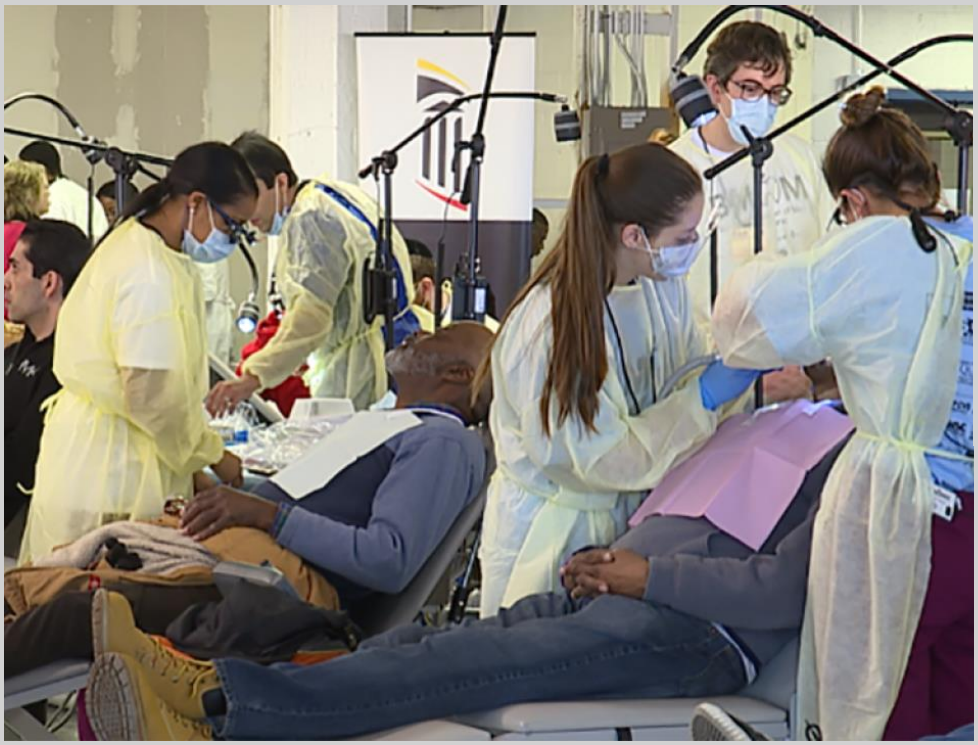

A Checkup for Cook County's Safety Net:

A Qualitative Review of Health Reform

December 2019

Health & Medicine
POLICY RESEARCH GROUP

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About Health & Medicine Policy Research Group

Health & Medicine is a Chicago based non-profit working to improve the health of all people in Illinois by promoting health equity. Founded in 1981 by Dr. Quentin Young, it was formed as an action-oriented policy center—nimble, independent, and focused on regional health issues. Health & Medicine's mission is to promote social justice and challenge inequities in health and health care. It conducts research, educates and collaborates with other groups to advocate policies and impact health systems to improve the health status of all people. Health & Medicine has successfully developed health policy recommendations and implementation strategies for different public and private entities, earning the trust of the legislature, advocates, the media, researchers and policymakers at all levels of government in Illinois to become the region's "honest broker" on healthcare policy matters. Learn more at www.hmprg.org.

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Executive Summary

The Affordable Care Act (ACA) precipitated a decade of reforms and reactions that have made a distinct impact on the Cook County health care safety net. "Reform" in health care encompasses a complex interplay of changes, forces, structures, and agents—including official legislation and rulemaking as well as the responses of government agencies, health care providers, payers, patients, advocates, private funders, and others. The health care safety net exists in constantly changing relationships to all the moving pieces that comprise the amorphous topic of 'health reform.'

Within a context of power inequities and deeply rooted systems of oppression, safety net institutions seek to provide care to mitigate their harm. When people reference a social determinant of health, whether it be housing, food, education, transportation, or jobs, there is also an imperative to explore the connection to structural inequities, based on root cause-level systemic oppression. Within safety net institutions, individual workers and patients attempt to find spaces within this broader context where services that meet basic health needs are accessible to all. Funders, advocates, and policy-makers are caught up in a similarly dynamic interplay as providers, patients, and payers. Even as people work to either personally meet their needs or to fill urgent gaps in services, many also work to nudge parts of the system to change direction while responding to ongoing change.

In 2016 Health & Medicine initiated a research project to explore the impacts, unintended consequences, and unfinished work of health reform—broadly defined—from the perspective of representatives of Cook County's health care safety net through interviews and focus groups with people working in the sector. In late 2018, we began the process of re-interviewing participants in our original research project as well as adding the perspective of stakeholders from additional sectors. Initial findings from this qualitative research served as the basis for an October forum entitled *The Chicago Forum for Justice in Health Policy: Health Reform Impacts, Challenges, and the Future*. Forum participants responded to our research findings as well as adding their own feedback and experiences. This report summarizes our learnings based on both our research and the forum proceedings.

Research Findings

Strengths and Assets

When asked to characterize the safety net overall, the individuals who Health & Medicine spoke with noted challenges, but also highlighted the distinct strengths of the Cook County safety net, especially the dedication of staff members and the rich array of collaborative organizations that share a mission to provide healthcare to all who need it. The new Governor's administration appears to be a source of hopefulness for many in the safety net, but given the lasting damage from the recent state budget impasse and continued threats from federal policy, most are looking for a period of stability and rebuilding.

Theme 1: Highly-skilled, mission-driven staff members are considered the greatest asset of safety net organizations.

A common refrain from respondents across the safety net is that their dedicated staff members are their most important asset. Respondents described staffs' drive to improve people's lives,

to serve people who others are unwilling to serve, and to constantly improve and innovate despite the challenges to working in the safety net. Respondents also described the sometimes overlooked skills of safety net workers including specialized case management, advocacy, and their ability to find and engage people who may be mistrustful of the healthcare and social service system.

Theme 2: Collaboration among safety net organizations in Cook County is a major asset of the local system.

The breadth of available services and the collaborative spirit of safety net provider organizations in Cook County is another area of strength and a source of resilience. Despite re-emerging challenges from rising uncompensated care for un- and under-insured patients and long-standing low Medicaid reimbursement rates, the safety net continues to provide essential services to its clients. Respondents described their collaborative efforts to meet community needs beyond the traditional boundaries of healthcare as a major strength. For instance, hospitals, FQHCs, and CBOs are currently working with elected officials and Housing Authorities to build partnerships and provide some funding for supportive housing that integrates clinical services and wraparound services for a subset of patients. While issues like the public-private divide can present barriers to collaboration, its shared mission of taking care of people in need unites the diverse members of the Cook County safety net.

Theme 3: Health reform, especially the Affordable Care Act, have had many positive impacts for the safety net system in Cook County and for the patients that it serves.

The largest positive aspect of health reform noted by participants was that the Affordable Care Act and Illinois' expansion of Medicaid meant far more coverage for patients and a significant investment in the health safety. Providers point to increased coverage and reductions in inpatient admissions that indicate that people are receiving more appropriate primary care, gaining greater health system literacy, and learning to use their new insurance.

Systems Complexity and Inequity

A common theme across the safety net was that system complexity and inequities within the safety net and society, impact patients and families, health workers, and safety net organizations.

Theme 4: Patients and families experience significant system complexity and inequities that impact both their health and ability to access healthcare.

Unmet healthcare and social needs persist and are rooted in long-term systemic oppression across the lived experience including racism, class inequity, xenophobia, and ableism, and ageism. Attempts to overcome these systemic barriers are stymied by often unnavigable complexity of health and human service systems, especially for those who are newly insured and are learning how to access healthcare. System complexity impacts many patients and families who access the safety net *despite* its lack of a smooth-functioning, supportive system for attaining, maintaining, and effectively using insurance and accessing services.

- Significant portions of the population served by the safety net remain **uninsured or underinsured,** and threats to stable access to insurance that meets people's needs abound:

    - **Cuts to enrollment assistance** to navigate eligibility and plan choice for subsidized commercial and Medicaid managed care plans
    - A dysfunctional **Medicaid redetermination** process plagued by poor communication that relies on unreliable mailing addresses for populations who move frequently
    - **Gaps in coverage** for oral health, mental health, long-term services and supports, and prescription medications
    - **Documents and verbal communications often do not meet patients' language needs** within healthcare delivery and in communication regarding health insurance
- Along with barriers to healthcare access, safety net patients endure the effects of the **inequitable distribution of the social determinants of health,** including housing, food, transportation, jobs and economic security, safety and freedom from violence.
    - **Policing and incarceration**—which have targeted communities of color—magnify the barriers to freely accessing a variety of systems that relate to these basic needs, such as housing, education, and credit
    - Bias against **harm reduction** practices and in favor of criminalization and punishment for people with substance use disorders simultaneously interferes with access to effective health care, multiplies unmet social needs, and worsens injustice
- Within a context of long-term un-redressed systems of oppression in society at-large and within healthcare, a variety of **attacks and threats from Federal officials** have sown worse distrust of systems, fear, trauma, and confusion—as well as withdrawal from systems—especially for groups already facing marginalization and oppression. These acts include:
    - The **vitriolic rhetoric** of the Trump Administration
    - Physical and verbal **attacks against immigrants** by law enforcement
    - An increase in **hate crimes**
    - The attempt to implement a wider **"public charge" rule** that has had a chilling effect on immigrants and mixed status families' enrollment in public benefits for which they are eligible
    - Attempts to add a **citizenship question to the census**

Theme 5. Health workers also experience significant system complexity and inequity that impact their ability to provide high-quality, affirming healthcare and other services—and their ability to continue working successfully in the safety net.

System complexity also impacts the capacity of health workers to manage the already challenging tasks of patient care and health education. Especially problematic areas of system complexity that affect all health workers involve accessing data across different Electronic Health Records systems and matching critical data on procedures, tests, and prescriptions to both provide care and to meet the requirements of frequently changing coverage rules and contracts related to managed care and Medicaid agency policy. **Safety net organizations frequently list their dedicated staff as their greatest asset**, but these challenges place a serious strain on the capacity of the safety net's workers:

- **Overwork and significant job stressors contribute to health worker burnout.** Burdens include:

    - The brief **15-minute patient visit** that seems to be standard among safety net clinics, but it is often grossly insufficient for supporting patients' health and social needs
    - The sense of inability to truly meet patients' health and social needs due to a **lack of resources**, time constraints, complex insurance enrollment, redetermination, and managed care processes; and systemic oppression that is larger than any one provider or organization
        - Threats and attacks on immigrants were frequently listed as a major contributor to stress, uncertainty, and fear that makes it difficult to focus on care
    - **Unmet needs of health workers themselves**, many of whom personally deal with systemic oppression, debt from the high cost of education, and other unmet social determinants of health due to structural inequity
    - The **hostile political climate** and attacks on immigrants and people receiving public benefits inflicts trauma on workers as well as patients
    - **Shortcomings of electronic health record systems** in accessing and freely sharing patient records, and the **absence of a statewide or regional health information exchange,** contribute to workers often having incomplete information about diagnosis and treatment history, test results, and prescriptions which can impact quality and efficiency of care
- Along with an overall **lack of equity, diversity, and inclusion in the health workforce**, **legal barriers** to working in the health sector for people with criminal records and **structural barriers** to professional school enrollment and graduation from an inequitable education system mean that healthcare teams often fail to reflect the communities they serve, a problem that both mirrors and exacerbates systemic injustice
- Unpaid or low-paid **family caregiving for people with disabilities and elderly people** makes up a large, fragile, and unsustainable portion of the work of the health care safety net
- **Competition within the health sector** for workers which pits institutions with vastly different resources against one another, contributing to turnover and recruitment challenges for some organizations

Theme 6. Safety net provider organizations experience system complexity that can damage parts of the safety net and have negative consequences in terms of health inequities.

On an organizational level, system complexity and health reform uncertainty are challenging for the safety net, and financial unsteadiness remains a threat. Some safety net providers have seen their proportion of uninsured patients rise recently, after several years of expanding coverage, even as they continue to rebuild capacity from the FY2016-FY2018 state budget impasse.

- During the state budget impasse, **Cook County lost some safety net organizations and workers** permanently and many others had to slow down new initiatives due to financial duress
- **Closures and mergers of safety net institutions related to broader changes in the health sector raise concerns** about gaps in care and loss of anchor institutions and associated jobs

- **Staffing and workforce issues** challenge safety net institutions, with significant attention being paid to shifting staff to handle managed care contracting and billing as well as to support patients through insurance processes and coordinate their care
- Threats **and attacks on the Affordable Care Act**, in addition to impacting the daily lives of health workers, patients, and families, also contributes to uncertainty and risk for safety net organizations' finances and operations
    - This includes past legislative efforts to roll back the law, battles in the courts, and administrative rules to weaken the ACA and safety net programs

Improving Flow of Public and Private Dollars

Two themes emerged from the data related to the flow of public and private dollars within the safety net. One of these relates to the flow of public Medicaid dollars now being mediated by managed care organizations. The other relates to private philanthropy.

Theme 7: Managed care adoption within Illinois Medicaid has resulted in several unintended consequences and complexity, while many remain hopeful that with some reforms, there is potential for successful managed care implementation.

A significant contributor to system complexity for the Cook County safety net is the shift to managed care for most of the people who use Medicaid. A contract rebid reduced the number of MCOs, a key demand from providers, but some argued that this simply magnified and concentrated operational problems. A Medicaid Omnibus bill enacted into law this year aims to address many of these ongoing concerns (among other issues not directly related to managed care). The concerns raised include:

- **Contracting, credentialing, prior authorization, and billing** that require each safety net provider organization to dedicate scarce staffing and resources to these tasks
- **Providers point to MCO denials** for care they insist was necessary and would have been paid under fee-for-service
- Despite contract requirements, **providers note that MCOs do not consistently meet language needs of all enrollees or the specific needs of people with disabilities**

Many providers remain interested in the promise of managed care to reduce overall costs and improve patient experience of care. Some noted that the state's regulatory model is still based on fee-for-service reimbursement and needs to shift to support capitation and alternative payment arrangements between MCOs and providers. General concerns about MCO accountability and state oversight were among the major motivators for the 2019 Medicaid Omnibus bill's managed care reforms, expected to be implemented in the coming months.

Theme 8: Private philanthropy plays an important role in sustaining the safety net and seeding new projects, but funding and processes could be more efficient to meet the needs of safety net organizations.

The complexity facing the safety net complicates the roles of funders who must decide where in this densely layered system to intervene with targeted investments. A few significant problems, along with suggested solutions, were mentioned by interviewees related to private philanthropy.

- While participants expressed appreciation for the opportunity to try new approaches—the frequent desire from funders for something "new" or "innovative"—it can come at

the expense of **sustained funding for prior initiatives that have been evaluated and proven effective**, or scaling up promising pilot projects
    - Solution: Provide more general operating support and funding to scale up and sustain proven programs to better enable organizations to focus on core services
    - Solution: One innovation that could aid the entire safety net is to develop a collective platform for connecting patients with organizations that can help them meet unmet social needs, such as food, housing, or legal support
- The **complex, often laborious process for grant applications** and reporting, which was noted is often for very small sums of money, could be made more efficient
    - Solution: Work with safety nets to understand their most urgent needs and build application processes and grant awards that are responsive to them
    - Solution: Perhaps develop more standardized application and reporting across funders
- Another issue that was raised is the **expectation that safety net organizations will settle for old, used medical equipment.** The issue was raised that while some used equipment, such as office chairs, may be appropriate, funders alienate safety net providers when they appear to imply that their patients do not deserve the same high-quality healthcare as non-safety net patients.
    - Solution: Build relationships with safety net organizations and create avenues for feedback on grant-making policies that affect them and their patients

Policy Recommendations and Areas for Future Research

Our reports concludes by offering policy and practice recommendations to help address the challenges of reform at the state, federal, and local level as well as recommendations for the philanthropy sector. Study participants noted many areas for systems improvement particularly related to the costs and complexity of the health insurance system, rising prescription drug costs, workforce shortages, and the IT and communications challenges of electronic health records. At the patient level, they noted that insurance is often unaffordable and that coverage gaps abound. At the same time, they recognized that there is insufficient engagement with people who are directly impacted by health reform and recommended that policymakers explore strategies to better listen to patients and health workers who are directly impacted by the reform process. Our recommendations reflect insights from safety net staff and leadership as well as Health & Medicine's own policy analysis. Finally, many questions were raised throughout this process so we end our paper identifying areas for possible future research.

Through our work Health & Medicine is committed to challenging inequities in health and healthcare and ensuring that healthcare is a human right, and this commitment is reflected throughout this paper. We hope that this qualitative review provides valuable policy, philanthropic, and research recommendations to support the safety net in Northern Illinois for decades to come.

Introduction

The healthcare policy and political landscapes in Cook County, the State of Illinois, and in the United States more broadly have shifted in both positive and negative directions over the last several years. Since the Patient Protection and Affordable Care Act (commonly referred to as the ACA) was signed into law in March 2010, millions of people across the nation have gained health insurance coverage. The ACA has weathered, so far, multiple attempts to undermine its effectiveness and outright repeal efforts within the legislative, executive, and judicial branches of government. Today, despite some important legislative losses to the breadth of the ACA, it remains largely in effect.

Through changes in administration at the national, state, and local level, the Cook County healthcare safety net continues to respond to the shifting landscape of ongoing health reform. In 2016, Health & Medicine Policy Research Group and Loyola University Stritch School of Medicine published research assessing the state of the Cook County safety net and recommending strategies to protect and build its capacity to adapt to the reforms, counter-reforms, and continued uncertainty of the ACA era.

One of the major provisions of the ACA allowed for expanded Medicaid coverage, which went into effect in Illinois in 2014. The coverage expansion followed the state's shift to Medicaid managed care in 2012, a law change that required at least 50% of Medicaid recipients to be in managed care plans. According to the Illinois Department of Healthcare and Family Services (HFS), about 80% of Medicaid enrollees statewide are enrolled in managed care.[1]

Many other health reforms have been undertaken at different levels of government, and some of these will be described as background information to contextualize the findings of this research. This study extends previous research examining the impact of the Affordable Care Act on the safety net, including our prior research in 2016, focused on the Cook County safety net and in our 2017 research (published in 2018), focused on the western suburbs of Cook County and part of DuPage County, Illinois. While the scope of each of these research projects is different, the focus remains on the impacts of health reform, unintended consequences, and possible future reforms. Our analysis is informed by years of experience in health reform policy research and advocacy. This research includes primarily qualitative data from interviews and focus groups with people who work at a range of safety net organizations including Federally Qualified Health Centers (FQHCs), safety net hospitals, health insurers, and community-based organizations. The work seeks to identify challenges as well as potential solutions to the system-wide impacts of ACA implementation and other health reforms on Cook County's safety net, while also identifying future research needs.

Setting the Stage

To provide some political context, it is worth examining Federal, state, and local levels of government as they relate to the Cook County safety net and the people who depend upon it. The 2020 presidential candidates have discussed many health reform options, including the potential future end of the ACA and of private insurance. A still relatively new Illinois

[1] Care Coordination Home. Illinois Department of Healthcare and Family Services. Retrieved from: https://www.illinois.gov/hfs/MedicalProviders/cc/Pages/defaultnew.aspx.

Governor, JB Pritzker, ran for office in part on a promise for covering more people via a "public option" while confronting the damage done by the state budget impasse from 2015 to 2017. Locally, the Cook County Board's tax allocation for Cook County Health (formerly called *Cook County Health & Hospitals System)* has fallen to a point that it no longer covers charity care, failing to cover the increasing costs of uncompensated care; in public statements, Cook County Health officials have both reiterated their commitment to their long-term mission of providing care to anyone who comes through their doors, but noted the fiscal challenge of providing over 50% of all charity care in the county. This has been coupled with requests for other nonprofit hospitals to increase their provision of charity care and notes that some hospitals will still send patients to Cook County Health for care.[2] Budget pressures and financial uncertainty co-exist with demands from Medicare, Medicaid, and private insurers to improve quality and implement innovative models of integrated, person-centered, trauma-informed care.

This study revisits the state of the safety net in Cook County in light of policy developments and sectoral trends both before and since 2016. Building on the previous study's investigation of hospitals, free and charitable clinics (FFCs), and FQHCs, we include two other key members of the safety net—1) Community-Based Organizations (CBOs) providing mental health care, substance use disorder services, and social services and supports for older adults, people with disabilities, and families, and 2) Medicaid managed care organizations (MCOs) operating in Cook County. The CBOs in this study have long been a part of the broad social safety net, along with many other agencies that provide housing, nutrition, transportation, education, and legal supports to low-income and marginalized communities. As insurers, government programs, and philanthropic organizations focus increasingly on integrating services that address social determinants of health with medical and behavioral health care, traditional members of the health care safety net, like hospitals and FQHCs, must build deeper relationships with members of the broader safety net to successfully support patients' health.

