Demographic Health Disparities and Health System Transformation: Drivers and Solutions

Introduction
Recent years have seen significant efforts to reform and transform the health care system in the United States. Numerous legislative and administrative reforms—the largest of which was the Affordable Care Act—have aimed to expand access to health care, reduce health care costs, improve health care quality and fundamentally alter the payment and care delivery structures used by payers and providers. Many of these efforts have been successful, but there is still significant room for future improvements.

Two such aspects of the American health care system that must be addressed further are the issues of health and health care disparities:

*Health Disparities:* Certain populations and demographic groups suffer from illnesses or morbidities at rates disproportionately larger than the general population. This disparity is present in numerous, highly significant conditions including obesity, diabetes, stroke, heart disease, asthma and cancer.

*Health Care Disparities:* Certain groups have disproportionately poor access to affordable care, including a lack of insurance or the means to afford insurance or care, as well as poor access to providers (e.g. no local hospital) or transportation. These populations also experience disparities in treatment, quality of care and outcomes.

These two forms of disparities are intrinsically linked and often align to create populations that have both poor health and less access to care that is affordable and of high quality. Because of these linkages, it is virtually impossible to address one type of disparity without touching upon the other.

This brief will provide a background on the types of health and health care disparities currently affecting our country, detail their drivers and summarize some of the current and potential health system transformation options for addressing disparities.

The Economic Consequences of Disparities
According to a 2009 study by the Joint Center for Political and Economic Studies, health disparities increase the costs of medical care for affected groups by as much as 31 percent. They estimate that these disparities cost our economy approximately $309 billion each year (2008 dollars) in avoidable medical costs and lost productivity due to illness.
Health care reforms that attempt to use a “rising tide lifts all boats” approach fail to recognize that some groups are figuratively anchored to the bottom. If actions are not taken to remedy the root causes of this anchoring, generalized reforms will be unlikely to benefit the populations that most need them.

Without addressing and mitigating the health disparities that have developed in our health care system, there is little chance of controlling health care costs in the long term. Alternatively, since reducing health care costs and improving population health are the primary goals of most health system transformation efforts, focusing on reducing disparities can have a disproportionately positive impact on achieving these goals and enhancing overall value in health care.

**Health and Health Care Disparities Across Demographics**

Disparities in health and care stem from a wide range of demographic, social and cultural factors. Many people also suffer the effects of more than one disparity simultaneously (e.g. low-income, Black and LGBT). Such experience, termed “intersectionality,” is complex and is not addressed by a focus on just one disparity, as illustrated below with life expectancy by race, gender and years of education.
Socioeconomic Disparities
The CDC defines SES as “a composite measure that typically incorporates economic, social, and work status. Economic status is measured by income. Social status is measured by education, and work status is measured by occupation. Each status is considered an indicator. These three indicators are related but do not overlap.” iii SES has a dramatic effect on average health and access to quality care. People with higher SES tend to be healthier while those with lower SES, suffer from fewer chronic health problems, have greater access to care, and have more opportunity to manage their own health decisions.

Underlying factors. People with lower SES are less likely to have access to healthy food compared to those with more resources. Healthy food tends to be more expensive. Furthermore, food deserts, which have little access to healthy, unprocessed food, often exist in low-income neighborhoods. Poor diets consisting of low-quality food heavy in fat, sugar and sodium can lead to obesity and the development of chronic health problems like diabetes or cardiovascular disease.

Additionally, people with low SES are exposed to environmental health problems at greater frequencies than those with more resources. iv They tend to live in neighborhoods that have higher rates of crime, less access to safe exercise venues and larger quantities of environmental toxins such as emissions from factories and urban concentration of car exhaust which contributes to asthma.

Socioeconomic disparities in health care. While low-income populations have the greatest need for health care, they tend to have sub-standard access to quality primary, preventative or specialty care. One study by the CDC v found that, on average, 19 percent of non-elderly adults
(18-64) had “no usual source of healthcare,” while this number jumps up to 32 percent for non-elderly adults in poverty.

Poverty makes it significantly harder to access health insurance and, by extension, affordable health care. Even if low-income people have access to insurance through Medicaid, their employer, or subsidized private plans, they may face difficulties in actually accessing care. For instance, lack of transportation or long work hours may interfere with access to a primary care physician or facility that accepts their insurance. Low-income urban and rural areas may have fewer primary care providers (designated as medically underserved areas/populations) and hospitals may be sold or consolidated, with facilities moving from low-income communities to nearby wealthier areas.

