



A Qualitative Review of Chicago's West Suburban Safety Net:

Consequences, Adaptation, and Recommendations for Future Reform

Tiffany N. Ford, MPH, Senior Policy Analyst
Wesley Epplin, MPH, Director of Health Equity
Margie Schaps, Executive Director

Health & Medicine
POLICY RESEARCH GROUP

Contents

| | |
|--|----|
| Executive Summary..... | 2 |
| Introduction..... | 4 |
| Quantitative Analysis of Population Demographics and the Health System in the Western Suburbs..... | 7 |
| Methods for the Qualitative Analysis..... | 9 |
| Qualitative Research Findings..... | 11 |
| Challenges Facing the Safety Net..... | 13 |
| Strengths of the Safety Net..... | 19 |
| Consequences of Health Reform..... | 21 |
| Recommendations..... | 23 |
| Concluding Statement..... | 34 |

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.

For more information about this study or to share your feedback, contact:

Tiffany N. Ford, MPH

Senior Policy Analyst for Health Reform and Health Equity, tford@hmprg.org, [@TiffNFord](https://twitter.com/TiffNFord)

Wesley Epplin, MPH

Director of Health Equity, wepplin@hmprg.org, [@WesleyEpplin](https://twitter.com/WesleyEpplin)

Health & Medicine Policy Research Group gratefully acknowledge funding for this report provided by the Community Memorial Foundation. The views and opinions expressed here are solely those of the authors and do not necessarily represent those of the Foundation.

Executive Summary

This study extends previous research examining the impact of the Affordable Care Act (ACA) and state Medicaid expansion on the safety net. The healthcare landscape in Illinois has changed dramatically over the past several years in response to health reform at both the federal and state levels. In addition to the expansion in insurance coverage ushered in by the ACA, in Illinois a 2012 shift in state law to Medicaid managed care—intended to both save money and better coordinate and improve patient care—required at least half of Medicaid recipients to choose or be auto-assigned into managed care plans by 2015. Today, years after implementation of these reforms, the safety net is still working to fully respond to these monumental shifts in health care financing and delivery.

The safety net has also faced a number of new and emerging challenges over the last year at the federal level—the repeal of the individual mandate, threats to immigrant health, and discussion of Medicaid block grants, to name just a few—and in Illinois where the impact of the budget crisis still reverberates and the transition to managed care continues. While the ACA remains the law of the land, the future of health reform remains anything but certain. The rapidly evolving political landscape has created an unprecedented level of uncertainty at all levels of the health care system and especially for the providers and staff of the safety net who must navigate this new environment while providing care for our community’s most vulnerable and marginalized residents.

Our study sought to analyze how the current political context is impacting the safety net sector while also examining overall adaptations to health reform, understanding its consequences, and identifying safety net stakeholders’ policy and philanthropy recommendations for future reform. Our research focused specifically on the safety net in western Cook County and eastern DuPage County, Illinois (the western suburbs of Chicago). Researchers conducted key informant interviews with executive leadership and focus groups with staff from thirteen area federally qualified health centers (FQHCs), hospitals, free and charitable clinics, insurers, and community-based organizations, using semi-structured focus group and interview guides.

“I don’t have any data on this but we have a segment of our mental health population that still pays a sliding scale fee, because they don’t have insurance, right, and some of those folks as was mentioned, are undocumented. I think that there are also folks that, even speaking from my own caseload, clients that I’ve worked with who maybe make more money than is allowed to qualify for Medicaid, but living in Cook County is very expensive, and so paying that \$300 a month or whatever for a marketplace insurance plan just really doesn’t work for them, and they end up coming and paying \$10 or \$40 on sliding scale fee. Which then, they get services, but that might prevent them from getting medical care, or something like that.”

-Focus group participant

Our qualitative analysis revealed six major themes which we grouped into two categories, “Challenges Facing the Safety Net” and “Strengths of the Safety Net”:

Challenges Facing the Safety Net

1. Persistent issues with insurance
2. Coverage does not equal access
3. Workforce recruitment, retention, and burnout
4. Fear and uncertainty due to the changing political context

Strengths of the Safety Net

5. The sector is resilient and adaptable
6. Organizations are mission-driven and community-connected

We also summarize twelve “Consequences of Health Reform” that arose in the thematic content analysis.

Our report concludes by offering policy and practice recommendations to help address the challenges of reform at the institutional, state, and federal levels as well as recommendations for the philanthropy sector, paying particular attention to issues facing the western suburbs. Study participants repeatedly expressed concern about the many populations in the region who continue to “fall through the cracks.” Our recommendations reflect insights like this from safety net staff and leadership as well as Health & Medicine’s own policy analysis. The section closes by presenting providers’ thoughts on how our system *should* function, advancing a vision of a stronger, more effective health safety net as well as addressing the policy changes that would be required to achieve that vision.

Through all our work, Health & Medicine is committed to eliminating inequities in health and healthcare and guaranteeing healthcare as a human right; 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 Western Cook and Eastern DuPage Counties for decades to come.

This paper is part of a larger project, [Creating Healthy Communities: Helping the Safety Net Navigate the Challenges and Opportunity of Health Reform](#), examining how the ACA and state level health reforms can support the move toward health equity and stronger communities in the Chicago area. The companion paper, [Beyond the Clinic: A National Health Equity Review](#), can be found [here](#).

Introduction

The health care safety net works to guarantee the human right to healthcare for all people. In its 2000 report, *America's Health Care Safety Net: Intact but Endangered*, the Institute of Medicine (now the Health and Medicine Division of the National Academies of Sciences) defined the “health care safety net” as, “those providers that organize and deliver a significant level of health care and other related services to uninsured, Medicaid, and other vulnerable patients.” For this paper, researchers also considered Federal and state programs that finance safety net healthcare such as Medicaid. Because recent years have marked a period of momentous change in terms of access to health insurance, systems transformation, and other reforms, research on the healthcare safety net within this context is especially valuable.

Health reform also remains an unresolved and contentious political issue, making ongoing monitoring and research critical to informing current and future decisions. *What have been the unintended consequences of recent health reforms? Who remains uninsured and underinsured? Where are the gaps? Who—or what—is falling through these gaps? What policy reforms are needed to guarantee affordability and access to high-quality and culturally-responsive healthcare? What can policymakers, philanthropy, advocates, and the public do to advance health reform and ensure healthcare access for all?* These are some of the overarching questions that stimulated this research.

This paper builds on [prior research conducted by the authors that focused on the Cook County safety net.](#)¹ Through collaboration between Health & Medicine Policy Research Group and safety net providers across the western suburbs, we were able to better understand and analyze the current state of the safety net in Western Cook and Eastern DuPage Counties and provide policy, philanthropic, and research recommendations for the future. This study examined challenges that exist within each safety net provider type and sought to understand how each unique component of the Cook and DuPage County safety net has responded to the reformed environment.

Background

This study extends previous research examining the impact of the Affordable Care Act on the safety net. Research conducted in fall 2014 with the Cook County Health and Hospital System and other safety net hospitals reported optimism about the future, while acknowledging significant challenges ahead.² Understandably, the healthcare landscape in Illinois has shifted dramatically since 2014 in response to both federal and state-level reform. Health & Medicine conducted a late 2016 analysis of the Cook County safety net which drew upon nearly three years of experience in the reformed environment; the study extended the range of safety net actors considered to include FQHCs, free and charitable clinics, and hospitals; and identified challenges as well as potential solutions to the system-wide impacts of ACA implementation and other health reforms on Cook County's safety net.³

In response to health reform at the federal and state levels, the healthcare landscape in Illinois has changed dramatically over the past several years. In March of 2010, the Patient Protection and Affordable Care Act (ACA) was signed into law. The ACA was passed with the goal of meeting the Triple Aim of: 1) improving patients' experience of care; 2) improving population health; and 3) reducing the per capita cost of healthcare. The concept of a quadruple aim has also been put forward, with the fourth suggested aim being focused on provider health and wellbeing.⁴ In the field of public health, there has been discussion of a triple aim for health equity, which would include: 1) expanding the understanding of what creates health; 2) taking a “health in all policies” approach, with health equity as the goal; and 3) strengthening the capacity of communities to create their own healthy future.⁵ While that discussion is important, many working in healthcare have adopted the triple aim into their work.

In some respects, the local safety net has attempted to take great advantage of the ACA to benefit patients. One of the major provisions of the ACA allowed for expanded Medicaid coverage, which went into effect in

Illinois in 2014. In Cook County coverage expansions began a year earlier under the provisions of a Medicaid section 1115 waiver, which allowed the Cook County Health and Hospitals System (CCHHS) to enroll patients in Medicaid under its “County Care” program. CCHHS successfully enrolled nearly 100,000 individuals in Medicaid in 2013, a year earlier than the ACA’s standard enrollment period. The coverage expansion followed the shift in state law to Medicaid managed care in 2012, a legislative change that required at least 50% of Medicaid recipients to either choose or be auto-assigned into managed care plans by 2015. Following the end of the extended 1115 waiver for the CountyCare early enrollment, CCHHS adopted the name for its new Managed Care Community Network which is one of the existing managed care organizations under contract with the State of Illinois.

At the state level, in 2014, Governor Pat Quinn’s Administration proposed a large restructuring of the state’s Medicaid program which became a federal Section 1115 Medicaid waiver application. However, the plan was derailed in 2015 when the Rauner Administration took office and removed the waiver from its negotiations with the Federal Center for Medicare Services (CMS). The failure of the waiver and the change in leadership have presented new challenges—including a two-year budget impasse in which the State of Illinois held up payments to providers—which resulted in cuts to vital health and human services. In addition, in October 2016 the Rauner administration submitted their own 1115 waiver to CMS to change how Medicaid dollars are spent in Illinois, with a focus on behavioral health transformation.^{6,7}

Overall, in Illinois, the shift to managed care has resulted in changing patient and payer mixes for all safety net institutions as the state assigns individuals to specific primary care sites for care. In November 2017, approximately 64% (1,935,826 out of 3,014,487) of Illinois Medicaid enrollees were in a managed care program.^{8,9} More broadly, the Kaiser Family Foundation has estimated that through the Affordable Care Act, more than 690,000 Illinoisans (in 2016) gained insurance from Medicaid expansion while almost 315,000 people became insured via the Marketplace (in 2017).¹⁰

Some national studies have illustrated that there has been a significant impact on safety net inpatient and outpatient systems and the care they provide as a result of ACA implementation, with most examining the first year of implementation. Given the large changes to both insurance coverage and some specific health system changes—such as widespread adoption of electronic health records—implementation has led to myriad consequences, such as a more complex patient mix that includes previously uninsured patients who are often seeking healthcare for the first time in many years thereby stretching the capacity of many providers. Some changes have been positive. For example, national health reform investments allowed dozens of FQHCs across the country to develop new facilities. In 2016, there were 1,367 health center grantees operating thousands of delivery sites across the U.S., with 45 FQHC health systems in Illinois that served approximately 1,266,000 patients across a few hundred sites.¹¹

Further, Federal investments expanded the National Health Service Corps, which has had a positive impact on the availability of providers, like physicians and nurse practitioners, at safety net institutions. Many patients who have gained insurance, some for the first time, now have choices for where they go for healthcare that they may not have had before. This has meant that safety net organizations have increasingly needed to compete to attract and retain patients, leading to an increased amount of competition and pressure to provide improved and expanded services of higher quality. These and other impacts of the ACA and Illinois reforms, including ones that have been helpful and those that are challenging, surfaced in our qualitative analysis and will be discussed throughout this paper.

In the years following implementation of major federal and state health reforms, the safety net is still working to fully respond to these and other shifts in healthcare financing and delivery. Also, during the course of this study, attacks on the safety net—including attempts to repeal the ACA, eliminate the individual mandate, roll back Medicaid expansion, and turning Medicaid into a block grant—have continued at the Federal level with Congressional Republicans and the Trump administration using both legislative and executive means to

weaken or otherwise reduce the effectiveness of the law. The links among politics and public policy, delivery and access to healthcare, and the health of the public are illuminated by the findings in this report. As physician and anthropologist Rudolph Virchow stated, “All diseases have two causes, one pathological the other political.”¹²

Political Context

This research took place during a period of significant political change: Illinois had just passed a budget, after approximately two years without one. This governmental delay slowed—or in some cases, stopped—payments for health and social services, impacting all types of health and social safety net providers. The change in governors in 2015 also led to shifts in several state health reforms by Illinois’ Executive Branch, which resulted in further uncertainty. In addition, this study began during a heated national debate over health reform heightened by the 2016 presidential election.