This work is being conducted in the context of unpredictable policy changes that can add additional strain and uncertainty to safety net organizations' planning. Safety net providers of all kinds, along with the communities they serve, are compelled by uncertain circumstances to navigate a landscape whose key features are being invented and reinvented in real time. Furthermore, the safety net system is dynamic—a change in policy for one part of the sector ripples to affect others; how each organization or group responds will change the decisions available to other members of the safety net. As one example of this, as Illinois has implemented managed care, a number of staffing issues have come up around handling contracting, billing, and reimbursements as well as the competition from MCOs for staff, such as social workers. Health workers have noted the challenges of having to deal with different and changing contracts, changes to drug formularies, and the need to support patients trying to understand what MCO would be best for them. So, what might seem as if it were a seemingly simple change to a different model of insurance can impact staffing, recruitment and retention, workflow, and add complexity for both workers and patients.

As a result of this uncertainty a "roadmap" or "blueprint" drawn up today could be largely obsolete tomorrow. Health & Medicine set out to understand how the safety net was

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[2] Thometz, Kristen. Cook County Health CEO Calls on Other Hospitals to Increase Charity Care. WTTW. November 1, 2019. Retrieved from: https://news.wttw.com/2019/11/01/cook-county-health-ceo-calls-other-hospitals-increase-charity-care

responding to changes in health reform and managing the risks associated with the uncertainty of the future. Health reform in the past decade has included efforts to expand insurance coverage and protect the rights of marginalized groups, but there are also efforts to undermine or sabotage these goals to protect entrenched interests. This report explores the complex interplay of structural, historical, and political forces bombarding the safety net today and asks: *What are the strengths they have relied on to adapt and thrive amidst health reform, its unintended consequences, and the political backlash it sometimes sparks? Where are the gaps that threaten their ability to continue to serve Cook County communities and what do they need to build capacity in those areas?*

Throughout this report, we understand the effects of 'health reform' as a complex process that includes both legislation and policy change as well as the ways people and institutions respond by adopting or resisting reforms and participating in the broader discourse on healthcare and health policy. "Health reform" refers to this process, and not to its direction or consequences, positive or negative. This research aims to uncover the wide range of topics within the realm of "health reform" and the "health safety net", broadly defined.

Health reform, in this context, includes:

- Formal legislation and administrative changes
- Executive agencies' rulemaking and additional interpretation of policies, their official policy guidance, and their inter-agency communication with regard to policy implementation
- Private and public entities' anticipation of, and planning for, the effects of policy change
- The mindsets and attitudes toward changes in policy and practice of people working in or receiving services from the health sector
- Funding decisions, from the public and private sector, to directly support service delivery and to encourage practice-level changes in service delivery
- Technological change that occurs simultaneously with policy change and the extent to which this new technology is adopted or avoided
- The effects of changes in health care delivery on public health goals of addressing unmet social needs of patients and families, and the response of the public health system
- Research and evaluation of policies and of responses to policies
- The extent and manner of interactions, responses, and information flows among the actors (e.g., policymakers, healthcare providers) at different levels of reform (e.g., policy and practice levels)

Cook County Demographics:

Some basic Cook County demographics and socio-economic data are shared in the chart below for context, with a comparison to 2016.[3,4]

Table 1. Population, Race, and Hispanic Origin

	2016	2018
Total Population	5,228,455	5,180,493
White	3,430,375	3,391,043
Black or African American	1,263,790	1,236,170
American Indian or Alaskan Native	38,448	38,253
Asian	392,048	408,151
Native Hawaiian or Pacific Islander	3,890	3,873
Two or more races	99,904	103,003
Hispanic or Latino	1,316,361	1,323,017

Table 2. American Community Survey 2016 and 2017

	2016 ACS	2017 ACS
Poverty Rate	16.7%	15.9%
Child Poverty Rate	24.2%	23.0%
Unemployment Rate	9.7%	8.7%

[3] Annual Estimates of the Resident Population by Sex, Race, and Hispanic Origin for the United States, States, and Counties: April 1, 2010 to July 1, 2018 more information
2018 Population Estimates. American FactFinder. United States Census Bureau. Retrieved from: https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=PEP_2018_PEPSR6H&prodType=table

[4] Poverty Status in The Past 12 Months. American Community Survey 5-year Estimates. American FactFinder. United States Census Bureau. Retrieved from: https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=CF

Background: Policies and Trends Affecting the Safety Net as a Whole

With more change coming in 2020 and beyond, safety net providers are still accommodating the policy shifts and uncertainty that followed: Illinois budget impasse from July 1, 2015 to August 31, 2017; the 2016 presidential election; and the Illinois 2018 gubernatorial election.

Like many states and localities, Illinois and Cook County have seen some retrenchment from the gains made after the ACA expanded access to Medicaid and subsidized commercial insurance. Several national shocks to the ACA Marketplaces from the Trump administration—including the elimination of the individual mandate requiring minimum insurance coverage of most Americans, cuts to enrollment assistance and Marketplace cost-sharing reduction programs, and the refusal to defend the ACA in lawsuits challenging the legitimacy of the law's pre-existing condition protections—led to a decline in participation in the insurance Marketplace and an increase in uninsurance rates across the country. U.S. Census Bureau estimates show the rate of uninsurance increasing for all age groups in Cook County (see Table 1). Models that incorporate additional sources project an uninsurance rate as high as 14.4% in 2019.[5]

Attacks on ACA's insurance coverage expansion

- **Repeal of the individual mandate:** Creates uncertainty about requirement to buy insurance and sets a dangerous cycle into motion—reducing incentives for healthier people to buy insurance on the Marketplace may result in adverse selection and a sicker, costlier risk pool, which may drive insurers out of the Marketplaces and threaten their viability.[6]
- **Legal challenge to pre-existing condition coverage protections:** The Trump administration refused to defend the ACA's protections for people with pre-existing condition when a lawsuit challenged their constitutionality after the elimination of the individual mandate.[7] A sweeping ruling in that case in December 2018, in which a federal judge in Texas called for striking down the entire law, has been appealed to the 5th Circuit and may eventually be headed to the Supreme Court.
- **End of cost-sharing reduction payments:** the lowest income customers on the ACA Marketplace received both tax credits toward premium costs and subsidies to reduce their co-payments and deductibles. But legal challenges to the federal payments that funded those cost sharing reduction subsidies (House v. Burwell, etc) rocked the

[5] Open Data Network. Retrieved from: https://www.opendatanetwork.com/entity/0500000US17031/Cook_County_IL/health.health_insurance.pctui?year=2014&age=18%20to%2064&race=All%20races&sex=Both%20sexes&income=All%20income%20levels

[6] Kamal, Rabah; Cox, Cynthia; et al. How Repeal of the Individual Mandate and Expansion of Loosely Regulated Plans are Affecting 2019 Premiums. Kaiser Family Foundation. October 26, 2018. Retrieved from: https://www.kff.org/health-costs/issue-brief/how-repeal-of-the-individual-mandate-and-expansion-of-loosely-regulated-plans-are-affecting-2019-premiums/

[7] Musumeci, MaryBeth. July 3, 2019. Retrieved from: Explaining Texas v. U.S.: A Guide to the 5th Circuit Appeal in the Case Challenging the ACA https://www.kff.org/health-reform/issue-brief/explaining-texas-v-u-s-a-guide-to-the-5th-circuit-appeal-in-the-case-challenging-the-aca/

insurer market and led to drastic changes in pricing of plans on the Marketplaces ('silver-loading'). While lawsuits continue to move forward, with most decided in favor of making the cost-reduction payments, this is another source of confusion and uncertainty for both consumers and insurers.[8]

- **Litigation:** Marketplace insurers have also had to bring lawsuits to receive risk adjustment and risk corridor payments that were included in the ACA to stabilize new insurance markets, adding to the uncertainty in those Marketplaces[9]
- **Reproductive rights:** Rollbacks on the ACA's requirements for contraceptive coverage and non-discrimination based on gender identity (Section 1557) reduce access to health care for women and transgender people, and undermine reproductive rights [10, 11]
- **Short-term insurance:** Expansion of short-term, limited benefit health plans that compete with more comprehensive Marketplace plans but leave consumers with unaffordable out-of-pocket expenses in the event of illness or injury[12]

Access to healthcare for immigrants has been restricted by increased fear of deportation, which the Trump administration has exacerbated with its actions and threats to expand Immigration and Customs Enforcement raids into areas previously deemed off limits, including healthcare facilities and increased aggressive enforcement at the southern border and beyond. This follows decades of strict immigration enforcement under the Clinton, Bush, and Obama Administrations, which have also had a lasting impact on immigrant communities.[13] A federal rule to restrict citizenship pathways for immigrants who have received public benefits, including food assistance and Medicaid coverage, amplified fear in immigrant communities and reduced their participation in public health and welfare programs even before this "public charge" rule was finalized. As of this writing, the "public charge" is not in effect due to several court injunctions, but it could be enacted at a later date (read more here).[14] Estimates from the Kaiser Family Foundation warn of Medicaid and CHIP disenrollment rates ranging from 15 to

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[8] Keith, Katie. Insurers Can Continue Silver Loading For 2019. *Health Affairs. June 13, 2019.* Retrieved from: https://www.healthaffairs.org/do/10.1377/hblog20180613.293356/full/

[9] Keith, Katie. ACA Update: Risk Adjustment Litigation, DSH Cut Methodology. Health Affairs. September 27, 2019. Retrieved from: https://www.healthaffairs.org/do/10.1377/hblog20190927.674250/full/

[10] Keith, Katie. Religious, Moral Exemptions From Contraceptive Coverage Mandates: Second Verse, Same As The First. Health Affairs. November 9, 2018.
Retrieved from: https://www.healthaffairs.org/do/10.1377/hblog20181109.87594/full/

[11] Keith, Katie. Court Vacates Parts Of ACA Nondiscrimination Rule. Health Affairs. October 16, 2019.
Retrieved from: https://www.healthaffairs.org/do/10.1377/hblog20191016.336929/full/

[12] Pollitz, Karen; Long, Michelle; Semanskee, Ashley; Kamal, Rabah. Understanding Short-Term Limited Duration Health Insurance. Kaiser Family Foundation. April 23, 2018.
Retrieved from: https://www.kff.org/health-reform/issue-brief/understanding-short-term-limited-duration-health-insurance/

[13] Wolf, Zachary B. Yes, Obama deported more people than Trump but context is everything. July 13, 2019.
Retrieved from: https://www.cnn.com/2019/07/13/politics/obama-trump-deportations-illegal-immigration/index.html.

[14] Public Charge: Make the Right Choice for Your Family. Protecting Immigrant Families – Illinois. October 15, 2019. Retrieved from: https://drive.google.com/file/d/1p1Qoi1WLSjORINVLqpmZtGK18Vpt_zjU/view

35 percent among immigrant households that include non-citizens.[15] This translates to 2.1 to 4.9 million individuals losing health insurance coverage as a result of the rule. The lasting impact of depressing immigrant enrollment may be felt in the damage to the safety net providers who serve those communities and are likely to lose Medicaid revenue and add to uncompensated care costs. The Commonwealth Fund estimated that $68 billion in Medicaid and CHIP revenue, including $17 billion in hospital payments, are at risk from the public charge rule.[16]

The chart below shows that the estimated uninsured rate in Cook County rose in all age categories in 2017 after years of falling. This is considered to be due to the actions, policies, and rhetoric of the Trump Administration with regard to immigrants.

Table 3: Small Area Insurance Estimates of Uninsured Rates in Cook County Illinois[17]

	2014	2015	2016	2017
Under 19 years old	4.0%	3.0%	2.8%	3.3%
18-64	17.7%	13.4%	11.8%	12.3%
Under 65	14.1%	10.6%	9.4%	10.0%
65 and Older (from ACS)		1.3%	1.2%	1.5%

Managed care changes in Illinois

Another defining element of the safety net landscape is Medicaid managed care, which has changed significantly in Illinois since our 2016 safety net study. At that time, safety net providers pointed to the complexity and administrative burden of negotiating with 12 different Medicaid managed care organizations as a major challenge. Consistent with the recommendation we made in our first safety net report in 2016, a system-wide rebid of managed care contracts in 2017 reduced the number of MCOs and expanded their scope to all populations in every county of the state. Two MCOs now serve Cook County exclusively, and five others enroll members statewide. This is a positive step toward streamlining a cumbersome bureaucracy that diverted resources that were urgently needed for direct

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[15] Artiga, Samantha; Garfield, Rachel; Damico, Anthony. Estimated Impacts of the Proposed Public Charge Rule on Immigrants and Medicaid. Kaiser Family Foundation. October 2018. Retrieved from: http://files.kff.org/attachment/Issue-Brief-Estimated-Impacts-of-the-Proposed-Public-Charge-Rule-on-Immigrants-and-Medicaid

[16] Orris, Allison; Grady, April; Mann, Cindy. Public Charge Rule Would Have Significant, Negative Impact on Immigrants' Health Care and the Safety-Net Delivery System. The Commonwealth Fund. November 20, 2018. Retrieved from: https://www.commonwealthfund.org/blog/2018/public-charge-rule-negative-impact-immigrants-health-care.

[17] Small Area Health Insurance Estimates (SAHIE), United States Census. Retrieved from: https://www.census.gov/data-tools/demo/sahie/#/?s_statefips=17&s_stcou=17031&s_agecat=0&s_year=2017,2016,2015,2014

services; however, the smaller group of MCOs are facing ambitious demands from the Pritzker administration and its executive agencies, which expect them to serve a diverse population including seniors and people with disabilities. MCOs are also charged with implementing new programs in the 1115 Behavioral Health Transformation Waiver, approved by the federal government in May 2018, and taking leadership of Integrated Health Homes for the highest-need Medicaid enrollees. IHHs are discussed more on page 31.

Furthermore, many of the managed care concerns identified in the previous study were more fundamental to the basic operation of MCOs, regardless of their number. Those concerns remain, almost two years into the consolidated managed care program. Barriers to contracting with MCOs, inadequate networks for provider referrals, payment delays and claims denials, duplicative documentation requirements, and non-standardized processes for billing, prior authorization, and prescription drug formularies are all problems that cannot be completely resolved by reducing the number of MCOs.

In 2019, Illinois enacted a Medicaid Omnibus Act (SB 1321 / Public Act 101-0209) that addresses many of these concerns with managed care.[18] How this law is implemented and the extent of cooperation or conflict between providers, payers, consumers, government agencies, and elected officials will shape the decision-making and behavior of all members of the health care safety net. Below is a summary of key provisions of the Act that impact the safety net:

- **Reduce inappropriate payment denials**
    - The complexity of multiple, non-standardized billing processes continues to vex providers, and weighs especially heavily on safety net providers who serve large proportion of Medicaid patients. MCOs denied between 11% and 26% of Medicaid claims in the first quarter of Illinois' new, consolidated managed care program.[19] The Medicaid Omnibus Act addresses concerns about payment delays and denials with several ambitious reforms:
        - The law requires the creation of a new electronic Medicaid claims submission system, or "pipeline," to streamline reimbursement of provider claims and to improve the HFS oversight of MCO payments:
            - The "pipeline" of claims submissions would pass through HFS and then to MCOs. This will allow HFS to notify providers of claims issues that may result in rejection or denial of a claim, giving them the opportunity to quickly correct those problems and re-submit a clean claim.
            - Data from the pipeline will also improve HFS's capacity for oversight of MCOs by creating a complete, in-house record of all claims submissions.
        - Building on the process improvement of the pipeline, the law calls for the formation of Workgroups to standardize operational processes for billing

[18] Bill Status for SB 1321.Illinois General Assembly. 101st General Assembly (2019). Retrieved from: http://www.ilga.gov/legislation/BillStatus.asp?GA=101&DocTypeID=SB&DocNum=1321&GAID=15&SessionID=108&LegID=117946.
[19] Illinois' Medicaid managed-care program is costing hospitals. Modern Healthcare. April 1, 2019. Retrieved from: https://www.modernhealthcare.com/providers/illinois-medicaid-managed-care-program-costing-hospitals.

and payment across plans to ease the administrative burden on providers.
    - Recognizing that claims denials will always create some conflict between providers and payers, the law calls for a dispute resolution process for providers challenging MCO decisions to deny reimbursement for claims.
    - The law enforces a requirement for timely payment by introducing an interest penalty for each day a claim remains unpaid after 30-days, and requires MCOs to pay providers on the HFS expedited provider list at least as frequently as the HFS fee-for-service payment schedule for expedited providers.

- **Improvements to eligibility determination and redetermination process**
    - The Medicaid Omnibus Act also attempts to redress a long-standing complaint voiced by providers, consumers, payers, and advocates—the complex and highly disruptive process of Medicaid eligibility redeterminations. The process has been plagued by failures to reach Medicaid enrollees to alert them of their redetermination deadlines, administrative bottlenecks between state agencies that prevent information sharing, and backlogs and delays in processing redetermination applications. The law introduces reforms to eligibility determination and redetermination to stabilize the current system and improve the process to avoid future backlogs:
    - The Omnibus also required a review of the entire redetermination process to end the "revolving door" of eligible individuals losing coverage during the redetermination process
    - The law specifically calls for the expansion to new categories of beneficiaries of ex parte redetermination. *Ex parte* eligibility determination is based on current information available to state agencies, for example from SNAP and other non-medical benefit applications, to determine eligibility during redetermination without demanding documents from the beneficiary.[20]
    - Hospitals can now automatically enroll infants born to mothers who are covered by Medicaid.
    - The law also includes provisions to streamline processing of initial Medicaid applications. Illinois has been out of compliance with federal regulations and a state consent decree that require timely determination of eligibility and, in cases when determination is not made within 45 days, issuance of temporary medical benefit cards.[21] Backlogs in both initial applications and temporary cards are one cause of high claims denial rates, and the law simplifies the application process and charges state agencies with developing further improvements, such as real-time eligibility determination.[22]

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[20] Medicaid/CHIP Renewals: State Practices, Lessons Learned & Opportunities. Webinar. Coverage Expansion Learning Collaborative. Thursday, August 13, 2015. Retrieved from: https://www.medicaid.gov/state-resource-center/mac-learning-collaboratives/downloads/coveragelc-medicaid-chip-renewals.pdf.
[21] Dernbach, Becky Z. Illinois' Medicaid backlog leaves more than 100,000 without health coverage. Chicago Sun-Times. May 3, 2019. Retrieved from: https://chicago.suntimes.com/2019/5/3/18621229/illinois-medicaid-backlog-leaves-more-than-100-000-without-health-coverage
[22] Technical Summary of Senate Bill 1321: Medicaid Omnibus Bill. Illinois Health and Hospital Association. June 3, 2019. Retrieved from: https://www.team-iha.org/files/non-gated/finance/technical-summary-of-senate-bil-1321.aspx

- **Additional MCO oversight measures:**
    - Access to care and oversight of network adequacy are both impeded by errors and omissions in Medicaid MCO provider directories. Consumers seeking services and providers trying to make in-network referrals are thwarted and frustrated by directories that include providers who do not accept new Medicaid patients, do not practice at the location listed in the directory, or are no longer in network, for example. Similarly, state oversight of network adequacy is impossible without an accurate count of hospitals, physicians, mental health specialists, and other providers who are actually available to serve MCO members. The Medicaid Omnibus Act requires timely updates of Medicaid MCOs provider directories
    - The law also brings more transparency to MCO Medical Loss Ratios, requiring HFS to publish those calculations annually

Prescription drug prices and the 340B program

Rising, unaffordable prescription drug prices are another health policy trend that has emerged as an urgent issue for the safety net and beyond since our 2016 study. Drug prices in the U.S. outpace those of other developed countries, even after accounting for discounts negotiated with private insurers and pharmacy benefit managers.[23] Pharmaceutical companies in the U.S. set and raise prices with little or no regulation, and Congress has consistently refused to grant the federal Medicare program power to negotiate drug prices.[24] In the absence of regulation or negotiation, effective treatments are unavailable to many Americans who cannot afford list prices or whose insurance restricts coverage of the costliest drugs.

