



A Health Disparity Action Plan: Achieving Equity through Clinical Trials, Affordable Care, and Professional Development

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A Health Disparity Action Plan: Achieving Equity through Clinical Trials, Affordable Care, and Professional Development

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Abstract

Given the threatened nature of affordable care in the United States, it is crucial to underscore its importance. What is more, the reason such care is so important is the presence of an oft-unacknowledged disparity in access to quality care in this country and, indeed, around the world. A world without health disparities can be achieved and will be characterized by prompt and quality care available to all and at all stages of the care continuum. Further insurance reform is needed beyond the Affordable Care Act, while local care must be more accessible in rural, urban, and other underserved areas. Clinical trials must also undergo changes to ensure new drugs and treatments will be effective for all populations. Joint efforts between those conducting trials, medical practitioners, the FDA, and potential trial participant, are required for the development of treatment to be more personalized and more effective. A multi-pronged approach can eliminate inadvertent and systemic prejudices in the health field.

Keywords

Health Disparity; Clinical Trials; Affordable Care; Public Health

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ABSTRACT

Given the threatened nature of affordable care in the United States, it is crucial to underscore its importance. What is more, the reason such care is so important is the presence of an oft-unacknowledged disparity in access to quality care in this country and, indeed, around the world. A world without health disparities can be achieved and will be characterized by prompt and quality care available to all and at all stages of the care continuum. Further insurance reform is needed beyond the Affordable Care Act, while local care must be more accessible in rural, urban, and other underserved areas. Clinical trials must also undergo changes to ensure new drugs and treatments will be effective for all populations. Joint efforts between those conducting trials, medical practitioners, the FDA, and potential trial participant, are required for the development of treatment to be more personalized and more effective. A multi-pronged approach can eliminate inadvertent and systemic prejudices in the health field.

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INTRODUCTION

On March 21, 2010, with eyes trained on a big-screen television at one end of the Roosevelt Room in the White House, President Obama, Vice-President Biden, and a cadre of aides and supporters awaited the final decision on whether the Affordable Care Act (ACA) would be passed into law. It would, of course, be passed, and with the announcement President Obama stood to applaud, a hint of a smile across his face. Others were less reserved. Vice-President Biden beamed. A pair of aides embraced, while another pumped fists into the air. Across the conference table from

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the President, Franklin Delano Roosevelt appeared to look down from his portrait on Obama, the older man and the younger wearing the same closed-mouth smile though separated by decades and circumstances. Both knowing—FDR in 1933 and Obama on that day in 2010—that this was only the beginning, and that much work lay ahead.

In 2015 the United States government continued to make strides toward guaranteeing equitable and quality healthcare for all Americans with the announcement of the \$215 million Precision Medicine Initiative (PMI). The PMI will build on existing efforts to track and study the genes of patients and use genomic data to provide more effective care by creating a knowledge-sharing database consisting of, to start, one million patient volunteers from diverse backgrounds (Dzau, 2012 and The White House, 2015). In addition to providing DNA information, these volunteers will provide medical history, lifestyle information, and environmental information that will allow researchers to more quickly develop new treatments, while also assisting practitioners in more effectively treating patients (The White House, 2015).

While the ACA and the PMI represent significant steps toward providing the individualized, accessible care each patient needs, challenges remain. In order to achieve true equality in access and quality of care in the United States, a three-pronged approach to solving health disparity must be undertaken to address cost of healthcare, disparity in clinical trial make-up, and inadvertent prejudice on the part of practitioners. This approach consists of: making care affordable, utilizing heterogeneous clinical and drug trials, and building a diverse workforce and empowered communities.

Making Care Affordable

Prior to the ACA, health insurance laws catered to insurance companies. Those receiving insurance benefits through work were typically shielded from any adverse effects of this, but those who were self-employed or otherwise providing their own coverage lived with the possibility of either being refused insurance or facing steep prices in the event of failing health. In the wake of the ACA, companies face stricter rules surrounding who they must insure, which means coverage will be extended to, at minimum, those who seek an option that is relatively affordable.

For four decades leading up to the ACA, the healthcare gap between the rich and the poor became gradually wider. The ACA made significant strides toward a more equitable system for low-income individuals and families by fundamentally changing the way the health insurance business works, which includes efforts to improve quality of care and preventing inflated cost of care for those who otherwise can't afford it (Starr, 2011). Improvements following the ACA are clear. Indeed, in April 2015 a Gallup Poll found that the uninsured rate in the U.S. is currently the lowest it's been since the number was recorded beginning in 2008 (Levy, 2015). What is more, the rate has changed most sharply among lower income Americans and people of color— groups that are statistically the most at-risk to be without insurance (United States Census, 2015).

Ensuring that care is “affordable” though, provides no guarantee that all Americans will be able to pay for necessary treatment in a time of need, especially for those with pre-existing conditions, who are considered riskier to cover. Indeed, many Americans—particularly those who cannot afford available insurance options—pay exorbitant out of pocket costs, a number that totaled \$339.4 billion in 2013 (National Health Expenditures, 2015). While the ACA is the most ambitious effort in recent memory to make healthcare more equitable and widely available, it is also limited and less inclusive than models used elsewhere (Starr, 2011). Unlike countries such as

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Sweden or the United Kingdom, where a taxed citizenry takes on the burden of paying for healthcare, under the ACA individuals must pay for an often-significant portion of medical expenses. In other words, the health insurance and care industries in the United States are still treated like businesses. Those who can afford to pay for premium, timely care are most likely to receive it, and a clear disparity in quality of and access to care exists between wealthy and poor. These disparities are particularly disturbing when considering access to quality care for diseases such as cancer, where prompt and careful care is crucial for patient survival.