**Socioeconomic disparities in health status.** Because of the above population and health care system dynamics, low-income populations are significantly more likely to suffer from certain chronic conditions—including depression, obesity, diabetes and asthma—than individuals in higher economic brackets. Poor women suffer increased complications from childbirth, while poor children suffer from increased incidences of low-weight and premature births. These disparities are particularly destructive in the young, as chronic health problems can disrupt a child’s education and cripple their ability to overcome poverty in the future.

**Racial and Ethnic Disparities**

Racial and ethnic disparities in health and care are the result of a combination of social and economic factors. Our nation’s history of economically disenfranchising and segregating communities of color has resulted in a significant wealth gap (the average net worth of a white household is 13 times larger than the average wealth of a Black household and 10 times larger than the average wealth of a Hispanic household) and reduced the accessibility of education, healthy living environments and health care within minority communities. People of color are more likely to be relegated to low-skilled/low-pay labor pools and suffer from significantly higher risk of occupational health consequences or workplace accidents than white workers. Thus racial and ethnic minorities suffer disproportionately from the socioeconomic factors discussed above.

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1 We follow the Center for Health Equity Research and Promotion (CHERP) framework that “defines race as a sociocultural construct rather than a set of predictable biological or genetic characteristics…which is “based on a dearth of convincing scientific evidence for (1) a genetic basis for race, (2) a genetic explanation of observed racial disparities in the prevalence of complex disease, and (3) the efficacy of race-based genomics to reduce or eliminate such disparities.” For a discussion of current debates over the complex relationships between genes, race, and disease, see Fine et al. (9) and Roberts (10).
Discrimination and bias also impact the health of racial and ethnic minorities, regardless of SES. For example, a growing body of research shows that racial and ethnic discrimination is a multidimensional environmental stressor at the societal and individual levels. Higher lifetime discrimination and burden of discrimination among African Americans are associated with greater hypertension prevalence after adjustment for age, gender, and socioeconomic status. Links have been found between the perception of racism and cardiovascular health, and chronic stress (e.g. race-related vigilance) is associated with increased disease prevalence. \(\text{\textsuperscript{xv}}\)

**Racial and ethnic disparities in health care**

White Americans have significantly greater access to high-quality care than many minority groups. One study by the Agency for Healthcare Research and Quality (AHRQ)\(\text{\textsuperscript{xvi}}\) found that whites received higher quality health care in 60 percent of core measures compared to Hispanic Americans, 40 percent of core measures when compared with African Americans, and 20 percent of core measures when compared with Asian Americans. Additionally, this study found that whites had greater access to regular care than Hispanics, African Americans, or Asians, even when average incomes were taken into account.

Within the care environment, there are racial disparities in how confident and engaged patients are with their treatment plan. A study by Cunningham et al.\(\text{\textsuperscript{xvii}}\) found that approximately 45.3 percent of whites were highly activated (using Patient Activation Measure metrics), compared to 39.5 percent of African Americans and 24.8 percent of Hispanics. This has led to a disparity in the patient/doctor power dynamic, with whites considering their relationship with their doctor to be far more equal than that of Hispanics or Africans Americans.\(\text{\textsuperscript{xviii}}\)

**Racial and ethnic disparities in health status.** As a result of social, economic and health system challenges, significant racial disparities are found in overall health status, particularly in regard to chronic health conditions. In many cases these disparities are linked, making it difficult to address any one problem in a vacuum (e.g. higher incidences of obesity lead to higher incidences of diabetes).

White Americans are significantly more likely to self-report that they are in excellent or very good health than other groups\(\text{\textsuperscript{xix}}\) and are less likely to be obese\(\text{\textsuperscript{xx}}\) or diabetic\(\text{\textsuperscript{xxi}}\). African American men are more likely to be diagnosed with cancer than any other demographic, while Asian women are the least likely.\(\text{\textsuperscript{xxii}}\)

Here are two graphs from the 2012 CDC Cancer Surveillance Report\(\text{\textsuperscript{xxiii}}\) that illustrate the problem of disparities in disease prevalence.
Lesbian, Gay, Bisexual and Transgender Disparities in Health