Prescription drug costs are a burden for individual patients and also for providers who must purchase drugs for use in hospitals, clinics, and other settings. The federal 340B Program, created in 1992, was put in place to address drug costs for safety net providers. Under this program, pharmaceutical manufacturers agree to provide outpatient drugs to eligible safety net providers, including FQHCs and Disproportionate Share Hospitals, at a discount. When patients receive those drugs, the providers are reimbursed at the higher undiscounted price, creating a crucial revenue source to reinvest in other safety net services. This mechanism is intended to fulfill the program's goal to "stretch scarce federal resources as far as possible, reaching more eligible patients and providing more comprehensive services."[25] However, critics allege that some, though not all, 340B providers are profiting off the program rather than using savings to finance safety net care. Staff shortages at the Health Resources and Services Administration (HRSA), which oversees the 340B program, and limited reporting

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[23] Langreth, Robert. Migliozzi, Blacki; Gokhale, Ketaki. The U.S. Pays a Lot More for Top Drugs Than Other Countries. Bloomberg. December 18, 2015. Retrieved from: https://www.bloomberg.com/graphics/2015-drug-prices/

[24] Comparison of U.S. and International Prices for Top Medicare Part B Drugs by Total Expenditures. U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. October25, 2018. Retrieved from: https://aspe.hhs.gov/system/files/pdf/259996/ComparisonUSInternationalPricesTopSpendingPartBDrugs.pdf

[25] 340B Drug Pricing Program. Health Resources & Services Administration. Retrieved from: https://www.hrsa.gov/opa/index.html

requirements regarding the amount and use of 340B revenue make a clear accounting of the programs benefits and potential abuses challenging.[26] Various reforms have been proposed to improve oversight and tighten eligibility criteria to ensure the benefits of 340B discounts go to patients rather than enriching health systems.[27] However, the American Hospital Association and other defenders of the program argued that the documentation requirements in proposed legislation are excessive and would themselves divert resources from patient care.[28] Unfortunately, a more brute force policy appears to have won the day in the Trump administration—a 22.5% cut to 340B payments was included in a final rule issued in October 2019 despite those very cuts being ruled unlawful in a court ruling in May.[29, 30]

Cook County Budget and Cuts to Cook County Health

CCH is a major anchor of the health care safety net, as the main public hospital and the largest provider of charity care in the county. Its strength and sustainability is therefore crucial for all other providers, who depend on the public system as a provider of last resort and a driver of system-wide change in policy and practice. Over the last decade, the local tax subsidy from Cook County taxpayers to CCH to support care for hospital and ambulatory have been reduced by hundreds of millions of dollars to zero. Local taxpayer dollars that go to Cook County Health are stagnant and do not cover the cost of publicly provided free or reduced-cost healthcare.[31] Until 2016, some of this reduced support was made up for by reductions in uncompensated care due to increasing insurance coverage; however, since then the number of uninsured patients CCH sees has been rising, as has uncompensated care costs.[32] Without additional funding from the County, a CCH spokesperson told Crain's Chicago Business in October 2019, "We may be at a point where we need to limit charity care based on available resources."[33] While officials have also said that they would not turn people away, if they were to do so, this would be a retreat from CCH's mission and would be a gaping hole in the safety net for Cook County. At Health & Medicine's 2019 forum, a CCH executive said that a political solution of some type was needed to ensure long-term solvency of CCH.

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[26] Pearson, Elsa. Frakt, Austin. 340B is a well-intentioned drug discount program gone awry. STAT. March 22, 2018. Retrieved from: https://www.statnews.com/2018/03/22/340b-drug-discount-program-gone-awry/
[27] Conti, Rena M.; Nikpay, Sayeh; Gracia, Gabriela; Beeuwkes Buntin, Melinda J. Proposed Reforms To The 340B Drug Discount Program. Health Affairs. March 7, 2018. Retrieved from: https://www.healthaffairs.org/do/10.1377/hblog20180306.70004/full/
[28] AHA comments on HRSA's proposed omnibus guidance for the 340B program. American Hospital Association. October 27, 2015. Retrieved from: https://www.aha.org/letter/2015-10-27-aha-comments-hrsas-proposed-omnibus-guidance-340b-program
[29] King, Robert. CMS retains 340B, site-neutral payment cuts in final hospital payment rule. Fierce Healthcare. November 1, 2019. Retrieved from: https://www.fiercehealthcare.com/hospitals-health-systems/cms-retains-340b-site-neutral-payment-cuts-final-hospital-payment-rule
[30] Zaman, Shadid. Judge Rules 340B Cuts in 2019 Unlawful. May 7, 2019. Retrieved from: https://essentialhospitals.org/policy/judge-rules-340b-cuts-2019-unlawful/
[31] Executive Summary. Cook County Budget, Fiscal Year 2019. Retrieved from: https://www.cookcountyil.gov/sites/default/files/executive_summary_adopted_2019_web.pdf
[32] Cook County Executive Budget Recommendation, Volume 1. Fiscal Year 2020. Retrieved from: https://www.cookcountyil.gov/sites/default/files/service/v1-presrec-2020-dwngrd.pdf
[33] Quig, A.D. Inside the 2020 county budget Preckwinkle unveils today. Crain's Chicago Business. October 10, 2019. Retrieved from: https://www.chicagobusiness.com/government/inside-2020-county-budget-preckwinkle-unveils-today

The debate over the level of County tax allocation to Cook County Health coincides with an Office of the Independent Inspector General's (OIIG's) report that raised concerns about financial practices at CountyCare, County Health's Medicaid managed care community network (MCCN) (an insurance plan).[34] The OIIG report alleged mismanagement at CountyCare that resulted in $710 million in overdue payments to network providers and other vendors, and a failure to fully disclose financial losses. County Health leadership has contested these claims and presented findings from an external auditing firm, Deloitte, to defend CountyCare's financial practices, operational stability, and transparency to the County Health board, the County government, and the public.

A key factor in the conflicting findings from the OIG and Deloitte is the complexity of cash flow between the State Medicaid program, the County government, Cook County Health, CountyCare, and its network of providers. Thus, it is difficult to know what to make of the feuding between OIIG and County Health over the meaning of payment delays and rate cuts to Cook County Health's own providers: Are these red flags for management or run-of-the-mill workarounds to complex interactions with State and County appropriations, accounting, and budgeting processes? The aforementioned Deloitte report, commissioned by CCH, stated that CountyCare—again, an MCCN run by CCH—generates enough revenue to be solvent; however, the larger CCH system includes care for people who remain uninsured or under-insured, totaling approximately half a billion dollars in uncompensated care in both 2018 and 2019.[35, 36] Providing such care is central to the mission of CCH. Uncompensated care is covered in part through a variety of revenue streams, but the fiscal sustainability is unclear, as raised in some of the above quotes from CCH officials. Again, a political solution, likely in the form of either expanded health insurance coverage or additional public fiscal commitments to cover such care, is needed to ensure fiscal sustainability of CCH and fulfillment of its mission and core role it plays in the Cook County safety net. More broadly, the outcome of these arguments over interpretation of convoluted governmental structures can have a concrete impact on the lives of people served by the safety net, as County Health and County Board leaders have already raised the prospect of service cuts if CountyCare's financial viability is truly as at-risk as the OIIG report suggests.[37]

Hospital policy developments and industry trends as background and context for findings

Recent declines in insurance coverage and the prevalence of high-deductible health plans have affected the entire healthcare system, but hospitals have been especially hard hit by some policy developments. The federal government has long recognized the role of safety net hospitals in providing health care to low-income and uninsured patients, and the Disproportionate Share Hospital (DSH) payment program was designed to offset their financial

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[34] Schorsch, Kristen. Six Takeaways From Cook County Health's Response To The Inspector General. National Public Radio. September 6, 2019. Retrieved from: https://www.npr.org/local/309/2019/09/06/757998141/six-takeaways-from-cook-county-health-s-response-to-the-inspector-general
[35] Ibid.
[36] Cook County Executive Budget Recommendation, Volume 1. Fiscal Year 2020. Retrieved from: https://www.cookcountyil.gov/sites/default/files/service/v1-presrec-2020-dwngrd.pdf
[37] Schorsch, Kristen. Cook County Commissioners: What's Behind The County Health System's Big IOU? National Public Radio. June 27, 2019. Retrieved from: https://www.npr.org/local/309/2019/06/27/736209954/cook-county-commissioners-what-s-behind-the-county-health-system-s-big-i-o-u

burden. The ACA included a gradual reduction of DSH payments, a policy that presumed that hospital uncompensated care costs would shrink as more patients obtained health insurance that would cover their hospital bills. The Supreme Court decision that made the ACA's Medicaid expansion optional for states and disruptions in the Marketplace from lawsuits, cuts to enrollment assistance, and the overall uncertainty about the future of the law all eroded those expected insurance coverage levels. Uncompensated care costs have not fallen to the extent expected, and in the case of Cook County Health, which remains the provider of last resort for residents of Cook County and beyond, those costs are rising at unsustainable levels unless a political solution for increased funding is adopted.[38] Safety net hospitals that rely on DSH payments to survive are in no position to lose $43 billion through 2025, and hospitals have successfully advocated for delays to the ACA's DSH cuts.[39] Without a permanent solution, however, safety net hospitals are still burdened by managing the risk of losing significant revenue just as the proportion of uninsured patients has begun rising again.

The Cook County safety net includes both independent, unaffiliated hospitals and health centers and large systems that operate safety net sites. Chicago has one of the lowest levels of hospital market concentration in the country, though it has been consolidating in recent years. Hospitals face pressure to merge with health systems because of the complexity of health reform, the need to negotiate with increasingly consolidated insurers, and demands from payers and policy makers to build networks for coordinated care under value-based payment arrangements. Independent hospitals may struggle to manage the complexity of health reform, but market consolidation, driven by mergers, acquisitions, and closures, brings its own challenges.

The drive to consolidate the hospital market in response to forces in the health care system can conflict with the role of hospitals as anchor institutions in their communities.[40] Safety net hospitals are often the largest employer in their neighborhoods. An obvious response to low inpatient occupancy and unmet needs for primary care and specialty service is to reduce bed capacity and expand outpatient space. But the staffing changes that accompany that kind of shift in services can also impact community health, if jobs are eliminated in the process. A holistic view of the healthcare safety net must consider the health impact of these kinds of employment changes and ways to mitigate the harms of job loss without constraining the ability of hospitals to effectively meet community health needs.

In Illinois, the Health Facilities Services and Review Board (HFSRB) is tasked with this kind of decision-making when a health care provider proposes to build, expand, reduce, or eliminate hospital capacity. For example, in October 2019 the HFSRB approved the replacement of the

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[38] Schorsch, Kristen. Cook County Health Expects Its Financial Headache To Get Worse. WBEZ Chicago. August 27, 2019. https://www.wbez.org/shows/wbez-news/cook-county-health-expects-its-financial-headache-to-get-worse/2a55b459-5ae1-4177-b406-5ce6f919022a

[39] Siegel, Bruce. Essential Hospitals Laud Medicaid DSH Cut Delay in Funding Bill. America's Essential Hospitals. February 5, 2018. Retrieved from: https://essentialhospitals.org/general/essential-hospitals-laud-medicaid-dsh-cut-delay-funding-bill/

[40] Hacke, R.; KG, Deanne. Improving Community Health by Strengthening Community Investment. Robert Wood Johnson Foundation. March 15, 2017. Retrieved from: https://www.rwjf.org/content/rwjf/en/library/research/2017/03/improving-community-health-by-strengthening-community-investment.html.

current Provident Hospital, part of Cook County Health, with a new facility which will be 22% smaller, with fewer inpatient beds but more outpatient exam rooms and a more comprehensive emergency department.[41] A more fraught example that highlights the need for proactive planning with substantive community input is Pipeline Health's purchase and closure of Westlake Hospital in Melrose Park. The HFSRB approved an application to close the hospital in April 2019, after Pipeline argued that low occupancy and higher-than-projected losses necessitated closing Westlake in order to maintain two other newly acquired Pipeline hospitals, West Suburban Hospital in Oak Park and Louis Weiss Hospital in Chicago. Legal challenges have kept the hospital open for several months, and allegations of labor law violations and misuse of bankruptcy process by Pipeline are still being adjudicated.[42]

The Pritzker administration responded to concerns about the impact of sudden reductions in hospital capacity with new proposed requirements around public notice to give "communities more time to prepare and respond to potential changes in regional hospital service." To mitigate the economic effects of closures, the administration also charged the Department of Healthcare and Family Services with "engag[ing] in a community-based process to determine future healthcare delivery needs, administer grants to hospitals and healthcare providers to transform their facilities, and ensure that transformation benefits the community economically."[43] This all suggests a growing need for monitoring, long-term planning, and research with regard to the various pieces of the safety net, rather than the various actors making decisions without much regard for both communities and the broader safety net. When the HFSRB was reconstituted, there were plans to create a health systems planning office within the Department of Public Health. Unfortunately, this office was never created because the legislation did not have a fiscal note allowing for funding.

Federally Qualified Health Centers

Pressures from the uncertainty about the future of the ACA, declines in insurance coverage, specific attacks on immigrant communities, and ongoing challenges with both Medicaid eligibility processes and adapting to Medicaid managed care all impact Federally Qualified Health Centers (FQHCs) heavily. FQHCs face these challenges along with demands from federal primary care practice reforms that demand such changes as increasing use of electronic health records (EHR) and alternative payment models. Adapting to these reforms is difficult for any primary care practice, but financial constraints can reduce the capacity of some safety net health centers to accommodate the risks and upfront costs of these reforms, while at the same time, the full benefits of these reforms seem to be more of a promise that has not fully materialized than a reality. For example, while many seem to see some benefits of EHR adoption, there have long been complaints that EHR systems do not all transfer data

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[41] Schencker, Lisa. Bronzeville's historic Provident Hospital, 'a beacon of hope' since 1891, gets state approval for new $240 million facility. Chicago Tribune. October 23, 2019. Retrieved from: https://www.chicagotribune.com/business/ct-biz-provident-hospital-cook-county-approved-20191023-7owvykci6fbpjk43u7p7vfe3am-story.html

[42] Schencker, Lisa. Westlake Hospital poised to close after months of protests, legal wrangling. Chicago Tribune. August 9, 2019. Retrieved from: https://www.chicagotribune.com/business/ct-biz-westlake-hospital-closing-20190809-txyjyw2y5bazzhosdj754k6e74-story.html

[43] Illinois Department of Commerce and Economic Opportunity. A Plan to Revitalize the Illinois Economy and Build the Workforce of the Future. October, 2019. Retrieved from: https://www2.illinois.gov/dceo/Documents/IllinoisEconomicPlan2019.10.9.2019.pdf

seamlessly, so health workers are often working without full information, having to find workarounds, and still have to exert considerable effort and spend significant time using EHRs.

As insurance coverage expanded under the ACA, FQHCs have also faced increased competition from urgent care and retail clinics for their traditional patient base of low-income individuals and families. Yet FQHCs are also especially vulnerable to the growing fear in immigrant communities that seeking healthcare or public benefits will endanger individuals and their families, based on the aforementioned actions and threats from the Federal government. A likely "chilling effect" of the public charge rule was noted in immigrants choosing not to visit clinics for services or to enroll in benefits.[44]

The dual pressure of demands for practice transformation and disruption of patient volume places enormous pressure on the FQHC workforce. A national survey of FQHCs conducted during an earlier period of reform, from 2011 to 2014, found worsening working conditions for FQHC clinicians and staff who participated in a practice transformation demonstration project. FQHCs were not resistant to reforms, and their culture of person-centered, team-based practice and familiarity with both grant- and cost-based reimbursement made them uniquely positioned to implement medical home concepts and value-based payment models. However, FQHC staff cited disruptions to workflow from EHRs and alternative payment models, especially when they distract from face-to-face patient care, as a major factor negatively impacting professional satisfaction, work environment, and practice culture.[45]

With the added stressors of the Trump administration's rollbacks of ACA programs and the Rauner administration's long budget impasse from 2015 to 2018, in addition to a new round of Medicaid managed care reforms, Cook County FQHCs are under even more pressure to respond to demands for practice transformation with limited resources. In addition to the ongoing need to comply with federal Medicaid reforms, FQHCs must navigate the uncertainty of:

- FQHCs' role in Integrated Health Homes in Illinois
- The damaging effect of anti-immigrant rhetoric and policy, which impacts both patients and health workers
- Continuing challenges presented by Medicaid managed care
- Longstanding challenges with Illinois' Medicaid eligibility and redetermination processes

Although the challenges of reform are daunting, FQHCs have also demonstrated resilience and adaptability in trying circumstances. FQHCs on the north, south, and west sides of Chicago and in suburban Cook County have partnered with behavioral health providers to offer integrated

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[44] Illinois Department of Healthcare and Family Services Public Education Subcommittee Final Meeting Minutes June 6, 2019. Retrieved from: https://www.illinois.gov/hfs/SiteCollectionDocuments/PublicEduSubFINAL6619LTJLFINAL.pdf

[45] Friedberg, Mark W.; Reid, Rachel O.; et al. Federally Qualified Health Center Clinicians and Staff Increasingly Dissatisfied with Workplace Conditions. Health Affairs. August 2017. Retrieved from: https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2017.0205

behavioral health and primary care.[46] In a move that will support these efforts, Illinois recently became the first state to pass the American Psychiatric Association's model legislation requiring Medicaid and private insurers to cover *collaborative care* services.[47] Reimbursement for *collaborative care* will allow primary care providers to work together with behavioral health care managers and consulting psychiatrists to seamlessly integrate behavioral health services into primary care settings.

Community-Based Organizations (CBOs)

It is difficult to fully describe the many community-based organizations in Cook County that support people's unmet social needs. The safety net in Cook County includes a rich array of medical, behavioral health, and social services. Community mental health organizations and substance use disorder specialists are integral parts of any health care delivery system. Given the disproportionate rates of mental illness and substance use disorder among key constituents of the healthcare safety net—people in poverty and especially people who are homeless—safety net providers confront the need for access to behavioral health services every day. The growing number of older adults in the county also demands a robust aging care community-based network that is linked to primary care.

Safety net hospitals and FQHCs also serve many patients whose health concerns are inextricably related to social and economic factors in communities that have been gutted by systemic disinvestment in schools and infrastructure, mass incarceration and police brutality, and austerity policies that have rolled back basic welfare protections. Hospitals and FQHCs may provide social services and supports, but they also rely on Cook County's networks of CBOs to identify and intervene when individuals and families have unmet social needs. Importantly, many of these efforts fill in the gaps that exist specifically because of structural inequities, sometimes referred to as the structural determinants of health inequities, that maldistribute the social determinants of health. Sustainable, equitable change requires changes to policies, governance, and root-cause level factors that contribute to oppressive systems and values, such as racism and class inequity.

Community-based organizations that provide mental health, substance use disorder (SUD) services, and social services and supports for older adults, people with disabilities, and families face many common challenges. Managed care looms large amidst these obstacles, as providers of largely non-medical services work with payers with expertise in a medical model; related operational and cultural barriers abound. Medicaid credentialing and provider enrollment processes designed with physicians and other clinicians involved are difficult to navigate for many CBOs, but they cannot easily be reimbursed without that step. Core activities of CBOs, like outreach and engagement and home visits, had rarely been reimbursed in traditional managed care programs and do not obviously fit into a typical utilization management framework. Contracting with MCOs require CBOs to develop a novel infrastructure and staffing to calculate and communicate value, market their unique services, and negotiate complex

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[46] Integrated primary & Behavioral Healthcare. Thresholds. Retrieved from: https://www.thresholds.org/programs-services/integrated-primary-behavioral-healthcare/

[47] Mahmoud, Hosam; Sosa, Meryl Camin. Illinois Becomes First State to Pass APA's Model Collaborative Care Legislation. Psychiatric News. September 19, 2019. Retrieved from: https://psychnews.psychiatryonline.org/doi/10.1176/appi.pn.2019.9b28

contracts that presume another level of infrastructure as well as the information technology necessary for collecting and sharing detailed encounter and outcome data.

Technology Challenges

Beyond complying with managed care contracts, expectations for data reporting and security, and gaps in health information exchange, continue to be stubborn problems for Illinois safety net providers, especially CBOs. With increasing expectations for integration of medical, behavioral, and social services the capacity to share assessments, care plans, and comprehensive health records will become even more important. Financial, technical, and practice culture barriers exist for CBOs' participation in integrated care networks.[48]

- **Financial:** The cost of health information technology and the training and technical assistance necessary to use it effectively and securely is out of reach of many CBOs, who are still reeling from Illinois' two-year budget impasse. Community mental health, SUD, and social service agencies were excluded from the incentives to expand use of electronic health records in the 2009 HITECH ACT, and Illinois' investment in Health Information Exchange (HIE) has been minimal and not sustained to establish and operate a statewide or regional health information exchange.
- **Technical:** Building local workarounds for data exchange, in lieu of a state-wide or regional HIE, is especially difficult for CBOs linking to hospital and health center information platforms. In addition to the usual problems of interoperability across different systems, CBOs and medical providers tend to collect different kinds of information in different formats. CBOs typically produce case management records that are formatted to comply with the distinct billing and quality reporting for each sector. Medical records collect different information and were developed to comply with different billing and reporting requirements from those of many CBOs. Operational integration to create shared, universal records and care plans will be very difficult without a common foundation to make integrated medical-social-behavioral health data meaningful and actionable.
- **Practice culture:** CBOs that work with people with highly stigmatized conditions, such as mental illness, SUD, and HIV/AIDS, emerged in a culture of civil rights advocacy for their communities who have faced prejudice and discrimination in employment, housing, and other basic rights. While all providers recognize the benefit of integration, which depends on information sharing, differences in practice culture persist with regard to when and how to share sensitive information with all members of a care team.