The resultant uncertainty as to the future direction of health reform significantly impacted the conversations in this study. Widespread concerns regarding threats to the safety net and to specific marginalized communities were also an issue that surfaced during the study, which was conducted in the aftermath of the 2016 presidential election and at sites serving diverse communities.^{13, 14} This context undoubtedly impacts the work and perceptions of the safety net, those working within it, and the people who use it—and its importance cannot be ignored or overstated.

Applying this paper to your work

This research has been completed with a goal of providing new insights for policymakers, foundations, health advocates, healthcare provider organizations, researchers, and the general public to advance further health reforms to work toward a guaranteed human right to high quality, culturally-responsive healthcare. It is our hope to build upon this study and its findings through future research as discussed in the Recommendations section of this report. The authors also encourage discussion and feedback from readers and hope you will contact our research team to offer insights, perspectives, and questions, as we intend for this research to contribute to—and be a part of—ongoing conversations about health reform and a strong healthcare safety net at the county, regional, state, and federal levels.

Quantitative Analysis of Population Demographics and the Health System in the Western Suburbs

This paper was funded in part by a grant from the Community Memorial Foundation (CMF), and therefore our geographic area of focus includes CMF's 27 target communities in western Cook and eastern DuPage counties in the northeastern region of Illinois.¹⁵ In preparation of this paper, the research team sought data that would provide readers with basic, non-exhaustive demographic information for people served by health safety net organizations in the region and some information about the safety net itself in order to provide some context for the qualitative results of the study. Data sources include the Health Resources and Services Administration Uniform Data System (UDS) and the Center for Medicare Services Hospital Compare data system, both under the administration of the Federal Department of Health and Human Services.^{16, 17} While safety net institutions and population groups within the CMF region include a subset of those in Cook and DuPage counties, for consistency, the researchers have included available county-level data for the below indicators.

Federally Qualified Health Centers

Under the ACA, the federal government made increased new investments in the healthcare infrastructure through direct grant funding and an increase in third-party financing from coverage expansions to low- and middle-income individuals. The ACA initiated a five-year, \$11 billion expansion in community health center funding—eventually reduced under sequestration to \$9.319 billion over five years—to develop and support broader access to health care. Federal health centers appropriations averaged about \$1.7 billion annually prior to the ACA, supporting the centers' mission to expand access to care for uninsured and underinsured patients.¹⁸

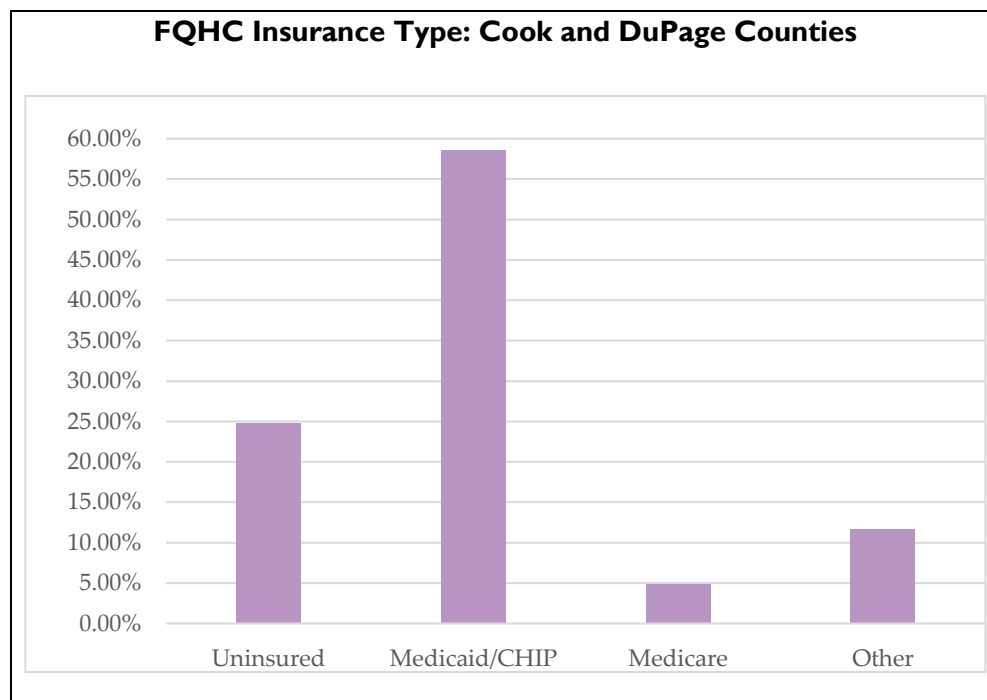
These community health center funds were later extended two more years to 2017 with \$3.6 billion of additional annual funding. Recently, funding was extended through 2019, with \$3.8 billion allocated for 2018 and \$4 billion allocated for 2019. However, the lack of long-term stability for this funding, and the recent lapse in funding, is concerning for FQHCs trying to make long-term investments without knowledge of how much funding will be provided in the future.¹⁹

At the same time that they possess such great assets, health centers confront a number of challenges to maximizing the value of this federal investment in expanding healthcare access. In meeting and maintaining performance goals, health centers face significant provider recruitment and retention problems. For instance, a recent survey of health centers found approximately two-thirds struggled to recruit physicians and about half had unfilled vacancies for not only midlevel clinicians but also behavioral health staff.²⁰

Additionally, health centers face significant financial challenges stemming from potential changes to their largest revenue sources, Medicaid and federal health center grant funding. Currently, Medicaid is the largest source of financing, accounting for nearly half of all revenues. Health center Medicaid Prospective Payment System (PPS) payments are intended to cover a wide range of ambulatory services and are adjusted annually to reflect changes in the Medicare Economic Index (MEI) as well as changes in the scope of services.^{21, 22} Although evidence suggests health centers are cost-effective, states are increasingly seeking to change the payment methodology toward one in which payment is bundled under alternative methodologies, such as periodic payments, payments tied to savings, or the use of per capita payments spanning all Medicaid-enrolled health center patients.²³ Like other health centers nationally, Illinois health centers were expected to benefit substantially under the ACA due to increases in health center funding and the expansion of Medicaid coverage.²⁴

The figures below describe the 2016 patient population served by FQHCs (n= 26) in Cook and DuPage counties according to HRSA UDS. For the two counties, the percentage of patients at or below 200% of the

Federal poverty level is 95.45% of the 837,345 total patient population. Roughly a quarter (24.98%) of the patient population is best served in a language other than English.



Hospitals

Safety net hospitals provide care to low-income, medically, and socially marginalized populations, including Medicaid beneficiaries and the uninsured. Safety net hospitals include hospitals that are both publicly and privately funded; they range from large teaching institutions to small community-based hospitals. Many face significant challenges serving diverse and complex patient populations and doing so regardless of patients' ability to pay.

Safety net hospitals play an essential role in the U.S. healthcare system by providing care for our neediest populations. They offer a full range of services including some services not offered by other hospitals, such as trauma and burn care, and often serve as training facilities for medical and nursing student.²⁵ They are also major providers of behavioral health care, specifically mental health care and treatment of substance use disorder.²⁶

Again, to provide context of a sample of hospitals in this area, the research team reviewed data from the Center for Medicare Services Hospital Compare data system which is under the broader Federal Department of Health and Human Services. The dataset does not include all hospitals in Cook and DuPage counties; it provides a snapshot of 55 hospitals across the two counties. Among the hospitals included, 89.8% of the Cook County hospitals and 100% of those in DuPage provided emergency services, 85.7% for the two counties combined.

The chart below shows ratings for seven indicators that hospitals in Cook and DuPage counties reported to the U.S. Centers for Medicare and Medicaid Services Hospital Compare data portal (n = 55). The chart shows a comparison of the groups of hospitals, those in **Cook, DuPage, and the two counties' hospitals' scores counted together**, compared against the national score, showing the percentage that are the **same, above, or below** the national average for each indicator. This is a selection of scores that can be considered in ranking hospitals.

National Comparison of Hospital Indicators: Cook and DuPage Counties

| | | Above National Average | Same as National Average | Below National Average | |
|-------------------------|----------------------------------|------------------------|--------------------------|------------------------|-------|
| Percentage of Hospitals | Mortality | Cook | 37.8% | 57.8% | 4.4% |
| | | DuPage | 83.3% | 16.7% | 0.0% |
| | | Combined | 43.1% | 52.9% | 3.9% |
| | Safety of Care | Cook | 33.3% | 33.3% | 33.3% |
| | | DuPage | 16.7% | 16.7% | 66.7% |
| | | Combined | 31.3% | 31.3% | 37.5% |
| | Readmission | Cook | 24.4% | 11.1% | 64.4% |
| | | DuPage | 66.7% | 33.3% | 0.0% |
| | | Combined | 29.4% | 13.7% | 56.9% |
| | Patient Experience | Cook | 16.3% | 18.6% | 65.1% |
| | | DuPage | 66.7% | 33.3% | 0.0% |
| | | Combined | 22.4% | 20.4% | 57.1% |
| | Effectiveness of Care | Cook | 0.0% | 89.1% | 10.9% |
| | | DuPage | 0.0% | 100.0% | 0.0% |
| | | Combined | 0.0% | 90.4% | 9.6% |
| | Timeliness of Care | Cook | 10.9% | 30.4% | 58.7% |
| | | DuPage | 33.3% | 16.7% | 50.0% |
| | | Combined | 13.5% | 32.7% | 53.8% |
| | Efficient use of medical imaging | Cook | 17.5% | 80.0% | 2.5% |
| | | DuPage | 50.0% | 50.0% | 0.0% |
| | | Combined | 90.9% | 0.0% | 9.1% |

Methods for the Qualitative Analysis

Understanding health reform as a process, this study sought to examine how the safety net in western Cook County and eastern DuPage County, Illinois has been affected by federal and state health reforms and the ways in which it is working to adapt to the reformed environment thus far. We considered health reform broadly, including both the Affordable Care Act as well as significant changes that have taken place at the state 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, including public and non-profit hospitals, FQHCs, free and charitable clinics (FCCs), community-based organizations (CBOs), insurers, and public entitlement programs. 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 among different types of providers and permitted us to examine the safety net as a holistic system of care. Secondly, we extended our analysis of the primary care safety net beyond the well-known formal members (e.g., FQHCs) and deliberately included the less-studied free and charitable clinics and community-based organizations that also support patients' health.

Given how rapidly changes can occur during health reform implementation, it is important to note that this study was carried out three years after the federal Medicaid expansion and individual mandate provisions of the ACA took effect; four years after Cook County implemented its "CountyCare" program which allowed the CCHHS to enroll the Medicaid expansion population one year before the rest of the state; and five years after Illinois began the expansion of enrolling its Medicaid beneficiaries into managed care plans. Thus, the study was conducted at a stage of health reform implementation which could no longer be considered brand new, and also one that had not yet fully matured.

Setting and Study Design

As this study was funded by the Community Memorial Foundation, our study focused specifically on the foundation's service area which includes "27 communities spanning western Cook and southeastern DuPage counties".¹³ For brevity, we refer to this area in the study as the western suburbs, referring to the western suburban area of Chicago.

To examine the safety net in the western suburbs, we conducted a qualitative study with safety net leadership and staff in order to: 1) create current snapshots of stakeholders within the safety net, 2) identify safety net members' common challenges after implementation of federal and state health reforms, and 3) uncover opportunities for philanthropy and policy to strengthen the safety net.

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 these organizations and conducted key informant interviews with executive leadership at thirteen different organizations. All key informant interviews and focus groups took place at the institutions themselves or over the phone. Our use of multiple sites, sources, and data collection methods increases trustworthiness of our data.

Data Collection and Participants

From June through October 2017, we conducted key informant interviews with executive leadership and focus groups with staff using semi-structured focus group and interview guides. These staff included positions such

as: patient navigator, program coordinator, program directors, executive directors, benefits coordinator, front desk staff, dentist, outreach coordinator, primary care providers, and case manager. Study participants came from a total of thirteen different FQHCs, hospitals, free and charitable clinics, insurers, and community based organizations. The research team at Health & Medicine Policy Research Group (Tiffany N. Ford and Wesley Epplin) created similar standardized, semi-structured interview/focus group guides one focused on healthcare provider organizations and another for community-based organizations that were used for both the focus groups and interviews with the leaders and staff. Ford and Epplin, experienced interviewers and focus group facilitators, shared moderating and note taking responsibilities for the interviews and focus groups. All interviews and focus groups were audio taped and Health & Medicine staff listened to and conducted thematic content analysis based on recordings.