Lesbian Gay Bisexual and Trans (LGBT) populations suffer from several severe health disparities that significantly harm their overall health. LGBT people experience discrimination, stigma, violence and rejection by their families and the community as a whole. xxiv

LGBT disparities in health care. LGBT access to health insurance has been affected by being barred from marriage and the benefits of family health insurance, as well as by unequal access to coverage through the workplace. LGBT people are denied care in some situations or experience
substandard care, and have been unable to visit their partners in health care facilities and engage with their partners’ caregivers in making medical decisions. However, the ACA and recent advances in marriage equality at the state and federal level have increased access to care and health insurance. xxv

In 2012, the Rainbow Health Initiative of Minnesota did a study xxvi on the state’s LGBT community and found that a significant portion of those surveyed were unwilling to reveal their sexual orientation even to their doctors out of fear that they would receive substandard care. Nearly a quarter of those who were open about their sexuality reported overt discrimination from providers that they attribute to anti-LGBT bias.

LGBT disparities in health status. Compared to heterosexuals, studies show that LGBT individuals are more likely to rate their health as poor, have more chronic conditions, and have higher prevalence and earlier onset of disabilities. Specific health issues disproportionately affect LGBT people as a whole, including mental illness, substance use and sexual and physical violence. xxvii Gay, bisexual and other men who have sex with men, while only 2 percent of the population, account for over half of those living with HIV/AIDS. Additionally, there has been a recent rise in infections among gay and bisexual men, with the highest rate among Black men. LGBT individuals also have higher rates of depression, anxiety and substance misuse, driven by stress, stigma and discrimination, xxviii while LGBT youth in particular are at significantly higher risk of suicide and homelessness. xxix

Gender Disparities in Health
Unlike socioeconomic, racial/ethnic and LGBT disparities, gender disparities operate in two directions, which is sometimes called the gender and health paradox. Men die younger and have more life-threatening chronic diseases, whereas women live longer but have more nonfatal acute and chronic conditions and disability. While men’s and women’s overall mental health is similar, specific conditions differ, with women having higher rates of depression and anxiety disorders than men, and men experiencing higher rates of substance abuse, antisocial behavior and suicide. xxx

Gender disparities in health care. More women report delaying or forgoing care (26 percent) due to cost than do men (20 percent). However, a higher share of women than men report that they have an existing connection to a health care provider or place, although among uninsured women, only half have a regular site of care compared to 60 percent of insured women. Women who are younger, Hispanic, low-income or uninsured are also more likely to lack connections to care. xxxi

As with racial and ethnic minorities, more women than men suffer discrimination and implicit bias in their relationships with health care providers. xxxii
The ACA includes benefits that specifically improve women’s health care, including free access to contraception and preventive services like mammograms, pap smears and well-women visits.

**Gender disparities in health status.** Women and men report fair or poor health at similar rates (15-17 percent respectively), but more women than men report a disability, handicap or chronic disease that limits activity or a health condition that requires care. Women on average tend to live longer and receive more health care than men.xxxiii

Heart disease, cancer and stroke, the three leading age-adjusted causes of death, are the same for men and women. However, more and younger men experience life-threatening coronary heart disease, cancer, cerebrovascular disease, emphysema, cirrhosis of the liver, kidney disease and atherosclerosis. In contrast, women face higher rates of chronic debilitating disorders such as autoimmune diseases and rheumatologic disorders as well as less life-threatening diseases such as anemia, thyroid conditions, gall bladder conditions, migraines, arthritis and eczema. Women also have more acute conditions such as upper respiratory infections, gastroenteritis and other short-term infectious diseases.xxxiv

While 15 percent of non-elderly adult women rate their health as fair or poor, this rate increases with age and is higher for Hispanic and Black women. More white women report ongoing health conditions that require monitoring, care or medication at higher rates than both Black and Hispanic women, although this could be due to differences in access to care and undiagnosed conditions requiring care. Lower-income women also report significantly worse health status than higher income women.xxxv

**Disparities in Health for People with Disabilities xxxvi**

**Disparities in the health care for people with disabilities.** AHRQ has documented access and quality problems that disproportionately affect people with disabilities. People with disabilities were significantly less likely than those without disabilities to receive surgery for early-state, non-small cell lung cancer which was linked to survival discrepancies between people with and without disabilities. Women with disabilities have much lower rates of screening mammography and Pap tests than women without disabilities.