Finally, CBOs of all types are struggling to rebuild amidst lasting damage from Illinois budget impasse during which the state operated without a budget and accumulated $17 billion in unpaid bills to social service providers. Even before the impasse, state funding for social services had fallen below providers' costs, and when payments ceased during the 736 days the

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[48] Post, Sharon. Policy Brief -- Perspectives On Data Exchange. Behavioral Health-Primary Care Integration Learning Collaborative. Health & Medicine Policy Research Group. June 2017. Retrieved from: http://hmprg.org/wp-content/themes/HMPRG/backup/PDFs/2017/BH_PCLearningCollaborativeDataExchangePolicyBriefFinal.pdf

state did not have a budget, CBOs were forced to cut budgets to the bone.[49, 50] Of 429 service providers who responded to a survey conducted by the United Way of Illinois:

- 91% of CBOs cut services to clients
- 36% reported that they expected to close
- 90% of homeless service providers limited intake of new clients, reduced services to current clients, laid off staff, eliminated whole programs, or closed work sites
- Social service providers took on $36 million in debt simply to continue operations during the impasse

Exacerbating workforce shortages facing community-based organizations, the budget impasse drove many experienced professionals out of health and human services entirely. With turnover as high as 25%, CBOs struggle to retain staff even as growing need and new programs for integrated care increase demand for behavioral health and social services.[51]

Efforts to address challenges to mental health and SUD providers

Mental health and substance use disorders are integral to the health safety net. The following points are important background.

- Illinois' FY2020 budget includes $40 million in new money for psychiatric services in the community mental health system, $7 million to improve mental health and SUD services in underserved communities, and directs 25% of state cannabis revenue to mental health and SUD services.
- Illinois is also pursuing large-scale changes to behavioral health that will make enormous demands on the mental health and SUD safety net. As Cook County safety net providers struggle to catch up on operational costs and long-term investments in staff and program improvements, concerns arise about their capacity to fully implement these reforms. Developing the staffing and operational capacity to implement new or expanded programs has already stretched the resources of mental health and substance use disorder agencies:
    - Expanding Medication Assisted Treatment requires significant expansion of the supply of MAT prescribers
    - The addition of Crisis Stabilization and Mobile Crisis Response to Illinois Medicaid state plan services has highlighted the shortage of community-based supports and post-acute services during and after crisis episodes[52]

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[49] United Way of Illinois 4th Agency State Budget Survey: High Level Findings. United Way of Illinois. June 2016. Retrieved from: http://unitedwayillinois.org/documents/UWIStateBudgetSurvey2016.pdf

[50] Mendoza, Susana A. Illinois Comptroller. Mending Illinois' Social Safety Net. Medium. September 6, 2019. Retrieved from: https://medium.com/@ILComptroller/mending-illinois-social-safety-net-ebea84237a7

[51] Ibid.

[52] Mobile Crisis Response (MCR) and Crisis Stabilization: Updating Illinois' Medicaid-funded Crisis Continuum. Illinois Department of Healthcare and Family Services. July 2018. Retrieved from: https://www.illinois.gov/hfs/SiteCollectionDocuments/MCRwebinarslidesfinal.pdf

- Implementing a new assessment tool, the Illinois Medicaid Comprehensive Assessment of Needs and Strengths, is time-consuming, labor-intensive, and because it is required of patients seeking mental, but not physical, health treatment, some advocates warn that it may violate parity laws [53]
- Mental health and substance use disorder providers, along with the rest of the healthcare safety net, must prepare for the launch of Integrated Health Homes, which will introduce changes to care coordination, service delivery, billing and payment, and quality measurement.[54]

Bills Related to Substance Use Disorder Services

Along with Executive Agency-led reforms, the Illinois General Assembly passed several bills in 2018 and 2019 to expand and improve mental health and SUD services, some of which are listed below:

- HB 2152 / Public Act 101-0251, the Mental Health Early Action on Campus Act,
  - Establishes minimum ratios for mental health clinicians at public colleges and universities
  - Requires public colleges and universities to develop partnerships with local mental health service providers to improve student mental health services
  - Requires staff training on student protections under the Americans with Disabilities Act[55]
- SB 3049 / Public Act 100-1019 allows clinical psychologists, clinical social workers, advanced practice registered nurses certified in psychiatric and mental health nursing, and other Medicaid-enrolled mental health professionals and clinicians, as well as Medicaid certified substance abuse centers and other facilities to receive Medicaid reimbursement for telehealth services. Previously, in terms of telehealth for mental health treatment, Illinois Medicaid reimbursed only psychiatrists, so this is an expansion of the variety of mental health providers who can be reimbursed for telehealth services.[56]
- SB 1707 / Public Act 100-1024 strengthens insurance parity requirements, including adding prohibitions on prior authorization and step therapy requirements for medication used to treat substance use disorders[57]
- SB 5109 / Public Act 100-0862, the Community Behavioral Health Care Professional Loan Repayment Program Act, calls for loan repayment assistance for mental health professionals practicing in

[53] Author's notes from June 28, 2019 Medicaid Advisory Committee Waiver Advisory Subcommittee Integrated Health Home – Children.(Unpublished).
[54] Appendix V Vision for Integrated Health Homes in Illinois. Illinois Department of Healthcare and Family Services. 2018. Retrieved from: https://www.illinois.gov/hfs/info/MedicaidManagedCareRFP/Documents/2018-24-001_RFP_Appendix_V.pdf
[55] Bill Status of HB 2152. Illinois General Assembly. 101st General Assembly. 2019. Retrieved from: http://www.ilga.gov/legislation/BillStatus.asp?DocTypeID=HB&DocNum=2152&GAID=15&SessionID=108&LegID=117837
[56] Bill status of SB 3049. Illinois General Assembly. 100th General Assembly. 2018. Retrieved from: http://www.ilga.gov/legislation/BillStatus.asp?DocTypeID=SB&DocNum=3049&GAID=14&SessionID=91&LegID=110579
[57] Bill status of SB 1707. Illinois General Assembly. 100th General Assembly. 2018. Retrieved from: http://ilga.gov/legislation/BillStatus.asp?GA=100&SessionID=91&DocTypeID=SB&DocNum=1707

community mental health center in an underserved or rural federally designated Mental Health Professional Shortage Area, pending appropriation[58]

- SB 1828 / Public Act 101-0356, the Overdose Prevention and Harm Reduction Act, improves overdose prevention efforts and creates a new statewide needle exchange program.[59]
- SB 2085 / Public Act 101-0574, established the Coverage of the Psychiatric Collaborative Care Model, amends the Illinois Insurance Code to require coverage of the Collaborative Care Model, a team based model for integrating behavioral health services into primary care settings[60]

Other SUD policies and trends

Since 2016, Illinois has received $82 million in federal funds to address the opioid crisis, including $15 million approved for addiction treatment services.[61]

- In July 2019, the Opioid Use Disorder (OUD) Withdrawal Management Subcommittee of the Medicaid Advisory Committee put forward recommendations to ensure that OUD treatment in Illinois is consistent with best practices. Specific policies proposed by the subcommittee include:
  - Updating and clarifying service definitions, quality metrics, data-sharing rules, and reimbursement methodologies to facilitate access to comprehensive services for evidence-based OUD treatment models, including peer support and case management, and to incentivize the best outcomes for people with OUD
  - Support hospitals to shift from inpatient detox models of withdrawal management that lack consistent connection to community-based medication assisted treatment after discharge to coordinated care models with strengthened capacity for transition planning, patient education, and overdose prevention[62, 63]

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[58] Bill status of SB 5109. Illinois General Assembly. 100th General Assembly. 2018. Retrieved from: http://www.ilga.gov/legislation/BillStatus.asp?DocNum=5109&GAID=14&DocTypeID=HB&SessionID=91&GA=100

[59] Bill status of SB 1828. Illinois General Assembly. 101st General Assembly. 2019. Retrieved from: http://www.ilga.gov/legislation/BillStatus.asp?GA=101&DocTypeID=SB&DocNum=1828&GAID=15&SessionID=108&LegID=119441

[60] Bill status of SB 2085. Illinois General Assembly. 101st General Assembly. 2019. Retrieved from: http://www.ilga.gov/legislation/billstatus.asp?DocNum=2085&GAID=15&GA=101&DocTypeID=SB&LegID=120169&SessionID=108&SpecSess=

[61] Herman, Christine. Illinois Receives $15 Million In Federal Funding To Address Opioid Crisis. WILL Radio. Illinois Public Media. April 15, 2019. Retrieved from: https://will.illinois.edu/news/story/illinois-receives-15-million-in-federal-funding-to-address-opioid-crisis

[62] Recommendations Page. Opioid Use Disorder Withdrawal Management Subcommittee, Medicaid Advisory Committee. Illinois Department of Healthcare and Family Services. July 19, 2019. Retrieved from: https://www.illinois.gov/hfs/About/BoardsandCommisions/MAC/access/Pages/RecommendationsPage.aspx

[63] Meeting Minutes. Opioid Use Disorder Withdrawal Management Subcommittee, Medicaid Advisory Committee. Illinois Department of Healthcare and Family Services. July 19, 2019. Retrieved from: https://www.illinois.gov/hfs/SiteCollectionDocuments/OUDWithdrawalManagementSubcommitteeMeetingJuly192019.pdf

- Further complicating the position of mental health and SUD providers is the temporary nature of many State reforms. A community-based provider must decide how much to invest in terms of hiring and training staff and building cross-sectoral partnerships for pilot program that may lose funding within a few years. 1115 Pilot programs include:
    - Residential and Inpatient Treatment for Individuals with SUD
    - Clinically Managed Withdrawal Management Services—intake, observation, medication services, and discharge services, for individuals in need of 24-hour structure and support to complete withdrawal and increased likelihood of continuing treatment and recovery
    - SUD case management—assist in accessing medical, social, educational, and other services for individuals with OUD/SUD who qualify for diversion into treatment from the criminal justice system
    - Peer recovery support services pilot
    - Crisis Intervention Services
    - Evidence-based Home Visiting Services
    - Assistance in Community Integration Services
    - Supported Employment
    - Intensive In-Home Services
    - Respite Services[64]

Efforts to support providers of care for people with disabilities and aging populations

Safety net providers are also called upon to provide care for people with disabilities and elderly people, including long-term care needs. The following points offer important background for those working with these populations.

- Health Choice Illinois, the reformed Medicaid managed care program that launched in 2018, replaced multiple managed care programs for different regions of the state with a consolidated group of MCOs serving all populations. The reduction in the number of MCOs was welcomed by safety net providers who were burdened by the unnecessary complexity of navigating different policies and practices of a dozen health plans. But HealthChoice replaces the Integrated Care Program (ICP) that specialized in 'seniors and people with disabilities' (SPD). While the ICP plans faced criticism from aging and disability advocates throughout their tenure in Illinois, they were contracted with the State to serve older adults and people with disabilities and, at least on paper, were accountable to the outcomes for these specific populations. The HealthChoice Illinois Plan Report Card, on the other hand, does not include a single measure that is specific to aging or disability
- HealthChoice Illinois implementation for people receiving long-term services and supports through 1915(c) waivers was delayed for several months
- As aging and disability services organizations continue to struggle to contract with MCOs, there is less accountability for the distinct outcomes related to independence and community integration that are priorities for most older adults and people with disabilities on Medicaid.

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[64] Frequently Asked Questions. Better Care Illinois: Behavioral Health Initiative. Illinois Department of Healthcare and Family Services. May 7, 2018. Retrieved from: https://www.illinois.gov/hfs/SiteCollectionDocuments/BetterCareIllinoisFAQs.pdf

Reform efforts to support families and children

The safety net provides crucial support for families and their children. The following points are important background with regard to families and children.

- Illinois Behavioral Health Transformation 1115 waiver, described above, includes expansion of infant and early childhood mental health consultation (I/ECMHC), a preventive model that pairs a trained mental health consultant with families and other caregivers in the natural settings where they learn and grow, such as homes, childcare centers, and preschools. A 2017 Illinois law prohibiting expulsion makes access to I/ECMHC more urgent, as services are needed to address behavioral health needs that would have led to expulsion.[65]
- Illinois is also pursuing approval for specialized Integrated Health Homes (IHHs) for children with high medical and/or behavioral health needs. Many details are unclear about reimbursement rates, service delivery, and coordination between MCOs, IHHs, and existing providers of case management and specialized care for children, but implementation of IHHs will be an important policy development defining the landscape for the safety net for Cook County children.
- A significant challenge created by State policy for childhood immunizations arose since the last report. In 2016, the Rauner administration enacted a rule change that restricted use of free vaccines provided by the Center for Disease Control and Prevention for children enrolled in the Children's Health Insurance Program (CHIP).[66] As a result, physicians had to bear the upfront cost of purchasing vaccines from manufacturers and then wait to file claims for reimbursement from MCOs after they provided immunizations to CHIP-enrolled children. The financial and logistical burden of this rule change led many physicians to refer families to public health departments for vaccinations, which overwhelmed the capacity of Chicago Department of Public Health in particular. In 2019, the Pritzker administration reversed the rule change and has been working with providers to increase participation in the CDC program, improve tracking of vaccinations for children in CHIP, and streamline reimbursement.[67]
    - The challenges of managed care described above—including payment delays and denial, churning between different MCOs, and difficulties joining provider networks—affect safety net providers serving children and adolescents. As state agencies and MCOs work to implement the reforms in 2019's Medicaid Omnibus bill to address some of these problems, providers serving foster children are preparing for the launch YouthCare, a managed care that would enroll over 36,000 current and former foster children in a single MCO, IlliniCare. The ACLU

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[65] Illinois's Approach to Building and Sustaining Infant and Early Childhood Mental Health Consultation. The Center of Excellence for Infant and Early Childhood Mental Health Consultation. (Undated). Retrieved from: https://www.samhsa.gov/sites/default/files/programs_campaigns/IECMHC/il-approach-building-sustaining-iecmhc.pdf

[66] Changes to the Vaccines for Children (VFC) Program: Participant Eligibility Verification and Billing. Illinois Department of Healthcare and Family Services. (Undated). Retrieved from: https://www.illinois.gov/hfs/SiteCollectionDocuments/VFC%20Webinar%20090716.pdf

[67] State Takes Action to Make Vaccines More Easily Available for Low-Income Children. Illinois Department of Public Health. July 3, 2019. Retrieved from: http://www.dph.illinois.gov/news/state-takes-action-make-vaccines-more-easily-available-low-income-children

has called for Illinois to delay the program's start date, "to prevent a rushed, disorderly and counterproductive rollout."[68] lion in SAMHSA funding to expand services in priority areas including Cook County:

- Expanding Medication Assisted Treatment and Naloxone availability, and outreach and engagement in communities, hospitals and jails
- Supporting the Illinois Prescription Drug Monitoring Program and the Illinois Helpline for Opioids and Other Substances

Health reform is a topic that is vast enough that a comprehensive review of the many potential topics would probably require a wiki-style resource, updated by perhaps thousands of people. This background section simply aims to provide the reader with a sampling of some of the significant reforms and trends in policy and practice since the 2016 report.

[68] Foster Parents, ACLU Resist Illinois Medicaid Plan Change NBC Chicago. November 16, 2019. Retrieved from: https://www.nbcchicago.com/news/local/foster-parents-aclu-resist-illinois-medicaid-change-565039802.html

Qualitative Methods, Scope, and Context for this Research

Understanding health reform as an ongoing, dynamic process, this study sought to examine how the safety net in Cook County, Illinois has been affected primarily by federal and state health policy reforms and the ways in which the system is working to adapt to recent health reforms, including the ACA and reforms that have occurred since its passage and alongside its implementation. Health reform, of course, did not begin or end with the ACA, but is an ongoing process that includes both large and small reforms, encompassing policy, practice, and programmatic changes, as well as a range of responses at the individual and organizational level.

This research was completed in order to provide a portrait of the safety net during a period of change and uncertainty, as well as to identify ways that policymakers and the philanthropic community can help strengthen the safety net system overall. Our goal was to generate new information about what is happening in the early post-ACA implementation era and to lay a foundation for future discussions about what actions can be taken to reinforce the safety net and further advance health reform.

We defined the safety net broadly as well, including public and non-profit hospitals, FQHCs, CBOs, and insurers. Our study is distinct from other safety net research in that we encompassed both hospital and primary care providers in a single study, which allowed us to direct our attention to exploring the connections and relationships among different types of providers and permitted us to examine the safety net as a holistic system of care. We also purposefully included CBOs that are serving many of the same people as FQHCs and safety net hospitals and are also impacted by and working within health reform; since our last Cook County-focused study, we have added information from organizations focused on behavioral health, aging, mothers and babies, and disability service providers.

Setting and Study Design

This study was funded by the Washington Square Health Foundation, a community foundation located in and focused on Cook County, Illinois. To examine the safety net in the western suburbs, we conducted a qualitative study with safety net leadership and staff in order to hear directly from people working to implement health reform at the ground level by supporting individuals seeking health and social services. This inquiry and analysis was meant to reveal and identify: 1) strengths and assets of organizations working within the safety net; 2) unintended consequences and unfinished work of health reform; 3) opportunities for philanthropy and policy changes to strengthen the overall safety net. Applying these lenses allowed the research team to review the qualitative data to identify eight themes and several sub-themes, which will be discussed later in this paper.

Convenience sampling was used to select hospitals, federally qualified health centers, free and charitable clinics, community-based organizations, and insurers based on their size, population served, and services offered. We organized focus group meetings with staff at two of these organizations and conducted key informant interviews with executive leadership and other staff at twelve different organizations, with two of these taking place at the same organization (a total of 13 organizations within the safety net were engaged). All key informant interviews and focus groups either took place at the organizations' sites or over the

phone. Our use of multiple sites, sources, data collection methods, and level of hierarchy of staff spoken with all increase trustworthiness of our data.

Data Collection and Participants

From December 2018 through July 2019, key informant interviews were conducted with executive leadership and focus groups with staff coming from a total of thirteen different FQHCs, hospitals, free and charitable clinics, insurers, and community-based organizations, using semi-structured focus group and interview guides. The research team at Health & Medicine Policy Research Group (Wesley Epplin and Margie Schaps) created a standardized, semi-structured interview/focus group guide that was used for both the focus groups and interviews with the leaders and staff from the different organizations included in the study, with minor adjustments made based both on the format and the flow of the discussion. In the interest of monitoring health reform and the safety net over time, this guide was based on guides used in our prior research, with some edits and updates. Epplin, an experienced interviewer and focus group facilitator, shared moderating and note taking responsibilities for the interviews and focus groups with another colleague who joined for a couple of the interviews and both of the focus groups. All interviews and focus groups were conducted by Schaps and Epplin were audio recorded and transcribed; Health & Medicine staff read transcripts and conducted thematic content analysis based on transcripts. To support open and honest conversations about challenges, both individual participants and their organizations were assured anonymity for their participation in this study.

Data Analysis

During our key informant interviews and focus groups with safety net leadership and staff, participants were asked to discuss the following key questions, with several sub-questions and prompts:

- How would you characterize the safety net in Cook County?
- How has the implementation of major national and state health reforms impacted the healthcare safety net in Cook County?
- How has the safety net adapted to the reformed environment?
- What are the unique assets of the Cook County's safety net providers?
- How can private philanthropy and policymakers support the safety net?

For the thematic analysis and writing stages of the research, Epplin was later joined by Sharon Post, an independent health researcher with many years of health policy research. The research team relied on thematic content analysis using both open and axial coding of key informant interviews and focus group analysis, which is a process of both relating and disaggregation of main themes during qualitative analysis. Through our key informant interviews and focus groups several key themes emerged and are described in the following section.

Research Themes and Findings

Section 1: Strengths and Assets Themes

While challenges exist, participants noted several strengths and assets within the Cook County safety net, including its dedicated staff members, collaborations, and the fact that health reform, including the ACA and Medicaid expansion, have continued to unfold. Three themes pertaining to these strengths and assets emerged from the data.

Theme 1: Highly-skilled, mission-driven staff members are considered the greatest asset of safety net organizations. A common refrain from respondents across the safety net organizations that participated is that their dedicated staff members are their most important asset. Respondents described the drive to improve people's lives, to serve people who others are unwilling to serve, and to constantly improve and innovate despite the financial, logistic, and political challenges to working in the safety net.

"You have to have a lot of grit to stay…on the front lines," one respondent declared, and many others echoed that sentiment. Safety net workers seek to provide care for people who are cut off from access to conventional health care saying, "Those were the individuals that we went out there looking for, because our focus here and mission is to serve people, is to prevent people from dying."

Respondents also described the sometimes overlooked skills of safety net workers, which include abilities pertaining to a range of demanding and complex tasks, performed in the context of staffing shortages, budget crises, and the burden of racism, class inequity, and other systemic oppression. Several examples from the data are relevant to highlighting the value of dedicated staff:

- Outreach workers and bilingual case managers find and engage people who have been marginalized, mistrust the healthcare and social service system, or simply cannot communicate without translation or other assistance
- One respondent cited data for their specialized case management program which showed an 86% improvement in SUD treatment completion. The respondent credits the commitment and perseverance of their staff, underscoring the crucial role that staff can play in patients' lives: "...we oftentimes are the only individuals who are believing in our clients, have high expectation[s] for clients, know that they can succeed, and treat them with dignity, respect and deliver the quality of service that you would want your most valued loved ones to receive."
- One participant noted that the sophisticated research capacity within the safety net itself tests innovative programs, translates evidence into practice, and lifts up the voice of patients as well as providers.
- Patient navigators and medical legal partnerships help individuals and families overcome barriers to access that persist despite expanded insurance coverage, such as unaffordable co-pays, navigating prior authorization requirements, and other benefits issues.
- Safety net advocacy brings crucial issues to the forefront of policy conversations—early childhood needs, systemic problems in Medicaid managed care programs, consumer protections across programs, and funding gaps in behavioral health.