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:

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

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 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.

Limitations

This study utilized a convenience sampling of safety net stakeholders in the western suburbs. 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 section are informative for reform, but they may not represent a complete picture of the safety net in the western suburbs and cannot necessarily be generalized to the safety net as a whole.

The study discussion guides asked safety net participants to make policy and philanthropic recommendations that might better support their work in the western suburbs. While study participants were well-informed of how policy and funding decisions play out in their daily work and in the lives of their patients, they did not always have a full understanding of health care policy context. Thus, our research mainly revealed the issues that policy or philanthropy can respond to with relevant context provided. As much as 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.

Qualitative Research Findings

This section examines major themes that arose from a convenience sample of focus groups and interviews with hospitals, federally qualified health centers, free and charitable clinics, community based organizations, and insurers. While our data collection took place in western Cook and southeastern DuPage counties, many of the issues discussed span geographic boundaries and echoed our 2016 study of Chicago area safety net providers.

The following key themes emerged from our analysis:

Challenges Facing the Safety Net

1. Persistent issues with insurance
2. Coverage does not equal access
3. Workforce recruitment, retention, and burnout
4. Fear and uncertainty due to the changing political context

Strengths of the Safety Net

5. The sector is resilient and adaptable
6. Organizations are mission-driven and community-connected

Consequences of Health Reform

- a. Increased insurance coverage for the previously ineligible
- b. High deductible marketplace plans and high co-pays make insurance unaffordable
- c. People who cannot afford services often chose to avoid healthcare
- d. Insurance complexity causes significant inefficiency and frustration for providers and patients
- e. Providers face drastic changes to the reimbursement, payer mix, and other funding
- f. Increased pressure to compete for patients who now have more healthcare options
- g. Free and charitable clinics have experienced significant change and a reduction in patients served
- h. Uninsured populations still need costly care
- i. Undocumented patients are still not eligible for insurance subsidies making care prohibitively expensive
- j. providers feel pressured to limit time with patients in order to see more of them, possibly compromising quality of care
- k. High stress, high demands, and lower pay make retention a challenge for the safety net
- l. Direct investments and reimbursement have led to significant benefits for the safety net

Overview: Health System Changes and Safety Net Responses

Overall, the safety net stakeholders interviewed identified the last few years as a period of increased investment in healthcare, with the exception of the state budget crisis which will be discussed. The following are some themes that were repeatedly identified by participants:

Increased Collaboration

Study participants noted more willingness to break down silos. Participants noted that this was particularly important in the western suburbs where there may be only one partner offering a particular service so providers have to work together to serve their clients. Overall, participants noted that their organizations have worked to deepen connections and partnerships with community-based organizations in order to meet patients' needs, rather than trying to become experts in those areas themselves.

Growing Focus on Population Health

The health safety net's shift to "risk-based" payments—in part due to Illinois adopting managed care as its Medicaid program—has made stakeholders even more committed to a broader conception of health. Public health and healthcare stakeholders increasingly recognize the importance of the social determinants of health—the conditions 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.²⁷ In addition, the so-called "triple aim" of health reform includes population health improvement leading the safety net to focus on the health needs of "panels" or groups of patients (similar to the way that managed care organizations define subpopulations of patients) and work to manage risks of sub-populations with differing health and social needs. This broader focus, plus increased investments in this area, has led safety net stakeholders to focus on population health. However, some respondents pointed out that the recent Illinois state budget impasse and threats to the ACA have resulted in uncertainty and some retrenchment.

One respondent noted the need to take on social determinants of health in earnest, with corresponding funding to do so. They said, "...it is a tricky thing that if you don't have a reliable and relatively deep funding source for those kinds of things you wanna make sure that you're not either dallying or being voyeuristic in the initiatives that you're doing." They also noted the need to network and partner with others in the safety net.

Changing Landscape for Free and Charitable Clinics

One free and charitable clinic respondent noted that Medicaid expansion led to a significant reduction in their budget and number of patients served and, while this led to the closure of some parts of the organization, it also allowed them to focus on newly evident gaps for uninsured, under-insured, and underserved patients. The respondent noted that this was a good indicator of increased coverage and an overall beneficial result of the ACA, but had concern about funders not realizing how much unmet need remains. They also noted that before the ACA they had a more diverse patient base but now see larger concentration of immigrants, many of whom were not included in the ACA, as well as younger patients who are often working but remain very low income or in poverty. Some of these young patients make too much money to qualify for Medicaid, but not enough to pay their portion of marketplace insurance. A respondent also noted that, unfortunately, there is less political will to fund public sector coverage and care for immigrants. They reported that this has led to less private sector funding for immigrant health as well since political will also plays a role in shaping those decisions. The result is a greater demand on public sector health services to provide care for all people, especially the remaining uninsured, including immigrants.

Staffing Changes

Participants noted an increase in hiring of care management staff as well as a need to ensure that organizations have enough clinical staff (an issue that will be discussed later in this section). The need to grow staff skills "on the fly" in response to health reform included areas like developing contracts, documentation and billing, claims denial management, and preauthorization increased during this period too. Respondents noted that the increased complexity of the system has at times led to interruptions in care.

Move to Electronic Health Records

Another monumental shift during this period was the widespread national rollout of Electronic Health Records (also known as electronic medical records or EMRs.) This has been a double-edged sword: EHRs have modernized record keeping to a large degree however EHR systems do not "talk" to each other across all institutions, leading to a lack of efficient data sharing and workarounds like faxing records. One respondent noted that they cannot make referrals directly in their EHR system. Several noted that they may not have records for what test was completed, what the results were, or what drugs someone is taking, leading to

inefficiencies for providers and patients, lack of information, and at times duplicate testing when records are not readily available. One respondent noted, “A universal EMR (EHR) would be awesome.”

Challenges Facing the Safety Net

Theme I: Persistent issues with insurance

As found in Health & Medicine’s prior research, the complexity of the insurance system within the safety net remains a significant problem. Some respondents in this study said that Medicaid managed care presents a number of hurdles in providing care. Changes in patients’ managed care plans and in managed care contracts led to frequent shifts in the insurance landscape and in patients’ and providers’ options. Some individuals seeking care have either made changes in their managed care plans or have had changes made for them with auto-assignment changing their options of services, medications, and providers. The practice environment in which providers, case managers, care coordinators, and other members of care teams operate is frequently changing too as some plans cancel contracts (or form new ones) with organizations providers have already made referrals to and where patients had provider relationships. This can limit the availability of referrals that match patients’ needs, desires, relationships, and physical location. Both the insurance landscape and different stakeholders’ formal contractual relationships—and the bounds of care—are being impacted by the combination of provider-MCO contract changes and individual enrollees’ plan changes.

This shifting landscape can lead to significant inefficiency as staff try to help frustrated patients navigate a constantly changing safety net. A respondent noted, “I could spend one whole day on one patient trying to get them care. Do you know how many patients I could help in one day (if I were not spending all this time navigating insurance)? And even then, I have no guarantee that there is going to be compliance, no guarantee that they’ll follow up, and they’ll end up back in my ER.” Respondents in the same focus group noted that they put a lot of work into care coordination but due to factors beyond their control, the hospital may end up penalized for a patient’s readmission despite their efforts. Many others noted the challenges patients face in terms of transportation and other factors that make compliance difficult.

Speaking to the complexity of managed care for providers and patients alike, one focus group respondent noted, “If I were in an ideal world, I would probably get rid of managed care, because it has created a lot of restrictions for a lot of patients when it comes to care.” Another spoke of the time when Medicaid was one program without managed care plans saying, “Back then, you referred someone, and it was covered. Now, ultrasounds, for example, have to be pre-approved. And before, you didn’t. So now someone who needs it urgently has to wait 24 hours or 48 hours.”

Some respondents also said that they would try to refer patients to specific doctors only to find they do not accept that patient’s plan. Home health providers might appear on an organization’s list of area providers but may not accept a patient’s insurance, saying, “I’m not getting paid and am not taking the patient.” Another respondent said that it is as if they have to fight to get paid for services given in good faith since insurance companies have carved out so many caveats to avoid payment. They observed that this decreases the ability of health systems to serve people because they are worried about getting paid so that they can pay their employees and keep the lights on.

One respondent said that hospitals have to re-review denials and spend time to get as much money back from insurers as possible. Another said that significant amounts of care that was formerly provided in-patient is now moving to the outpatient setting, but insurers do not want to pay for care provided to a patient who ultimately ends up needing to be admitted for inpatient stay or observation. Another respondent noted that variance in dental coverage is a significant problem because some plans cover only basic dental care while others offer a wider array of services; meanwhile, patients may believe that everything is covered and do not understand the lack of coverage. Respondents noted that patients also become confused when their primary care provider changes because of insurance changes.

A number of respondents' answers pointed to an overarching problem of high-cost, low-value insurance plans. They noted that under the ACA, not all plans are affordable for all people. Many respondents said that some patients make too much to qualify for Medicaid, but too little to be able to afford a good quality insurance plan on the marketplace, even with a subsidy. Also, given the cost, patients are often surprised to learn how little their plans cover. Many services are not covered so patients may end up paying thousands out of pocket in a year, especially in the case of a serious illness. If a patient chose a lower cost but higher deductible plan, they may not be able to afford the healthcare they need and may avoid care until much more expensive, emergency room services are required.

"I'm even hearing this from some of my colleagues. You know, people are making health decisions based on big large deductibles ... I mean preventive care is covered by ACA, but people are not seeking it out. Because they don't want to know if something is wrong because they don't want to spend the money to fix it."

One respondent shared that people may work in order to qualify for decent insurance only to discover that when they try to use their plans, coverage is not what they expected. Another respondent raised the question of whether patients can afford COBRA insurance when they lose a job. While it was noted that young adults being able to remain on their parents' insurance until age 26 is a huge win for health coverage, when people age out of those plans they often cannot afford premiums. Some patients will utilize a self-pay method of payment and shop around for procedures to get a lower cost. This suggests that although the current insurance system might help cover catastrophic costs and preventive care, there are significant coverage gaps and high costs.

In short, insurance coverage grew under the Affordable Care Act, driving uninsured rates to a record low nationally and in Illinois and expanding access to healthcare, especially preventive healthcare and primary care--a major shift that safety net stakeholders acknowledge and support. Still, the privatized insurance system, including the shift of Medicaid to managed care, was described by the safety net respondents in this study as complex for patients and providers alike, leading to a variety of frustrations, costs, and inefficiencies, with negative impacts on people's ability to access healthcare.

Theme 2: Coverage does not equal access

Our research confirmed that there has been a dramatic increase in health insurance coverage among the safety net patient population since the implementation of the ACA marketplace and Medicaid expansion, with study participants in hospital, FQHC, and CBO settings agreeing that there are "more people coming through the door." However, major gaps in accessing care still exist among the newly insured. One study respondent said, "I think that people may have more coverage, but they don't necessarily have more access." The increased complexity of the system was especially problematic for underserved populations and was exacerbated by systematic barriers that many patients face.

One hospital leader shared:

"I hear stories from our emergency department staff, that people that were assigned a Medicaid Provider—and this was back when the expansion happened—that they would try to access care with that provider, and they were—even though they were assigned to that provider, the provider was not accepting patients. And so there were lots of glitches in Illinois' Medicaid expansion that made it—while people technically had a card and coverage—there were many more covered, the accessibility for care wasn't probably as significant or effective as you might have thought."

Notices to Medicaid patients to select managed care plans were sent via mail but were not delivered because recipients moved. A study participant mentioned that many of their underserved patients had difficulty keeping up with mail, especially since many safety net patients are not stably housed to begin with.

Our study participants commented that access to and availability of necessary services increased as a result of health reform, but it was extremely difficult for patients to manage their healthcare once they had these services. According to study participants, patients and safety net staff spend additional time trying to figure out which managed care organization they belong to, and especially attempting to find pediatricians, orthopedists, psychiatric providers, and dentists. Due to system complexity and varying literacy levels, and without proper community-based resources and case management services, patients are not able to effectively navigate services. Each of these issues represents a major inefficiency in our reformed healthcare system.