Researchers suggest that disparities in treatment may be the result of patient preferences due to competing needs that result from their complex health conditions, as well as erroneous assumptions and stigmatizing attitudes among clinicians. In a Los Angeles County survey, 13-18 percent of those with disabilities reported being treated unfairly at their health care provider’s office because of their disability.xxxvii

**Disparities in health status for people with disabilities.** People with disabilities are much more likely than the nondisabled to report being in fair or poor health. One study found that only 3.4 percent of adults without disabilities reported fair or poor health, compared with 30.6 percent of those with difficulty seeing or hearing, 37.9 percent of those reporting movement difficulties, 51.8 percent of people with emotional difficulties and 63.8 percent of those with cognitive difficulties. For instance, a far larger percent of people with major difficulties walking report being frequently depressed or anxious than of those without disabilities.
Among adults with a disability, reports of fair or poor health were highest among Hispanics, American Indians and Alaska Natives, and lowest among Asians.

Finally, people with disabilities also have higher rates of risk factors that worsen overall health and lead to conditions such as heart disease and certain cancers. For instance, people ages 18-44 who have disabilities were more likely than those without disabilities to be obese, smoke cigarettes, and be physically inactive during leisure time.\textsuperscript{xxxviii}

**Current Reform Efforts**

Medical analysts and experts have identified health and care disparities as a significant problem for several decades. These experts have suggested a variety of potential reforms to reduce disparities, some of which are currently being implemented.

In 2008, the Kaiser Family Foundation suggested a four-part policy platform aimed at addressing race-based health care disparities:\textsuperscript{xxxix}

- Raising public and provider awareness of racial/ethnic disparities in care
- Expanding health insurance coverage
- Improving the capacity and number of providers in underserved communities
- Increasing the knowledge base on causes and interventions to reduce disparities.

The ACA includes major reforms which are aimed at increasing access to insurance, improving care opportunities in underserved communities and promoting systems to evaluate reform efforts. Medicaid expansion and state insurance exchanges expand access to insurance for millions, including large numbers of low income people and those in communities of color, making it one of the most effective polices in reducing disparities. Unfortunately, the full potential of this coverage expansion is yet to be realized, since non-citizens are excluded from both standard Medicaid and the exchanges and, to date, 21 states still refuse to expand Medicaid. The racial and ethnic dynamics of this resistance is clear. Nationally, over a quarter of the potential beneficiaries of Medicaid expansion are Black and of the states that were part of the Confederacy, only Kentucky and Arkansas have expanded Medicaid.\textsuperscript{xl}

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\hline
\textbf{State} & \textbf{Est. Uninsured} & \textbf{18-44 Ages} & \textbf{18-44 Ages} \\
& & & \\
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Alabama & 116,000 & 254,000 & 1,253,000 \\
Florida & 195,000 & 682,000 & \\
Georgia & 126,000 & \\
Hawaii & 289,000 & \\
Kansas & 291,000 & \\
Louisiana & 381,000 & \\
Maine & 200,000 & \\
Mississippi & 395,000 & \\
Missouri & 293,000 & \\
Nebraska & 226,000 & \\
North Carolina & 595,000 & \\
Oklahoma & 226,000 & \\
South Carolina & 292,000 & \\
South Dakota & 34,000 & \\
Tennessee & 352,000 & \\
Texas & 1,186,000 & \\
Utah & 180,000 & \\
Virginia & 253,000 & \\
Wisconsin & 107,000 & \\
Wyoming & 15,000 & \\
\hline
\end{tabular}
\caption{Number of residents who won't gain access to Medicaid and are likely to remain uninsured, in states that have not yet expanded Medicaid.}
\end{table}
In addition to expanded coverage, the ACA included these specific provisions to address health disparities:

- Data collection: requires collection by race, ethnicity and language preference for federally funded health care, public health programs, government surveys or other activities.
- Equal care: elevates federal efforts to support equal care, regardless of race through policy goals and increased powers of HHS agencies addressing health disparities.
- Research: expands research on health and health care disparities.
- Workforce: encourages racial and ethnic diversity through grant programs and funding professionals who agree to work in underserved areas.
- Cultural competency: supports programs for health care providers through model curricula for cultural competency and education.
- Preventive care: addresses disparities through program such as funding for prenatal and postnatal care, HIV/AIDS prevention and oral health.