This finding is relevant as a baseline understanding of the safety net, and becomes even more relevant with regard to system complexity faced by workers in the safety net, burnout, and challenges faced by safety net institutions, all of which will be discussed in the pages ahead.

Theme 2: Collaboration among safety net organizations in Cook County is a major asset of the local system. The breadth of available services and the collaborative spirit of safety net provider organizations in Cook County is another area of strength and a source of resilience during times of crisis like the recent State budget impasse. Despite re-emerging challenges from rising uncompensated care for un- and under-insured patients and long-standing low Medicaid reimbursement rates, the safety net does "provide the care that is expected from these institutions." In particular, one respondent said that a large local public hospital and the network of FQHCs—especially in Chicago—are sources of strength, and both have deep historical ties to their communities. Although respondents carefully articulated the need for more services and better integration across silos, they also recognized that Cook County has "been in the forefront of understanding what it means to provide safety net care and care in the community for all patients," and is "far ahead of the curve" compared to other areas in Illinois and in the U.S.

Respondents described their collaborative efforts to meet community needs beyond the traditional boundaries of healthcare as a major strength. Housing is an urgent need in Cook County, and hospitals, FQHCs, and CBOs are working with elected officials and Housing Authorities to build partnerships and provide some funding for supportive housing that integrates clinical services and wraparound services for a subset of patients.

At the same time, several people identified areas where collaboration among safety net providers could improve. One barrier to more efficient collaboration is information; different branches of the safety net do not always know what others are doing. Setting up a repository to collect and disseminate information on ongoing projects serving the safety net could be a task for funders, who stand to benefit from improved collaboration among their own grantees, at least in terms of greater efficiency, effectiveness, and reach for the people foundations seek to support.

As the safety net serves more insured patients insurance companies are also in need of guidance on how to support providers on the Medicaid and the commercial side. One insurer acknowledged that, while they are looking for new ways to support the safety net in the context of health reform, "we aren't sure what that means yet," but noted that they consider the specific impact of any initiative on the safety net before implementing it.

Others raised the issue of collaboration between and among unequal partners in the safety net. Some providers, for example, are parts of large systems that have more resources than independent hospitals. From a funder's perspective, this raises the question of whether to regard the safety net as one whole system, or to distinguish among independent safety net providers, who have no alternative for funding things like capital improvements, and system-affiliated safety net providers, which have, in theory, access to their parent organization's resources.

Another division that sometimes threatens to undermine the collaborative spirit of the Cook County safety net is the public-private divide. Participants from a large public healthcare

organization noted that it is not sustainable for its hospitals to be "the referral source for the uninsured" for all other hospitals and primary care sites. The pattern of private safety net providers' referrals was cited as a driving force in ballooning uncompensated care costs.

Although a shared mission of taking care of people who need support for their health and wellbeing unites the diverse members of the Cook County safety net, these divisions are part of the reality of serving marginalized populations and must be considered during planning and implementation of health reform.

Notwithstanding opportunities to collaborate better, overall, participants seemed to find the degree of collaboration among organizations within the Cook County healthcare safety net to be a strength and asset that can be built upon to improve patients' healthcare and health.

Theme 3: Health reform, especially the Affordable Care Act, has had many positive impacts for the safety net system in Cook County and for the patients that it serves.
Medicaid expansion has been very important for the Cook County safety net. Providers point to increased coverage and reductions in inpatient admissions that indicate that people are receiving more appropriate primary care, gaining greater health system literacy, and learning to use their new insurance.

One participant from a CBO noted another effect of the ACA:"the amazing empowerment and de-stigmatizing value of having insurance," especially for people involved with the criminal-legal system. Insurance coverage itself and the erosion of stigma contributed to a move from reactive to proactive approaches to healthcare. With insurance, people could get care before, and even prevent, health emergencies. One interviewee shared, "we found people weren't going to jail [as] frequently." Providers serving populations who had been marginalized responded to these changes, and teaching people how to use insurance and access regular primary care are now 'standard operating procedure' for intake with individuals for whom those resources had seemed permanently out of reach.

For FQHCs in particular, having the support of Medicaid improves access for patients who might not otherwise go to a primary care clinic. It also means that staff are no longer, "chasing after folks…to help cover a little tiny bit of their cost of care." Safety net hospitals, however, continue to see Medicaid patients in emergency departments and reimbursement remains below the cost of care. Safety net hospitals still regard the ACA as a strong contributor to "the survival and thriving capacity" of hospitals and other safety net providers.

While people who were newly insured were learning how to access services, advocates were learning from the process of implementing Medicaid expansion and other ACA programs at the state-level. This turned out to be important when safety net providers and advocates needed to protect the gains they had made. As one respondent shared, the ACA implementation experience "gave a lot of people the tools and knowledge that they need to be able to respond when Medicaid was attacked." Having well-trained and experienced advocates on-hand is critical to maintaining the long-term success of health reform.

Section 2: System Complexity and Inequity Themes

Many of the concerns and issues raised by participants fit into themes related to system complexity and inequities within the safety net and society and how these inequities impact

patients and families, health workers, and safety net organizations. Three themes emerged from the data related to these categories.

Theme 4: Patients and families experience significant system complexity and inequities that impact both their health and ability to access healthcare.

Sub-Theme 4a. Systems of oppression are longstanding, remain prevalent for many patients and families, and have severe impacts on people's health and healthcare access. Unmet health, healthcare, and social needs persist and are rooted in long-term systemic oppression across individuals' lived experience including but not limited to: racism, class inequity, genderism, xenophobia and anti-immigrant nationalism, ableism, and ageism. Some participants mentioned various manifestations of these inequities, with links to the maldistribution of social determinants of health.

Racial inequities in health status and outcomes were noted as persistent in Cook County. Respondents cited instances of worse health status for Latinx people and higher infant and maternal mortality for Black people.

Respondents who have devoted their lives to bearing witness to and eliminating these inequities shared painful experiences of attacks on Medicaid expansion framed by the racist narrative that public benefits are somehow handouts to "undeserving" Black people.

The bronze-to-platinum tiers on ACA insurance marketplaces were an all too familiar reminder of the rationing of care based on class and wealth. Meanwhile, the working poor are squeezed by low income eligibility thresholds, meaning that a long overdue raise in the minimum wage could make them ineligible for Medicaid and other means-tested benefits.

Class- and race-based exclusion from housing—whether via pricing people out of housing, discrimination, or via discrimination in other areas such as policing—undercut the mission of the healthcare safety net, whose resources are concentrated in city centers where housing is increasingly unaffordable. Displacement of low income people and people of color with low incomes from Chicago to the suburbs has contributed to a mismatch between where the safety net has been built and where people live. This is compounded by inequities in the transportation network that have only been exacerbated by displacement.

The latest threats to immigrant communities come on top of many other longstanding inequities. Respondents noted, for example, that neglect of translation services blocks access to necessary health care, that many immigrants are locked out of long-term services and supports programs, that behavioral health programs often lack linguistic and cultural competency, and that most healthcare providers fail to recognize and respond to the traumatic experiences that many immigrants have faced and continue to endure.

Respondents also discussed the harm from the Trump Administration's rhetoric and the increasing willingness of Immigration and Customs Enforcement agents to enter into what had been considered "sensitive" locations in prior administrations to both pursue and detain immigrants. These threats, actions, and detentions have had serious impacts on the health, wellbeing, trauma and fears and have also impacted immigrant families' willingness to remain in public programs, seek healthcare, and in some cases, to even leave their homes. The "public

charge" rule changes—which as of this writing are not in effect due to court injunctions—have contributed to fears and uncertainty among immigrants and mixed-status families.

Healthcare settings continue to fall short of the needs of people with disabilities by not meeting accessibility standards. Although there are standards for accessible diagnostic equipment from the U.S. Access Board, for example, hospitals and clinics rarely observe them. Communication is also an accessibility issue, with a great deal at stake. Without ASL interpreters or assisted communication devices, a person has no way of knowing what is happening or what decisions are being made in their medical visits—this is the stuff of "deaf community nightmare stories," according to one respondent. This exemplifies ableism in healthcare and broader society, in which the accessibility needs of people with disabilities are not being met. Gaps in access to supports like communication equipment and wheelchairs persist across the healthcare safety net but are notably worse for people who are incarcerated and for immigrants with disabilities. It was noted during one interview that people with disabilities have also been on the frontlines of defending Medicaid and the ACA, in spite of the fact that these system reforms do not fully meet their needs.

Attempts to overcome these and other systemic inequities are stymied by the complexity of health and human service systems, especially for those who are newly insured and are learning how to access care. System complexity impacts many patients and families who access the safety net *despite* its lack of a smooth-functioning, supportive system for attaining, maintaining, and effectively using insurance and accessing services. What may look like innocuous, if tedious, bureaucracy takes on a much more suspicious light in the context of systemic oppression. A theme from respondents' comments is that marginalization based on race, ethnicity, sexual identity, gender, and disability generate mistrust in the healthcare system. In the context of systemic oppression, offering an insurance card does not immediately assuage mistrust.

Enrollment assistance and system navigation is designed to help people understand how to use their insurance; however, the unwelcoming, sometimes traumatic, experiences people have had within the healthcare system itself often serve as a barrier. The safety net had long used "a very reactive healthcare approach," accessible to uninsured people only during emergencies; shifting to an approach emphasizing primary care, prevention, and wellness requires overcoming ongoing systemic oppression while seeking to actively build trust in the healthcare system. One respondent drove this point home, describing new Medicaid enrollees "who literally stated they [feel they] are not worthy of health insurance."

Participants pointed out that safety net organizations that are part of the safety net must recognize that the unmet social needs they are trying to address—poverty, education, housing, etc—are rooted in racism. Safety net institutions need to acknowledge how this affects their work before they can contribute to redress of these inequities. Respondents shared that within organizations themselves, at a minimum, it is critical to have true representation of Black and brown communities in decision making and daily operations.

Sub-Theme 4b: Threats to insurance coverage and healthcare access are ongoing. Despite the ACA's expansion of coverage, the Cook County safety net "still has an uninsured problem." Respondents noted that as the federal government has cut funds for marketing, outreach, and insurance navigators during open enrollment periods, Medicaid enrollment has declined and uninsurance rates have been going back up. Some respondents also mentioned that there has been a chilling effect of the aforementioned instances of anti-immigrant actions and rhetoric that have contributed to withdrawals from insurance, other public programs, and from healthcare.

> *"You have three quarters of a million people who got coverage but you had no increased investment in treatment."*
>
> *-Focus group participant*

While in fact there *was* increased investment in treatment, the idea that there is *insufficient* investment in treatment came up repeatedly, and the quote in the nearby textbox from a focus group participant was noteworthy for the *impression* that there was not a net increase investment in treatment from health reform. Those who still have insurance continue to encounter gaps in meaningful access to the care they need**.** Respondents highlighted shortages of providers who accept Medicaid among pediatric dentists and specialists for children with disabilities requiring families to drive very long distances, sometimes crossing the border into Indiana, to reach providers for their children. Dental coverage for transition-age youth is largely absent because dental coverage ends at age 21. It was also noted that early identification and intervention for lead exposure in Cook County is challenging. One respondent expressed anger at the fundamentally unfair structure of preventive care for children, where providers serving families with Medicaid are given "nine minutes, maybe, to do developmental screens," while families with private insurance have long consultations with their child's doctor because their insurance pays for the time and resources of a full preventive visit. On the other hand, the behavioral health service package covered by Medicaid is more expansive than private insurance, with coverage for team-based models and community supports like Assertive Community Treatment. However, rates are too low to maintain and grow provider capacity, so many people have to wait until they are in jails or prisons to receive behavioral health treatment instead of it being available in their communities.

Several respondents mentioned the unfinished work of reforms which expanded the volume of insured patients but did not change reimbursement models or invest in increased service capacity. Payers described their frustration with a safety net that is "still so dependent on their enhanced reimbursement through the fee-for-service models" and cannot "fully embrace a value-based approach or population health-based approach to care." Providers outline their plans to pursue risk-based contracts and value-based models, but shared that they felt held back by outdated reimbursement models that pay low rates for some services, create unfunded mandates for outreach and care coordination services that are not billable, and neglect the "parallel investment in increasing services and modernization of the foundation of treatment." The end result for patients is that they have health insurance coverage but do not always have access to the healthcare they need.

Sub-Theme 4c. Poor communication in rollouts of new programs harm access to care and contribute to healthcare access inequities. Healthcare reform is inherently complex, given the need for regulations to protect patient safety and ensure financial sustainability. But the patient experience of reform can either be more or less confusing and stressful depending

on how programs are rolled out and communicated. Respondents pointed out problems in this area, perhaps best summarized by the statement, "policy makers make decisions all the time that impact people who don't look like them, who don't have the same experience, and there's a lot of projection." Specific examples include:

- The frequent name-changes in Medicaid programs that individuals are enrolled into and out of, from Accountable Care Entities to Managed Care Organizations to Integrated Health Homes. The burden ends up on individuals and families to navigate these changes. Communication from state agencies is often conveyed in jargon-laden language that most people will not understand.
- The absence of a channel for parents to give input on care coordination and other reform programs for children in Medicaid: "We're talking about engaging with providers and engaging with stakeholders. Nowhere on the chart was parent perspective."

Respondents noted state agency silos as one cause of poor communications. HFS, the Medicaid agency, for example, does not have expertise in mental health and substance use disorders while the Divisions of Mental Health and Substance Use Prevention and Recovery within the Department of Human Services lack Medicaid expertise. These government-level communications challenges filter down to the patient level in the form of muddled, confusing updates and instructions about program changes. Managed care adds another layer and more opportunities for confusion. One respondent mentioned that MCO leadership who lack a fundamental understanding of the concepts of peer support, long-term services and supports, and transitions from institutions to integrated community living, or durable medical equipment needs, nonetheless draft contracts that define how these services and supports are deployed and reimbursed. There were many calls for the state, local governments, and MCOs to listen to people in their programs who are directly impacted by the reform process rather than only seeking input from professionals who are paid to attend stakeholder meetings.

Sub-Theme 4d. Medicaid redetermination has been a major contributor to gaps in health insurance coverage, as well as uncertainty, stress, and extra work that has negatively impacted many safety net patients. Almost every respondent brought up the Medicaid eligibility redetermination process as a source of confusion and aggravation, and listed it as a barrier to healthcare access. The State must determine initial eligibility for Medicaid prior to enrollment, and they also redetermine eligibility on a regular basis to ensure program integrity and compliance with federal legislation. One respondent emphasized that there is a backlog in initial enrollment and redetermination applications, including for enrollment of pregnant women, "which is just an enormous risk." After a person successfully enrolls in Medicaid, they face a confusing series of subsequent applications to choose a managed care plan, to switch plans during open enrollment, to choose a new plan if a current plan is shutting down or merging with another, and for redetermination of eligibility. For people who move frequently and people who are houseless, simply receiving notification of redetermination deadlines is a challenge. But moving "everyone online…is not necessarily a viable option for our patients" either.

The result of a dysfunctional redetermination process is that people lose coverage, not because they are ineligible, but because their documentation was incomplete or was not processed in time. Eligible individuals can re-enroll, but in the meantime they have lost their managed care plan and primary care assignments, and some assume that they are no longer eligible and fall

off the radar completely losing access to providers, prescriptions, and any regular source of prevention and treatment. Some providers have lists of patients who are up for redetermination in the next few months, and they work with those patients to complete their applications. But the system is still inefficient and "expensive for everyone."

People who are enrolled in Medicaid's Seniors and People with Disabilities category face a redetermination process that can be even more senseless and burdensome. While there is something farcical about redetermining a permanent disability—" if somebody has Down syndrome, why does there need to be redetermination for that?"—the consequence for the individual can be "very hard and very cruel." Finding a specialist and making an appointment to confirm a permanent condition, like a disability or frailty due to age, is logistically and physically difficult, and if the attempt is not successful, it can result in loss of insurance and disruption of services.

Of course, whenever possible, safety net providers will see patients even if they lose Medicaid coverage, but delays in re-enrollment cause serious cash flow problems for hospitals and other providers, and referrals are even more difficult when a redetermination application is still pending. Some providers have built new departments and systems to assist with benefit eligibility but following up on every application is beyond their capacity. One respondent even recalled offering to buy a new fax machine for a State benefits office to improve application processing. These are costs and burdens that safety net organizations are taking on to manage this process.

The broken redetermination process is thus stressful and harmful to patients directly, and also adds pressure to the provider systems upon which they depend. Respondents did not object to the basic rationale for redetermination; as one summed up: "People who have died, people who have moved out of the state, they should absolutely be taken off…But the process to keep people *on* needs to be less cumbersome."

Definition and Implications of Social Determinants of Health and the Structural Determinants of Health Inequities

The social determinants of health are "the conditions in the environments in which people live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks."[3] Social determinants of health are shaped by the distribution of money, power, and resources.[4]

"Structural determinants of health inequities, more simply referred to as structural inequities, refers to the systemic disadvantage of one social group compared to other groups with whom they coexist and the term encompasses policy, law, governance, and culture…"[3] An influential paper from the World Health Organization's Commission on the Social Determinants of Health notes that "'structural determinants' refer specifically to interplay between the socioeconomic-political context, structural mechanisms generating social stratification and the resulting socioeconomic position of individuals.[4]

Citations: 3 National Academies of Sciences, Engineering, and Medicine. 2017. Communities in action: Pathways to health equity. Washington, DC: The National Academies Press. doi: 10.17226/24624. Retrieved from: https://www.nap.edu/download/24624.
4 Solar O, Irwin A. A conceptual framework for action on the social determinants of health. Social Determinants of Health

Sub-Theme 4e. The long-term inequitable distribution of the social determinants of health is a major driver of health inequity. Without basic needs of housing, employment, food, and safety met, it is not realistic to expect people to prioritize health care and prevention.

Reforms like managed care and Accountable Health Care Communities are supposed to be oriented toward social determinants of health, and safety net providers are actively experimenting with solutions to housing, community violence, food security, and transportation. But stable, permanent funding is rarely available and sufficient and while programs can support individuals, it often stops short of policy change that have a sustainable, population-wide impact via public policy. Aside from community-based organizations that engage in advocacy—of which there are many—it is relatively rare to hear about healthcare safety net organizations focusing on a level of intervention that addresses the structural determinants of health inequities through changing policies and governance systems. When these organizations do engage in advocacy, it often centers on issues pertaining to the safety net itself, which have obvious importance to both organizations and the people they serve.

Barriers also exist for specific groups, such as people with disabilities and people re-entering communities from prison:

- **Affordable housing** is frequently not accessible, although disability advocates have a lawsuit pending challenging the lack of accessibility in affordable housing and homeless shelters. In addition to affordability challenges, access to safe and healthy housing is a challenge.

  Laws that exclude individuals who have been incarcerated from public housing pose an enormous roadblock to re-integration. For those recovering from mental illness and substance use disorder, stable housing is essential to success.

  Although there is greater recognition of the relationship between violence, trauma, and health, one participant noted, "we haven't figured out the community health role in addressing violence."
- **Transportation** is another intransigent problem to which a network of reachable, efficient, affordable, and sustainable solutions have not been found for all patients. This is especially true for people with disabilities. Public programs like Pace and private sector companies like Uber and Lyft have both been challenging for safety net providers to work with.
- **Policing and incarceration**—which have targeted communities of color—magnify the barriers to freely accessing a variety of systems that relate to these basic needs, such as housing, education, and credit.
- Within the broader society, bias against **harm reduction** practices and in favor of criminalization and punishment for people with substance use disorders simultaneously interferes with providers' ability to support access to effective health care, multiplies unmet social needs, and worsens injustice.

While structural barriers demand more systemic change, there are 'bright spots' as health care safety net organizations' experiments with housing-as-health approaches are receiving more attention and, slowly, more funding; although this falls short of policy change and does not match the scale of the affordable housing shortfall. One participant shared an example of low-income older adults having gained access to free fresh produce through partnerships with farmers markets.

Many respondents offered reminders that the Cook County safety net has a long history of crossing boundaries between health and social needs because this holistic perspective is part of their mission. By, for example, working with Cook County Jail to reintegrate people into communities ("providing a service that nobody else in the State of Illinois wanted to provide") and utilizing medical-legal partnerships, patients are provided support to navigate the public benefit processes and challenge illegal discrimination. Also, these interventions recognize and ameliorate the effect of inequitable societal distribution of housing, food, and educational resources on health.

