban areas[55]. The assessment estimates that Illinois will need approximately 1,100 additional providers by 2030 to meet the needs in these areas and across the state[55]. Close to ten million Illinoisans live in HPSAs for access to mental health providers.[56] Estimates indicate that *"52.5% of adults with co-occurring mental health and substance abuse conditions received neither mental healthcare nor substance use treatment"*[23].

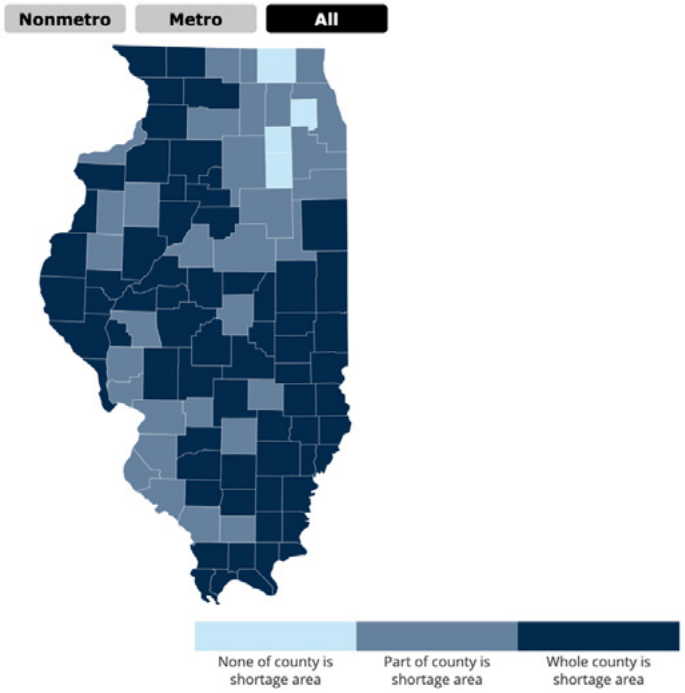
Hospital closures have exacerbated healthcare service shortages and access issues. In July 2020, Trinity Health announced its plans to close Mercy Hospital, a well-known and essential resource that served the Chicago Southside and its predominantly Black residents. Trinity argued that other hospitals could absorb the population served by Mercy. However, the next closest options are often less able to meet the community's needs.

The total costs of care weigh heavily on a person's decision to seek needed health care services. Expanding access to affordable healthcare has been a key initiative of the Pritzker Administration, including being the first state to extend access to full-benefit Medicaid coverage for 12 months postpartum, regardless of immigration status or how the pregnancy ends. The Administration also created the Medicaid Family Planning Program to provide access to a broad array of family planning and family planning-related services at an income level that is higher than the regular income level for Medicaid, and the Health Benefits for Immigrant Adults (HBIA) and Health Benefits for Immigrant Seniors (HBIS) programs to provide Medicaid-like coverage to older noncitizen adults.

During the COVID-19 Public Health Emergency (PHE), HFS also implemented the COVID-19 Uninsured group, as noted earlier in the report, to ensure uninsured Illinois residents – regardless of income – could access COVID-19 testing, vaccines, and treatment (monoclonal antibodies and oral antivirals) without premiums or co-pays, regardless of immigration status. Further, Illinois extended COVID-19 PHE's continuous eligibility requirement beyond federal requirements to children aging out of the Children's Health Insurance Program (CHIP), postpartum noncitizens, and noncitizens covered under the HBIA/HBIS programs to apply the maintenance of eligibility (MOE) equitably and ensure all customers remained covered during the PHE. The complexities of cost as a barrier to care are discussed in more detail in the following sections.

Figure 20. Health Professional Shortage Areas: Primary Care, by County, 2022-Illinois

Image: Data. HRSA.gov, November 2022



Source: data.HRSA.gov, November 2022.

Dental health as a key factor in overall health is well reported, showing that Black and Hispanic high school children had some of the lowest visits to quality dental care. Black and Hispanic children overall in Illinois were extremely unlikely to visit a dentist at 19.2%, while Hispanic children were at 17.8%[17]. HFS is working with Medicaid MCOs to improve timely access to dental care. For example, one Medicaid MCO worked to get an expansion of dental services into a couple of high DIA zip codes, some MCOs offer "dental events" to increase access to dental care in communities, and one MCO purchased a "dental van" to bring dental care into communities.

> *"Because I know that inside, I don't think they're providing much primary care. I mean, we lost a whole amazing mammogram suite there [at Mercy Hospital]. That was one of the best in Chicago."*
>
> *TASK FORCE MEMBER*

"It was just one of those things where I realized after they announced the closure of Mercy, I was like, this is the third hospital that I mainly work at. I was at Metro South, I was at St Mary's and Streator, and I remember thinking, this is going to be extremely dangerous because those patients -- literally, there wasn't another hospital for a 25-mile radius. They also had labor and delivery, and the question was, where are these people going to go and deliver when we're talking 25 miles away of Country Road."

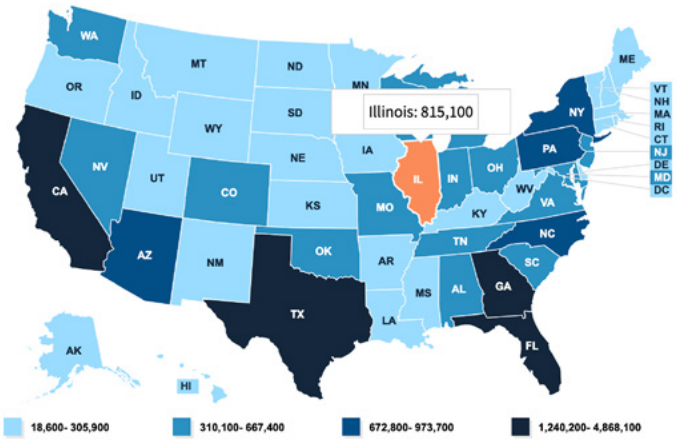
TASK FORCE MEMBER

"We found my uncle in a diabetic coma because he couldn't afford his medication. His everyday life, now, is someone trying to take care of him because he can't take care of himself."

SOUTH COOK TRANSFORMATION REPORT, MARKHAM RESIDENT

Figure 21. Health Insurance Coverage of the Total Population (2021)

Image: Kaiser Family Foundation Health Insurance Coverage by State[58]



Location	Uninsured
Illinois	815,100

ACCESS TO HIGH-QUALITY HEALTH INSURANCE

Access to high-quality insurance is a vital component of health. Insurance is a key determinant of the procedures or medications individuals can afford to access promptly to attend to their health. In Illinois in 2022, approximately 815,100 people lived without insurance and severely limited access to life-saving care.[57] Insurance companies impede healthcare access for members when they impose limits on coverage of services to only in-network providers, cultivate narrow provider networks, or delay treatment through unnecessary prior authorization requirements. Limited insurance often translates into higher out-of-pocket costs. These costs disproportionately impact low-income individuals and families who must decide between getting needed care and potential financial ruin.

Many diseases affecting Black and Brown communities in large numbers require high-cost medications and treatments. People with diabetes with limited or no insurance coverage may, at times, be confronted with choosing between filling a prescription for insulin or having money for food or rent. The Alliance for Health Equity Community Health Needs Assessment for 2019 for Chicago and Cook County found that women enrolled in Medicaid during pregnancy had a three-times greater risk of dying within one year of pregnancy when compared to women with private health insurance[7]. (As noted above, Illinois took action and, in 2021, became the first state in the nation to provide full Medicaid benefits with continuous eligibility for 12 months postpartum regardless of immigration status or how the pregnancy ends).

The Illinois Medicaid program does not charge premiums or co-pays, and Illinois recently capped the cost of insulin for people with private health insurance coverage. Additionally, in April 2021, HFS and the Illinois Department of Insurance issued a healthcare affordability report, extensively highlighting the importance of affordable healthcare and providing various policy options for Illinois to consider to improve affordability and access to health insurance. Results were broken out by race, ethnicity, geography, and immigration status. After this report was published, Illinois implemented the Health Benefits for Immigrant Seniors and Health Benefits for Immigrant Adults programs, an expansion of a Medicaid-like program providing health coverage to noncitizens, and in 2023 passed legislation to implement a State-Based Marketplace, which will provide the state with more resources and better data to provide targeted outreach to communities who are uninsured and, by allowing the state to control the user interface, open up the possibility of additional policy options to help improve health coverage affordability.

"I get my routine tests, but when it came to my mammogram, the two locations near me, two hospitals, they turned me away because they didn't take my insurance. I have issues with traveling and panic attacks. So, guess what? I haven't had a mammogram in 2 years."

SOUTH COOK TRANSFORMATION REPORT, DOLTON RESIDENT

"The insurance companies are now practicing medicine. What's happening is these doctors are doing what insurance companies say do, not on what the patient's needs and health concerns are [...] Several times I needed an MRI or CAT scan, and the doctor told me, 'I cannot do it.' I said, 'What do you mean you can't do it? You just told me I needed that.' He said, 'The insurance is not going to authorize [it].' So now the insurance has become the physicians."

TASK FORCE MEMBER

ACCESS TO HIGH-QUALITY EMPLOYMENT AND A LIVING WAGE

Black and Brown communities disproportionately contend with income insecurity compounded by historically racist policies that have prevented them from building foundational wealth, gaining equal access to employment opportunities, and establishing home ownership. Exclusion from full participation in economic opportunity impacts generations of families, reflected in Black people having the lowest rates of wealth accumulation compared to other racial or ethnic groups in the United States.

The interagency workgroup on poverty and economic security (2020) reported declining social mobility at the state level and within the United States. *"The share of Illinois children who earn more than their parents has declined by almost 50 percent over the last 50 years."*[59] Black households in Illinois have the lowest median annual household income at $33,730 compared to $47,082 in Hispanic households and $62,517 in White households[17]. Addressing deep and persistent poverty across Illinois will be critical to improving health outcomes and assuring Black and Brown communities can thrive.

Access to gainful employment that provides a living wage and access to health insurance and other health benefits is essential to addressing life expectancy gaps. According to the Urban League, *"roughly 24% of US civilian workers lack access to any form of sick pay, nearly 34 million people. One in-depth study examined access to sick pay among Black workers (regardless of occupation) and found that only 56% had access to paid sick leave and 44% had access to paid leave to care for a sick family member"*[3].

Many Black and Brown communities, as well as White communities in rural areas of Illinois, lack access to employment in or near their communities that provide a living wage and health insurance or other health benefits. Job training programs and employment programs often do not effectively meet needs, especially those of disabled populations.

The interplay between employment and benefits programs is complex. Low-wage earners face balancing ambitions for professional growth and pay increases with the potential loss of benefits vital to their well-being. For some individuals, a raise in pay may carry a heavy cost if the increase in annual income makes them ineligible for Supplemental Nutrition Assistance Program (SNAP) or Medicaid benefits. Resolving such structural paradoxes is necessary for creating conditions for Illinoisans to thrive.

> *"I had a friend who passed away, [she was retired], and she worked for the city, and they never paid one hundred percent of her health care. Her health care was like five hundred dollars a month or something ridiculous, and it's like – she was on a pension, so she struggled with paying that, and she was, you know, not well"*
>
> *TASK FORCE MEMBER*

> *"So, I get the childcare subsidy, and then I get a dollar-an-hour raise. But now I'm bumped off the eligibility, but my dollar an hour raised doesn't cover the $95 a week. But I still get my SNAP and my WIC. […] Medicaid is the last man standing often, but each of the requirements – I'm eligible [here] and here, and I'm on my way to self-sufficiency, [but] they're cliffs to just navigate."*
>
> *TASK FORCE MEMBER*

The Illinois Commission on Poverty Elimination and Economic Security (Poverty Commission) was established under the Intergenerational Poverty Act (HB5191) in June 2020 to improve policymakers' understanding of the root causes of poverty and economic insecurity in Illinois, support efforts to ensure residents have equal opportunity to achieve economic security, and ultimately, reduce and eliminate poverty in Illinois by making policy and other recommendations to the legislative, executive, and judicial branches of the State.