**Health Equity in Health Care Transformation: Community Catalyst Recommendations**

Increasingly, the health policy discussion is focused on transforming the way health services are delivered and paid for. As policymakers, consumers and other stakeholders grapple with options for reform, reducing disparities based on race income and other factors must occupy a more central role in this discussion. A year before passage of the ACA, Community Catalyst prepared a joint policy proposal on addressing health disparities with the National Immigration Law Center, National Immigration Forum and Joint Center on Political and Economic Studies.

Building on these recommendations, Community Catalyst proposes a six-part set of policy reforms especially relevant to health care transformation:

1. **Expand Coverage and Access to Care to All U.S. Residents.** Use the ACA option to expand Medicaid in all 50 states. Using state or federal funding, make all lawfully residing non-citizen immigrants eligible for public welfare programs, including Medicaid and CHIP, without a five-year waiting period, and provide access and subsidies within insurance exchanges for undocumented immigrants. Increase funding for safety net and Medicaid providers while implementing financial rewards for those who provide high-quality care to vulnerable populations (e.g. the federal Delivery System Reform Incentive Payment waivers being implemented in several states).

2. **Improve Data Collection and Metrics on Disparities.** In order to effectively address health and care disparities, stakeholders must have reliable, evidence-based and consistent metrics for evaluating disparities and measuring progress towards greater equality. Data should be collected by gender, race, ethnicity, sexual orientation, gender identity, preferred languages and disability status. For instance, in an effort to gain a better understanding of disparities facing communities of color, immigrants and refugees, Oregon passed data equity legislation that established uniform and culturally competent
standards for collecting data on race, ethnicity, preferred languages and disability status in surveys and reports by state health agencies.

3. **Implement Socioeconomic Risk Adjustments in Payment Reform.** SES risk adjustments would recognize that providers that disproportionately serve low-income populations may have worse outcomes on unadjusted measures (such as preventable hospital admissions) due to socioeconomic factors beyond their control. Incorporating SES risk adjustment in payment and delivery reform programs would reward, or at the least not penalize, providers that provide care to vulnerable communities.

4. **Ensure that All Providers are Culturally Competent.** Training all clinicians and support staff to be more linguistically and culturally competent has potential to improve patients’ ability to fully access and participate in their care. It should be mandated that all providers meet The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (CLAS standards). Additionally, it is important that clinicians recognize and minimize both implicit and explicit biases that may lead to inequities in care and lack of effective communication between providers and patients. In addition to training current health care personnel and ensuring that education programs for future health care workers include appropriate training modules, policymakers can use incentives to increase the diversity of the workforce, including physicians.

5. **Reallocate Resources to Address Social Determinants of Health.** Addressing the socioeconomic disparities at their roots can improve community health as well as reduce costs within the medical system. These projected or actual savings can be captured to make investments to address these root causes, such as housing, transportation and public safety. For instance, Massachusetts now taxes comprehensive health plans and directs the revenue towards addressing outstanding population health problems. In New Jersey, community-based Accountable Care Organizations with consumer representation have been established through legislation, building on the work of Dr. Jeffrey Brenner, the Camden Coalition of Health Care Providers and community-based and faith organizations. A portion of savings will be allocated through a community process.

6. **Promote a More Diverse Workforce and Integrate Trusted Community-Based Providers Such as Community Health Workers (CHWs).** Utilize the tools available in the ACA to diversify the health care workforce at all levels and hold health systems and providers accountable for meeting specified goals. Support and fund the use of CHWs (also known as a promotor, peer supporter, community health advocate and community health liaison, among other titles), frontline public health workers who are either a trusted members of and/or have a deep understanding of the community served. This close relationship enables the CHW to serve as an effective link between health/social services and the community to facilitate access and improve cultural
competency in service. By providing support for patients, acting as educational advocates and navigators and working with care teams, these community facilitators can reduce disparities, improve outcomes and reduce costs.\textsuperscript{xlix}

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\textsuperscript{4} Morello-Frosch, R., & Lopez, R. (2006). The riskscape and the color line: Examining the role of segregation in environmental health disparities. Environmental Research, 102(2), 181-196. doi:10.1016/j.envres.2006.05.007


\textsuperscript{7} www.hRSA.gov/shortage/mua/


Community Catalyst is a national non-profit advocacy organization building consumer and community leadership to transform the American health care system.

www.communitycatalyst.org