Experiences of criminal-legal system-involved populations

The ACA had a huge impact on people leaving Cook County Jail—the largest population of newly Medicaid eligible individuals under its expansion. But there are still gaps in access to healthcare, housing, and employment due to exclusionary laws, discrimination, and system complexity. People who received medications in correctional facilities frequently cannot access those medications when they return to the community. Every person who is receiving Medication Assisted Therapy in a correctional facility, for example, is supposed to be enrolled in Medicaid before they are released, but it often falls on community-based organizations to ensure that everyone is signed up immediately and that there is continuity of care.

Even when people leaving correctional facilities are successfully enrolled, they may not know how to use insurance or how to seek health care outside of jails and prisons. Simultaneously navigating a complex court system and a convoluted health insurance program are even more challenging when combined with the stigma attached to incarceration and the persistent response to SUD as a crime rather than a health issue. Diversion and deflection programs are more accepted now and can help; however, the safety net system also needs to find "ways to bridge health care supports for people who are at risk of being incarcerated." Alternatives are also needed to police responses to mental health crisis, which fall short of providing the necessary healthcare, and often re-involves people in the criminal-legal carceral system instead of the health safety net.

The Cook County healthcare safety net itself has been thwarted in its attempts to respond to the specific needs of criminal-legal system-involved populations. Hospitals and health systems that plan to hire preferentially from the communities they serve find that laws block people with criminal records from employment in health care settings, for example. Medical-legal partnerships and community-based organizations that serve such people are sometimes able to overcome these barriers to employment, but we cannot realistically reduce recidivism and expect people to be successful after release if we do not change laws that interfere with stable housing and regular employment.

Sub-Theme 4f. Attacks and threats from Federal officials continue to spread fear and uncertainty and can contribute to people withdrawing from care and from other activities. While some level of system complexity is a by-product of well-intentioned reforms,

the same cannot be said for the attacks and threats on groups already facing marginalization and oppression. Specific policies, like the "public charge" rule, as well as anti-immigrant rhetoric from the Trump Administration, have re-energized an atmosphere of fear that has driven immigrants to forgo benefits for which they are eligible and has prompted some people to ask to be removed from programs in which they were enrolled. Some agencies, including FQHCs, have described cases in which immigrants who are U.S. citizens withdraw themselves and their children from services after threats against immigrants from Federal officials. Concerns were also raised related to the Trump Administration's attempt to add a citizenship question to the 2020 US Census. These threats and attacks fit within a much longer history of injustice and attacks on immigrants in the U.S.

While some participants expressed fear of attracting hostility if they were too public about accepting patients regardless of immigration status, they were undeterred. They recognized their role in creating safe zones, educating immigrants about their rights, and protecting immigrant members of their own workforce.

Theme 5. Health Workers' Experience of System Complexity and Inequity[69]

Sub-Theme 5a. System complexity and inequity impact workers' abilities to manage the already challenging tasks associated with patient care and health education. Especially problematic areas of system complexity that affect all health workers involve accessing data across different electronic health record systems and matching critical data on procedures, tests, and prescriptions in order to provide care and meet the requirements of frequently changing coverage rules and contracts related to managed care and Medicaid agency policy. Safety net organizations frequently list their dedicated staff as their greatest asset, but these challenges place a serious strain on workers' capacity.

Sub-Theme 5b. Recruitment and retention challenges impact health workers and the organizations that employ them. Expanding insurance coverage increased demand for services, and safety net organizations have struggled to recruit and retain staff to meet those growing needs. Safety net organizations find themselves in competition with one another for qualified staff. Several safety net organizations mentioned competition from MCOs for staff, especially care coordinators and behavioral health staff. But an MCO participant shared that they have trouble hiring case managers as well. One FQHC offered a possible explanation, that the shift from inpatient to outpatient services is creating more demand for community-based care management for everyone in the safety net, but workers with the necessary "flexibility

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[69] *Note: Discussions of "the safety net" can obscure the daily activity of the actual workers who provide services. The word, "workforce," which can be useful for descriptive purposes, can gloss over the fact that workers are not an agglomeration made up of faceless people. Rather, health workers each are individually working within a system and society of complexity and inequity and make up the staff at each organization and a broader workforce. This paper frequently uses "health workers" to center the discussion on an understanding that individuals are each trying to handle the stress and work of being within the safety net, not moving as a monolithic "workforce." The workers are also variably represented—or not—by unions and within organizations with variable levels of resources, both of which impact their degree of control over their workplaces.*

and critical thinking" to perform case management for complex patients outside of a centralized office are in short supply.

Safety net organizations with limited resources are frustrated by vacancies and turnover, but several respondents acknowledged that the debt burden of new graduates compels them to seek the highest-paying jobs, even if they believe in the mission of the safety net. In a vicious cycle, staffing shortages and reimbursement shortfalls make safety net jobs even more stressful as overworked staff compensate for missing resources. As one respondent explained, a person often "comes in under their job description but is also doing four other things." Respondents recommend reforming reimbursement rates to cover the costs of the most effective care, but also point to the need for either affordable education or loan repayment programs that make long-term work within the safety net viable for people seeking a career as a health worker. Forming a true health career trajectory should include physicians and nurses, but safety net organizations point out the need for investments in a full continuum of health workers and career paths, including but not limited to occupational and respiratory therapists, physician assistants, social workers, and peer support specialists. Respondents also highlighted shortages of safety net specialty care for children, which are so acute that families with infants and young children travel from other counties to Chicago to access specialty care providers who accept Medicaid.

A participant who works at an aging service provider emphasized the condition of the long-term care workforce saying that they are "the lowest paid people doing the most intensive work." Unpaid or low-paid family caregiving for people with disabilities and older adults also makes up a large, fragile, and unsustainable portion of the health care safety net workforce. One respondent described the high-level work that family caregivers do, like using feeding tubes and administering injections. While a home care aide would be prohibited from providing these services, the respondent said, we "expect the family to do it." Family caregivers provide 80% of care to older adults, often sacrificing their jobs and income and their own health. Moreover, the burden of caregiving falls more heavily on Black and Latinx families because they tend to use nursing homes at lower rates than white families. Recruiting and retaining workers to support an aging population, and their family caregivers, will require a change in the basic labor model for long-term services and supports.

Sub-Theme 5c. A lack of full equity, diversity, and inclusion in society is mirrored in the health workforce and negatively impacts workers, organizations, and patients. Systemic racism and other oppressions date back to before the founding of the U.S. Exclusion from health careers, for example, is deeply tied to inequities and racism in other sectors such as education. In our inequitable society, legal barriers to working in the health sector for people with criminal records and structural barriers to professional school enrollment and graduation contribute to healthcare teams often failing to reflect the communities they serve. This problem both mirrors and exacerbates systemic injustice, in terms of representation and career opportunities in the health sector and in subpar care. Healthcare is shown to be more effective when delivered by someone who has some similarity in ethnic and racial background to their patient because patient and provider have some common experiences and a greater ability to form trusting relationships. On the other side of the coin, a lack of diversity in the workforce has negative impacts on patient care in terms of cultural humility and structural competency. This challenge both results from and contributes to inequities in society and within the health sector itself.

Sub-Theme 5d. Health worker burnout threatens the long-term wellbeing of the sector's greatest asset: their dedicated, mission-driven staff members. Safety net workers are under pressure to provide care while maintaining the fragile financial viability of safety net providers and complying with operational and administrative demands of "the alphabet soup" of confusing, and seemingly ever-changing, reforms, often reduced to acronyms that can be difficult to track. The financial model of Federal grants drives the standard 15-minute patient visit at FQHCs, for example, but the multiplying checkboxes from reform program requirements, billing, and record keeping—"none of which individually are inherently wrong"—combine to become "untenable" within the allotted time for many patient visits.

The burnout risk of 'click fatigue' is magnified by the shortcomings of electronic health record systems, which, for many respondents, failed to deliver on their promises of efficiency and seamless data sharing. Barriers to accessing and freely sharing patient records, and the absence of a statewide or regional health information exchange, means that workers often have incomplete information about diagnosis and treatment history, test results, and prescriptions, despite the time spent entering data and 'checking boxes.' Mission-driven workers who choose to practice in the safety net are not surprised by stressful working conditions and patients' medical complexity and social needs. But, respondents warned, these workers will burnout when they are not able to meet those needs due to lack of time and resources, when they must perform several jobs due to staff shortages, and when electronic health record reporting takes time away from patients.

There is a history of safety net workers supporting one another and "being able to de-escalate and make sure that everybody's okay." Social workers who cared for people with HIV during the height of the AIDS crisis needed to "support each other when they were losing patients" while broader society stigmatized the disease. Health workers in the safety net today are continuing in that tradition of fighting for marginalized communities' access to healthcare. Hospitals and health centers described standing up to attacks on immigrants by protecting their own workers who are from mixed status families, supporting access to healthcare for immigrants as those rights are under attack, and advocating for licensing and employment opportunities for immigrant health care workers. One respondent acknowledged, "a curious trauma that's happening where you want to be able to support [immigrant] families the best way possible, but you don't have access to resources that are needed."

Another respondent insisted that addressing care team burnout would require tripling or quadrupling the current resource investment. To give the problem the attention it deserves, providers must consider the impact of trauma and systemic oppression on safety net workers themselves. Resources that respondents recommended include Mental Health First Aid and trauma-informed care training directed at the stress experienced by staff as well as by patients as well as shifting the culture of "toughness" in ERs. Respondents discussed the need for conversation about stress, burnout, vicarious trauma, and self-care and encouragement to take time off when needed.

Theme 6. Safety net provider Organizations' Experience of System Complexity and Inequity

The Cook County safety net is composed of a diverse array of organizations that serve patients and employ health workers while responding to changing needs and uncertain directions of

health reform. It is important to consider not just the individual experiences of patients and health workers, but also the impact of change at the organizational level.

This research investigated the experience of a few types of safety net organizations: hospitals, FQHCs, behavioral health providers, and CBOs providing mental health care, substance use disorder services, and social services and supports for older adults, people with disabilities, and families. Respondents from these organizations described the impact of system complexity and inequity on their decision-making and day-to-day activities. Additional sectors included since our last study are behavioral health, aging, mothers and babies, and disability service providers.

Sub-Theme 6a. Attacks on the Affordable Care Act have exacerbated uncertainty and resource shortages for organizations, as well as their health workers and patients. All safety net organizations reported having been negatively impacted by attacks on the ACA, including legislative efforts to repeal or roll back the law, court battles over financing for insurance subsidies and other appropriations in the ACA, and administrative rules to weaken the ACA and other safety net programs (such as the 340b prescription drug rebate program and enhanced Medicaid payments to safety net hospitals). Cuts to enrollment assistance and a general atmosphere of fear and uncertainty affect individuals, who may go without insurance, while the resulting increase in the uninsured rate in Cook County creates more financial risk and uncertainty for safety net organizations.

At the same time that these organizations must play the role of provider of last resort for un- and under-insured patients, they must also compete for patients who do have insurance, as these reimbursements support the viability of safety net organizations. Patients with insurance have a choice in providers, which is a positive development. But with the expansion of insurance came a rollback of some sources of public support for traditional safety net providers. Without additional public funding to support operations, there is increased pressure for revenue from insured patients which must cover more costs, including the costs of uncompensated care. Thus, safety net organizations must balance their mission of meeting the needs of un- and under-insured patients with the heightened urgency to sustain that mission primarily from one funding stream—reimbursements from caring for insured patients.

Sub-Theme 6b. There has been lasting damage from Illinois' state budget impasse. Cook County safety net organizations continue to rebuild capacity that was lost or damaged during the state budget impasse. Respondents offered stark reminders of the impact that continues to reverberate throughout the safety net:

- The safety net lost some organizations permanently, and providers outside of the Medicaid system, like domestic violence agencies, were hit especially hard.
- Critical staff with training and expertise who were driven out of the sector or left the state during the chaos and uncertainty of the budget impasse may never return.
- Safety net organizations demonstrated resilience during the budget crisis, but while they scrambled to simply keep their doors open "all the other things that are in queue to improve…or bring in new personnel…or grow…[were] put on hold."

Sub-Theme 6c. Workforce and staffing issues place significant stress on organizations and have impacts on the functioning of both individual organizations and the broader

safety net. Many of the concerns of health workers themselves, described above, are also present at an organizational level. Recruitment and retention affect individual workers and their teams because shortages and turnover shift more tasks onto fewer people who have less experience in a particular setting while constant cycles of onboarding and training for new workers contribute to burnout and turnover. Such vicious cycles and inefficiencies are also expensive for organizations and interfere with strategic plans to expand service capacity and improve access to high-quality services in the safety net. Respondents described specific workforce challenges from an organizational and employer perspective and ways they have attempted to address them:

- Safety net organizations, specifically FQHCs, were early adopters of physician extenders, such as advanced practice nurses (nurse practitioners) and physician assistants. But those clinicians still require licensed physicians to supervise and support their work, and safety net providers compete with much wealthier organizations for physician staff.
    - FQHCs are partnering with APN training programs, which exposes students to the safety net and helps generate interest in safety net careers.
    - FQHCs also partner with medical schools to help train students within the safety net, in the hopes of contributing to interest and comfort working in primary care safety net settings. Medical school debt limits many clinicians' ability or willingness to remain working in the comparatively lower paid safety net. Loan repayment programs, such as the National Health Service Corps program, can help to a degree, but they are limited in scope and reach.
- For safety net hospitals, the greatest need is for nurses, where turnover and shortages are the highest, and the current workforce tends to be older and closer to retirement age.
- Across the safety net, patient outreach in general is short-staffed and genuine outreach activities are too often deferred to make time to respond to demands created by managed care.
- There appears to be a crucial period, about two and a half years after a clinician begins work in behavioral health safety net organizations where turnover is highest, but workers who stay that long tend to stay for their whole career. Therefore, it is crucial to reduce obstacles to individuals practicing at the top of their licenses and barriers to career advancement in those early stages. For example, processes for obtaining clearance to work with DCFS youth can take several months and severely impacts recruitment and retention efforts for behavioral and social service providers.
- The closure of City of Chicago mental health clinics put pressure on private providers, including FQHCs who were not adequately staffed to serve patients with serious mental illness. Hiring psychiatrists, psychologists, and social workers was an unexpected expense without a clear funding source.

Sub-Theme 6d. Electronic health records have not yet met their promise and have posed significant challenges for institutions, as well as health workers. Although many respondents shared hopes and plans to utilize technology to improve care, the conventional approach to electronic health records appears poorly aligned with the needs of safety net organizations. A respondent described a feeling of being caught between government demands and physician expectations: EHR systems that the federal government requires for reporting and documentation are also unpopular with physicians who complain that they are too slow and take time and attention away from patient care. Another gap between "gold standard" EHRs and safety net practice culture is that these systems do not always capture data on unmet social needs, like housing stability and food security, although many providers have begun doing such screenings.

The Health Information Technology for Economic and Clinical Health Act (HITECH Act), which was enacted under Title XIII of the American Recovery and Reinvestment Act of 2009, has promoted and expanded the use of health information technology.

Learn more: https://www.healthit.gov/sites/default/files/hitech_act_excerpt_from_arra_with_index.pdf

However, safety net organizations recognize that "a shocking amount of [information exchange] is still faxing directions" between providers, and that more seamless data sharing has huge potential benefits for their patients. Expanding coordinated care models is a major challenge that respondents identified and connecting providers with linked health records is "a really significant piece of that puzzle.' One respondent described a successful pilot that linked primary care to behavioral health, social service, and hospital providers with a shared health record that drastically reduced wait times for supportive housing placement.

Despite such success stories, safety net organizations report a great deal of stress associated with EHRs, and, as one respondent notes, "Illinois did not move forward with any significant Health Information Exchange." Safety net patients and health workers in a fragmented system are heavily impacted by that decision.

Sub-Theme 6e. Mergers and facility closures often occur without appropriate system planning, threatening access to care and jobs while also eliminating anchor institutions within communities. Increasing consolidation is a trend throughout the U.S. healthcare system since our previous study in 2016. Hospitals, physician groups, behavioral health providers, insurers, and long-term care providers have all seen high volume of merger and acquisition activity, and sometimes these deals result in independent safety net organizations being absorbed in much larger systems. Respondents were cognizant of the local impact of changes in ownership and "the evolutional transformation of healthcare in this country" represented by national megamergers like CVS and Aetna. Some expressed concern that huge systems will be more likely to cut less financially well-performing parts of their system—the safety net components—while their market concentration gives those large non-safety net systems more power over the remaining safety net organizations' ability to hire staff, make referrals, and participate in coordinated care networks.

Other respondents noted the need for planning to avoid "unexpected cataclysms where an organization is open on Friday but closed on Monday and there hasn't been preparation or

forethought into what should be there in that area." For hospitals in particular, respondents were frank about the likelihood of closures of units or whole hospitals: "Part of [healthcare] transformation is going to mean hospitals closing." Individual safety net hospitals are faced with hard decisions about how to use scarce resources to best meet needs in their communities, which can mean eliminating service lines that are underutilized and costly to maintain. While a hospital will "make sure that those resources were in place" at other providers before eliminating a service, one respondent wondered if safety net organizations are ready to cooperate in the creation of "a really good clinically integrated network among multiple organizations [with a] shared understanding that that puts [helps] them secure their future," without requiring mergers or consolidation.

Illinois has a Health Facilities and Services Review Board and a Certificate of Need Program. According to the board's website, "The Health Facilities Planning Act (Act) (20 ILCS 3960), established Illinois' certificate of need (CON) program. The CON program promotes the development of a comprehensive health care delivery system that assures the availability of quality facilities, related services, and equipment to the public, while simultaneously addressing the issues of community need, accessibility, and financing. In addition, it encourages health care providers to engage in cost containment, better management and improved planning." More information can be found here.

Concerns about closures and mergers led several respondents to mention the need for planning, especially for repurposing hospital buildings to meet community healthcare needs; retraining their workers to keep jobs in the community; and addressing the "suburbanization of poverty" by expanding the safety net presence outside of the City of Chicago. One respondent emphasized the role that safety net organizations themselves could play in this process, noting that such assessment and planning are local issues, "that's not going to come out of Washington." The issue of safety net institutions, especially hospitals, serving as anchors of communities, providing jobs and stability, was also discussed.

Sub-Theme 6f. Behavioral health organizations have experiences that are particular to both them and their patients that demand additional reforms for the proper functioning of the behavioral health portion of the safety net. From the perspective of the behavioral health safety net, two reform initiatives loom large: Medicaid expansion and parity legislation. Under the ACA, people with behavioral health conditions gained insurance *and* access to care that insurers are now mandated to cover.

HRSA's investment in integration has had an impact on Cook County's behavioral health capacity as well. One safety net system now has behavioral health consultants available at all of its ambulatory primary care sites, and the growing consultative psychiatry models and utilization of LCSWs as behavioral health case managers in FQHCs will likely receive a boost from a 2019 law requiring Medicaid coverage of Collaborative Care, a model for treating mental illness in primary care settings. Legislation raising rates for community mental health and SUD centers should help shore up capacity for referrals in a sector that was badly damaged by the State budget impasse and the closure of City of Chicago mental health clinics.

One safety net provider also sees hope for the future of community-based, integrated SUD treatment. Advances in care models allow people with co-occurring mental illness and SUD to

receive services in the community, and models are being tested for treating primary SUD diagnoses with community-based wraparound models.

Despite these positive developments, however, behavioral health care providers in the Cook County safety net still lose money on every Medicaid service and must raise money to fill in that shortfall. Private sector agencies rely heavily on private foundation funding, and public sector providers depend on unpredictable budget decisions from state and local governments. The needs for practice-level reform are already demanding: building the infrastructure and staff capacity to implement integrated care models, transforming practices to become trauma-informed, and creating teams that can reach and engage youth in earlier stages of illness were each cited. These are enormous projects, and they are hampered by below-cost reimbursement rates which replicate provider shortages and high turnover, which in turn disrupt teams that are critical to effective behavioral health interventions.

Expanding access to SUD prevention and treatment continues to be especially challenging, as these providers are siloed from the overall healthcare system, even from behavioral health care. Some challenges include:

- Regulations for inpatient detoxification; certification requirements for drug treatment centers; and differing assessment, service delivery, and reimbursement methodologies that are still not fully aligned with Medicaid.
- The persistent stigma of MAT (especially buprenorphine and methadone), despite evidence for effectiveness causes confusion and conflict.
- These conflicts clash with the expectations of reform and managed care. The flexibility expected of managed care, for example, is blocked by inflexible Department of Human Services rules, and providers get stuck in the middle between compliance and innovation.
- According to one participant, traditional SUD industry practice where everything is 30 days, whether you wanted or needed or not, is an arbitrary timeframe that goes against clinical need; however, it is still done because it is a published guideline.