In March 2022, the Poverty Commission released a 5-year strategic plan focused on addressing structural drivers of poverty rather than individual challenges. The initial strategic plan marks the first step in a 15-year path to eliminate intergenerational poverty with ambitious goals to 1) reduce deep poverty in the State by 50% by 2026, 2) eliminate child poverty in the State by 2031, and 3) eliminate all poverty in the State by 2036. The Commission developed five action pillars to improve the economic mobility of those living in deep poverty through a multi-generational approach to improve long-term outcomes for all, including 1) ensure Illinois is the best in the nation for raising families, 2) stabilize homes and communities, 3) ensure just and equitable access to economic security programs, 4) address barriers to paid work, education, and advance, and 5) support trusted community-based providers to serve the needs of those in deep poverty. The full 5-year strategic plan can be found here.[60]

Illinois has recently taken substantial steps toward adopting living wages for nursing home workers, who are disproportionately people of color. In early 2020, just as the pandemic began to exert its devastation on communities of color and especially on nursing home residents of color in those communities, HFS started a comprehensive, in-depth review of nursing home services and funding in Illinois with an emphasis on discovering and addressing inequities. HFS' review consisted of dozens of weekly online meetings with nursing home stakeholders, reviewing data and identifying root causes, and eventually proposing comprehensive Medicaid payment reforms adopted by the Illinois Legislature in April 2022 and implemented beginning in July 2022. Reforms totaled over $700M in annual funding and targeted understaffed homes that the agency found were comprised disproportionately of Medicaid-funded residents as well as Black and Brown residents. The reforms included

funding for Illinois Medicaid to pay its (resident) share of the costs of a new minimum pay scale for certified nursing assistants (CNAs), the backbone and (super-)majority of the nursing home care team and an occupation comprised disproportionately of people of color. The nursing home CNA pay scale was traditionally flat, with pre-pandemic wages averaging $14-15/hour. Nearly half (49%) of the employed CNAs in the State of Illinois are people of color (Census Bureau; 5-year average ending 2021) versus 30% for all occupations in the state. Black or African American CNAs comprise 2.5 times as high a percentage of their occupation (32%) as compared to the workforce as a whole (12%). As of April 2023, a majority of nursing homes (approximately 400 of 700) representing 15,000-20,000 CNAs were participating in this voluntary program, which requires employers to pay between $1.50 and $8.00 more per hour for experienced or promoted CNAs as they pay for newly trained CNAs.

Smart Start Illinois is a multi-year plan to ensure that families raising our youngest Illinoisans have access to quality home visiting, early intervention, and child care, alongside other services available through other state agencies. Smart Start will make transformative, generational investments in early childhood education and care. It will begin funding first-in-the-nation Smart Start Child Care Contracts to bring stability to the field by raising childcare worker wages and enhancing program quality. This investment builds on recent raises for childcare workers and COVID-19 relief funding distribution. It also includes additional funding for early intervention programs to increase provider rates by 10% and allow thousands of children and families to maintain access to these critical services. In-home visiting includes an investment to expand services to more families needing support. In addition, it provides funding to cover increased Child Care Assistance Program participation.

ACCESS TO HIGH-QUALITY EDUCATIONAL OPPORTUNITIES

Completing high school has long been an established predictor of long-term health. A quality education is an important step towards earning higher wages and achieving financial stability and its associated long-term health benefits. A high school education is estimated to add about seven years to life expectancy[37].

High school completion rates are also connected with family income. A 2011 study found that a history of segregation in the United States has not only led to continued racial and ethnic segregation of schools but that Whites and Asians are disproportionately represented in higher-performing schools.[61] The same report found that disparities in school performance are likely due to racial and ethnic disparities in poverty and not the racial composition of schools[61]. Funding for high-quality schools that can improve access in poor and historically disadvantaged areas is also lacking. Across the US, majority non-White school districts receive $23 billion less annually than their predominantly White counterparts.[62]

High school graduation rates have been increasing in minority communities in Illinois during the last decade. In 2021-22, 90.5% of White youth graduated compared to 85% of Hispanic/Latina/o/x and 79.5% of Black youth.[63]

A high school diploma is the minimum credential needed for post-secondary education and most jobs today. Illinois must do more to reduce the attainment gaps. Investing in high-quality educational assets and support programs and making them available from early childhood to higher education is necessary to equal the opportunity to thrive and reach full potential.

Figure 22. High School Graduation Rates by Race-Ethnicity in Illinois[64]
Image: https://datacenter.aecf.org/data/line/9735-high-school-graduation-rates-by-race-ethnicity

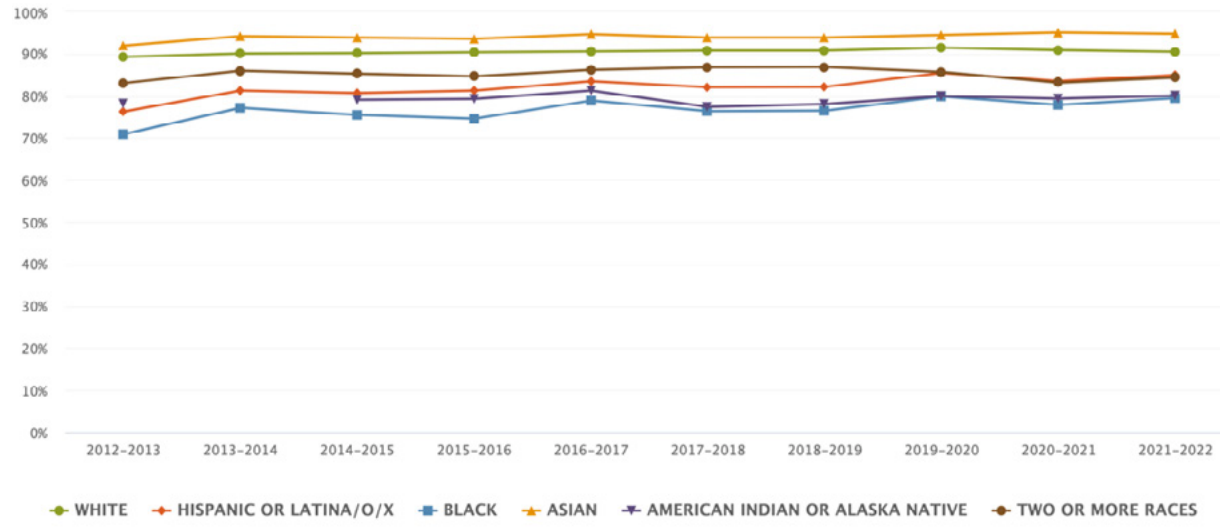


Figure 23. Illinois Report Card 2022 Graduation Rate[65]

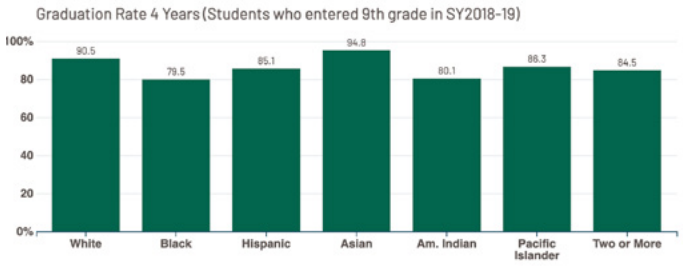
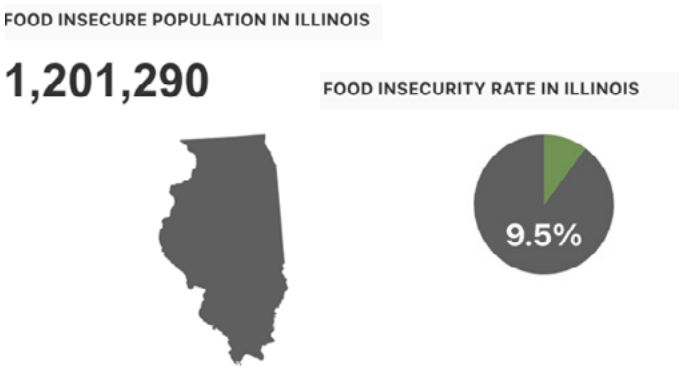


Image: https://www.illinoisreportcard.com/state.aspx?stateid=IL&source=trends&source2=graduationrate

Figure 24. 2021 Food Insecurity in Illinois



"We spend 30 million on this building, 50 million on that building, 25 million on this building, and none of that is a high school, a high-performing high school. None of that is a grocery store."

TASK FORCE MEMBER

"You have to invest in early childhood education and experiences so that they [students] can give back to their communities, and [then] grow a person to give back to their communities"

TASK FORCE MEMBER

Figure 25. Food Insecurity Among Overall (all ages) Population in Illinois [69]

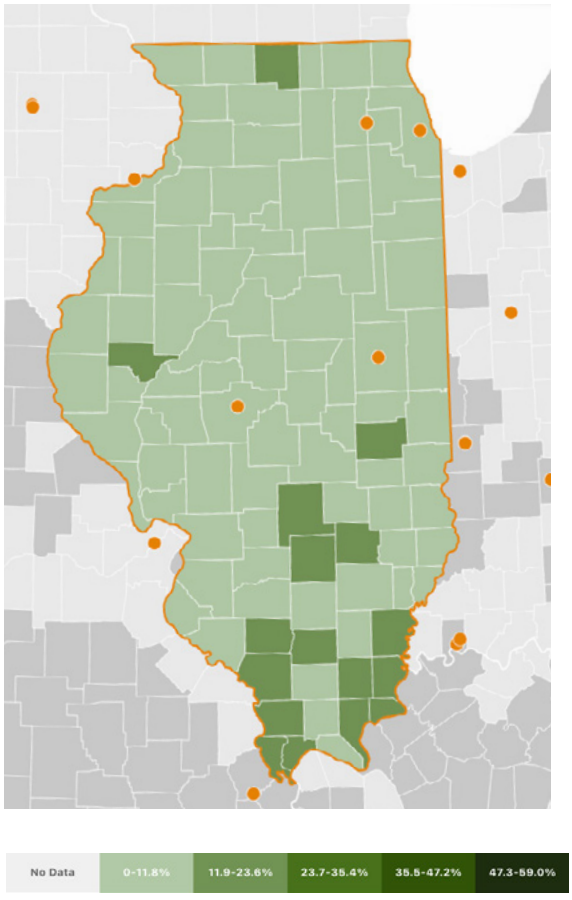


Figure 26. Geographic Distribution of Food Insecurity in Cook County, Illinois (2020). Source: Feeding America (Map the Meal Gap 2020

Food Insecurity in Cook County Illinois (% of residents experiencing limited or uncertain access to adequate food)

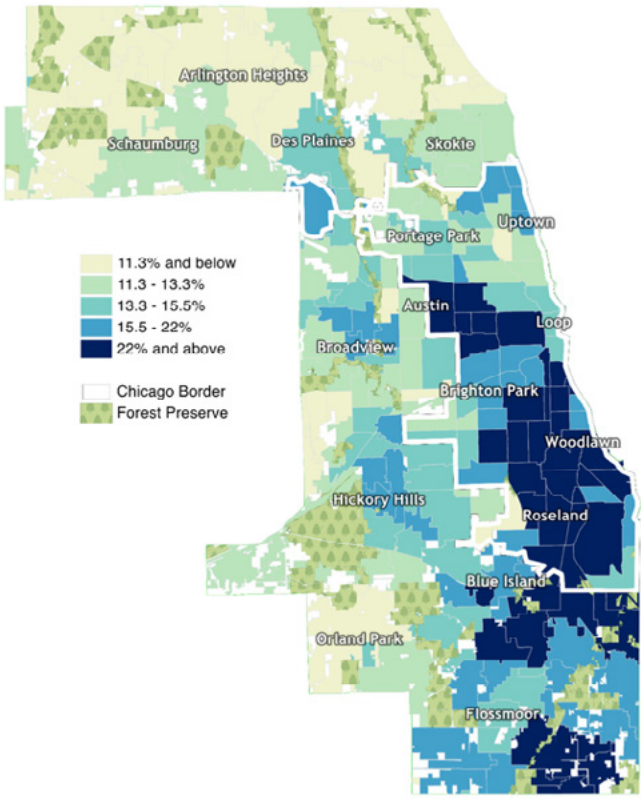


Image: Food Insecurity Among Overall (all ages) Population in Illinois

RELIABLE ACCESS TO HIGH-QUALITY FOOD

More than 36% of Black households have experienced food insecurity in comparison with 32% of Hispanic households and 18% of White households. In Cook County, 39% percent of its residents live in areas of low food access. "Research indicates that communities with access to healthy foods and limited access to convenience stores have healthier diets and lower rates of obesity."[66] Low-income communities of color are less likely to access supermarkets and healthy foods[67] and tend to have a higher density of fast-food restaurants and other sources of unhealthy food, such as convenience stores.[68]