Theme 3: Workforce recruitment, retention, and burnout

Workforce recruitment, retention, and burnout remains a safety net challenge. Study participants in all settings commented that safety net staff are burned-out by heavy patient workload, unsustainable provider to patient ratios, and low pay. This trend cannot be overstated. The work that safety net providers do is demanding and they often lack necessary support and other beneficial resources. Providers in the safety net are often members of the communities they serve and carry their personal trauma and the traumas of their patients to work each day. Ultimately this burnout is not only detrimental to staff and patient care, but also to the financial health of safety net institutions. The stress and trauma of increased explicit verbal and physical hostility toward both people of color and immigrants in the current political context also contributes to burnout and is discussed in more detail later in this report.

Participants in the study commented that safety net systems have “so many goals and things to get done and it is hard to do it all.” Due to the data needs of managed care and HER as well as requirements to see a certain number of patients each day, staff are spending less time with patients and more time entering health data into a computer, including narratives and coding. Newly insured patients are often seeking care for the first time in years and thus have more complicated health needs, placing additional demands on providers’ time. Many patients also have multiple complex physical and mental health co-morbidities as well as unmet social needs which add to the time and attention patients require. The stress of being unable to fully meet these patients’ needs contributes to workforce burnout.

The complexity of referral networks and covered services leads to safety net staff at times spending entire work days navigating a single patient’s care. Even then, there is no guarantee that the patient will have the resources to follow through with a referral or be “medically compliant,” study participants added.

This continuous workplace stress has significant negative impact on employees over time.

Provider Burnout

The extensive demands placed on providers generally, but especially on those working with patients experiencing complex health and social needs, has led to significant provider burnout. One recent National Academies of Medicine discussion paper noted that “workload, time pressure, clerical burden, and professional isolation” all contribute to burnout, and the qualitative analysis in this paper discusses issue of recruitment, retention, and burnout. The discussion paper also noted that clerical burden, often manifested in the pressures of clinical documentation via updating electronic health records, can take up to 50% of a provider’s work time. This means that if a provider is working full time and providing care for most or all of those hours, they may be spending close to an additional full-time equivalent on documentation. Provider burnout is further linked to lower patient satisfaction, worse health outcomes, and may contribute to higher costs. This is a national problem and certainly one that local safety net providers will need to focus on in order to improve healthcare quality, improve patients’ experience of care, and reduce healthcare costs, all of which are linked in part to provider retention and employee morale.

While various protective factors against burnout were identified among our study participants, none of these factors should be considered a replacement for policy change that fully supports and enriches the workplace experience of safety net staff.

“Working for a FQHC, there is a lot for the patients, but not a lot for providers. We are still required to see a certain number of patients in a limited amount of time that we are given. So we feel like we are not able to give them the time that they need. And we tend to have to finish a lot of our work at home, or on our day off. So a lot of our colleagues prefer to go to another organization where they might get paid more, have more services, more nurses, more help with referrals, to help with the phone calls that we just do not have here. So I think it is hard for us to recruit providers.”

The lack of resources—financial, staff, and service—in this tumultuous political time is another source of stress among safety net staff. Given the impending changes to state and federal health insurance systems, safety net employees find themselves wondering whether or not they will be out of a job in a month or a year. One focus group participant mentioned that the “hospital is looking at the bottom line,” when describing layoffs that had taken place a few months prior to the discussion. In addition to staff layoffs due to the lack of resources, one safety net executive mentioned that they had noticed high staff turnover rates in part linked to the Illinois budget crisis. “We have had lots of staff moving out of state—to states that have budgets,” the interviewee joked. In a focus group with community-based organizations, another respondent said that clinicians are moving out of state and patients feel that their resources are going away because of the political environment. The respondent went on to add that patients questioned why they were losing resources, asking “It’s because of Rauner, isn’t it? It’s because of Trump, isn’t it?”

Safety net stakeholders are doing their best to staff up to the growing demand of their patient population, however resources like finances and physical space to house additional providers sometimes serve as barriers. Insufficient staffing levels affect not only clinicians and also mean there are not enough people to help with observation, case management, and patient admission. One safety net staff member specifically mentioned that between the hours of 5:00 to 9:00 in the evening, their clinic is regularly understaffed. Recurring situations like these only add to the overall burden on staff members.

These persistent stressors drive some safety net staff members to consider working in non-safety net institutions. One FQHC staff member characterized this well, “A lot of colleagues prefer to go to another institution with more services, more staff, nurses, more help, et cetera...Support that we don’t have here.” A few hospital and FQHC leaders mentioned the difficulty in attracting and retaining providers in their system since salaries in non-safety net institutions are often high, commenting that “after their National Health Service Corps contract is up, often providers will leave.” Safety net staff also felt it was important to note the impact provider turnover has on patients, and as one study participant said, “It can be difficult to tell a patient that someone who they used to see is no longer there.” Staff turnover often leads to interruption in care for patients. In addition, both staff and leadership felt that an aging health workforce meant that recruitment and retention of safety net staff was more important than ever. While regular staff turnover is mitigated by workforce protective factors (mentioned in the Adaptation to the Reformed Environment section below), retention remains a critical concern.

“Recruit and retain. Unfortunately, we lose a lot of providers. A lot of providers come in because there is a loan repayment process (National Health Service Corps) and once that is taken care of, once that is over, they tend to leave. So there is no incentive for the provider to stay...they’re able to make more money, there are more services, more assistance. They don’t have to feel like they have to go home and continue working—until midnight.”

Theme 4: Fear and uncertainty due to the changing political context

The data collection for this study took place from June to October 2017 during a time when the future of the Affordable Care Act was uncertain, the state of Illinois had only just passed a fully funded budget for the first time in over two years, and discriminatory language was increasingly commonplace among governmental officials. Given that context, our study naturally led to politically charged discussions. In nearly every focus group and interview with safety net staff and leadership, study participants mentioned that they had not yet

had the opportunity for a concrete internal discussion about the impact of the political context on their respective organizations, but that this study had encouraged them to do so.

Following the 2016 presidential election, the uncertainty surrounding the ACA increased. Study participants mentioned that the heightened precariousness of national health reform harmed patients psychologically as concern about their wellbeing and future insurance status grew. These concerns continue unchecked as safety net staff do not have concrete information to provide aside from informing patients that their institutions will accept them regardless of insurance status. In various focus groups, staff mentioned feeling at times unprepared to respond to patients' concerns.

“If the ACA were repealed, it would go back to the way it was, where a lot of our patients lose their insurance again. And then we would lose reimbursement for services, and it would be a problem.”

Threats to the Affordable Care Act were a major theme when discussing safety net stakeholders' adaptations to health reform. Study participants mentioned that the uncertainty surrounding the ACA is leading to cuts in services and staff. Some safety net participants said that these cuts are not merely financial, and pointed to institutions pulling back from partnerships and de-siloing efforts that had become popular and necessary during the first years of ACA implementation. So while some de-siloing continues, lack of resources and uncertainty are slowing down efforts. Safety net leaders described that institutions are preemptively taking steps back because they are unsure what the healthcare landscape will look like in the coming months and years, saying that there is a “potential [for institutions] to get ‘burned’ by dismantling of the new safety net.” Many of the adjustments that institutions are making during this tumultuous time are intended to ensure their organization's vitality through this ever-changing health reform process and do not directly benefit the health or care of the patient.

Another major issue identified in interviews was threats to the state as a financially stable funding stream. In Illinois, safety net systems were also burdened by operating in a state without a budget. Many study respondents mentioned that receiving late or no payments impacted their organization's ability to provide services. One safety net leader summed up the compounding struggle:

Structural Oppression and Health

Structural oppression in the U.S. is long-standing and impacts the health of all residents. The current administration has ushered in an era of increased hostility and discrimination against people who have been historically marginalized due to classism, racism, ethnocentrism, nativism, genderism, ableism, and many additional and overlapping systems of oppression. The relationship of these systems to the current U.S. political context was summed up in a recent article in the *New England Journal of Medicine (NEJM)*:

*...[E]vents linked to the recent presidential campaign and election have given rise to fear and anxiety in many Americans. Research suggests that these events can have negative health effects on people who have been direct targets of what they perceive as hostility or discrimination and on individuals and communities who feel vulnerable because they belong to a stigmatized, marginalized, or targeted group. It is worth exploring the scientific research in this area and considering its implications for health care providers.**

As the *NEJM* article makes clear, health safety net stakeholders and health providers have an important role in protecting people's health against the threats posed by longstanding systems of oppression and increased hostility toward marginalized groups. National health reform remains a subject of contentious policy debate, making this research all the more relevant for policymakers, philanthropy, and the public at large.

* Williams, D., Medlock, M. (2017). Health Effects of Dramatic Societal Events – Ramifications of the Recent Presidential Election. *The New England Journal of Medicine*. 376:2295-2299. DOI: 10.1056/NEJMms1702111. Retrieved from: <http://www.nejm.org/doi/full/10.1056/NEJMms1702111>

“We are at the epicenter of dysfunction at the state level, diminished resources at the county level. [It] is just an island of Illinois and this [referring to federal ACA repeal and replace efforts] is gonna make that island tank faster.”

Another source of fear is heightened explicit racism, nationalism, and anti-immigrant hate in both speech and actions. The vitriol and actions of the current federal administration toward various marginalized groups has had an impact on people’s health, wellbeing, and health behaviors.² This has been documented in scholarly literature and the qualitative data in this report sheds light on what this looks like in Cook and DuPage counties. The western suburbs of Cook and DuPage County are often a port of entry for immigrants. Respondents noted that a main fear for immigrants and people living with immigrants was driving since they were concerned about being stopped by police and facing questions about their immigration status or being detained by Immigration and Customs Enforcement (ICE.) Some respondents noted that they had seen several children who were fearful and did not know what would happen with their parents.

They also noted that parents and staff have experienced increased amounts of fear both before and after the 2016 Presidential election, some of which were realized. In one reported incident a staff member’s spouse had to leave the county due to immigration enforcement, and since they had six children and the family could not be together in the U.S. they opted to go to Mexico together. The staff member was born and raised in the U.S. and did not know anyone in Mexico. This speaks to the reality—and associated fears and traumas—faced in

Threats to Immigrant and Undocumented Populations

The health safety net exists within a political and economic context that impacts both stakeholder institutions, staff, and the patients who rely on them. Under the Trump administration, U.S. Immigration and Customs Enforcement has expanded the reach of their efforts to arrest, detain, and deport immigrants beyond the (also harmful) policies and practices of prior administrations, with an increased focus on people who have been in the country for a long period of time.¹ This policy change, coupled with the increase in anti-immigrant rhetoric from government officials and hate groups, has drastically impacted the health, wellbeing, and behaviors—including health seeking behaviors—of immigrants and their families. It has also had vast impacts on the degree of stress felt in these communities.^{2,3,4} Public health and healthcare professionals may try to carry out their responsibility to help people feel safe and be safe moving about their communities, but sanctuary cannot currently be guaranteed. There are steps that can be taken to protect immigrants: some local jurisdictions have put forward “sanctuary” ordinances, and healthcare providers can do a lot within their own organizations. By following the Public Health Actions for Immigrants Rights (PHAIR) guide, safety net organizations can make progress on this health issue.⁵ Locally, the Public Health Woke coalition (of which Health & Medicine is a member) is helping collect and share resources.^{6,7} In summary, an intersectional approach is needed in order to effectively help patients affected by a variety of systems of oppression based on intersecting identities, of which immigration status is only one.

¹ U.S. Immigration and Customs Enforcement. *Fiscal Year 2017 ICE Enforcement and Removal Operations Report*. Retrieved from: <https://www.ice.gov/sites/default/files/documents/Report/2017/iceEndOfYearFY2017.pdf>

² Southern Poverty Law Center. (2017, February 15). *Hate Groups Increase for Second Consecutive Year as Trump Electrifies Radical Right*. Retrieved from: <https://www.splcenter.org/news/2017/02/15/hate-groups-increase-second-consecutive-year-trump-electrifies-radical-right>

³ Williams, D., Medlock, M. (2017). *Health Effects of Dramatic Societal Events – Ramifications of the Recent Presidential Election*. *The New England Journal of Medicine*. 376:2295-2299. DOI: 10.1056/NEJMms1702111. Retrieved from: <http://www.nejm.org/doi/full/10.1056/NEJMms1702111>

⁴ Artiga, S., Petry, U. (2017, December 13). *Living in an Immigrant Family in America: How Fear, Toxic Stress are Affecting Daily Life, Well-Being, & Health*. The Henry J. Kaiser Family Foundation. Retrieved from: <https://www.kff.org/disparities-policy/issue-brief/living-in-an-immigrant-family-in-america-how-fear-and-toxic-stress-are-affecting-daily-life-well-being-health/>

⁵ Public Health Awakened. (2018, February 9). *Guide for Public Health Actions for Immigrant Rights*. Retrieved from: <https://publichealthawakened.com/guide-for-public-health-to-protect-immigrant-rights/>

⁶ Collaborative for Health Equity Cook County. (2018). *Public Health Woke: Protecting Immigrant Health*. Retrieved from: <https://www.checookcounty.org/protectimmigrants>

⁷ Health & Medicine Policy Research Group. (2018) *Sanctuary Healthcare for All: Protecting the Rights of Immigrants and Marginalized People*. Retrieved from: <http://www.hmprg.org/Events/Sanctuary+Healthcare>

many communities in the western suburbs. Many community members, whether they are patients or staff, are either directly impacted themselves or know people who are impacted by immigration enforcement.