Sub-Theme 6g. Service providers focused on older adults play a vital role in the safety net and face specific challenges that have broader implications for the system. Older adults are an important constituency of the healthcare safety net. One reason so many people find themselves in need of safety net services, such as Medicaid, in older age is the lack of a viable long-term care insurance program. Some companies offer long-term care insurance policies, but in the early stages of that industry "the actuaries were not doing a good job of estimating what the cost of care would be." When costs greatly exceeded premium revenue, some companies went out of business and others raised premiums drastically. The ACA included a national long-term care insurance program, the CLASS Act, but it was never supported by a sustainable funding mechanism. The country as a whole lacks an insurance safety net for long-term needs in older age.

Without stable financing from an insured population, it is not surprising that the long-term care delivery system is also highly fragmented, depending on a patchwork of programs for health care and social supports. Community-based organizations specializing in aging services spend a great deal of time piecing together service packages that meet as many needs as possible, with some success. One aging services CBO has been developing a closed loop referral system to connect patients leaving clinics and emergency departments to home- and

community-based services. Without a system in place to make those connections, services like home-delivered meals can be lost in the list of recommendations in follow-up or discharge instructions.

FQHCs are also responding to the aging populations in the communities they serve, adapting their historic focus on parents and children to serve older adults. But a backlog of Medicaid applications and struggles with managed care organizations' service authorization processes cause delays and gaps in access to care, whether from more traditional medical and aging service providers or from primary care providers branching out into geriatric care.

As mentioned in the sections on health worker experiences, within this complex system a significant burden falls on family caregivers who have very little access to supports, like respite care, that they need to maintain their own health while caring for their loved ones.

Section 3: Themes Related to Improving Flow of Public and Private Dollars

Two themes emerged from the data related to the flow of public and private dollars within the safety net. One of these relates to the flow of public Medicaid dollars now being mediated by managed care organizations. The other relates to private philanthropy.

Theme 7: Managed care adoption within Illinois Medicaid has resulted in several unintended consequences and complexity, while many remain hopeful that with some reforms, there is potential for successful managed care implementation. The shift from fee-for-service to managed care in Medicaid over the last few years has had far-reaching consequences for the Cook County safety net. Several research participants acknowledged the limitations of the fee-for-service model, which "does not recognize workforce challenges" and "actually impedes our ability to deliver the best care." Safety net providers share the overall goals of managed care—improved efficiency and service coordination, value-based care, and flexibility to pay for innovative models. As one FQHC respondent stated, "if we expect to keep our patients and to do what it is that we do, we're going to have to start taking on risk." Other respondents praised the improved coordination of immunizations for children and progress in improving transportation services under MCOs.

But managed care also brought its own complexity, and because fee-for-service regulations remained largely unchanged, providers have not seen the promised benefits of flexibility and innovation.

Many respondents from safety net providers reported having to add dedicated staff to handle MCO prior authorization, credentialing, and billing processes. A safety net hospital respondent described claims denial rates rising from 3-4% under fee-for-service to 25% under managed care. Responding to denials and resolving payment disputes requires even more staff time and seriously impedes cash flow.

CBOs who were new to contracting with insurers struggled to join networks and get reimbursed for services. Care coordination staff turnover and a general unfamiliarity with disability and long-term services and supports further impeded aging and disability agencies from thriving under managed care. Durable medical equipment (DME) request approvals and

referrals for community transition services to assist nursing facility residents to move into more integrated settings have both dropped recently, according to one respondent. This puts pressure on disability service organizations to navigate DME approval processes and pay up-front for moving and transition costs for people transitioning out of institutions. A State consent decree requires MCOs and state agencies to conduct outreach and screenings of people living in institutions to identify those who wish to move into the community. But short-staffing at state agencies and turnover at MCOs mean that accountability is quite limited, and the result is falling numbers of transitions. However, as this respondent pointed out, demand for transitions has not fallen: "There's a constant flow of disabled people into nursing homes. And so it's not like if all of a sudden everybody changed their mind, and thought nursing homes are great."

Other respondents mentioned another barrier to effective oversight of MCOs—siloes between state agencies themselves. In particular, many mental health, substance use disorder, aging, and disability services are funded and regulated by different agencies from those regulating other healthcare providers. All of those services are included in MCO contracts; however, miscommunication and poor coordination among state agencies interferes with the state's role in holding MCOs accountable to their contracts and the law. Although contract compliance and state agency regulations may seem distant from local safety net activity, "Cook County is going to be burdened with what our state is doing, because [MCO oversight is] a state role." Cook County community-based organizations described delays in access to home care services due to miscommunication between MCOs and the State Community Care Program operated by the Department on Aging, for example.

MCOs themselves have frustrations with the implementation of managed care in Cook County. To the extent that MCOs have been able to introduce new value-based or population health approaches, they found that the infrastructure for such models—for billing, data sharing, nurse care coordination, as examples—was largely missing in safety net hospitals. This infrastructure, the respondent explained, had not been necessary in fee-for-service Medicaid because the State built in enhanced payments to support safety net hospitals. But with the introduction of managed care, these hospitals found themselves unprepared for the billing and care coordination processes that were more or less standard at non-safety net hospitals that had more experience with commercial insurance contracts. Adding to this problem was the fact that the Illinois Medicaid program did not provide rules or documentation of procedures for billing before launching managed care, "so it was left to managed care companies to implement and figure out the billing practices and billing rules." Emphasizing the opacity of managed care implementation, this respondent described the process of getting state billing guidelines for managed care as "what's happening under the radar." It took five years for MCOs to get billing guidelines from the State, they explained, and, while this is not well-recognized, it has been a source of many of the complaints about billing complexity and claims denials, especially from providers.

This echoes an argument from a respondent in the behavioral health safety net—that the State did not update rules governing service delivery to align with new managed care payment models. "We have fee-for-service whether it is in managed care or not in managed care," and "even when you bring managed care into Medicaid that doesn't change the nature of how providers deliver services." The nature of service delivery is still defined by fee-for-service rules that define service eligibility, covered benefits, staffing requirements, and other details. In a concise summary of many other respondents' frustrations with managed care implementation, they concluded, "we've layered [managed care] on top of the existing system but we haven't fixed the foundation."

In Health & Medicine's 2016 research paper on the health safety net, the issue of the large number of MCOs was discussed. "In addition, many FQHC staff and executive leadership discussed the large number of managed care organizations that exist, making the current healthcare landscape more complex and competitive than these systems would like." Later in the paper, there was a recommendation that, "Illinois should reduce the number of managed care organizations (MCOs) and ensure that communication to patients is clear and understandable." The managed care organization rebid that resulted in a reduced number of contracts, occurred under the administration of Governor Bruce Rauner in early 2017. The paper can be read here.

For patients, providers, and MCOs, managed care continues to be a significant contributor to system complexity. A contract rebid reduced the number of MCOs, a key demand from providers (and a recommendation in prior research; see pop-out box for more information) but one respondent argued that this simply magnified and concentrated operational problems. The State's rebidding process also resulted in the loss of Family Health Network, a safety net hospital-sponsored managed care plan that was founded in 1995. The five safety net hospitals who operated FHN were left to start over, rebuilding contractual relationships with the plans' physicians network and other providers, without the benefit of FHN's infrastructure and capital.

A Medicaid Omnibus bill enacted into law this year, after this research data was collected, aims to address many of these ongoing concerns, and is described in the *Introduction and Background* section of the paper.

Theme 8: Private philanthropy plays an important role in sustaining the safety net and seeding new projects, but funding and processes could be better aligned with the needs and capacity of the sector. The complexity facing the safety net complicates the roles of funders who must decide where in this densely layered system to intervene with targeted investments. A few significant problems, along with suggested solutions, were mentioned by interviewees related to private philanthropy.

One overarching sentiment that came through this research was the need for sustainable funding for effective programs. While participants expressed appreciation for the opportunity to try new approaches, the frequent desire from funders for something "new" or "innovative," can come at the expense of sustained funding for prior initiatives that have been evaluated and proven effective or to scale up promising pilots. Respondents described two related problems. On the one hand, seed funding is available for many different kinds of projects "without really evaluating what's actually working." On the other hand, when existing programs have data proving their effectiveness, there is less funding available for actual implementation and

sustainable operation. As one respondent asked, "how do you keep good ideas going when it's really hard to find the ongoing source of funding to keep them sustainable?"

In addition to the operational advantages—more time and resources going into the actual work of helping people who rely on the safety net—a grant system that is more responsive to safety net organizations will also be more responsive to the needs of the people they serve. Respondents shared experiences of navigating application processes that relied on misunderstandings of safety net resources and needs and, on the other hand, moments when funders were open to being educated on specific issues facing safety net organizations. One FQHC respondent described the frustration of securing federal resources to open new clinics but struggling to fund the staff needed to actually provide services. While that is a Federal Government funding oversight, the blind spots in grant funding are especially problematic when whole new lines of service are urgently needed. For example, when FQHCs needed to hire psychiatrists to take on patients from the city mental health clinics that Chicago shut down they could not fully meet patients' needs with public and private dollars.

There is also a risk of alienating safety net providers when funders appear to imply that their patients do not deserve the same high-quality healthcare as non-safety net patients. This was the experience of a respondent who recalled a funder's expectation that safety net organizations would settle for old, used medical equipment, such as X-ray machines. This approach from the funder conflicted with the respondent's sense of mission, "our focus is high quality…because we think everybody walking through here deserves that."

Participants' comments on philanthropic funding echoed their thoughts on publicly financed safety net programs: Decision-makers should listen to the people impacted by the decisions being made. A funder that targets one service need, for example, misses the "twenty elements that [people] need…the conflicting priorities of urgency" in the lives of people the safety net serves. Safety net organizations that work directly with specific communities, and members of those communities themselves, understand the complex, shifting needs that cannot be easily targeted with a SMART goal.

One respondent offered her "gut instinct" response on safety net funding challenges: "if you need housing, and you're taking care of dental, you know you're missing the boat on what really needs to be taken care of in order for people to succeed and thrive and achieve what they're trying to do."

The complexity of needs in the safety net and the variety of possible responses calls for strong leadership. The Cook County safety net as a whole exists at "an intersection of not just health and healthcare services but really around social determinants and community violence and safety and things of that nature." Modest funding and fragmented authority are "not enough to get things across the finish line" in this complex and challenging environment.

West Side United and CAPriCORN were examples respondents offered of successful efforts to convene diverse partners for ambitious projects in Chicago. Notably, the CAPriCORN initiative is a Patient-Centered Outcomes Research Initiative (PCORI) funding from the Federal Government. But for system-wide problems, one respondent suggested that State government agencies had to play a leadership role and use its 'levers...that are powerful enough to keep people on task."

Other respondents voiced concern about the reduced willingness of government, especially Cook County government, to fund safety net healthcare given that the expansion of insurance under the ACA gave way to moving the focus to other pressing structural budget problems, such as pension debt. Yet safety net organizations face structural funding crises of their own—respondents pointed out that providers lose money on some services, such as reproductive health, mental health, and oral health services, even when patients have insurance. Federal appropriations for safety net programs, such as the Older Americans Act that finances many community-based services and support for older adults, are not keeping pace with the growing needs of an aging population, and reauthorization fights and budget deadlocks lead to "funding cliffs" that consistently threaten whole sectors of the safety net with extinction.

Funding Recommendations from Study Participants

- **Increase general operating support.** Respondents recommended that funders provide more general operating support and funding to scale up and sustain proven programs to better enable organizations to focus on doing that work. One respondent suggested that funders support safety net-wide infrastructure for a collective platform for connecting patients with organizations that can help them meet unmet social needs, such as food, housing, or legal support. Such a project would provide operational support for existing programs that depend on connections between disparate services, and also drive new innovations in integrated, technology-enabled care. Such platforms exist but they are cost prohibitive for many safety net providers and connectivity is limited.
- **Streamline grant application and reporting processes**. Respondents pointed to examples of grant reporting requirements distracting from providing care and services. The reporting requirements and administrative costs of applications and reporting can be significant enough that some applicants question whether or not grants are worth it, especially if the funding amount is relatively small. Funders could work with safety net organizations to streamline grant processes to make applying and reporting more efficient.
- Funders should think about what the **highest quality, state-of-the-art equipment** and services look like and shape their funding opportunities to support that investment.
- Foundations should consider ways to **regularly engage grant applicants** about potential oversights in their grant offerings and applications to identify blind spots and opportunities for improvement.

  A CBO respondent's story showed that a more collaborative approach is possible. When a large funder announced a grant opportunity that did not include any applicants who were "prepared to talk about disability access or…to have a fund in [their] annual budget to deal with accommodation costs," this CBO raised the issue and found it was "a good way to start having that conversation," to educate the funder on disability issues and develop a relationship to provide input on grant programs that open more opportunities for people with disabilities.
- **Grantees may seek out new opportunities to provide feedback to funders.** One participant talked about trying to organize funders to align with the needs of grantees.
- **Private philanthropy should recognize and invest in the assets identified by safety net participants:** having a strong advocacy arm within safety net organizations that can support policy interventions and public funding for core safety net services.

Funding Conclusion

Again, while private philanthropy plays a crucial role in supporting the safety net, both in terms of filling in gaps and supporting new initiatives, it is important to keep private grants in context. The Illinois state budget impasse provides a good example of the ways in which public funding provides the bulk of safety net funding, with private philanthropy providing a support role. The need to sustain advocacy and policy solutions is paramount, given that the safety net is much more driven by public dollars and public policy.

Policy Recommendations and Approaches

The policy recommendations are informed by participants and the authors' own policy expertise. The notes below include general recommendations as well as more general ideas for advancing improved policy. Given that both State of Illinois and Federal policies have significant impacts on the funding and functioning of the safety net, the policies below focus primarily on these two levels, with occasional mention of local policy.

For the sake of brevity and readability, the recommendations here attempt to share some initial policy directions that may begin to make progress on some of the issues raised by participants. These are not fully developed policy briefs, but instead, a notion of what objectives policymakers should consider. Recommendations were driven by what participants shared rather than a comprehensive policy review. First, we address recommendations at "both Federal and State Level" of policy, followed by issues that pertain to one or the other (state or Federal).

State and Federal Level Policy Recommendations and Approaches

This section contains issues and recommendations that may be approached from either the Federal or state levels or by both in combination.

Issue Area: Participants noted frustrations with costs and system complexity, driven in part by the current convoluted, labyrinthine health insurance system.

Recommendation: Pursue a national or state-wide public program that provides *actual* universal coverage. This could reduce or eliminate significant work and confusion on the part of patients, health workers, healthcare organizations, and government agencies with regard to private health insurance coverage.

Issue Area: There is insufficient engagement with people who are directly impacted by health reform, leading to reforms that may be mis-informed or result in a range of potential unintended consequences. Participants said that policymakers need to listen to patients and health workers who are directly impacted by the reform process.

Recommendation: State and Federal officials should commit to ongoing efforts to better and more creatively include the perspectives and ideas of everyday people—especially patients who use the safety net—and providers in decision-making processes. These processes can be tested and, as needed, become required by law. In undertaking this, a focus on equitable and inclusive engagement is necessary to develop policy and systems change that reflects the needs of the people who use the safety net. Illinois officials could commit to in-depth health planning across its many health-related agencies and provide funding to fully staff the effort. Part of the mandate for such an effort would be to engage patients and health workers, rather than simply seek the limited input of professionals who are paid to attend stakeholder meetings.

Existing structures at the state level, such as the Medicaid Advisory Committee—while they provide some opportunity for feedback—are not fully accessible from the disability perspective or in terms of scheduling and timing. Also, when people do share perspectives within such public bodies, their thoughts are not always fully taken into consideration.

Issue Area: Healthcare and health insurance were both noted as unaffordable and patients face gaps in coverage.

Recommendation: Policies should be advanced to reduce or limit costs of insurance and healthcare to improve people's economic situations, increase health insurance coverage, protect against faulty health insurance products, and promote access to healthcare. Below are a few recent legislative actions related to these priorities:

- In 2019, the U.S. House of Representatives introduced the Protecting Pre-Existing Conditions and Making Health Care More Affordable Act, which focused on improving the ACA, improving affordability, advancing protections for people with pre-existing conditions, and stopping the sale of junk insurance. The bill did not advance after its introduction.[70]
- A U.S. House bill, HR987, which addressed short-term "junk" insurance plans that do not cover pre-existing conditions or meet other ACA consumer protections, passed the House but failed in the Senate in 2019.[71]
- At the state level, in 2018, legislation to define and regulate those junk insurance plans, HB2624 SA 3, passed both houses of Illinois' General Assembly, but was vetoed by Governor Rauner.[72]

Issue Area: Prescription drugs are sometimes unaffordable for patients and the Federal 340B program could be improved to better support patients and safety net organizations.

Recommendation: State and Federal officials should focus on prescription drug affordability, as patients may either forgo other necessities to pay for medications or may not pick up a prescription due to cost.

- While in this and other research the Federal 340B program has been identified as a "bright spot" in health policy, it is not without problems as the program is not universally available. Also, the Trump Administration is currently seeking to cut 340B payments, although this decision is currently held up in the courts.[73]
- Another recent move on this front is passage by the Illinois General Assembly of SB0667 in November 2019, which, if signed by Governor Pritzker, will work to limit insulin prices for some consumers and direct the Illinois Attorney General to investigate why insulin prices have gone up so much.[74]

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[70] Protecting Pre-existing Conditions & Making Health Care More Affordable Act of 2019. March 2019. Retrieved from: https://energycommerce.house.gov/sites/democrats.energycommerce.house.gov/files/documents/Health%20Care%20Bill%20One%20Pager.pdf

[71] 116th Congress. H.R. 987 - Strengthening Health Care and Lowering Prescription Drug Costs Act. February 6, 2019. Retrieved from: https://www.congress.gov/bill/116th-congress/house-bill/987/all-actions.

[72] Bill Status of HB2624. Illinois General Assembly. 100th General Assembly (2018). Retrieved from: http://www.ilga.gov/legislation/BillStatus.asp?DocNum=2624&GAID=14&DocTypeID=HB&SessionID=91&GA=100

[73] CMS moves forward with site-neutral payments, slashes 340B payments. Modern Healthcare. November 1, 2019. Retrieved from: https://www.modernhealthcare.com/payment/cms-moves-forward-site-neutral-payments-slashes-340b-payments

[74] Bill Status of HB0667. Illinois General Assembly. 101st General Assembly (2019). Retrieved from: http://www.ilga.gov/legislation/BillStatus.asp?GA=101&DocTypeID=SB&DocNum=667&GAID=15&SessionID=108&LegID=116604

Issue Area: Systems of oppression are longstanding, remain prevalent for many patients and families, and have severe impacts on people's health and healthcare access. Participants noted health inequities linked to racism in particular. Other forms of oppression were also discussed. Systemic oppression in the U.S. is linked to inequities in the distribution of social determinants of health, healthcare access, and health status and outcomes and can only be addressed by a monumental, sustained approach to all areas of public policy and practice.

Recommendation: Both Federal and State governments should adopt an approach of considering racial equity impacts and health equity impacts of all policies. Racism and other systemic oppression were listed in the findings as factors harming safety net patients and providers. Here are some promising examples of the use of such tools:

- The Government Alliance for Racial Equity published a Racial Equity toolkit, available here.[75]
- Locally, Chicago United for Equity (CUE) trains fellows on racial equity impact assessments and organizes for adoption of the racial equity impact assessment tool by state and local governments.[76]
- Human Impact Partners published this guide for health impact assessments. Requiring health equity impact assessments in public policy at Federal, state, and even local levels could guide decision-makers' efforts with regard to reducing and eliminating health inequities.[77]

Recommendation: Given the lasting impacts of systemic oppression and injustice on health inequities, governments at all levels should develop approaches that begin to work to uncover truth, foster reconciliation, and to advance reparations.

- There was some recent discussion on this front in June 2019 when a subcommittee of the House Judiciary Committee held a hearing focused on reparations for slavery.[78] As an example of such a policy, Chicago passed a reparations ordinance related to torture by Police Commander Jon Burge in an attempt "to redress any and all harm that was suffered at the hands of Jon Burge or his subordinates."[79]

Issue Area: Participants noted that the absence of easily accessible patient records that can be transferred via EHRs—and the lack of a statewide or regional health information exchange—forces health workers to take on the risky, stressful task of making decisions with incomplete information about diagnosis and treatment history, test results, and prescriptions. Despite the significant efforts health workers make inputting information, it is often not fully accessible across healthcare settings.

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[75] Neslon, Julie; Brooks, Lisa. Racial Equity Toolkit An Opportunity to Operationalize Equity. Local and Regional Government Alliance on Race & Equity. December, 2016. Retrieved from: https://www.racialequityalliance.org/wp-content/uploads/2015/10/GARE-Racial_Equity_Toolkit.pdf

[76] Chicago United for Equity. Retrieved from: https://www.chicagounitedforequity.org/

[77] Bhatia, Rajiv. Health Impact Assessment A Guide for Practice. Human Impact Partners. 2011. https://humanimpact.org/wp-content/uploads/2011/01/HIA-Guide-for-Practice.pdf

[78] Stolberg, Sheryl Gay. At Historic Hearing, House Panel Explores Reparations. New York Times. June 19, 2019. Retrieved from: https://www.nytimes.com/2019/06/19/us/politics/slavery-reparations-hearing.html

[79] Establishment of "Reparations for Burge Torture Victims" fund. City of Chicago. April 15, 2015. Retrieved from: https://chicago.legistar.com/LegislationDetail.aspx?ID=2262507&GUID=A5B9864A-02CC-4339-A54E-3133B9865983&Options=Advanced&Search=.