> *"Do you have access to high-quality food? The Austin community…is a food desert. So, we're looking at 'do you have access to high quality food?' 'How do we get you access to high-quality food?' We know that we're not going to get a Whole Foods anytime soon."*
>
> *TASK FORCE MEMBER*

While corner stores and gas stations offer convenience, they do not provide affordable, high-quality food. The current rate of inflation is creating even greater food insecurity across Illinois and impacting Black and Brown families. According to The Consumer Price Index, All Urban Consumer prices increased 6.4 percent from January 2022 to January 2023. Consumer prices for shelter increased 7.9 percent during the same period, accounting for nearly 60 percent of the total increase in all items less food and energy. The 7.9-percent increase was the largest 12-month advance since June 1982, when prices for shelter rose 9.0 percent.[70]

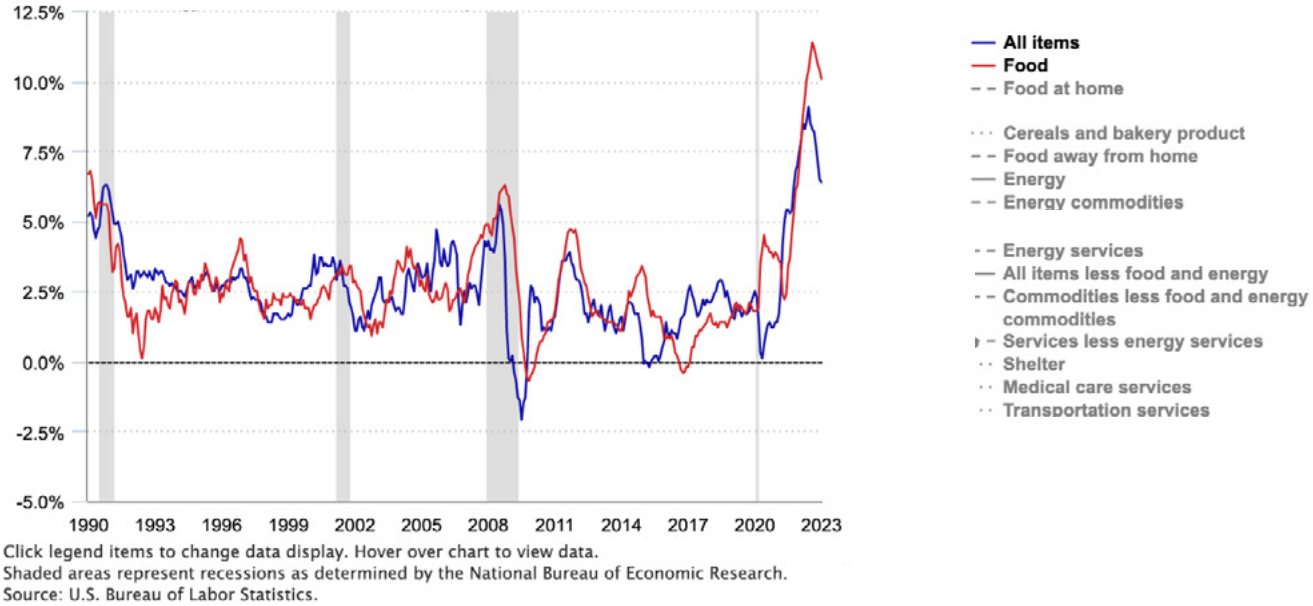
To increase access to healthy food, HFS requests expenditure authority through an 1115 demonstration waiver to cover food and nutrition services. HFS is proposing to offer these services to Medicaid members who are identified as being food insecure and have a chronic condition such as diabetes or cancer, a behavioral or mental health condition, or are pregnant or up to 60 days postpartum. HFS seeks to provide a broad array of food and nutrition services through the Medicaid program, including case management, nutrition education, coaching, skill development, and group nutrition classes. HFS is also requesting authority to assist in identifying healthy foods and permanent food sources, application assistance for SNAP and other available resources, stocked refrigerator and pantry when transitioning out of institutional settings or prolonged hospitalization, medically tailored and home-delivered (or pick-up) meals, and cooking supplies for meal prep and nutritional welfare.

Some Medicaid MCOs also provide nutrition counseling, diabetes education, and weight management classes. During the pandemic, some MCOs responded with food giveaways and pop-up farmers' markets in disproportionately impacted areas.

ACCESS TO SAFE AND RELIABLE TRANSPORTATION

Most rural communities in Illinois are not served by public transit, and restrictions on pick-up and drop-off points across counties severely limit people's ability to access needed services. People using Medicaid transportation services or the PACE public transit system may wait hours for rides, making it difficult to make scheduled medical appointments. Long travel times and delays in pick-up inhibit people's ability to access healthcare. In less densely populated

Figure 27. 12-month Percentage Change, Consumer Price Index, selected categories, January 1990-January 2023
Image: U.S. Bureau of Labor Statistics



parts of the state, people must travel further to access vital services like Level I or II trauma hospitals, pharmacies, fresh foods, and labor and delivery centers. According to the 2021 Transformation Data and Community Needs Report of East St. Louis, pregnant Black women have experienced grave barriers to transportation, impeding access to prenatal care.[71] To expand access to transportation services, Medicaid began covering a ridesharing service during the COVID-19 PHE, and HFS is working to cover this mode of transportation going forward.

> *"It's very challenging when someone is sick and not up to taking care of themselves (…) You have to have a community, a church or a network to help you (…) If there's nobody [to do that] and if you don't have a car or Ventra [public transportation] card, people just get stuck in their homes."*
>
> *CHICAGO HEIGHTS RESIDENT*

> *"There is no public transportation. We have a bus. It drives around Carbondale. We have Jackson County Mass transit who will pick our client and take them to their doctor's appointment, or take them back home. But if you live in Anna, which is about twenty minutes away by another county, you can't come to Carbondale and see a doctor or a dentist, or anything else."*
>
> *TASK FORCE MEMBER*

03
SECTION THREE

Assessing Root Causes Within Systems of Care

Many of the root causes of health disparities in Illinois stem from the challenges systems face in meeting vulnerable communities' complex and diverse health needs. The inability to adequately address these challenges perpetuates barriers that thwart health. The Task Force calls for addressing the root causes described below.

Individual and Community-Level Barriers

LACK OF ACCESS TO HIGH-QUALITY HEALTH AND SOCIAL SUPPORT SERVICES

The Penchansky and Thomas model of access to care identifies five distinct dimensions: affordability, accommodation, availability, accessibility, and acceptability.[72]

Affordability relates to prices of services compared to patients' income, ability to pay, and existing health insurance. This dimension has a disproportionate impact in areas of concentrated poverty across Illinois.

Accommodation relates to how easy or difficult it is for someone to make an appointment and be seen. For example, hourly wage earners in Illinois may struggle to schedule appointments if appointments are only available during daytime business hours.

Availability relates to the number of clinicians, clinical facilities, and specialized programs available to meet demand. Specialty care, such as Ophthalmology or Endocrinology, is extremely limited outside of Illinois' largest metropolitan areas. It is not uncommon in Illinois for patients to wait 4 to 6 months to see a psychiatrist or some specialists.

Accessibility relates to patient travel time, location, and availability of personal and public transportation resources. Specialty care shortages in rural parts of Illinois may require patients to travel two hours or more for an appointment. For patients requiring ongoing treatment, this dimension can be particularly burdensome.

Acceptability relates to the perceptions that patients and clinicians have about one another. For example, many women prefer to receive healthcare services from a female provider, or patients whose first language is Spanish may prefer a Spanish-speaking provider. Race and racism, as highlighted previously, also play a significant role in the dimension of acceptability in access to healthcare and social services.[73]

Although in recent years, some progress has been made, the State's systems of care are not built to meet the complex needs of people with physical and intellectual disabilities. The Americans with Disabilities Act (ADA) was a step toward addressing the needs of disabled citizens, but more is needed. Physical, technical, and intellectual discrimination persists in our systems of care. It must be overcome to increase access to high-quality care for people with disabilities, especially those who are Black and Brown and those who come from disadvantaged and underserved communities.

According to the report *It Takes More Than Ramps To Solve The Crisis Of Healthcare For People With Disabilities*, *"the roots of these quality-of-care shortfalls include inadequate training of clinicians and other healthcare professionals, poor executive oversight to enforce the ADA, limited funds and few financial incentives for upgrading equipment and hiring and training support staff members to assist patients, and misperceptions and stereotypes about disability."* Many, if not most, service providers across the health and social service landscape recognize the need and have a desire to implement more accessible service solutions to support access for people with disabilities. Costs and a lack of clarity on what changes need to be made to improve access often hinder the implementation of inclusive solutions.

> *"I would like it that the policies be a little bit more flexible [in terms of] understanding of the diversity of our communities. Have a better system of connecting and working with people with different language accents from the disability community who use augmented communication [or] ASL. That there is a better-streamlined process for state workers, providers, organizations who serve individuals with different communication needs [and] that there is a clearer understanding of – this is how you access an interpreter, a language translator."*
>
> *TASK FORCE MEMBER*

LACK OF TRUST IN SYSTEMS OF CARE

Distrust of healthcare and social service systems arises from direct negative personal experiences with disrespectful, insensitive, or racist service providers. Awareness of historical marginalization and discriminatory or biased practices contributes to people of color not seeking healthcare or needing supportive services. Disparities will persist until communities have a seat at tables where decisions about health and human services resources are being made, and communities' knowledge bases are respected and considered as valuable as academic knowledge. Systems that infantilize communities and do not consider lived experience as valuable as other forms of knowledge will maintain the status quo. Communities will continue to seek indigenous support and knowledge instead of in collaboration with health and human resources. Many community-based service providers engender trust because they are in and of the community, often possessing lived experiences that make them attuned to clients' needs. Until healthcare systems and social service providers work with trusted community-based organizations to repair and build bonds of trust with patient populations, change will not occur.

The HFS Healthcare Transformation Collaboratives are centered around the community telling HFS what services they need, and the application process includes engaging the community in developing the proposals, including completing a Racial Equity Impact Assessment (REIA) tool. While it was not required, all HTCs have a Community Health Worker (CHW) component central to their initiatives, and the HFS 1115 waiver request will help HTCs further invest in their CHW infrastructures.

> *"I thought about that a long time ago, I mean, like 30 and 40 years ago, because I kept saying, why do we continue to have repeated service, repeated issues? Why do we have this recidivism? Why do we have this revolving door thing, you know? The answer is because nobody wants to solve the problems."*
>
> *TASK FORCE MEMBER*

> *"CHW's best work is in the community, in health fairs, representing the social agencies that help them do their best work. But most importantly, they can bridge the gap between the patient and the social agency."*
>
> *TASK FORCE MEMBER*