Fear has also led to changes in patient behavior. People who are afraid to drive have to use other less reliable forms of transportation or become homebound. Some respondents said that patients are not seeking care because of this fear. One particular program for undocumented patients saw a drop in patients from 600 to 500. One respondent noted that asking patients to fill out a form with a name, address, and phone number can make people fearful, even when staff try to reassure people that the information is only for internal use. This fear impacts staff, too. One study participant shared that a patient had recently asked a staff member about their immigration status, and they cannot recall this happening before at their site.

Respondents noted that there have been some organizational adjustments to help patients and communities feel and be safe. Respondents noted that they have tried to reassure patients of their safety, but fear remains. In one instance, a 911 call to have a patient transferred from a clinic to a hospital led to a police officer demanding documentation related to the patient's immigration status. While staff worked to protect the patient, there was some escalation in the moment. Eventually a meeting with local police and clinic leadership was held to try to ensure that this did not happen again. The episode speaks to the fact it may not be possible to realize safety and sanctuary in the current political climate, although they remain goals for many health organizations.

Federal cancellation of Deferred Action for Childhood Arrivals (DACA) was also brought up during data collection. Respondents noted that people with DACA status were fearful about whether or not they would be able to attend college. They noted that many children are experiencing extreme stress around this issues which impacts their mental health and broader wellbeing.²⁸ The unmet need for mental healthcare and psychiatric care is relevant here, too. In short, the political climate has had significant impacts on the health and wellbeing of communities served by and working within the safety net.

Strengths of the Safety Net

Theme 5: Adaptability and Resilience of the Safety Net

Respondents noted that while this has been an especially turbulent time for the healthcare safety net, it is not the first time the system has faced substantial threats or changes. In the early 1980's, Medicaid block grants threatened to destabilize the safety net, and participants noted that they survived welfare reform in the 1990s. Federal Medicaid block grants were again debated recently as part of efforts to repeal or scale back the ACA and Medicaid. The uncertainty of federal and state health reform as well as other compounding factors (such as the two-year lack of a state budget in Illinois), left safety net stakeholders trying to "read the tea leaves" to figure out what would come next and how they might best respond to changes.

During this time, the size and scope of the organization seemed to considerably impact its flexibility in responding to challenges. Both FQHC and hospital stakeholders reported that there has been an increased drive to become a "one-stop-shop" and house more services within a single organization, which is driven by a number of factors. First, safety net stakeholders are seeking greater stability and flexibility. Providing more services in-house can lead to more reimbursements staying within a given health system. This may result in more seamless, flexible, and comprehensive services for patients with fewer gaps and less waiting time, inefficiency, and mistakes. For health systems, it may help them to remain financially stable and flexible, with greater ability to fund more staff to provide better care and more services. One respondent noted that a larger organization has the resources to allow staff to learn how to adapt to these changes by, for example, participating in continuing education programs about health reform or pursue new partnerships to support patient health. On the other hand, smaller health systems with fewer staff may have less resources and ability to participate in such opportunities. The desire for stability may be rooted organizations' drive to achieve their

missions which usually focus in some way on improving people’s health and providing consistent access to the care and services they need.

In addition to the benefits of organizational growth to become “one stop shops” for patients, the respondents in this study all mentioned the huge benefits of partnerships among healthcare and community-based organizations. They valued the increased ability to easily refer patients to other entities for care despite the data exchange and insurance challenges mentioned previously. They noted that some nursing homes have stepped up to provide care via Medicare Part B, sharing that it costs a lot but it may help get a patient back on their feet and reintegrated into their home and community with a caregiver in place.

Many respondents pointed to the role health systems innovation plays health improvement overall. One free and charitable clinic respondent noted that one of the greatest assets of their sector is the ability to innovate to keep people at the table, including both physicians and those hospitals and partners who provide volunteer staff support. Another respondent remarked that they received a grant to expand psychiatry services, noting that it helped fill a huge and specific gap in their community. Other respondents noted that having staff trained to do a variety of tasks was helpful in building flexibility into their organization—staff could move from an area experiencing low demand at a certain time to another area of work was in high demand. Having different categories of health workers trained to help with referrals was another example shared. However, another respondent alluded to some work tasks being beyond their training, and that continuing education could be useful for providing better care to patients.

Another innovation mentioned by a respondent is a network card for people who live within the community but do not have insurance. The card helps patients access discounted prices. The “membership” has benefits even if it is not the same as insurance.

One FQHC respondent provided another example of how the safety net is innovating in the face of shrinking financial resources. In the past, health centers received a sizable budget for marketing and promotional materials during the ACA enrollment period, however that funding has since lapsed. To address this challenge, the FQHC made their own advertising materials and repurposed old materials. When funding for patient navigators was also cut leaving only three navigators on staff, the same FQHC also planned enrollment workshops with groups of patients as opposed to one-on-one sessions.

Other noteworthy safety net resiliency assets listed by respondents included existing high-quality obstetrics and gynecological care and a 340b prescription program to provide discounted drugs.

In short, the health safety net has a strong commitment to providing for patients’ needs and modifying their services to meet those needs. One respondent shared, “I believe that we exist to serve the patients, and not the other way around; our job is to see the new reality and evolve to meet it. If we don’t need to be there or do the things we used to do, that’s fine, we should change. Or, if we eventually don’t need to be there, that’s fine, because our mission is to make sure that the services are being provided.” Noting that an organization may complete its mission and no longer be needed—that it may successfully work itself out of a job—shows the sector’s great commitment to the health and wellbeing of patients.

Theme 6: Organizations are mission-driven and community connected

Respondents stressed the importance of partnerships, noting that these partnerships were often the result of long-term investments in relationships. They emphasized that adaptable relationships were essential given the changing landscape, and that personal relationships often enhanced these efforts. In particular, free and charitable clinics found that partnering with hospitals and physicians was critical to meeting their patients’ needs. Respondents mentioned that the connections that had formed among healthcare providers and social service community-based organizations led to increased intersectionality (such as housing and addiction treatment) in addressing patients’ needs. Another focus group cited a planned merger of a local FQHC and a social service CBO in the west suburbs that had the potential to improve and expand services. Support of the

broader community was also reported to be essential in building and maintaining partnerships, fostering trust, and securing funding.

Many respondents in this study noted that having dedicated leadership, staff, and board members was exceptionally helpful in guaranteeing their success and in being an adaptable organization. One said that when leaders' "hearts are in it" for patients' care, it becomes a part of the ethos and practice of a given organization among all staff.

Dedication to mission and connection to community also seem to be protective factors in staving off staff burnout and boosting morale. Some respondents noted that love for the population served and mission-driven coworkers encouraged some employees to remain at their organization. Another respondent stated that seeing the impact of their work—improvements in health or social wellbeing, or helping a patient find a shelter—was especially rewarding. Respondents also shared that being part of the community helped them to see the results of their work and boosted morale. This was especially true when employees got to see patients in their full community context or could remember patients from the last time the provider saw them or their family member. Teamwork was also noted as a contributing factor in employee morale.

It is important to note that these protective factors against work stress did not outweigh the overarching challenge that burnout represents for the safety net. More interventions are needed to promote the health and wellbeing of workers.

Consequences of Health Reform Summary

The following outcomes and consequences of reform (including unanticipated consequences) emerged from our focus groups and interviews, and each is important for policymakers, systems leaders, funders, and others to consider when undertaking changes to the current health system or future health reforms.

- a. **Reform increased insurance coverage for some community members who were previously ineligible.** Expansions to Medicaid eligibility criteria provided coverage for hundreds of thousands of previously uninsured Illinois residents. The ACA also ensured that essential health benefits were included in all insurance plans.
- b. **High deductible marketplace plans and high co-pays for some services have made the ACA unaffordable for many.** People who make too much money to qualify for Medicaid often do not make enough money to afford an ACA marketplace plan, especially not one with a low deductible. These individuals may also make too much money to qualify for sliding scale payment schedules for health services.
- c. **People who cannot afford care often chose to avoid healthcare services.** Given personal financial constraints, individuals may avoid healthcare, even if it is urgently needed. Patients may run out of medications and not refill it or they may not seek care until there is an emergency.
- d. **Insurance complexity causes significant inefficiency and frustration for patients and providers to provider alike.** As a result of changing managed care contracts, providers do not always know where they can refer patients and what medications are covered. Providers sometimes have to change patients' medication due to coverage changes, even when other medications work better. Respondents noted that while doctors can log into a system to find a list of providers in a patient portal, those lists are often not updated or accurate. Varying reimbursement terms from different insurers make it difficult for providers to be accurately informed. Some providers continue to experience growing pains as they learn to navigate the new managed care landscape.
- e. **Health reform drastically changed the reimbursement structure, payer mix, and overall funding for health services.** Some safety net stakeholders have experienced an increase in reimbursement for specific services and patients, some are seeing an increase in not reimbursable

services, and others are experiencing a combination of the two. Because many previously uninsured patients are now eligible for coverage, systems that historically served patients regardless of insurance are now receiving reimbursements. At the same time, since many patients have high cost ACA plans, they may receive services at hospitals that they cannot afford. This places an unexpected burden on hospitals to provide unsustainable “pseudo charity care” for these patients.

- f. **Providers face increased pressure to compete for patients who now have more health care options.** The increase in the population of insured patients has resulted in competition among providers—something they had neither expected nor prepared for. Some have had to rely on new tactics to attract and retain patients.
- g. **Free and charitable clinics have experienced a period of significant change and a reduction in the number of patients served as newly insured community members seek care in other settings.** Many patients who previously received services at FCCs gained insurance through health reform and now receive care from other safety net providers. FCCs continue to serve a smaller but still significant population. However they noted some demographic shifts, such as serving a mostly foreign-born—documented, undocumented, or quasi-documented—population. Clinics have experienced a reduction in funding and there is some concern that funding will be further reduced despite high demand. Free and charitable clinics continue to work to adapt to changing needs and many have branched into new service areas like healthcare navigation.
- h. **Remaining uninsured populations still need care that is costly to provide.** Due to the lack of reimbursement for the remaining uninsured, the cost of care for these individuals is becoming prohibitive for safety net systems. Uninsured patients often wait until they are very sick to get care because they lack access to preventive or primary care.
- i. **Many adult safety net patients are undocumented and remain ineligible for subsidies on the marketplace or Medicaid.** Given their mission, safety net stakeholders provide care to all, including a large uninsured undocumented patient population. With increased threats to undocumented individuals, these populations may not reapply for Medicaid for their eligible children or other relatives. This could result in a reduction in reimbursements for safety net entities serving this population.
- j. **Requirements to see a certain number of patients in a limited amount of time places pressure on providers.** This pressure, reflected by providers regardless of setting, causes safety net providers to consistently feel that they do not have enough time to best serve their patients. These unrealistic expectations start a chain reaction that begins in the exam room, throws off front desk scheduling, and ultimately disrupts overall care delivery.
- k. **High stress, high demands, and lower pay make provider retention difficult in safety net settings.** Safety net providers face high stress, high demand environments, often with less support than non-safety net providers. Loan repayment programs assist in attracting providers, but once the repayment period ends, many systems lose providers to higher-paying, lower-stress settings.
- l. **Large investments in the health safety net system—through both direct investments via grants and reimbursement for patients who were previously uninsured—have led to great benefits for the sector.** These investments have included grants for a national rollout of Electronic Health Records as well as grants for Federally Qualified Health Centers and a broad shift toward population health, quality improvement, and reduction in per-capita cost of care.