Recommendation: Either the Federal Government or State of Illinois should fund the creation of a health information exchange for the entire state.

Recommendation: EHR systems should be required to have better interoperability and laws and regulations should enable appropriate access of patient records across EHR systems so that both patients and providers can access information in a timely fashion. Any EHR policies must consider upfront and ongoing costs and ensure that technological advances are accessible to safety net providers and patients. Special attention may also need to be paid to handling privacy concerns and any technological challenges raised by differing confidentiality requirements for different kinds of health information.

Issue Area: Health workforce investments are needed to make recruitment easier, reduce provider shortages, make education and career advancement affordable and accessible, and advance equity and inclusion.

Recommendation: At the Federal level, the National Health Service Corps (NHSC) program could be expanded and improved upon with additional funding and more options to: 1) expand access to health careers; 2) bring more people into service within the health safety net and for longer periods of their careers; 3) reduce providers' education debt; and 4) expand access to care generally and to specialty care, specifically.

As an example of one potential expansion of the NHSC, a recent paper in Health Affairs noted the opportunity for its loan repayment program to apply to health workers who provide services at home or out in the community, noting that for mental health professionals, the program is limited to people who provide a majority of care in a clinic setting, neglecting an acute need to expand the home and community based mental health workforce.[80]

Recommendation: At the state level, an increase in investment in scholarships and loans that focus on people seeking education in a range of health professions would support people's ability to successfully pursue and achieve employment in the health sector.

The recent five-year economic plan published by the Pritzker Administration discusses several issues and actions pertaining to health workforce, and a few current and potential actions.[81] The plan notes shortages in such professions as nursing, home health aides, nursing assistants, medical and lab technicians, and nurse practitioners.

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[80] O'Donnell, Heather; Davis, Kristen; Mestan, Samantha. Building the Community-Based Mental Health Workforce to Expand Access To Treatment. Health Affairs. October 24, 2019. Retrieved from: https://www.healthaffairs.org/do/10.1377/hblog20191022.281887/full/.

[81] A Plan to Revitalize the Illinois Economy and Build the Workforce of the Future. State of Illinois (JB Pritzker Administration). October 2019. Retrieved from: https://www2.illinois.gov/dceo/Documents/IllinoisEconomicPlan2019.10.9.2019.pdf

State Level Policy Recommendations and Approaches

Issue Area: Participants noted problems meeting the requirements of frequently changing managed care contracts and formularies and a significant degree of problems associated with time spent dealing with denials and contracting.

Recommendation: The state could work to make managed care contracting smoother for providers and patients by considering: 1) reducing the frequency with which contracts can be changed; 2) reducing the amount of variability allowed from one contract to another; 3) improving State oversight and accountability for managed care; 4) providing technical assistance to providers.

Related to this, the Illinois Collaboration on Youth is leading an advocacy campaign requesting that Governor Pritzker add a funding request to his FY 2021 budget for a Medicaid Technical Assistance Center to support human service organizations' ability to bill for services.[82]

Issue Area: As noted in Sub-theme 4d, Medicaid redetermination has been a major contributor to gaps in health insurance coverage as well as uncertainty stress and extra work that has negatively impacted many safety net patients and providers.

Recommendation: Implement and monitor the successes, gaps, or shortcomings of SB 1321 / Public Act 101-0209, known as Illinois' Medicaid Omnibus Bill of 2019, which focuses on both managed care reforms and on redetermination.[83]

Public agencies, lawmakers, and advocates should note where there are shortcomings that suggest potential future reform opportunities. Illinois should seek to move its Medicaid program from a laggard in terms of eligibility redeterminations to a leader in which most redeterminations are completed without gaps in coverage by using better processes to maintain enrollment for all eligible individuals.

Issue Area: The research revealed that the agency regulations pertaining to Medicaid reimbursements are more aligned with the fee-for-service Medicaid system rather than the managed care program, which hampers the ability of the safety net to fully adopt and benefit from value-based payments.

Recommendation: Illinois should approach payment reform to align reimbursement with expectations for care coordination and the integration of medical, behavioral health, and social services. Resources devoted to monitoring highly prescriptive rules for provider service delivery, staffing, and coding should be shifted to more sophisticated oversight of managed care, which the State has expected to drive innovation, not reinforce the fee-for-service bureaucracy.

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[82] Advocacy page: Medicaid Technical Assistance Center. Illinois Collaboration on Youth. Retrieved from: https://www.icoyouth.org/capacity-building/medicaid-technical-assistance-center?utm_source=ICOY+Contacts&utm_campaign=c483c1def7-Racial_Disparities_on_the_Rise_for_Youth10_6_2017_&utm_medium=email&utm_term=0_ba62da2d9f-c483c1def7-294182893

[83] Bill Status for SB 1321.Illinois General Assembly. 101st General Assembly (2019). Retrieved from: http://www.ilga.gov/legislation/BillStatus.asp?GA=101&DocTypeID=SB&DocNum=1321&GAID=15&SessionID=108&LegID=117946

Issue Area: Reimbursements for mental health are frequently insufficient for providers to be able to accept Medicaid patients, contributing to insufficient access and unmet mental healthcare needs.

Recommendation: Illinois should pursue rate reform that would increase funding for services provided to Medicaid patients in community mental health centers or behavioral health clinics.

For background, community-based behavioral health providers and SUD treatment service providers did receive rate increases in 2019 as a result of SB0262 / Public Act 101-0007 and SB1814/Public Act 101-0010, respectively.[84] Illinois also took the lead in requiring insurance coverage of the evidence-based Collaborative Care Model for integration of behavioral health consultation in primary care by passing SB2085 / Public Act 101-0574.[85] Two bills that could have further advanced this and other reforms, one in the Senate (SB1673) and another in the House (HB2486), were introduced in 2019, but neither advanced to passage.[86,87]

Federal Level Policy Recommendations and Approaches

Issue Area: Various legislative and administrative attacks on the ACA and on other policies such as the "public charge" rule cause uncertainty and reduce insurance enrollment and use of the safety net. These attacks can make it difficult for various actors within the health safety net to fully implement health reform or set realistic long-term expectations about policy, practice, and funding.

Recommendation: Federal officials should cease attacks on the Affordable Care Act and Medicaid and focus on filling the gaps left by the ACA, like the ongoing unaffordability of many health insurance plans' premiums, deductibles, and co-payments, as well as the cost of prescription drugs.

Recommendation: Federal officials should cease the attempts to change the "public charge" rule to penalize immigrants who seek necessary public benefits, like Medicaid, for themselves and their families.

Recommendation: Federal elected officials should seek legislation to expand health insurance coverage to cover everyone in the U.S.

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[84] Bill Status of SB0262. Illinois General Assembly. 101st General Assembly (2018). Retrieved from: http://www.ilga.gov/legislation/BillStatus.asp?GA=101&DocTypeID=SB&DocNum=262&GAID=15&SessionID=108&LegID=116189

[85] Bill Status of SB2085. Illinois General Assembly. 101st General Assembly (2018). Retrieved from: http://www.ilga.gov/legislation/billstatus.asp?DocNum=2085&GAID=15&GA=101&DocTypeID=SB&LegID=120169&SessionID=108&SpecSess=

[86] Bill Status of SB1673. Illinois General Assembly. 101st General Assembly (2018). Retrieved from: http://www.ilga.gov/legislation/billstatus.asp?DocNum=1673&GAID=15&GA=101&DocTypeID=SB&LegID=118850&SessionID=108

[87] Bill Status of HB2486. Illinois General Assembly. 101st General Assembly (2018). Retrieved from: http://www.ilga.gov/legislation/billstatus.asp?DocNum=2486&GAID=15&GA=101&DocTypeID=HB&LegID=118513&SessionID=108

Issue Area: The U.S. lacks a long-term care insurance program for elderly people and other people who may have long-term care needs, such as people with disabilities.

Recommendation: Develop a bill that includes appropriate funding for a Federal long-term services and supports insurance program for people who are aging and who may become disabled.

One participant noted that the Community Living Assistance Services and Supports (CLASS) Act was passed into law as Title VIII of the ACA, but it did not have the necessary funding and was not fully implemented. It was then repealed in 2013. This may serve as a basis of a future program.

Illinois is examining a potential income tax that will provide limited long-term care insurance for people over 18 years who need it.[88]

Issue Area: Attacks on immigrants and their families, including the attempt to expand the "public charge" rule as well as ICE and other agencies' raids, detentions, family separations, and deportations of immigrants.[89]

Recommendation: The Trump Administration should cease its attacks—including policy, rhetoric, and physical attacks, in the form of Federal law enforcement actions—on immigrant communities.

Recommendation: Local safety net organizations should adopt protective policies, training, and practices to support immigrants and provide safe, welcoming, and affirming healthcare. The Illinois Coalition for Immigrant and Refugee Rights runs the Illinois Alliance for Welcoming Healthcare, which can provide technical assistance. Learn more here.[90] Also, Public Health Awakened published and has updated the Public Health Actions for Immigrant Rights guide here.[91]

Issue Area: Many participants noted in this and in past research that the 15-minute patient visit at FQHCs is a limitation based more on scarcity of time than the needs of patients, and, in light of increasing expectations for integrated, person-centered care, feels arbitrary and counterproductive.

Recommendation: The Federal government should increase and sustain investments in FQHCs to an amount that organizations are able to move toward models of care focused on need and are able to move away from a time-limited patient visit. The recommendations for managed care reforms above could also facilitate more flexible arrangements for FQHCs

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[88] New payroll tax is pioneering experiment to help Washington state seniors age at home. Kaiser Health News. June 10, 2019. Retrieved from: https://www.seattletimes.com/seattle-news/health/new-payroll-tax-is-pioneering-experiment-to-help-washington-state-seniors-age-at-home/

[89] Public Charge: Make the Right Choice for Your Family. Protecting Immigrant Families – Illinois. Updated October 15, 2019. Retrieved from: https://drive.google.com/file/d/1p1Qoi1WLSjORINVLqpmZtGK18Vpt_zjU/view

[90] Illinois Alliance for Welcoming Healthcare. Illinois Coalition for Immigrant and Refugee Rights. Not dated. Retrieved from: https://www.ilalliancehealth.org/

[91] Guide for Public Health Actions for Immigrant Rights. Public Health Awakened. Updated February 9, 2018. Retrieved from: https://publichealthawakened.com/guide-for-public-health-to-protect-immigrant-rights/.

to conduct more comprehensive patient visits that include necessary screenings, consultations, care planning, and interventions.

Limitations

This study utilized a convenience sampling of safety net stakeholders in Cook County. This methodology means there is the potential for selection bias and response bias of participants. Another related limitation of qualitative research methodology is that the data are directly informed by both who is and who is not in the room. This means that the key themes described in this report are informative, but they may not represent a comprehensive picture of the safety net in Cook County and cannot be generalized to the safety net as a whole. As one example, patients were not specifically included in the convenience sample; while certainly some participants may have also been safety net patients, the role and perspective that they were representing was primarily that of workers or leaders within the Cook County safety net. While this study added valuable perspectives from CBOs focused on such populations as people with disabilities, elderly people, and mothers and children, there is a vast array of CBOs in Cook County that focus on many topics, with potential for additional nuance and varied experience that was not included in the sample.

The study discussion guides asked safety net participants to make policy and philanthropic recommendations that might better support their work in Cook County. While study participants were well-informed of how policy and funding decisions impact their work and the lives of their patients, most participants do not have a role that allows them to spend their workday focused on healthcare policy context, which requires significant study to engage fully. On the other hand, this same group provided the invaluable on-the-ground experience that policy advocates and researchers often miss if they are not engaged in such practice. Some of the participants in this study were policy advocates or researchers and provided perspectives that were helpful when including policy context to this research. That said, a larger sample size could have enabled additional policy advocates to have been included.

This research revealed practical issues that policy or philanthropy can respond to with relevant context provided. To the degree possible, researchers used their existing knowledge of health reform and health policy to make connections between the issues raised and policy and philanthropy recommendations to address them. Lastly, the Cook County safety net is a large, dynamic system that is constantly changing due to shifting policy and practice contexts in the county, and at the state and Federal levels; rather than ongoing monitoring of the safety net and the impacts of reform, this research provides a collective snapshot of perspectives for a succinct timeframe.

Future Research Questions and Directions for Practice

There were many questions prompted by the themes and sub-themes in this paper that went beyond the scope of this research. Below are some general descriptions of some of these areas of policy and practice, with a few potential questions and areas of interest for possible future research. These questions may also be helpful for practitioners to consider or for potential practice-based research.

Issue area: Workforce

While safety net organizations in Cook County identify their dedicated staff as a major asset, they also noted the significant stressors of system complexity and inequity which contribute to burnout and retention issues.

Research questions:

- What are the staff turnover / retention rates and average tenure of different types of staff within the Cook County safety net? How do these rates compare with other jurisdictions? How do these rates compare to similar positions in non-safety net systems?
- What is the relative diversity of staff at safety net hospitals, FQHCs, and CBOs? How does this compare to the patient/client populations served? How do individual organizations compare to one another?
- What are the various drivers of burnout and turnover among staff at different levels within the Cook County safety net? What could be done to ameliorate the system complexities and inequities that negatively impact staff?
- How has the Illinois budget impasse impacted the Cook County safety net workforce, organizations, and patients in the longer-term?
- Could a dedicated healthcare workforce planning entity help operationalize large-scale Medicaid reforms that depend on an adequate supply of well-trained health workers? How could such an entity ensure workers are trained to implement new models of integrated medical, behavioral health, and social services?

Issue area: Social Determinants of Health and Structural Inequities

Many safety net providers are focused in some manner or another on social determinants of health.

Research questions:

- How are safety net organizations focused on trying to positively impact the social determinants of health?
- Are safety net organizations also trying to change structural inequities via a focus on policy change? As an example, to what degree are hospitals trying to help a small subset of patients with housing versus working to change policies related to affordable or supportive housing?
- Are/how are safety net organizations incorporating anti-oppressive praxis generally or anti-racist praxis, specifically?
- What role do medical-legal partnerships (MLPs) play in supporting patients? What gaps in MLP-partnerships exist? Is the data from MLP cases being collected and reviewed for common policy problem, as a basis for informing reform?

Issue area: Managed Care
As noted in one of the themes, managed care adoption within Illinois Medicaid has resulted in several unintended consequences and complexity, including issues with changes in contracts and formularies, and issues with billing, denials, and oversight.

Research questions:

- What have been the relative benefits and burdens of managed care in Cook County (or Illinois more broadly) to patients, health workers, and safety net organizations?
- To what degree is it efficient, helpful/unhelpful to have several private managed care organizations? Could value-based payments be integrated into a single Medicaid payer, perhaps moved back to HFS?
- What state policies need to change to fully realize the promises of managed care?
- How is oversight and accountability of MCOs being handled and how can it be improved?

Issue area: Charity Care
One participant said that its hospitals could not continue to be "the referral source for the uninsured" for all other hospitals and primary care sites.

Research questions:

- What should the distribution of charity care look like in Cook County?
- How much actual charity care is being provided annually?
- How should this be tracked?
- To what degree are taxpayers getting a fair deal with regard to tax-exemption for nonprofit hospitals?
- Who is responsibility is charity care?

Issue area: The "Safety Net"
The metaphorical health and social *safety net* is an amorphous topic, with varying degrees of understanding and agreement about what is considered a part of the safety net.

Research questions:

- What should the safety net in Cook County look like?
- What should be considered part of the safety net?
- What are the proper roles for the varying pieces—some of them organizations and others programs—to play in current policy and practice as well as future directions?
- How can we begin to plan for a seamless safety net?
- What is the role of the safety net in a system that has actual universal health coverage?

Issue area: Benefits of EHRs and Health Information Technology (IT)
Participants noted some of the burdens and promises of EHRs.

Research questions:

- What is the relative unrealized benefit of the promise put forward by EHRs and other health IT? How could Cook County or Illinois (more broadly) support the safety net to reap the full promise of EHRs and other Health IT?
- While individual providers attempt to improve electronic data collection and exchange, what County-wide health information exchange processes can impact patient care across the safety net?
- Could all hospitals—safety net and non-safety net—send admission, discharge, and transfer (ADT) alerts to community physicians to improve engagement with

primary care after an emergency room visit or hospital admission? What are the barriers to a Cook County ADT alert system?

Conclusion

This research sought to reveal and identify: 1) strengths and assets of organizations working within the safety net; 2) unintended consequences and unfinished workof health reform; and 3) opportunities for philanthropy and policy changes to strengthen the overall safety net. The themes and subthemes provide some significant description aligned with these three queries, from the vantage point of people working at hospitals, FQHCs, MCOs, CBOs, and insurers in the safety net, translated by the researchers. Additionally, the researchers have sought to include both direct policy recommendations from participants and some informed by the challenges they shared.

In short, health reform has had many positive impacts over the last decade, yet many people are challenged by un- or under-insurance, a system that is complex and inequitable, and consistently in a state of flux. Based on these issues, the system is therefore not trusted by all. Likewise, outside of the system, many people in Cook County struggle with systemic oppression and the maldistribution of social determinants of health, due to structural inequities in our public policies and practices.

Questions abound on these issues, like "How can we improve the safety net so it works better?" or "What reforms are needed next to provide insurance to cover all people?" Given the many shortcomings of the system as it is today, it can be bewildering to attempt to understand the system itself, let alone know where to engage or try to make a reform. This research attempts to shed some light on the system as it is, where health reform has come up short, some remaining challenges, and opportunities for future reform for the Cook County safety net.

One of the first questions we asked of participants in this research was about how they would characterize the Cook County safety net. In the introduction of interviews and focus groups, the research team gave a brief description of what they considered to be a part of the safety net. Sometimes the questions and clarifications received in response to these questions revealed perceptions of the safety net that helped illuminate the depth of the challenges Cook County faces in getting health reform right in such a complex system. Many times, some variation of the question, "What do *you* consider to be the 'safety net'?" was asked by a participant before they would answer, showcasing the complexity of the safety net and the lack of a common definition, even for those working within it. One research participant gave this edited answer, underscoring the degree of fragmentation among the many organizations in the safety net:

> *"So when people talk about 'safety net,' they look at the healthcare system as a system and it's not a system—so, [the] first issue is, it is not a system. They're all independent companies, organizations, foundations, and they don't all work in a care coordinated model. But the perception is somehow you have this major [system] and it's going to coordinate all these services and they all have...interests…So I think when people think of the safety net, they're thinking of—this is a system of organizations that choose to work together, and that's not true."*

Another quote that stood out from the data was this edited response to a question, highlighting the continued struggles that people have to gain and maintain health insurance:

> *"I came in [at] the hardest times of their lives and get them on insurance… it just was constant, it was that working for it…'I make barely enough to make it, but I'm over what that limit is.' And so then [you say], 'Oh, well I can get your child insured, but I can't get you insured.' And...there wasn't much I could actually do because 'you do make too much.' But when you really look at it, it's just like there's no way on earth this is too much money, like you are making bare minimum to survive…It's like that safety [net] that I picture it—but like the holes are huge and I was just like they've been stretched out."*

Both of these quotes speak to the unfinished work of health reform: many people remain uninsured, the safety net does not work as a well-coordinated fluid system, and there is significant complexity and inequity. This is despite the hard and heroic work of dedicated staff at safety net organization and successful efforts to collaborate across the system. Paradoxically, the safety net and health reform have helped—and continue to help—many people in significant ways, yet much work remains to be done to realize the promise of a comprehensive, seamless safety net.

Health equity is often understood as a future goal or outcome, but it can also be understood as a "*process of assurance* of the conditions for optimal health for all people that requires at least three things: 1) valuing all individuals and populations equally; 2) recognizing and rectifying historical injustices; and 3) providing resources according to need." Health inequities will be eliminated when this process of health equity is achieved (cite: Jones, Camara. Systems of Power, Axes of Inequity: Parallels, Intersections, Braiding the Strands. Medical Care. Volume 52, Number 10, Supplement 3. 2014).

Healthcare is one among many of these resources that people need to be healthy and that we need to distribute in an equitable manner to achieve this process of health equity. As more organizations within the safety net and in public health adopt *health equity* as part of a mission and vision for their organizations, it is worth noting how far short the safety net in Cook County, and beyond, is in achieving universal health insurance coverage or a smoothly functioning system. Health inequities—the unfair, unjust, and remediable differences in health status and outcomes measured across different population groups—are literally matters of life and death.

As we debate what health insurance and healthcare delivery systems should look like in the U.S., Illinois, and Cook County, especially in the midst of a Presidential Election year, this research provides some valuable insights on what has gone well with health reform, the unintended consequences, and the unfinished work of guaranteeing the human right to healthcare for all people.