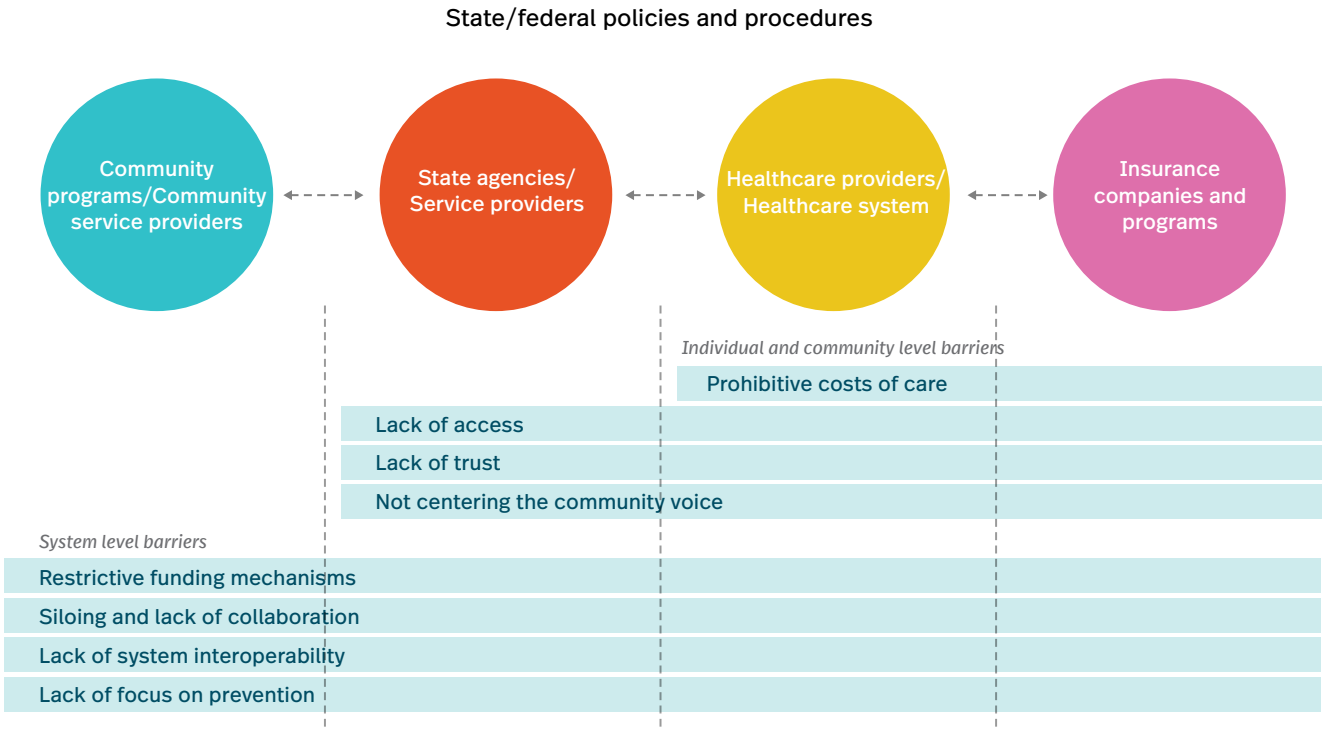
NOT CENTERING THE COMMUNITY VOICE IN DECISIONS

Decisions made without community involvement fail to deliver solutions to those in need. Disparities will persist until community members have seats at the tables where decisions about health and human services resources are made. The State must also recognize that a history of ignoring or otherwise not prioritizing community needs has contributed to mistrust of State-driven solutions. Work must be done on the State's part to repair these relationships and build trust toward a shared goal of creating healthy and thriving communities.

> *"We need to identify the gaps in services. We need to also stop putting money where these people [government and state agencies] are doing all of this planning [and] where they want the money to go. The money needs to go to the communities where you have the greatest need."*
>
> *TASK FORCE MEMBER*

> *"I don't think it's [the] government['s] or non-profits' job to sort of implement health. But I do think if we help communities build the infrastructure that is needed to self-sustain these things and help communities have the paradigm...these are the things that are necessary for a thriving community."*
>
> *TASK FORCE MEMBER*

Figure 29. Root Causes Across the Service System



PROHIBITIVE COSTS OF CARE

The issues related to the potentially crushing healthcare costs are vast and complex. Elsewhere in this report, it has been noted that the prohibitive cost of care drives avoidance or disengagement in healthcare. The total cost of care exceeds what appears on a co-pay or medical bill. Unaccounted-for expenses include those associated with taking time off work, transportation to and from medical appointments, parking, and, in some cases, child care. The full cost of receiving care forces individuals with limited financial means to make tradeoffs that may compromise their health.

Avoiding preventive and routine care activities due to explicit and hidden costs contributes to worse health outcomes. For those living in poverty, low-wage earners, or those who have insurance with high deductibles, often avoiding care outweighs its perceived benefit. The cost of care is a significant issue for all Illinoisans, especially as deductibles, co-insurance, and co-pay costs continue to rise. Over 16 million Americans have significant medical debt, and nearly half of working-age adults report skipping or delaying needed medical care due to costs.[74] Health equity will remain unreachable until cost-related barriers to accessing and engaging in preventive and routine care are removed.

> *"If you go to a diabetes specialist, the co-pays are extremely high. So sometimes you say, 'you know what? I can't afford to go to the specialist.'"*
>
> *MARKHAM RESIDENT*

System Level Barriers

INSUFFICIENT FOCUS ON PREVENTION AND WELLNESS

The Task Force believes the State's systems of care conceive of health as the absence of disease rather than the presence of well-being. According to the Health Care Cost Institute, total spending on preventive services in 2019 across the U.S. was about $204 per person, representing about 3.5% of total dollars spent on healthcare services[75] over the year.[76] Increased effort to address social needs, well-being, and whole-person care is required across the health system to address prevention and engagement with health services to improve outcomes.

> *"We need to start practicing preventative measures, and that's across the board. We only spend a fraction of a percent on prevention now."*
>
> *TASK FORCE MEMBER*

> *"How can we work with MCOs [Managed Care Organizations] that are Medicaid funded and privately funded for footwork in this effort of bringing in wellness and forward movement in prevention."*
>
> *TASK FORCE MEMBER*

> *"I hate to say this. But I don't think people want to solve the problem."*
>
> *TASK FORCE MEMBER*

LACK OF COLLABORATION ACROSS SECTORS AND AGENCIES

The long history of health and social services operating in isolation from one another has led to a siloed environment that inhibits the ability to deliver integrated and coordinated care to populations with complex needs. Over time, state agencies evolved separate data systems, making data sharing and collaboration difficult. This level of separation and entrenched barriers leads to dysfunction that contributes to systemic inefficiencies that impede individuals and communities from obtaining needed services, often leaving community members to navigate complex systems by themselves.

The Task Force believes that a collaborative State-wide effort is necessary to improve agencies' abilities to work together more effectively so that no matter where a person enters the health and human services system, they will receive seamless guidance and assistance to meet their complex health and social needs. For example, the Children's Behavioral Health Initiative has been testing a portal for youth and families needing mental health services. Information entered through the portal is transferred to an Interagency Crisis Staffing Team composed of representatives from all State child-serving agencies that work to deliver timely services.

The Task Force recognizes efforts across the State to work more collaboratively to address complex health needs, most notably the Healthcare Transformation Collaboratives and the work done to address maternal and infant mortality. To maximize the impact of these efforts, extending opportunities for collaboration should be explored and, when appropriate, pursued.

> *"When we were trying to work with our three-way data use agreement with Public Health, [it] was a disaster to try to get lawyers to sign off on it. It took an obscene amount of time."*
>
> *TASK FORCE MEMBER*

> *"I think for one thing…there is a lack of communication between departments and divisions and organizations and groups and the providers."*
>
> *TASK FORCE MEMBER*

> *"Service providers and solutions need to take things a step further in quality and not just one-stop solutions."*
>
> *TASK FORCE MEMBER*

"We just don't work well across departments or agencies. Even within my agency, we don't really – we're pretty siloed within our offices and divisions. Like I said, there are children's health things happening in many places or health things happening or whatever. We just don't always know what's happening on the other side of the department because we don't work all that well together."
TASK FORCE MEMBER

"Typically, depending on what emergency room you're working in, we tend to have crisis workers that work in the emergency department to help give resources. But the problem is, are the patients really following through? […] Thinking that everything's going to happen in that one visit and the idea of making a phone call, scheduling an appointment, getting someplace, having the transportation to get to the place, to actually go through with the appointment. A lot of these patients get lost in the scramble."
TASK FORCE MEMBER

"If we can move to a place where communication, sharing, collaboration is encouraged and, you know, when the Division of Rehab, Division of Developmental Disabilities, Mental Health, and Family Support Services are all able to talk to each other in some way to share resources. I think that can help with service delivery, but also help with maybe addressing any misunderstandings they have with each other."
TASK FORCE MEMBER

EXISTING FUNDING MODELS LIMIT IMPACT

Many people who live in poverty have multiple needs that an individual agency can rarely address. Difficulty navigating between multiple service providers burdens already stressed people, often requiring them to repeat redundant intake processes to the point that they stop seeking help. Many give up, convinced that the State is deliberately making it difficult for them to access needed assistance. Until models are developed to upgrade the infrastructure to support interagency cooperation and integrated applications, and the state and Illinois General Assembly (ILGA) direct funds to those solutions, the existing pathways will remain a barrier to improvements in health and wellbeing.

Another limitation of the existing funding paradigm is the avoidable administrative burden imposed on organizations that deliver needed services. Community-based organizations can often do the difficult work that State and health systems struggle to accomplish efficiently and cost-effectively. However, the current funding paradigm requires organizations to devote precious time and resources - that should go toward helping people in need - to applying for and securing grants or trying to convince agencies to fund services at a level that covers operating costs. The ILGA must make a concerted effort to simplify funding mechanisms for community-based organizations and service providers, or the good they might do for communities will remain constrained.

"We build databases to do all of this work, but none of it is integrated at all. I think the problem with it is different funding streams have different requirements, and that gets in the way of things"
TASK FORCE MEMBER

"But as a smaller agency, we have to deal with reimbursement systems with what we're doing, and that's a whole different conversation. I don't want to get too much off the topic, but we have to deal with reimbursement systems that are not equitably sustainable. We're a grassroots organization, we're not a million-dollar agency."
TASK FORCE MEMBER

"How can we as a task force address people who are buried in paperwork preventing them from doing service work through a policy lens through our work?"
TASK FORCE MEMBER

LACK OF DATA AND SYSTEM INTEROPERABILITY

Though the Task Force recognizes initiatives underway to improve data sharing between agencies, the status quo practice of not sharing customer data impedes the delivery of healthcare and social services. These efforts must be expedited.

Illinois established Innovation Incubators ("i2") through the State Chief Information Officer's (CIO) office in collaboration with the Governor's strategic priorities. Beginning with healthcare and human services and progressing to public safety and business and workforce agencies, the "i2s" help identify and prioritize business needs for data interoperability. HHSi2's flagship program, the Illinois Shared Interoperability Platform (ISIP), launched a new initiative with the Illinois Department of Human Services and reengaged a Department of Children and Family Services pilot. ISIP is piloting a master data management agreement to provide agencies with more comprehensive personal data. The HHSi2 team is also working on data alignment, data-sharing, and matching projects focused on improving service delivery and outcomes.

One of the HHSi2 data-sharing "use cases" now in development is exploring the use of vital records from the Department of Public Health to confidentially, and where appropriate, improve identification of racial and ethnic characteristics of Medicaid customers so that inequities in

the delivery and impact of services can be identified, tracked, and addressed. This use case is a first and fundamental step towards HFS' stated mission to place equity at the center of everything the agency does – including its administration of Medicaid, the State's largest program and source of healthcare for 32% of the State's population.

Healthcare systems are also steadily improving their data capture. However, sharing patient data between healthcare systems' electronic medical record (EMR) services (to the extent they even have EMR services versus only paper records) persists and inhibits collaboration. Data sharing between insurance systems and other parts of the health ecosystem is plagued by delays and restrictions, driven mainly by a lack of system interoperability and data privacy concerns. These issues leave providers without a complete picture of their patients and clients and cause costly delays in delivering needed and informed care.

To improve access to critical data sharing, Illinois Medicaid has launched a statewide data exchange platform to deliver vital information to Illinois Medicaid providers in a timely and secure manner. Under the first phase, the platform enables admission, discharge, and transfer (ADT) alerts to be shared with Medicaid providers whose patients visit a hospital or emergency department. By sending real-time ADT notifications from the admitting or discharging facility to a patient's care coordinator or primary care provider, Illinois seeks to improve care coordination, provide higher-quality care, and realize more successful outcomes. Future phases of the HealthChoice Illinois ADT will enable the sharing of other data types to support HFS' medical program quality strategy.

> *"We as a State agency are siloed [and] so is our data, and it's very broken. I'm not collecting all the same data points, or, you know, we could all three be running a social service agency, and I could be treating Mr. Smith, you could be treating George Smith, and you could be serving GP Smith. Does that make sense? So, data is hard, and it's difficult to even get that sense."*
>
> *TASK FORCE MEMBER*

> *"The information sharing agreements are technocratic; they aren't handled in a corporate enterprise sense but more in a patient private information sense, which requires movement to the legislature to ultimately fix"*
>
> *TASK FORCE MEMBER*

Until data sharing and systems interoperability become a reality, fundamental change in health outcomes cannot occur.

A Call to Action

As highlighted in the above sections, the state of health among Black, Brown, and other marginalized groups across Illinois is a regrettable outcome of a long history of systems of governance and systems of care that have failed to address the complex needs of the poor and marginalized in our society. The State faces a multi-system level problem requiring a cohesive and coordinated multi-system strategy. There is no one cause for the state of health seen among Black and Brown communities or solution for the problems outlined in the report. This unacceptable state of inequity is about the inability of our health systems to work together to solve the needs of the people of Illinois. State leaders and key stakeholders must recognize this critical breakdown and prepare to institute needed changes.