Recommendations

Health & Medicine sought to examine the implementation of the ACA and state level health reforms to learn how this seismic shift was impacting safety net organizations within the western suburbs of Chicago. It is important to emphasize that this study took place during a time of extreme political uncertainty, with the Republican-led Senate continuously attempting to advance legislation that would effectively dismantle the ACA. These attempts were ongoing throughout much of our data collection.

This study's geographic region was especially interesting, as an inaccurate narrative often exists about the western suburbs. While health care and social service providers recognize the need for safety net resources in the area, there are many who are not cognizant of this need. One hospital leader said that "there are many people who would not think that there is any major problem or major safety net need in the general population. They often also don't perceive that there is that big of a problem in the collar counties or in the suburban areas." Our study revealed that there are still large populations who rely on the local safety net and many others that are falling through the cracks in the western suburbs.

Who Continues to Have Unmet Needs?

During interviews and focus groups, participants were asked about who and what is "falling through the cracks" or "Whose needs are not being met?" Often, such discussions arose as a natural progression of the conversation.

Participants noted that low-income people and people with disabilities are generally being left behind by the safety net or have unmet needs, despite the system's best efforts. As previously discussed, low-income people often cannot afford high co-pays and premiums for healthcare. In addition, people with disabilities often have complex needs, including provision of services to fulfill activities of daily living and access to healthcare more broadly.

The issue of unmet needs among older adults was also frequently mentioned. Participants specifically noted the needs of medically fragile seniors for whom there are not adequate services in place and said that this is especially true for low- and moderate-income people. The issue of elder abuse and neglect and the broader need for an improved long-term care system was also shared. One participant said that if people cannot afford the care that they need, they will often be sent home where they will then fail and end up returning to the emergency department when other care could have helped avoid this cycle. Additionally, the issue of social isolation (older adults not having a support network of people around them) was discussed. Some participants noted that older adults' children may have moved out of state, away from their aging parents who could benefit from familial support.

Participants also noted that children who have special medical needs are frequently falling through the cracks and are not receiving the care that they need.

The fact that many immigrants were left out of coverage expansion and subsidies under the Affordable Care Act has left a significant portion of the safety net patient population without insurance, largely mirroring the state and national context. Respondents noted that only some immigrants qualify for marketplace subsidies and may not make enough money to afford insurance even when subsidies are available. Also, many immigrants do not qualify for Medicaid even though their need matches other recipients based on income. Research participants also shared that many immigrants experience trauma related to increased threats and actions from Immigration and Customs Enforcement and this has impacted people's mental health, their ability to go about daily life, and their health seeking behaviors, as discussed elsewhere in this paper. It was also noted that while health systems often request documentation for proof of income when determining a patient's sliding scale eligibility, some immigrants may not be able to get this documentation which can be a barrier to care. At the same time, FQHCs respondents, for example, noted that they will see a client regardless

of documentation and that when possible they try to forward patients to hospitals as needed when a patient is referred.

Transportation also came up frequently as many patients struggle to secure reliable transportation to get to clinical appointments, pick up medications, and in daily life. Transportation impacts clinical operations when patients miss or are late for appointments due to transportation inequities. In particular, it was noted that people with disabilities are often underserved by the transportation sector. Participants also spoke about the need for clients to go to special needs doctors, along with the concern that transportation services cannot always be relied on to get them to these services. One respondent pointed out that some patients with disabilities may not know about transportation options available through Medicaid Managed Care. These inequities leave many relying upon Uber or friends for transportation, which may not work for all patients.

Research participants highlighted that finding conveniently available specialty services for some patients can be difficult. While these services may be available at a public hospital, these facilities may be far away and it can be difficult for care coordinators to figure out transportation. One respondent added that English is not the first language of many patients which only compounds transportation barriers.

The relative scarcity of psychiatric services also came up frequently. One participant shared that people who have an addiction and are dually diagnosed can experience a delay in care since service options are somewhat limited. The participant added that there is a relatively high rate of relapse for people with addiction and that many patients need improved long-term quality care in this area. In the absence of such programs, when patients decide to seek addictions services the wait may be a week or two. “For an addict,” the respondent noted, “that can feel like five years.”

Opportunities for Progress

With the passage of the ACA and implementation of state health reform, many in the safety net anticipated opportunities as well as challenges as they prepared to care for millions of newly insured individuals. While the previous section highlighted consequences of health reform identified by study respondents, this section seeks to provide recommendations that might address some of those consequences.

During the research process, safety net executive leadership and staff at various levels were asked specifically about how philanthropy and policy might work to support the western suburban safety net. Given the current federal and state political landscape, research respondents had an array of recommendations, ranging from specific funding needs to broad and sweeping policy change.

In order to bolster a robust safety net system, each of these recommendations should work to advance health equity. Health equity is defined as a process of assurance of the conditions for optimal health for *all* people and requires three things: 1) valuing all individuals and populations equally, 2) recognizing and rectifying historical injustices, and 3) providing resources according to need.²⁹ As such, a focus on interventions at the larger, structural level is needed to ensure that the safety net in the western suburbs (and beyond) is most efficient and effective in providing quality care for their patient population. In Health & Medicine’s recent paper, *Beyond the Clinic: A National Health Equity Review*, we delve deeper into strategies that safety net stakeholders can use to respond to structural inequities and promote health equity.³⁰

Recommendations

Recommendations related to policy, philanthropy, collaborations, and future research emerged from this qualitative inquiry. The issues raised and recommendations made below reflect the thinking of safety net research participants while “Health & Medicine Recommends” reflects the researchers’ analysis and recommendations.

Combined Recommendations

Later in this section we provide separate recommendations for philanthropy and policy, however the tables below are intended to highlight the connection between those recommendations. Specifically, we hope they demonstrate that while philanthropy can address specific issues within the safety net, a broader and more sustainable response to issues raised by study participants requires policy intervention. The tables below illustrate gaps where philanthropy and policy may play a role.

Fragmentation and Cost

| | |
|---|---|
| <p>Issues Raised in Qualitative Research</p> <ul style="list-style-type: none"> • The current safety net system serves many uninsured and underinsured patients • Many patients cannot afford high deductible insurance plans • Patients and providers are navigating fragmented clinical settings • There is an increased need for behavioral health services which exceeds current capacity • Many patients cannot afford their medications | |
| <p>Philanthropy Recommendations</p> <ul style="list-style-type: none"> • Provide funding for uninsured and underinsured patients • Fund expansion of insurance premium assistance programs • Fund pharmaceutical assistance programs • Fund positions to support internal services in areas of need so that safety net organizations can move toward becoming “one stop shops” | <p>Policy Recommendations</p> <ul style="list-style-type: none"> • <u>Federal</u>: Pass a universal coverage, single-payer health insurance plan • <u>State</u>: Develop a plan to move to a single-payer system or Medicaid lookalike where every resident has health insurance • <u>State and health systems</u>: Examine scope of practice laws in Illinois and develop expanded, reimbursable provider categories • <u>Health Systems</u>: Examine models of care that use expanded staffing categories for behavioral health and implement these models |

Funding

| | |
|---|--|
| <p>Issues Raised in Qualitative Research</p> <ul style="list-style-type: none"> • Unrestricted funds are needed to allow safety net organizations to be as nimble and responsive to patient need as possible • Safety net stakeholders need consistent funding to continue operations, especially when the political future is uncertain • Flexible, multi-year funding is hard to come by • Two-year funding cycles are often planned well in advance of receipt of philanthropic funding, yet major political changes in the health landscape are ongoing and impact work plans • State safety net funding was uncertain and flowed very slowly during the two-year budget impasse making safety net providers uncertain about their ability to pay bills and remain open and forcing the closure of some providers | |
| <p>Philanthropy Recommendations</p> <ul style="list-style-type: none"> • Fund services and programs if (or when) state payments are interrupted • Allow flexibility in funding so that money can be spent as needed in the changing political environment • Provide multi-year funding whenever possible | <p>Policy Recommendations</p> <ul style="list-style-type: none"> • <u>State</u>: Maintain a fully funded state budget delivered before the start of the Illinois fiscal year |

Social Determinants of Health

| | |
|---|---|
| <p>Issues Raised in Qualitative Research</p> <ul style="list-style-type: none"> • Transportation to appointments is a barrier to care • Unstable housing for patients interrupts care • Safety net staff are paid low salaries • Older adults are unable to afford long-term care • Post-acute patients need help navigating their return to the community (i.e. medication, home care, transportation) | |
| <p>Philanthropy Recommendations</p> <ul style="list-style-type: none"> • Fund safety net organizations to support the social determinants of health • Fund a local shared social service resource portal • Fund safety net staff salary increases | <p>Policy Recommendations</p> <ul style="list-style-type: none"> • <u>State and local</u>: Advance policies that focus on reducing economic inequality and supporting healthy communities • <u>Institutional</u>: Improve connections and build new partnerships to fill gaps in people’s social needs |

Health & Medicine Recommends: *Institutions within the safety net can use their influence to weigh in on local, county, and state policy issues that matter to health. Health institutions and providers have a prominent role in our society and their voices are respected and valued by policymakers on topics beyond healthcare.³¹ For more information on this topic, read our companion report, [Beyond the Clinic: A National Health Equity Review](#).*

Philanthropy Recommendations

| |
|--|
| <p>Issues Raised in Qualitative Research</p> <ul style="list-style-type: none"> • Study participants expressed the need to increase staffing so that existing staff can experience less stress and be better able to perform their duties ultimately improving patient care. In addition, funding for food, celebrations, and other interventions to increase staff morale were mentioned. Respondents also discussed a desire for continuing education. • Respondents from all safety net settings highlighted the need for access to funds to try new things, with one hospital leader commenting, “Private philanthropy plays a role in innovation. I hope they never forget that.” Study respondents need access to resources to test innovative interventions and the opportunity to scale-up should these innovations prove successful. |
| <p>Philanthropy Recommendations</p> <ul style="list-style-type: none"> • Fund staff support and retention programming and services within safety net institutions. • Fund innovative programming, collaborations, and new ideas that emerge among safety net stakeholders. |

Health & Medicine Recommends: *Trauma-informed institutions and staff have been shown to improve staff morale and retention. To reap these benefits, safety net stakeholders should begin the process of becoming trauma-informed institutions.*

Policy Recommendations

Reimbursement

Issues Raised in Qualitative Research:

- Medicaid reimbursement rates are too low to attract and maintain providers who serve that patient population. Illinois has one of the lowest match rates from the Federal Government for Medicaid spending. Respondents said that some specialty care services, such as psychiatry and dentistry, had limited availability for Medicaid patients due to low reimbursements which lead many providers not to accept Medicaid patients.
- Many patients, especially aging patients, do not have advanced directives and they are receiving multiple costly procedures even though their quality of life is likely to be very low even after a successful procedure. Many patients can benefit from having difficult conversations about how they would like their end of life care to be carried out. Some doctors are uncomfortable with this; others do it, but sometimes conversations conclude without signed advanced directives.
- A financial planning and counseling component to end of life care is needed as people may be placed in a setting in which they spend down their assets without fully understanding the consequences.
- Illinois has multiple types of case management, making it difficult to code properly and ensure reimbursement.

Policy Recommendations:

- State: The state should better monitor and enforce Medicaid managed care organizations' provider networks to ensure an adequate supply of primary and specialty providers (e.g. psychiatry and dentistry).
- State: Adequate accountability and oversight measures of managed care by HFS must be established.
- State: The Department of Human Services should reduce and streamline case management billing codes so that it is easier for health systems to both categorize the type of case management needed and be reimbursed.
- State: Ensure that reimbursements for end of life planning are optimized so that more advanced directives and financial plans are developed and put on file to help patients get care that matches their goals.
- Institutional: Doctors need training on how to carry out end of life education with patients; such conversations should take place annually for patients over 65.

Health & Medicine Recommends: *Increased conversation and critical examination is needed among safety net system stakeholders and policymakers to empower the sector to care for older adults. The current system of care is not sufficient for an aging population. People who are aging and have disabilities are not well served. Given the expected growth in our aging population, the system needs to learn more about these challenges and prepare to address them with patients.*

Behavioral Health

Issues Raised in Qualitative Research:

- Mental health services are not as available as primary care services. Specialized mental health services, such as services for child abuse, can be especially difficult to find.
- Hospital respondents noted that when an adult patient arrives at an emergency room, the state-required screening process for mental health intake into an inpatient psychiatric setting takes too long—up to 48 hours on business days. This means that someone can arrive at an emergency department on a Friday and not receive a screening until Tuesday. Only under limited circumstances can adults easily receive in-patient psychiatric care (such as being a threat to oneself or others), which limits access and leads to patients cycling in and out of emergency departments as well as long waits for care when they are in psychological distress.

Policy Recommendations:

- State and institutional: Prioritize integration of behavioral health—including both psychiatry and addiction services—with primary care to make mental health services more accessible and not an add-on service.
- State: Develop and utilize a screening for adults experiencing mental health distress that is similar to the process and criteria of the Screening, Assessment, and Support Services used for children experiencing psychological distress. This process can ensure prompt, same-day screening with services provided seven days a week.

Electronic Health Record Integration and Information Exchange

Issues Raised in Qualitative Research:

- Electronic health records can be helpful, but they are not connected across all institutions so providers cannot easily and immediately access information about a patient’s history, test results, medications, procedures, and consultations with other providers. This can lead to significant gaps in information during patient encounters.
- Providers and other staff often need a patient’s permission for record transfer. They must place a request, wait for, and process records which might be faxed or scanned from other institutions.
- During a patient encounter, providers may lack some key information about their patient and may not be able to move forward with a treatment plan or may move forward without all information.
- Providers might duplicate services, prescribe medication without knowing all potential risks, or send a patient to costlier ED services, especially if they are unable to get preapproval for something that may have been addressed at another institution. They may have to ask patients to come back for another visit or conduct unnecessary follow-up via phone once information arrives.
- Patients may have to return for another visit because of the information gaps causing delays in care and, depending upon the individual, increased burdens on the patient related due to missed work, transportation, or childcare.

Policy Recommendations:

- Federal: Fund health information exchanges and require health systems to move toward interoperability with integration of electronic health records.
- State: Illinois should fund and set-up a public, statewide electronic health information exchange or fully fund the regional exchanges (that had been set up with Federal funding but shut down under the current administration) so that data can be easily transferred across institutions and platforms.
- Institutional and local: In the interim, western suburban safety net stakeholders should work toward integration of local EHR systems by pursuing data sharing agreements across institutions.

Managed Care Information System

Issues Raised in Qualitative Research:

- Safety net staff members noted a lack of consistently updated and accurate information about managed care in terms of: which providers a patient can be referred to; which MCOs are contracted with which other organizations; and what medications and services can be reimbursed under each MCO. These problems lead to delays in care and inefficiencies.
- Respondents expressed a need for increased communication with MCOs about decision making, the potential impacts of those decisions, and problems that arise when decisions are implemented.

Policy Recommendations:

- State and institutional: Healthcare and Family Services should create an online portal for bi-directional communication among managed care organizations and providers to allow them to be aware of and influence decision making.

Health & Medicine Recommends: *Monitor implementation of Illinois Public Act 99-0725, which became law in August 2016. Many issues related to Medicaid managed care raised by respondents will hopefully be addressed by PA 99-0725 which seeks to improve patients' healthcare choices in Medicaid managed care by ensuring timely, updated, clear, and reliable information related to providers and medications. It will also help patients easily compare plans and ensure patients have access to help when they encounter problems receiving care.*

Scheduling Patient Appointments According to Need

Issues Raised in Qualitative Research:

- The standard fifteen-minute appointment time was discussed repeatedly as a problematic element of primary care delivery. Respondents pointed out that patients have a varied number, degree, and complexity of morbidities and their social needs outside of clinical settings differ widely. This means that different patient visits require different amounts of time, often going far beyond the fifteen minute allotment. Some respondents said that this causes undo stress on providers and often means that a patient has to schedule additional visits rather than having all of their needs met in a single visit.

Policy Recommendations:

- Federal: The Federal requirements that FQHCs have a minimum number of patient visits each year should be changed to allow for more flexibility in appointment length so providers can offer care based on the needs of each patient.
- Institutional: Safety net organizations should schedule patients according to their health needs rather than attempting to maintain a fifteen-minute regular appointment time limit.

Health & Medicine Recommends: *Health workforce issues were raised throughout the interviews and focus groups, yet research participants did not have many specific policy recommendations in this area. Instead, researchers drew upon our broader health workforce activities to identify the following recommendations:*

- *Illinois should implement the recommendations developed by the state-mandated taskforce on Community Health Workers.*³²
- *Examine and modify scope of practice laws in the state to ensure that all providers are able to practice at the top of their licenses, education, and expertise.*
- *The following three recommendations were developed by state-wide engagement that included health workforce issues (and in which Health & Medicine was involved). These are direct quotes from lengthier recommendations included in the cited report:*
 - *“Consolidate many state operated scholarship and loan repayment programs to operate similarly as strictly loan repayment to enhance marketing opportunities, standardize reportable outcomes (who/where) and minimize administrative expenses.”*
 - *“Incentivize lending through pre-enrollment options with commitment to rural learning program. Develop rural/underserved learning programs possibly through peer mentoring. Develop affirmative action guidelines to assure that opportunities for those with limited financial resources to qualify for loans are not diminished.”*
 - *“Expand loan repayment to include all clinical careers, including but not limited to physicians, surgeons, psychologists, midlevel providers and allied health professions (i.e. physician assistant, clinical officer, pharmacist, nurse practitioner, pharmacy technician, certified nurse’s aide, occupational therapist, clinical social worker.”*³³

Collaboration Recommendations

By engaging with representatives from various settings within the safety net of the western suburbs, our study revealed the great potential of increased collaborations among research participants and external partners.

Healthcare Navigation

Issues Raised in Qualitative Research:

- Healthcare navigation and insurance enrollment services remain a significant need for many patients and some safety net institutions may not be able to fully fund all needed services in-house.

Collaboration Recommendation:

- Local FQHCs, safety net hospitals, CBOs, and funders: Pool funding and other resources to share patient navigation and enrollment services across safety net providers, using existing resources and staff as a starting point. Seek opportunities to share funding, overhead, and distribution of services.

Welcoming Healthcare for Immigrants and Other Marginalized Groups

Issues Raised in Qualitative Research:

- Immigrants have experienced increased threats (and corresponding trauma) from Federal changes to immigration enforcement and may not seek healthcare services as they have in the past. Other groups who have experienced marginalization and oppression also often experience increased threats, harms, and trauma. Healthcare settings need to ensure that their spaces are welcoming and as safe as possible for immigrants and other marginalized groups so that they can provide services to patients and support their health and wellbeing.

Collaboration Recommendation:

- Local FQHCs, safety net hospitals, CBOs, and immigrant rights organizations: Healthcare organizations can partner with immigrant rights organizations and other healthcare organizations to advance welcoming and affirming healthcare settings.*
- Healthcare organizations can begin internal learning about how they can protect immigrant rights (and the rights of others) by beginning to utilize.**

* Williams, D., Medlock, M. (2017). Health Effects of Dramatic Societal Events – Ramifications of the Recent Presidential Election. *The New England Journal of Medicine*. 376:2295-2299. DOI: 10.1056/NEJMms1702111. Retrieved from: <http://www.nejm.org/doi/full/10.1056/NEJMms1702111>

**Public Health Awakened. (2018, February 9). *Guide for Public Health Actions for Immigrant Rights*. Retrieved from: <https://publichealthawakened.com/guide-for-public-health-to-protect-immigrant-rights/>

Social Determinants of Health

Issues Raised in Qualitative Research:

- Many patients have social needs which health systems would like address through additional services and resources. However screenings and referrals that address social determinants of health-related needs are not carried out uniformly across the system, though some health systems have begun to do this.

Collaboration Recommendation:

- Local FQHCs, safety net hospitals, and CBOs: Provide opportunities for shared learning among health systems that have begun to carry out screenings and referrals for social determinants so ideas, techniques, and questionnaires can be shared to promote innovation. Assess learning from states and jurisdictions that have made progress on addressing the social determinants in the safety net setting.

Extended Transportation Service

Issues Raised in Qualitative Research:

- Several staff who participated in a focus group mentioned that nearby transit options have overlap during morning and afternoon hours but there are significant gaps and periods with little to no coverage.

Collaboration Recommendation:

- Local transportation service providers, local FQHCs, and hospitals: Staff suggested that coordination of schedules among transportation providers could lead to better coverage, make transportation more available for patients, and boost efficiency overall.

Collaborative Purchasing of Durable Medical Equipment

Issues Raised in Qualitative Research:

- Many people need modifications to their homes as they age or if someone with a disability and limited mobility lives in the home. During one focus group, a respondent who was involved with purchasing addressed the issue of medical equipment. The participants shared that this is a major need and that they spend a lot of money on a relatively small number of lifts for local residents. These lifts remain city property but are installed and removed as needed.

Collaboration Recommendation:

- Local municipalities' elected officials and managers: There may be an opportunity for several municipalities in the region to determine their collective needs for lifts and other durable medical equipment and agree to purchase items jointly to increase bargaining and negotiating power. This may save money and increase the amount of equipment available. Municipalities could also partner to support the development of a small business that refurbishes and fixes durable medical equipment, a strategy that has been deployed in other communities.

Connecting Providers, Policymakers, and Other Decision Makers

Issues Raised in Qualitative Research:

- Some research participants expressed concern that there was a relative lack of communication between safety net stakeholders and the elected officials whose decisions frequently impact the health of patients and the healthcare system. They also pointed to a disconnect between health workers and decision makers (like executives and administrators at managed care organizations) who impact safety net functioning and patient health.

Collaboration Recommendation:

- FQHC and hospital staff and leadership, elected officials, managed care executives, and funders: Direct, bidirectional communication should be established between safety net staff and leadership including elected officials and decision makers at managed care organizations.

Future Research Recommendations

This section highlights emergent issues from our qualitative data collection that require additional research in order to make concrete policy or philanthropy recommendations.

Emergent Issue: FQHC staff highlighted inefficiencies in the existing vaccine provision system being labeled in a way that sometimes causes patients to not receive needed vaccines based on the type of health insurance they have.

Future Research Questions: What would an efficient and accessible system of vaccine provision look like, one that would eliminate problems stemming from vaccines being provided and stored for specific categories of patients?

Emergent Issue: Participants reported that colleagues have left Illinois due to low reimbursement rates and the recent budget crisis. Further research is needed to better understand the scope and severity of this phenomenon.

Future Research Questions: What are the health workforce implications of people leaving the state? What have other states done to maintain their health workforce?

Emergent Issue: Respondents noted that we do not provide enough support for aging populations. With a population that is increasingly outliving the social support provided by family and friends and younger family members finding it difficult to take care of their parents, more support is needed.

Future Research Questions: What would a multi-decade plan of health care transformation that guarantees access to healthcare and social supports for people as they age look like? What does an “age friendly community” look like and what can we learn from others who have implemented these plans (particularly New York)?

Emergent Issue: Respondents said that communications to both safety net staff and patients about coverage of services and contracts with providers are not kept up-to-date. This causes reduced access and inefficiency and contributes to frustrations for patients and staff.

Future Research Questions: How are current modes of communication between MCOs and safety net staff and patients falling short? How can they be improved?

Emergent Issue: Study participants were concerned about regularly changing managed care contracts which negatively impacts continuity of patient care, medication coverage, and reimbursement.

Future Research Questions: What are rules and best practices around MCOs contract changes? How can we best monitor managed care contracts and patient outcomes?

Emergent Issue: Some respondents said that there were limited options in terms of pharmacies where they could send patients who needed discounted prescriptions.

Future Research Questions: Do all safety net hospitals and clinics have contracts with all of the close-by 24-hour pharmacies for the 340b program?

Emergent Issue: Safety net staff and providers expressed concerns about staff burnout and retention, in part related to economic inequities stemming from low pay and high loan repayment costs.

Future Research Questions: To what degree can loan repayment and wage increases lead to better staff and provider job satisfaction and retention? How would training in trauma-informed practice impact local safety net providers and systems?

Emergent Issue: Respondents shared that providers who were listed as contracted with specific MCOs often said they were unable to take Medicaid patients using a variety of unsubstantiated excuses to refuse patient referrals.

Future Research Questions: To what degree do providers who are contracted with Medicaid managed care deny services to patients or care managers seeking to connect patients to care?

Emergent Issue: A large population of people with disabilities, especially those who are aging and have disabilities, need help with the activities of daily living. People with disabilities are increasingly living longer and experiencing health challenges associated with aging. Exacerbating this, inflation has reduced the utility of the reimbursements to fund staff who can provide these types of services and supports.

Future Research Questions: What are best practices from around the country for provision of services related to the activities of daily living for people who are aging and those who are aging and have disabilities so that these community members do not need to become impoverished in order to receive safety net services?