The following section outlines a comprehensive set of solutions for affecting change at multiple levels of the State's health systems. Complex systems-level problems require a comprehensive and coordinated strategy, broad buy-in, commitment to finding common ground, and a shared vision of transformation. The Task Force encourages members of the General Assembly, leaders of State health agencies, advocacy groups, and community representatives to commit to enacting the multi-system level strategy outlined below. Only by committing to a shared vision and agreeing to work together for the health of Illinois' most vulnerable can we make the substantial changes that will move the needle on health outcomes.

Additionally, the Task Force recognizes ongoing internal work within the identified agencies - including IDHS, HFS, and IDPH - that was not thoroughly investigated or recognized due to time constraints. Therefore, the following section outlines a broad and systematic approach to solving identified needs and barriers in the State's care systems. Further work is required to investigate, validate, and develop specific and implementable solutions for these recommendations.

04
SECTION FOUR

Developing Innovative Systems of Care to Reduce Health Disparities

Idea Generation

To develop the strategic plan, Task Force members participated in five workshops to develop recommendations for addressing identified root causes of health disparities. These recommendations are intended to augment existing initiatives to reduce health disparities and inform public policies to overcome known barriers to improved access to health and social services, education, and employment. The workshops generated ideas for how the State of Illinois might:

- Address the six key health-related social needs driving poor health outcomes
- Expand access to high-quality healthcare
- Reduce disparities across five key health outcomes areas (maternal health, mental health, trauma/ACEs, chronic diseases, and disability)
- Promote health equity and community voice in decision-making
- Improve service systems in support of integrative care models

The output of the sessions is listed below.

1 ADDRESS THE SIX KEY HEALTH-RELATED SOCIAL NEEDS DRIVING POOR HEALTH OUTCOMES

The State and its agencies should consider making additional investments in expanding access to:

- Affordable housing and homelessness prevention programs
- High-quality educational opportunities
- Gainful employment opportunities
- A stable and living wage
- Safe and inviting environments (free from violence)
- Healthy and affordable food

2 EXPAND ACCESS TO HIGH-QUALITY HEALTHCARE

The State and its agencies should build on the work already being done and consider additional investments that increase access to high-quality healthcare for areas in the State with reported limited access. Such investments could include:

- Additional funding for community health centers and other solutions that put high-quality care closer to communities in need
- Expanded access to community-based culturally-fluent supportive services such as mental healthcare and substance use disorder treatment
- Development of combined health and social services wraparound services that focus on the whole person
- Expanded and improved care coordination and navigation services
- Implementation of telehealth services and closing the digital divide
- Decrease prohibitive out-of-pocket healthcare costs
- Address workforce gaps in the healthcare sector
- Ensure physical environments, language, and intellectual diversity are not barriers to high-quality care

3 REDUCE DISPARITIES ACROSS FIVE KEY HEALTH OUTCOMES AREAS (MATERNAL HEALTH, MENTAL HEALTH, TRAUMA, CHRONIC DISEASES, AND DISABILITY)

Additional investments by the State to improve key health outcomes could:

- Increase access to healthcare services reflective of needs in communities facing significant disease burden
- Expand access to supportive and culturally relevant services for health needs from “people who look like me” and “who I can relate to”
- Address implicit bias and racism within healthcare systems
- Address physical and intellectual disability barriers within health and social service systems
- Develop continuous funding models and sustainable solutions specific to these communities in need

4 PROMOTE HEALTH EQUITY AND COMMUNITY VOICE IN HEALTH AND HUMAN SERVICES DECISION-MAKING

The State and its agencies should consider additional investments in health equity that:

- Direct resources to historically marginalized communities and those with the greatest need
- Center community voice in conversations and decisions about the state of health in the community and community assets
- Assure that community knowledge is valued and an integral part of any response
- Fund more community-based and community-driven solutions organized by and taking place within BIPOC communities
- Address systemic racism and discrimination in healthcare and social services

5 IMPROVE HEALTH AND HUMAN SERVICES SYSTEMS IN SUPPORT OF COLLABORATIVE CARE MODELS

The State should consider additional investments in its agencies that:

- Quickly improve data sharing and system interoperability towards better customer care and service experiences
- Create a culture of sharing and collaboration across departments and agencies
- Assure State services, both in-person and online, meet the complex and multiple needs of communities

Recommendations

The ideas generated during the workshops became the basis for a set of recommendations for bringing change to individuals, communities, and the public health field that will reduce health outcome disparities seen in historically marginalized populations.

Note: The broad mandate of HB 0158 required the Task Force to look across Illinois' entire health ecosystem. The recommendations that follow represent potential opportunities for addressing health disparities. Further refinement and planning will be required to validate, develop, and realize any of them. Additional details on each recommendation can be found in the appendix.)

Pursuant to 20 ILCS 5175/Art. 125, the Health and Human Services Task Force submits the following recommendations for achieving a system that will improve interagency interoperability with respect to improving access to healthcare, healthcare disparities, workforce competency and diversity, health-related social needs, and data sharing and collection. These recommendations require broad action across the state health landscape, including the Illinois General Assembly, the Governor's office, State Agencies, Health Systems, and community organizations to achieve the desired outcomes and eliminate health disparities across Illinois. To achieve the below recommendations, the State must first address funding, workforce, and policy issues that limit the success of these ideas.

1 ADDRESS THE SIX KEY HEALTH-RELATED SOCIAL NEEDS DRIVING POOR HEALTH OUTCOMES

1.1 Consider Creating a Pilot Program to Develop Assets That Address Social Determinants of Health in Areas of Historic Disinvestment. This pilot program could build on the R3 (Restore. Reinvest. Renew.) initiative to identify a willing community (or several communities) of high need and collaborate to develop social service and health assets that fill existing gaps.

1.2 Consider Investing in Community-Based Organization Capacity to Empower Expanded Services That Address the Six Key Health-Related Social Needs. Conceive and pilot a sustainable funding mechanism to support and expand the reach of community-based organizations (CBOs).

1.3 Assure All Managed Care Organizations (MCO) Cover Clearly Defined Health Related Social Needs (HRSN - Related Services. HFS currently has an 1115 waiver in the public comment phase. The waiver seeks federal Medicaid funding for a broad range of services to address Health Related Social Needs (aka HRSN) and, if approved, will be implemented through the MCOs.

1.4 Explore Establishing Clear and Readily Accessible Pathways to Employment for Historically Disenfranchised Populations. Take a restorative justice lens to remove barriers to employment for those most impacted.

1.5 Examine Funding Programming Aimed to Increase Health Literacy and Preventative Health Practices for Children in Communities with Reported Poor Health Outcomes. Focus on prevention by educating the next generation of Illinoisans on healthy habits and promoting a whole health mindset.

1.6 Initiate a Campaign to Raise Public Awareness of Social Determinants of Health and Resources for Addressing Them. Invite community input to develop campaigns and outreach programs aimed at improving health literacy and awareness in communities of color.

2 EXPAND ACCESS TO HIGH-QUALITY HEALTHCARE

2.1 Develop a Statewide Cross-Sector Strategic Plan to Address Healthcare and Social Service Workforce Gaps. Focus on bringing people from communities of high need into the healthcare workforce by expanding the pipeline of Community Health Workers, Doulas (birth and death), and other direct peer advocates and service workers. The goal is to improve the representation of Black and Brown individuals at provider and leadership levels.

2.2 Investigate Potentially Expanding Community Health Centers to Enable Easier Access to Specialty Care, Behavioral Health, and Integrative Social Services. Federally qualified and community health centers deliver high-quality and integrative care solutions in areas of high need, but more are needed.

2.3 Expand Funding for Collaboratives That Unite Healthcare and Social Service Providers with Community-Based Organizations to Address Whole Health Needs. Seek additional funding for the Department of Healthcare and Family Services' Healthcare Transformation Collaboratives model that fosters health system and community-based organization collaboration.

2.4 Consider Providing Comprehensive Care Navigation Services for Populations with Complex Health Needs. Regardless of where a person enters the health and human services system, ensure a consistent approach to navigation involving multiple agencies and systems. These services should be Medicaid reimbursable under an eventual 1115 demonstration waiver.

2.5 Analyze the Need for Additional Telehealth Services in Certain Fields and Geographies.

2.6 Develop Strategies to Overcome Poverty and Cost of Care Barriers That Deter People From Getting Healthcare. Investigate direct or guaranteed payment options and how to cap out-of-pocket costs.

2.7 Review Medicaid Eligibility Criteria to Identify Needed Changes So People Are Not Forced to Choose Between Pay Raises and Medical Coverage. Develop and pilot solutions to reduce the Medicaid eligibility cliffs and transition people confidently to marketplace or employer plans.

3 REDUCE DISPARITIES ACROSS FIVE KEY HEALTH OUTCOMES AREAS (MATERNAL HEALTH, MENTAL HEALTH, TRAUMA, CHRONIC DISEASES, AND DISABILITY)

3.1 Assure funding of successful programs that remove disparities are not subject to removal based on changing priorities.

3.2 Look for additional ways to incentivize preventive and community-based services in the healthcare system. Expand coverage to support the development of more education and community support programs focused on the needs of communities of color.

3.3 Promote the development of preventative and culturally relevant support programs for four key areas.

- **Maternal and Infant Health Support Solutions.** Look at opportunities to expand funding for community-based doulas to address the need for prenatal and 12-month postpartum care
- **Mental Health Support Solutions.** Consider piloting affordable community-based mental health care options for youth and adults. As part of a broader strategy to reduce mental health gaps, use trained community members to help bridge the long transition between diagnosis and connection to appropriate care
- **Trauma Support Solutions.** Expand community-based support services for people grieving from gun violence or suffering from violence-related trauma
- **Chronic Disease Support Solutions.** Evaluate and consider investing in solutions for culturally responsive support, education, and resources (e.g., community-based hypertension management programs) for addressing chronic diseases in communities

3.4 Initiate a Statewide Program to Develop Trauma-Informed

3.5 Systems Across Illinois' Healthcare and Social Services Ecosystem.

3.6 Improve Screening for Trauma and Associated Navigation to Community-Based Care and Resources in All Healthcare Settings.

3.7 Improve Access for People with Disabilities Across the Health and Social Service Landscape.

4 PROMOTE HEALTH EQUITY AND COMMUNITY VOICE IN HEALTH AND HUMAN SERVICES DECISION-MAKING

4.1 Support Expansion of the Use of Community Health Workers and Other Peer-Based or Community-Based Support Roles. Work with the Illinois Community Health Workers Association (ILCHWA), community health workers, and advocates to develop appropriate roles that will provide the highest impact from community-based peer support

4.2 Formalize More Professional Development Pathways for Community Members to Pursue Health and Social Services Jobs. This includes appropriate training and certification across all community health worker (CHW) roles and other peer advocates

4.3 Ensure Equitable Access to Sustainable Funding Opportunities for All Community-Based Organizations. Conduct an audit of grants and contracts to assure equitable access

4.4 Create or Expand an Existing Comprehensive Community-Informed Asset Map of Health-Related Services and Resources for Addressing Social Determinants of Health. This data should be integrated into State resource maps and support improved care navigation

4.5 Establish Structural Mechanisms for Communities to Have Decision-Making Authority Regarding the Kinds of Services Needed to Address Their Health Priorities.

4.6 Continue to Identify and Address Individual and Systemic Racism in the Health and Social Service System Through Education, Intervention, and Corrective Actions.

5 IMPROVE HEALTH AND HUMAN SERVICES SYSTEMS IN SUPPORT OF COLLABORATIVE CARE MODELS

5.1 Continue to Update Intake and Engagement Processes for Benefit Services to be Respectful and Humane. Look across in-person and digital touchpoints to develop a more streamlined, trauma-informed, and human-centered approach to intake and engagement

5.2 Expedite the Creation of a Data-Driven 360-degree View of Clients Across Health and Social Services. Capture needs and history of encounters to guide informed and effective services

5.3 Redouble Efforts to Build a Single Database and Service Interface to Facilitate Integrated Care Navigation Across Healthcare and Social Services. Integrate and share community-informed service data to build a comprehensive view of needs that can then inform tailored care navigation

5.4 Launch a Centralized State of Illinois Whole Health Data Hub. Utilize a neutral third party to design a model that enables sharing all available State health and social services data

5.5 Leverage Funding Agreements and Contracts to Incentivize and Drive Collaboration Among Service Providers and Community-Based Organizations.