Envisioning a Stronger Safety Net

We closed each of our interviews and focus groups with the following question: *“If you could describe a better safety net system for the western suburbs, what would it look like? What might need to change in order to accomplish that?”* The responses to this question varied slightly across system and staff position, but one theme remained clear: safety net staff and leadership want a comprehensive, one-stop-shop healthcare system where patients can receive all of their services under one roof. They want to care for patients without the stress and barriers of complex insurance system. One participant even said that we need to “get rid of managed care [because there are] lots of restrictions for patients when it comes to care.”

Safety net stakeholders want to care for patients in an environment where immigration, language, and income do not obstruct care. They envision a fluid, coordinated, and collaborative system that promotes “warm hand-offs” among providers. Many respondents noted that a universal coverage, single payer health insurance system would be an ideal safety net. One focus group respondent said it best: “Universal healthcare would be so beautiful for the U.S.”

Concluding Statement

Health & Medicine Policy Research Group is committed to unearthing inequities in health and healthcare and ensuring that the safety net is strengthened in order to fulfill the promise of healthcare as a human right. In this spirit, we recognized the value of a qualitative review of the impact of health reform at both the national and state level on safety net providers in Western Cook and Eastern DuPage Counties and provide policy, philanthropic, and research recommendations for the future.

It is estimated that through the Affordable Care Act, more than 690,000 Illinoisans (in 2016) gained insurance from Medicaid expansion while almost 315,000 people became insured via the Marketplace (in 2017).³⁴ This represents nearly half of the formerly uninsured population in the state, and is a significant win locally, for the state, and the country overall. Participants in the study recognized the value of this coverage increase, sharing that newly acquired coverage allowed people to receive necessary care that had been delayed for years, sometimes decades. However, this surge in newly insured patients increases patient demand and complexity for the safety net system. Now more than ever, safety net stakeholders must be vigilant about staying informed of state and national reforms in order to provide high-quality, comprehensive care for their patients. Our study revealed significant adaptation and innovation among safety net stakeholders, as well as some challenges in the wake of major national and statewide health reforms.

When asked to dream of an ideal safety net system, study participants revealed a desire to move beyond the fragmented and frustrating private health insurance system toward a national, universal, single-payer health system. This would help lessen or eliminate many of the problems they identified, including the gaps in coverage and financial burdens experienced by patients—and the many inefficiencies in healthcare delivery and associated burdens on providers and staff. Ensuring that everyone has equitable access to lifesaving healthcare is a goal shared across the safety net.

This research advances a call to action to advance health equity by people working in the safety net, philanthropic funders, and policymakers. Identification of both persistent and new problems that contribute to health inequities can be a springboard for change. Problems in the safety net, and in society more broadly, can seem overwhelmingly large and the perspective that something is “not politically feasible” or “unrealistic” are frequent responses to calls for both sweeping and incremental reforms. However, these negative perspectives can become self-fulfilling prophecies in which changes and reforms that could support health and save lives do not become politically feasible in part because the demands for them are not sufficiently strong, numerous, or persistent. However, all health workers across all areas of practice have a responsibility to explain both the problematic characteristics of the health safety net and demand reforms that could advance people’s health, and health equity more broadly.

Finally, we would like to acknowledge and express appreciation for the participation of members of the western suburban safety net, including staff and executive leadership at various federally qualified health centers, hospitals, free and charitable clinics, insurer, and community-based organizations throughout the area. Their time, candidness, and thoughtful responses were critical to the fulfillment of this research. We

High-quality, accessible, affordable, culturally-responsive healthcare is a matter of life and death. Inequitable living conditions—and inequitable healthcare access and quality—cause health inequities, which are systematic differences in health status and outcomes observed across different population groups that are unfair, unjust, and remediable. Inequities in society are shaped by the distribution of money, power, and resources. As noted in depth in Health & Medicine’s recent paper, *Beyond the Clinic: A National Health Equity Review*, health system stakeholders can work to challenge and eliminate these inequities more broadly to reduce differences in health status and outcomes.*

*Health & Medicine Policy Research Group. *Beyond the Clinic: A National Health Equity Review* (March 2018). Retrieved from: <http://www.hmprg.org/Programs/Strengthening+the+Safety+Net+in+Illinois+After+Health+Reform>

would also like to gratefully acknowledge funding for this research provided by the Community Memorial Foundation. Thank you all for your shared commitment to strengthening the healthcare safety net and improving the health and wellbeing of our communities and our region.

Endnotes

- 1 Health & Medicine Policy Research Group. Strengthening the Safety Net in Illinois After Health Reform: An Examination of the Cook County Safety Net. (June 2017). Retrieved from: <http://www.hmprg.org/Programs/Strengthening+the+Safety+Net+in+Illinois+After+Health+Reform>
- 2 Coughlin, T. A., Long, S. k., Peters, R., Rudowitz, R. & Garfield, R. Evolving picture of nine safety-net hospitals: Implications of the ACA and other strategies.(2015). Kaiser Family Foundation Issue Brief. 1-13. Retrieved from <http://files.kff.org/attachment/issue-brief-evolving-picture-of-nine-safety-net-hospitals-implications-of-the-aca-and-other-strategies>
- 3 Health & Medicine Policy Research Group. Strengthening the Safety Net in Illinois After Health Reform: An Examination of the Cook County Safety Net.
- 4 Bodenheimer, T., Sinsky, C. From Triple to Quadruple Aim: Care of the Patient Requires Care of the Provider. (2014). Annals of Family Medicine. Vol. 12 No. 6. 573-576. Retrieved from: <http://www.annfammed.org/content/12/6/573.full>
- 5 Ehlinger, E. We need a Triple Aim for Health Equity. (October 2015). Minnesota Medicine. Retrieved from: <http://www.astho.org/Health-Equity/2016-Challenge/Ehlinger-Commentary-Article/>
- 6 Illinois Department of Healthcare and Family Services. Illinois' Behavioral Health Transformation Section 1115 Demonstration Waiver. Retrieved from: https://www.illinois.gov/hfs/SiteCollectionDocuments/1115%20Waiver%20for%20CMS%20Submission_final.pdf
- 7 Illinois Department of Healthcare and Family Services. Illinois' Behavioral Health Transformation Section 1115 Demonstration Waiver.
- 8 The Henry J. Kaiser Family Foundation. State Health Facts. Medicaid & CHIP. Current Medicaid & Chip Enrollment. Total Monthly Medicaid and CHIP Enrollment. (November 2017). Retrieved from: <https://www.kff.org/health-reform/state-indicator/total-monthly-medicaid-and-chip-enrollment/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>
- 9 Illinois Department of Healthcare and Family Services. Medical Providers. Total Care Coordination Enrollment for All Programs (December 2017). <https://www.illinois.gov/hfs/MedicalProviders/cc/Pages/TotalCCEnrollmentforAllPrograms.aspx>
- 10 Kaiser Family Foundation. Interactive Maps: Estimates of Enrollment in ACA Marketplaces and Medicaid Expansion. Retrieved from: <https://www.kff.org/interactive/interactive-maps-estimates-of-enrollment-in-aca-marketplaces-and-medicaid-expansion/>
- 11 Health Resources and Services Administration. 2016 Health Center Data. Health Center Program Grantee Data. Retrieved from: <https://bphc.hrsa.gov/uds/datacenter.aspx?q=d&year=2016&state=IL#glist> ; <https://bphc.hrsa.gov/uds/excelhc/2016/national>
- 12 Bierman, A., Dunn, J. Swimming Upstream: Access, Health Outcomes, and the Social Determinants of Health. (January 2006). Journal of General Internal Medicine. 21 (1): 99-100. Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1484628/>
- 13 Southern Poverty Law Center. Hate groups increase for second consecutive year as Trump electrifies radical right. (February 15, 2017). Retrieved from: <https://www.splcenter.org/news/2017/02/15/hate-groups-increase-second-consecutive-year-trump-electrifies-radical-right>
- 14 U.S. Immigration and Customs Enforcement. Fiscal Year 2017 ICE Enforcement and Removal Operations Report. Retrieved from: <https://www.ice.gov/sites/default/files/documents/Report/2017/iceEndOfYearFY2017.pdf>
- 15 Community Memorial Foundation. Geographic Service Area (2018). <http://cmfdn.org/about-us/geographic-service-area/>
- 16 Health Resources & Services Administration. Health Center Data. Uniform Data System (UDS) Resources. Retrieved from: <https://bphc.hrsa.gov/datareporting/reporting/index.html>
- 17 U.S. Centers for Medicare & Medicaid Services. Hospital Compare. Retrieved from: <https://www.medicare.gov/hospitalcompare/search.html>
- 18 Heisler EJ. Federal Health Centers: An Overview. 2016. Congressional Research Service. <https://fas.org/sgp/crs/misc/R43937.pdf>
- 19 Pear, R. From Clinics to Child Insurance, Budget Deal Affects Health Care. (Feb. 8, 2018). The New York Times. <https://www.nytimes.com/2018/02/08/us/politics/budget-deal-health-care.html>
- 20 National Association of Community Health Centers (2016). http://nachc.org/wp-content/uploads/2015/10/NACHC_Workforce_Report_2016.pdf
- 21 Alternatively, states, in agreement with FQHCs, may also use an Alternative Payment Methodology (APM) that pays at least the PPS rate.
- 22 42 CFR 405.2462
- 23 Shin P, Sharac J, Barber Z, Rosenbaum, S. Community Health Centers and Medicaid Payment Reform: Emerging Lessons from Medicaid Expansion States. 2016. RCHN Community Health Foundation and the Commonwealth Fund. http://publichealth.gwu.edu/sites/default/files/downloads/GGR_CHN/Community-Health-Centers-and-Medicaid-Payment-Reform-45.pdf
- 24 Shin P, Sharac J, Rosenbaum S. Community Health Centers and Medicaid at 50: An Enduring Relationship Essential for Health System Transformation. Health Affairs, 2015, 34(7): 1096-1104.

25 Coughlin TA, Long SK, Peters R, Arguello R. Strategies in 4 Safety-Net Hospitals to Adapt to the ACA. 2014. Kaiser Family Foundation.

<https://kaiserfamilyfoundation.files.wordpress.com/2014/06/8600-strategies-in-4-safety-net-hospitals-to-adapt-to-the-aca.pdf>

26 Illinois Health and Hospital Association (IHA). Illinois Safety Net Hospitals. 2016. Illinois Health and Hospital Association (IHA). <https://www.ihatoday.org/g/uploadDocs/1/safetynetbackgroundunder2016.pdf>

27 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. <https://www.nap.edu/download/24624>

28 Kritz, Fran. New Report Finds Recent Immigration Actions and Proposals Affect the Health of Immigrant Families. Dec 14, 2017, California Health Report. Retrieved from: <http://www.calhealthreport.org/2017/12/14/new-report-finds-recent-immigration-actions-proposals-affect-health-immigrant-families/>

29 Jones, Camara P. Social Determinants of Equity and Social Determinants of Health. (Undated). Presentation on behalf of the Centers for Disease Control and Prevention. Retrieved from: <https://minorityhealth.hhs.gov/Assets/pdf/Checked/1/CamaraJones.pdf>

30 Health & Medicine Policy Research Group. Beyond the Clinic: A National Health Equity Review (March 2018). Retrieved from: <http://www.hmprg.org/Programs/Strengthening+the+Safety+Net+in+Illinois+After+Health+Reform>

31 Health & Medicine Policy Research Group. Beyond the Clinic: A National Health Equity Review.

32 Illinois Department of Public Health. Community Health Workers in Illinois -A Value-Driven Solution for Population Health. Retrieved from: <http://www.dph.illinois.gov/sites/default/files/publications/dochw-report-1-19-16.pdf>

33 Governor's Office of Health Innovation and Technology. APPENDIX A: INTEGRATED DELIVERY SYSTEM RECOMMENDATIONS. Retrieved from: https://www.dropbox.com/sh/jozqkv6asf6j7m3/AAD_eA99_g3qmUreSo_nuffa/FINAL%20Work%20Group%20Report?dl=0&preview=RecommendationsAppendix.pdf

34 Kaiser Family Foundation. Interactive Maps: Estimates of Enrollment in ACA Marketplaces and Medicaid Expansion. Retrieved from: <https://www.kff.org/interactive/interactive-maps-estimates-of-enrollment-in-aca-marketplaces-and-medicaid-expansion/>