5.6 Encourage and Incentivize a Culture of Collaboration Across Health and Social Service Sectors. Reduce duplicative efforts in support of a simplified, integrative, and patient-centered care model

05
SECTION FIVE

Conclusion

The magnitude of areas identified for needed improvement outlined in the Task Force mandate and the various recommendations indicate a significant amount of work to be done in the coming years and decades. Systemic change to Illinois' health and human services infrastructure requires a long view and immediate and near-term actions.

The Task Force proposes that the Governor and General Assembly recognize that translating recommendations into actions requires extraordinary effort, resources, time, and political will. It is the shared hope of the Task Force that this report fosters a sense of urgency to the vital work that must be done to realize needed changes to ensure the well-being of Illinois and all its residents.

> *"Change will not come if we wait for some other person or some other time. We are the ones we've been waiting for. We are the change that we seek."*
>
> *– BARACK OBAMA*

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SECTION SIX

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07
SECTION SEVEN

Appendix

Recommendation Details

1 ADDRESS THE SIX KEY HEALTH-RELATED SOCIAL NEEDS DRIVING POOR HEALTH OUTCOMES

1.1 Consider Creating a Pilot Program to Develop Assets That Address Social Determinants of Health in Areas of Historic Disinvestment.

Solution Description: This solution seeks to aid community health by funding community health infrastructure as prevention. It builds on the approach taken in the innovative and popular R3 (Restore. Reinvest. Renew.) initiative to right the wrongs of injustice and historic disinvestment in Black and Brown communities. A pilot could include funding for the development of better educational offerings, improved access to food, development or renovation of housing, improved community health assets, employment solutions, and environmental solutions. The program should outline the parameters and work closely with communities to develop solutions.

Solution Details: In recognition of a history of systemic racism, the State must enter this initiative with the sole purpose of helping improve community health. It must empower the community to drive decisions about community priorities and the intended use of funds. Data and community-informed asset mapping (see recommendation 4.4) will be needed to assess gaps in access to health services and infrastructure for meeting health-related social needs.

The Task Force recommends piloting such a program with an interested community and refining and scaling the solution based on the achievement of agreed-upon outcomes. Metrics related to acceptability, ease of implementation, and others should be developed to measure program success.

For this recommendation and the next, the State should explore all opportunities to maximize federal matching dollars towards these efforts, but State funding may need to be appropriated to achieve such a solution, as federal Medicaid funding is likely unavailable.

Reference: R3 grants[77] fund programs in Illinois communities that have been harmed by violence, excessive incarceration, and economic disinvestment. The communities that are eligible for R3 funding were identified, in part, by their rates of gun injuries, child poverty, unemployment, and incarceration.

1.2 Consider Investing in Community-Based Organization Capacity to Empower Expanded Services That Address the Six Key Health-Related Social Needs.

Solution Description: Communities require a network of community-based service providers of supportive services for those in need. Community-based and community-driven solutions refer to an activity or an organization that is organized and takes place within the BIPOC communities. Potential additional funding could focus on community organization capacity building. Additional funds could help sustain, strengthen, and extend existing programs to better meet their communities' needs.

Any future funds should encourage and require a collaborative approach to integrative care services to meet complex social needs. The State should outline a plan for sustained support so CBOs can focus on service delivery instead of pursuing funding (see recommendation 4.4).

Sustainable funding has thus far been elusive and will take significant effort. The Task Force suggests that the ILGA form a joint House/Senate committee to work with the Governor's Office of Management and Budget and state HHS agencies to develop such a funding mechanism. In parallel, there should be efforts to develop technical assistance programs to enable CBOs to secure pathways to sustainability.

Additional Solution Details: Potential solution areas to create or expand include:

- Affordable housing and homelessness prevention programs. Where possible, the work of the Task Force should support and augment the recommendations outlined in the Home Illinois Report[78] and bring a community-based approach to the solutions to end homelessness
- Educational support programs and interventions
- Violence reduction programs
- Employment and training programs that better meet the diverse and intersectional needs of Black and Brown communities, including those with disabilities
- Healthy and affordable food solutions
- Direct funds to people to afford high-quality food, housing, transportation, and employment
- Financial support for communities to build gardens to provide local access to healthy and fresh food
- Financial support to faith-based organizations and local businesses to establish a food pantry program
- Connective services between nutrition assistance programs and healthy and high-quality food access
- Hiring community health workers and other peer advocates to serve as trusted links into health care and social services
- Explore federal Delta Region Authority funding for the southernmost rural region to build up communities

1.3 Assure All Managed Care Organizations (MCO) Cover Clearly Defined Health Related Social Needs (HRSN)-Related Services.

Solution Description: The State and MCOs should work together to expand coverage to include services addressing health related social needs (HRSN), such as income, education, food access, housing, unemployment, and health equity. As programs are developed and implemented, MCOs should focus on covering community-based, high-quality service solutions.

Additional Solution Details: HFS is submitting an 1115 Medicaid waiver to fund community-based services to address social determinants of health coordinated through a Medicaid health plan. This 1115 waiver application requests a federal Medicaid match to test covering Health Related Social Need (HRSN) benefits in managed care, such as housing and nutrition support. The State and MCOs must work with service providers on implementation to create care navigation solutions. The State might consider leveraging the MCO oversight committee to ensure that prevention efforts are included in plans and look to include HRSN coverage in the quality assessment metrics MCOs must meet.

Reference:
Medicaid Managed Care: Strategies to Address Social Determinants of Health & Health Equity Report December 2021

1.4 Explore Establishing Clear and Readily Accessible Pathways to Employment for Historically Disenfranchised Populations.

Solution Description: The Task Force believes identifying and reducing barriers to employment affecting minority and marginalized communities is vital to a community's health by starting with an audit of current employment practices across the state, state partners, and, to the extent possible, private employers and developing a restorative justice approach for removing barriers to jobs that provide a living wage and health benefits.

Additional Solution Details: The Task Force recognizes that the ILGA has made recent advances in policy, including "Ban the Box" and programs that enable individuals to learn and train for jobs while supporting their families. The Task Force believes more can be done to increase access to the workforce and gainful employment opportunities. Measures could include loosening employment requirements, addressing background checks and drug testing, criminal record leniency for people who have served time in the corrections system, and culturally competent and relevant employment training services for Black and Brown job seekers, recent immigrants, and those with disabilities. The audit would identify barriers that continue to exist and disproportionately impact Black and Brown communities.

Reference: National Conference of State Legislators[79]

1.5 Examine Funding Programming Aimed to Increase Health Literacy and Preventative Health Practices for Children in Communities with Reported Poor Health Outcomes.

Solution Description: The State should strive to promote health habits through health literacy programs and health engagement practices for children, young adults, and families. Schools often serve as community and family activity centers and can be leveraged to connect families to health coverage, health and wellness programs, and health care and social services they may seek. IDPH, HFS, and schools should collaborate on supporting health literacy and engagement for kids and families. Funding directed to local public health departments could support this need, and a focus should be placed on under-served communities.

Additional Solution Details: Potential solution areas to create or expand include:

- Introducing culturally relevant and age-appropriate health and wellness curriculum and educational modules, promoting healthy behaviors from an early age
- Content that is engaging and able to accommodate multiple learning modalities
- School programs for which students can obtain course credit as they learn about and practice whole health
- Curriculum that introduces health-related social needs, including units on financial literacy and healthy financial habits
- Routine screening in schools to identify a broad range of health needs in students and families and the ability to connect them to needed health and social services
- Partnerships with HFS, social service agencies, community organizations, MCOs, and health agencies to develop and deliver needed health and social services
- Data sharing and system interoperability (see Section Five)
- Community input into campaigns and outreach programs aimed at improving health literacy and awareness in communities of color

Reference: National Academy of Medicine[80]

1.6 Initiate a Campaign to Raise Public Awareness of Social Determinants of Health and Resources for Addressing Them.

Solution Description: The Task Force believes in preventative health programming to engage people in new health habits that improve health outcomes. Relevant to all aspects of a whole health model will be the inclusion of the National Institute of Health's (NIH) Eight Dimensions of Wellness: body, mind, work, spirit, finances, community, emotions, and environment. This effort could also serve as a vehicle for defining the State's new approach to improving individual and community health to support health equity, focusing on well-being and disease prevention. A collaboration across sectors would be required to create and maintain this interagency public awareness campaign.

Additional Solution Details: Potential solution areas to create or expand include:

- Engage communities in the content-creation process and development of messaging
- Employ youth to use their genius in arts and music to create content for public awareness campaigns that center on youth health and wellness
- Utilize community health workers and other peer advocates to create messages and engage communities
- Develop a campaign using influencers, local celebrities, and their followers to promote messages and encourage new behaviors

- University of Illinois Urbana-Champaign (UIUC) and Dr. Ruby Mendenhall have been working on an effort called the #JoyHappyHope Campaign[81], a community-driven public awareness mental health venture that the Task Force believes can be a model for community input and creativity in this effort. The campaign involves co-creating with youth low- and high-tech wellness tools that foster joy, happiness, and hope, especially in communities with high levels of gun violence

Educational Solution Details: Potential solution areas to create or expand include:

- Integrate financial literacy and entrepreneurship training into employment training programs
- Encourage MCOs to increase the utilization of community health workers (CHW). Many Medicaid MCOs employ or fund CHW services with their administrative dollars. Invite dialogue with community members about clinical research and provide training on citizen/community science and the importance of community voice and participation in advancing scientific discoveries to meet their needs
- UIUC and Dr. Ruby Mendenhall have been working on an effort to train youth as citizen/community scientists

References:
National Library of Medicine[82]
Samaritan Health[83]

2 EXPAND ACCESS TO HIGH-QUALITY HEALTHCARE

2.1 Develop a Statewide Cross-Sector Strategic Plan to Address Healthcare and Social Service Workforce Gaps.

Solution Description: Significant workforce gaps in mental health, specialty care, nursing, and direct service are major barriers to the goal of improving access to high-quality care across the state. The state must create a strategic plan to address these gaps and improve the overall workforce pipeline to support health equity and improve health outcomes.

Additional Solution Details: Potential solution areas to create or expand include:

- Establish educational and training pathways for more community members to be employed in the health and social sector
- Improve visibility and representation of Black and Brown individuals across the healthcare space, especially at the provider and leadership levels
- Focus on community representation and hiring more people from different backgrounds to build healthcare ranks with "people who look like me" or "people who share my experiences"
- Address gaps in direct service workers

References:
- The Equity and Representation in Health Care Act[84] will reduce health disparities while also addressing workforce challenges at community-based providers who see a high proportion of Medicaid and uninsured patients to prioritize providers from racial, ethnic, and other demographics that are under-represented in health care
- National Academy for State Health Policy[85]

2.2 Investigate Potentially Expanding Community Health Centers to Enable Easier Access to Specialty Care, Behavioral Health, and Integrative Social Services.

Solution Description: Federally Qualified Health Centers (FQHCs) and community health centers bring together high-quality and integrative care solutions in areas of high need. However, more are needed to increase access in Illinois. The State should work closely with the Illinois Primary Health Care Association (IPHCA) to support and fund the development of new centers and the expansion of existing ones in identified areas of high need. The combination of available health and support services should be driven by community input and community needs. The Task Force recognizes that the significant healthcare workforce challenges must be addressed before expanding access to these critical healthcare services.

Additional Solution Details: Potential solution areas to create or expand include:

- This model should support cooperation and partnership with existing non-profit community providers, such as those who already provide employment assistance, food banks, and transportation, instead of trying to duplicate relevant services already available in the community
- A focus should be placed on repurposing existing community spaces instead of new construction (e.g., closing schools and churches and renovating abandoned buildings)
- A sustainable model tailored to serve rural communities must also be developed

References: New Markets Tax Credit Coalition[86]

2.3 Expand Funding for Collaboratives That Unite Healthcare and Social Service Providers with Community-Based Organizations to Address Whole Health Needs.

Solution Description: Partnerships and collaborations between healthcare providers, social services providers, community-based organizations, businesses, and financial institutions are vital for bringing sustainable health resources into communities of high need. The Task Force believes there are lessons to be learned from the Healthcare Transformation Collaboratives pilot programs that can be applied to the planning and expansion of related efforts. Community and program representatives, Task Force co-chairs, and HFS leaders will benefit from meeting twice a year to discuss the progress of HTC initiatives and their possibilities for expansion.

Additional Solution Details: Potential solution areas to create or expand include:

- Identify additional institutions and organizations in communities of high need willing to collaborate to address the community's well-being
- Incentivize healthcare and social service systems to hire community health workers to collaborate with residents

References:
Illinois Department of Healthcare and Family Services[87]
Center for Healthcare Strategies[88]

2.4 Consider Providing Comprehensive Care Navigation Services for Populations with Complex Health Needs.

Solution Description: Investigate opportunities to support expanded care navigation services, including tools for conducting comprehensive patient or client needs assessments and providing referrals. Identify people with complex needs and connect them to comprehensive community-centered care. Facilitate compliance by leveraging community health workers (CHWs) or by training community members as citizen/community scientists to play roles in preventing certain chronic diseases and guidance for managing complex health needs. All proposed solutions require technical and data systems to support comprehensive care navigation, a collaboration between originating service providers and community-based organizations (CBOs), and 'warm hand-offs' between them.

Additional Solution Details: Potential solution areas to create or expand include:

ED-Based Solution
- Implement trauma and holistic dimensions of wellness (e.g., Samaritan) assessments into healthcare providers' intake processes and create incentives for them to work more closely with community members
- Connect patients to a community-based care navigator or CHW for assistance accessing needed services and resources
- Collaborate with Managed Care Organizations (MCOs') care navigation services providers
- Assess the requirements for replicating the Christ Medical Center hospital-based service model shown to be successfully reducing readmissions

State Service Agency-Based Solution
- Look to expand Illinois' 'no wrong door policy,' an integrated, person-centered access service delivery system for individuals with significant needs and unserved populations comprising a robust public and private organization network
- See Section 5 for technical system details to support this goal

MCO-Based Solution
- Expand care navigation services for medium to high-risk members
- Deploy CHWs to connect with high-risk members to explain health coverage and available services and then direct them to available services

References:
Illinois Department of Human Services[89]
California Healthcare Foundation[90]

2.5 Analyze the Need for Additional Telehealth Services in Certain Fields and Geographies.

Solution Description: Establish policy-making permanent payment parity with in-person services in the commercial insurance market. Facilitate the development of equitable and sustainable models for care delivery for those without Wi-Fi, technology devices, or the technical literacy required to use telehealth services.

Additional Solution Details: Potential solution areas to create or expand include:

- Establish payment parity between in-person and virtual appointments in the commercial insurance market, recognizing the effort and infrastructure needed from healthcare providers to support telehealth-based visits
- Continue with appropriate oversight with coverage for appointments delivered via telephony
- Expand and standardize best practices for telehealth usage
- Support the development of equitable digital infrastructure. This could include expanding access to Wi-Fi, providing technology devices, or other innovative solutions for narrowing the digital divide. One effort already underway includes Governor Pritzker's Connect Illinois, an initiative launched in August 2019 to expand broadband access across the entire state. Connect Illinois includes a capital investment from Rebuild Illinois, the creation of a Broadband Advisory Council and Broadband Office, and a new program to provide - at no charge - all Illinois public K-12 students access to high-speed broadband. The initiative includes a $400 million broadband grant program and a $20 million capital program for the Illinois Century Network, a high-speed broadband network serving K-12 and higher education institutions

2.6 Develop Strategies to Overcome Poverty and Cost of Care Barriers That Deter People From Getting Healthcare.

Solution Description: Convene a team of experts, including the House Committee on Healthcare Access & Affordability, state health, human service (HHS) agencies, and external subject matter experts (SMEs), to address costs that impede many from achieving a healthy life. The 2021 Healthcare and Family Services (HFS) and Department of Insurance (DOI) Feasibility Report for Coverage Affordability Initiatives in Illinois assesses options depending on how they are designed to make healthcare more affordable while balancing the cost to the state. The Task Force believes that to drive higher engagement in care, the State should evaluate direct or guaranteed payments and the viability of capping out-of-pocket costs.

References:
Illinois Department of Health and Family Services[91]
Forbes[92]
The National Academies of Sciences, Engineering, Medicine[93]

2.7 Review Medicaid Eligibility Criteria to Identify Needed Changes So People Are Not Forced to Choose Between Pay Raises and Medical Coverage.

Solution Description: Convene a team of experts, including researchers, service providers, economists, and policy and insurance experts, to study the structural factors that create "eligibility cliffs." Develop and pilot solutions to reduce the Medicaid eligibility cliffs and transition people confidently to marketplace or employer plans.

The Task Force recognizes that there are limits to what the state can do under existing Federal law. Currently, people who transition from Medicaid to Affordable Care Act (ACA) coverage have access to income-adjusted subsidies that act as a step-down and aim to avoid this cliff. The Task Force believes that other solutions, possibly those developed in other states, should be studied and piloted. The development of the state-based health insurance exchange, Public Act 103-0103 (HB 579)[94], signed by the Governor on June 27, 2023, will assist with the state's ability to improve marketplace plans.

Additional Solution Details: Potential solution areas to create or expand include:

- Look to address customers' concerns about transitioning from Medicaid coverage through developing "user-friendly" communications and data-driven facts
- Allow Medicaid-like coverage in lieu of marketplace plans at some income levels

References:
Illinois General Assembly[94]
National Conference of State Legislators[95]
The Center for Community Solutions[96]
Fed Communities[97]

3 REDUCE DISPARITIES ACROSS FIVE KEY HEALTH OUTCOMES AREAS (MATERNAL HEALTH, MENTAL HEALTH, TRAUMA, CHRONIC DISEASES, AND DISABILITY)

3.1 Identify Opportunities to Provide Long-Term funding for Programs and Services that Address the Five Key Areas of Health Outcomes, Including Maternal Health, Mental Health, Trauma/Adverse Childhood Experiences (ACEs), Chronic Diseases, and Disability.

Solution Description: Changing priorities in the state can result in defunding of key health-related infrastructure, exacerbating disparities and diminishing past efforts. The Task Force recommends that the Budgeting for Results Commission (BFR) look for ways to secure funding in the appropriation process for programs that can demonstrate reductions in health disparities. The Illinois General Assembly will need to investigate the validity and constitutionality of this recommendation and identify a viable path forward.

3.2 Look for Additional Ways to Incentivize Preventive and Community-Based Services in the Healthcare System.

Solution Description: The State should expand coverage to support the development of education and community support programs focused on the needs of communities of color. These services will also need to be available to people with private insurance.

3.3 Promote the Development of Preventative and Culturally Relevant Support Programs for Four Key Areas.

Solution Description: Community-based and culturally competent education and related supports are required to augment provider-driven care. These include screenings, increasing awareness and engagement in preventative health, and improving education. Community health workers and other community-based programs should be prioritized. Managed care organization (MCO)-supported community-based or peer-based programs could be a basis for catalyzing needed services.

Maternal and Infant Health Support Solution Descriptions: Look for opportunities to expand funding for community-based doulas to address the need for prenatal and 12 months of postpartum care, including:

- Work with Medicaid partners and community organizations to support the increased utilization and funding of doula services for prenatal and postpartum care for up to one year. Doing so will support ongoing collaborative work between IDHS's Division of Early Childhood and community and state agencies
- Support education and training for community-based doulas

References:
- See the Illinois Task Force on Infant and Maternal Mortality Among African Americans (January 2021) report[98] for an outline of the work being done to address Maternal and Infant Health across Illinois
- Illinois Maternal and Child Health (MCH) Action Plan[99]
- National Health Law Program[100]

Trauma Support Solution Descriptions: Expand community-based support services for people grieving from gun violence or suffering from violence-related trauma.

- Increase support needed to develop and expand community-driven solutions for addressing the multiple ways trauma can manifest in communities
- Offer training in how to identify trauma, increase access to death/grief doulas, develop trauma reduction programs, or support the creation of healing circles led by trained community members or professionals (e.g., physicians and

therapists). Extend support to family members, loved ones, and those impacted by violence
- Fund community-based violence prevention programs
- The Department of Human Services, through the Reimagine Public Safety Act[101], is supporting programs, training and technical assistance, and community convener efforts in 22 Chicago communities and 15 areas across Illinois. These programs focus on violence prevention, youth development, and high-risk youth interventions. Violence prevention-community support teams will provide culturally responsive, trauma-informed, therapeutic interventions focused on reducing traumatic stress symptoms and improving community functioning for individuals who have experienced chronic exposure to firearm violence
- Illinois Healthcare and Family Services (HFS) requests a federal Medicaid match to support the Reimagine Public Safety Act in its 1115 Healthcare Transformation waiver request[102]

Mental Health Solution Descriptions: Consider piloting affordable community-based mental health care options for youth and adults. In addition to the new Children's Behavioral Health Transformation Initiative[25], the Task Force calls for addressing the mental health needs of youth and adults in rural and socially vulnerable areas experiencing mental health service gaps. As part of a comprehensive plan, the following recommendations should be explored:

- Develop community-based solutions utilizing trained community health workers (CHWs) and licensed social workers (LCSWs) or peer support to bridge the long wait times for mental health services
- Culturally responsive individual/community trauma-informed therapy approaches available in schools for children with unmet mental health needs
- HFS recently received approval for a state plan amendment (SPA) to receive a federal match for expanding access to mental health services in schools. This will provide Illinois more Medicaid funding for eligible children receiving Medicaid-covered health care services in schools. This approval advances the expansion of school-based health services to improve healthcare access, especially for youth mental health services
- Additional equitable telehealth and virtual care models should be developed to supplement current efforts underway and continue to meet growing mental health needs in areas of high social vulnerability

Chronic Disease Solution Descriptions: Evaluate and consider investing in solutions for culturally responsive support, education, and resources (e.g., community-based hypertension management programs) for addressing chronic diseases in communities.

- Fund programs for community-based peer-support programs that address health, wellness, and lifestyle changes, educational programs, access to culturally relevant resources and guidance, and increasing access to preventative services

References:
- Children's Hospital New Orleans[103]
- American Psychological Association[104]
- Blue Cross Blue Shield of Illinois[105]

3.4 Initiate a Statewide Program to Develop Trauma-Informed Systems Across Illinois' Healthcare and Social Services Ecosystem.

Solution Description: Trauma-informed care has been promoted and established in communities nationwide bipartisanly. Illinois should become the nation's first trauma-informed state, with all state service agencies adopting trauma-informed policies, procedures, and systems. The model should encompass police, juvenile and adult justice, health, social service, and education systems and support forming a team of trauma-informed systems experts to work on a statewide strategy.

Building a trauma-informed state requires four key activities:

- Assess processes and procedures at points of service to identify potential re-traumatization risks
- Develop methods to better identify trauma in the people accessing state and health services
- Expand options for appropriate referrals to community-based services to address trauma
- Develop a public awareness campaign about Trauma/Complex Trauma/ACEs and their lifetime impacts on a person's health and well-being

State agencies should implement training in trauma-informed service in all aspects of their work

References:
- SAMHSA's Trauma and Justice Strategic Initiative July 2014[106]
- SAMHSA Spotlight[107]
- National Governors Association[108]

3.5 Improve Screening for Trauma and Associated Navigation to Community-Based Care and Resources in All Healthcare Settings.

Solution Description: Trauma often manifests as vague physical symptoms, and so may go unrecognized by health care providers not trained to recognize and connect those symptoms.

Healthcare systems across Illinois, especially those serving communities facing endemic violence and significant social problems, should implement trauma-informed screenings and referral processes to ensure people receive appropriate care. Trauma assessments should be implemented at the point of care (e.g., Emergency Departments), and referrals to community-based providers developed as hospital protocol in areas characterized by high poverty and violence. Existing hospital-based screening and referral programs should be leveraged and expanded.

Training should include the key principles of a trauma-informed approach, including safety, trustworthiness, and transparency; peer support; collaboration and mutuality; empowerment, voice, and choice; and cultural, historical, and gender issues outlined in the Clinician Guide for Trauma-Informed Care.

References:

- Christ Medical Center has a program to screen for trauma and directly refer to a community-based trauma support team
- Rush has an ACEs initiative screening prenatal persons and making appropriate referrals
- Florida has a universal prenatal and infant screening for trauma - FL Healthy Start Coalitions
- CalMatters[109]
- Clinician Guide for Trauma-Informed Care[110]

3.6 Improve Access for People with Disabilities Across the Health and Social Service Landscape.

Solution Description. There needs to be increased awareness of the health disparities faced by those with disabilities and the need for those with disabilities to be better supported across the health and social services landscape. State and community-based service providers must be better supported in identifying and implementing changes that increase access and acceptability of services for those with disabilities. Changes made to serve those with disabilities ultimately make services more accessible for all. The Task Force recommends the development of disability advisory panels to work with state agencies, health systems, and communities to eliminate barriers to care. In addition, funding must be allocated for CBOs, state agencies, and health providers to implement changes that increase access for people with physical and intellectual disabilities.

Additional Solution Details: Potential solution areas to create or expand include:

- Train staff and providers to accommodate better and treat people with disabilities
- Require hospitals and health providers to have the necessary equipment (e.g., height-adjustable examination tables, platform scales, and lift equipment) to conduct full examinations of patients with disabilities
- Make information available in various formats, such as large print, text-to-speech technologies, and braille, for people with impaired vision or blindness
- Provide coordination of care for people with disabilities
- Hire people with disabilities and intersectional identities for navigation roles to assist people with disabilities and ensure their needs are met
- Expand employment training programs to be more inclusive of those who learn differently or need additional support
- Update the IDHS requirements for obtaining services through the Department of Developmental Disabilities (DD) based on the level of functioning (mild, moderate, or severe) over an IQ score

References:

Duke Health[111]

Illinois Disability and Health Action Plan 2012-2017[42]

4 PROMOTE HEALTH EQUITY AND COMMUNITY VOICE IN HEALTH AND HUMAN SERVICES DECISION-MAKING

4.1 Support Expansion of the Use of Community Health Workers and Other Peer-Based or Community-Based Support Roles.

Solution Description: Look for innovative ways to leverage Community Health Workers (CHWs) and other community-based support workers across the care continuum and expand their training and education pathways. (Note: CHW is an umbrella term referring to over 150 service provider titles. For more information, see The Six Pillars of Community Health Workers – NACHW[112]).

CHWs can impact efforts related to outreach, education, prevention, training, and health literacy (similar to how they were leveraged during the COVID-19 pandemic), as well as support programs, assessments, and care navigation. All the HFS healthcare transformation collaboratives include CHWs. Medicaid MCOs employ CHWs and subcontract with institutions and organizations providing CHW services. Existing community college programs and health training pathways should be engaged to expand access to training and certification. The HFS 1115 Healthcare Transformation waiver requests a federal match to support CHW training. Information on sustainably financing CHW employment can be found here: NACHW.org.[113]

Additional Solution Details: Potential solution areas to create or expand include:

- Utilizing CHWs to help improve awareness, increase understanding, and ease fears related to prevention and screening
- Deploying CHWs for outreach and education as part of a state-supported marketing and outreach campaign to enroll eligible individuals in programs that provide needed benefits and coverage
- Building on MCOs' existing efforts with CHWs to help people better understand their healthcare coverage and navigate them to needed services
- Having MCOs create new roles for CHWs to engage hard-to-reach populations
- Having state agencies work with CHWs to expand health outreach efforts
- Integrating CHWs into state programs and healthcare systems' teams to conduct home visits in communities where they live

References:

Information on the impact CHWs and other community-based solutions had in Chicago during the COVID-19 pandemic response can be found in The National Association of Community Health Workers (NACHW) Vaccine Experience Final Report[114]

Further information on the CHW workforce's impacts at the state and local level can be found in NACH's Translation Summary Assessing CHW Workforce[115]

4.2 Formalize More Professional Development Pathways for Community Members to Pursue Health and Social Services Jobs.

Solution Description: Extending pathways to employment in the health and social sectors (e.g., certified nursing assistants (CNAs), emergency medical technicians (EMTs), nurses, and social workers) should start with making community-based health work achievable. This can be done by providing a living wage, connecting CHWs to other opportunities in the health and social service sectors, focusing on messaging and promoting the value and benefit of work in community-based healthcare, and making health and social work more desirable.

Reference:
CHRT[116]

4.3 Ensure Equitable Access to Sustainable Funding Opportunities for All Community-Based Organizations.

Solution Description. Consider convening an outside agency to conduct a comprehensive assessment of grant processes mandated at federal and state levels and consider changes to requirements for awarding grants. An audit of current funding requirements is needed to identify and eliminate burdensome requirements that impede organizational sustainability. Create resources for CBOs to help them better access funds, write effective grant proposals, meet grant requirements, overcome capacity issues, receive technical assistance, and operate more efficiently. Partnerships with larger, well-established organizations can provide mutual benefits and help CBOs accomplish their missions.

HFS provided a technical assistance consultant to organizations with limited capacities that sought to apply for Healthcare Transformation Collaborative grants. The Task Force recognizes that, in many cases, this may require changes to State law and State regulation and new ways to determine impact and accountability.

References:
- The Skillman Institute in Detroit conducted a racial equity audit to assess equity in grantmaking and identified multiple ways to create more equitable funding. Illinois should reference this to guide the development of its own audit.
- California Strategic Growth Council[117]
- The Skillman Foundation[118]

4.4 Create or Expand an Existing Comprehensive Community-Informed Asset Map of Health-Related Services and Resources for Addressing Social Determinants of Health.

Solution Description: Engage communities in community-driven assessments of current health and social services assets and programs. A community-first lens should ensure assets and services are calibrated to meet local needs. Existing structures - like the newly developed Birth to Five Action and Family Councils formed in regions across the state - can support gathering community input and data. MCOs and their coverage areas should be included in the assessment. The ILGA should make funds available to appropriate agencies to contract with an academic or social impact consulting partner to conduct the assessment.

References:
National Center for Farmworker Health[119]
Build Healthy Places Network[120]

4.5 Establish Structural Mechanisms for Communities to Have Decision-Making Authority Regarding the Kinds of Services Needed to Address Their Health Priorities.

Solution Description: Structures should be put in place to integrate the community's voice into decisions regarding its health. A "nothing about us without us" policy should guide all decisions regarding communities' health and human service needs. New and creative ways to engage communities in solutions development in health and wellbeing matters should be explored (e.g., health make-a-thons to generate ideas for addressing local needs). Community participants should be compensated for their participation.

4.6 Continue to Identify and Address Individual and Systemic Racism in the Health and Social Service System Through Education, Intervention, and Corrective Actions.

Solution Description: Assess the racial dynamics and discriminatory factors that create reluctance in Black and Brown community members to seek healthcare and social services. Develop a plan to eliminate racism and other biases from our health and service systems. Continue to require and refine training delivered to the health and social service sectors in pursuit of a more inclusive and welcoming health ecosystem.

Reference:
The Commonwealth Fund[121]

5 IMPROVE HEALTH AND HUMAN SERVICES SYSTEMS IN SUPPORT OF COLLABORATIVE CARE MODELS

5.1 Continue to Update Intake and Engagement Processes for Benefit Services to be Respectful and Humane.

Solution Description: DHS, HFS, and other customer-facing State agencies should develop human-centered processes and interfaces to create better service experiences. Bringing a service mindset to Illinois' entire HHS system is vital to reducing inequities and creating affordances that people feel work for them. For example, there is room for improvement in data sharing across public benefit programs

and opportunities to enroll beneficiaries in programs they qualify directly–identifying ways to remove the potential for re-traumatization in service encounters, whether online or in-person, is essential for creating better experiences.

References:

Center on budget and policy priorities[122]

SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach[106]

SAMHSA: Building Resilient and Trauma-Informed Communities[107]

*Note: For solutions, under **Further Improve Service Systems in Support of Integrative Care Models**, The Task Force recognizes significant work is already underway. The Task Force believes subject matter experts should be convened to identify opportunities and barriers to achieving this vision and doing so promptly. Additionally, securing adequate funding for these system-level infrastructure projects has been an ongoing challenge and a significant barrier to realizing the goals of improved interoperability.*

5.2 Expedite the Creation of a Data-Driven 360-degree View of Clients Across Health and Social Services.

Solution Description. Integrated data gives service providers access to more information about a customer and their comprehensive needs. Integrating customer data can support service development improvements based on service utilization histories. Data collected should include benefit history across DHS and HFS, status on enrollment, claims data, service usage data, health-related social needs (HRSN) assessments, ACEs scores, trauma/complex trauma assessments, and social vulnerability index (SVI) scores.

This recommendation and the two that follow have complex legal and financial ramifications that need addressing. The Task Force recommends convening a group of legal, IT, and subject matter experts to identify the opportunities and barriers to realizing this concept.

References:

Health IT Outcomes1[23]

5.3 Redouble Efforts to Build a Single Database and Service Interface to Facilitate Integrated Care Navigation Across Healthcare and Social Services.

Solution Description: An integrated service tool offers a comprehensive view of available and appropriate services for community members. It also supports improved care navigation and a culture of "warm hand-offs." This concept requires data sharing between agencies to improve continuity of care and with healthcare systems to integrate with electronic health records.

References:

- The State of Illinois Health and Human Services Innovation Incubator (HHSi2[124]) has some cross-sector data initiatives underway that are beginning to support their model
- UniteUs[125], formerly NowPow and FindHelp[126], provides a social services database with the most comprehensive view of available services across the state
- The Integrated Referral and Intake System (IRIS[127]) includes an embedded protocol for service providers to facilitate a warm hand-off instead of just a list of referrals that may be difficult to understand and navigate. This allows social service organizations to track and confirm whether individuals received the needed services
- North Carolina's NCCARE360[128] is the first statewide coordinated care network that better connects individuals to local services and resources. NCCARE360 solves a fragmented health and human services system by connecting providers and organizations across sectors in a shared technology network. In the NCCARE360 network, providers can electronically connect individuals and families who have unmet social needs to community resources. NCCARE360 also allows easy feedback and follow-up to help close the care loop for individuals and families seeking help
- Politico[129]
- All In: Data for Community Health[130]
- National Care for the Homeless Council[131]

5.4 Launch a Centralized State of Illinois Whole Health Data Hub.

Solution Description: A third-party vendor will help facilitate the collection and sharing of all state health data to support improved access and information sharing. A new centralized data hub can support collecting and securing access to cross-agency, sector, and community data for trend identification and planning efforts. This more open and centralized approach will (1) provide a more accurate view of what is going on, (2) measure progress toward goals, and (3) increase innovative solutions to public health problems. This concept aligns with the Department of Mental Health's recommendation that the Community Behavioral Health Organization consider a third-party provider as a centralized repository for behavioral health data rather than HFS's Enterprise Data Warehouse.

Additional Solution Details: Potential solution areas to create or expand include:

- Privileges and purposes must be established to use data in the hub to ensure security
- Community members must have a voice in how privacy is established and monitored
- This approach would support the inclusion of more detailed race/ethnicity variables in ongoing tracking and data efforts
- A user-friendly interface is needed to support access for all key users
- Ongoing monitoring is needed to determine whether the data and information systems are functioning to serve individuals and systems in the region

References:
Maine Health Data Organization[132]
Health IT[133]

5.5 Leverage Funding Agreements and Contracts to Incentivize and Drive Collaboration Among Service Providers and Community-Based Organizations.

Solution Description: Articulate the types of activities needed from health and social service providers (i.e., more collaboration between CBOs, between Social and Health systems and CBOs, and between Social and Health systems themselves, increased partnerships, and data sharing) and write them into funding, contract agreements, and policies and procedures. The State should incentivize system partnerships to address a person's whole health regardless of the complexity and breadth of services needed. This concept includes partnerships across sectors and between large organizations and community-based health services outlined in previous recommendations.

5.6 Encourage and Incentivize a Culture of Collaboration Across Health and Social Service Sectors.

Solution Description: Encourage data sharing across all health-related services and agencies to reduce red tape in data-sharing processes and find ways to incentivize interagency collaboration. Data-sharing models should be well-conceived, designed, and piloted. The State should also audit existing data-sharing agreements and identify ways to reduce complexity or barriers to collaboration.

References:
- The Illinois Longitudinal Data System (ILDS[134]) is working on getting shared data into the cloud, where authorized users can access it for research and analysis (thus simplifying the number of data-sharing agreements needed)
- Healthcare Innovation[135]
- The Playbook[136]
- Center for Healthcare Strategies[137]