To achieve health equity in this country, medical care must be affordable. In order to make care truly affordable though, additional steps need to be taken to defray costs to low- and middle-income Americans. Many Americans put off visits to the doctor for fear of cost, which can ultimately cost individuals more in emergency room visits, and certainly results in poorer health and in some cases, greater loss of life.

Utilizing Heterogeneous Trials

Paired with affordable access is the way drugs and treatments are developed—through clinical trials and drug trials. Evidence gathered through trials is essential for determining which drugs and treatments are best suited for specific diseases. Practitioners and researchers use information gathered from these trials to steer real-world practices. Because white Americans are the largest ethnic group in this country, many trials are predominantly white. Results of such trials, therefore, tend to ignore important comorbidity and other information that impact the way a drug or treatment will affect patients who are people of color. As such, not only do many people of color in the United States face challenges regarding equal access to quality care, but there exists a gap between how collective knowledge is applied by practitioners.

Many trials inadequately account for differences along racial and ethnic lines. Numerous studies show that trials studying diseases that disproportionately affect one racial group are not appropriately represented in the makeup of the trial. For example, African Americans suffer from prostate cancer at a much higher rate than patients of other races, yet in a recent NIH trial, only 4% of participants were African American (Centers for Disease Control, 2016 and National Institute of Health 2013). Given that these types of disparities are common there is a significant gap in the effectiveness of treatment for non-white patients. Appropriate care, therefore, can only be administered if clinical and drug trials represent the population of those who suffer from a given disease.

Building a Diverse Workforce and Empowered Communities

Central to appropriate care is also patient-centered care. The United States government's commitment to precision medicine is a necessary first step to achieving care that is individualized and patient centered. However, ensuring a diverse and culturally educated workforce in healthcare, medicine, and the sciences is key to ensuring such care is available to all. A concerted effort must be made to not only personalize medical care when caring for the body, but attention must also be paid to cultural competency of healthcare workers in order to properly address health disparities (U.S. Department of Health and Human Services, 2016). We must continue to value an appreciation of culture and community, integrating it into science and medicine.

Recent research supports the notion that a more diverse healthcare workforce will have positive effects on closing gaps in health across racial and ethnic groups (Hill, Jones, and Woodworth, 2018 and Alsan, Garrick, and Graziani, 2019). This work suggests that pairing patients with providers that share demographic similarities such as gender, race, or religion result in better

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health outcomes. Such research, when put into practice, raises questions related to equity and belonging, and appears to recommend segregation of one kind or another. However, the fact remains that people of color especially often lack the opportunity to visit a healthcare provider that is of the same racial or ethnic group due to lack of diversity in the workforce, which is a shortcoming in the field that must be addressed.

Access to care and health research represent a two-fold problem with healthcare in this country. Without thoughtful care, patients are at risk of being passed through the medical system without adequate treatment. Typically, disparities in health and access to healthcare fall on racial and ethnic fault lines, which is a distinction that can be remedied with increased attention to the ways care is provided and clinical and drug trials are conducted. A key piece to ensuring that our science and medicine takes these factors into consideration is to make sure the workforce represents the population it is studying and caring for.

Also of significance is the need for communities and individuals to be empowered to effect change. Local empowerment can be achieved to an extent by ensuring that the healthcare workforce represents the communities they serve. However, a concerted effort to employ the principles of the local empowerment continuum—which helps define opportunities for action from the individual to the political or social level—is crucial to populations taking ownership and experiencing positive change in health especially (Laverack, 2004).



Figure 1: The local empowerment continuum
Source: Laverack, 2004. p. 48.

Individuals must feel that they have agency to seek out quality care and contribute to increased access to quality care. As noted elsewhere, however, community empowerment requires communication and coordination between affected individuals and those seeking to serve communities in need, such as organizations and government agencies (Moten and Schafer, 2012, and Labonté and Laverack, 2008). Given the complex nature of health-related issues in this country, any attempt to effect change without thoughtful collaboration among stakeholders and community members, will experience limited success.

Racial Inequality and the IOM Report

Inequality exists in this country in a myriad of forms and has resulted in a clear and unacceptable gap in access to quality healthcare—and health—for people of color. Possible causes of disparities in quality of care along racial and ethnic lines are numerous and include the fact that white people are insured at higher rates than other races, and that white Americans tend to visit physician offices more, and emergency rooms less, than non-white patients (U.S. Census 2015 and Levy, 2015). Health disparity is especially problematic in the area of preventable diseases. Specifically, minority groups are subject preventable hospitalizations at rates almost double that of white patients (U.S. Department of Health and Human Services, 2016). While many Americans

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struggle to afford quality health care, it is undeniable that the greatest burden of poor health and lack of care falls on people of color. Whatever the cause, this disparity represents an injustice that must be reversed.

Efforts to improve access to quality care are underway in pockets across the county. Washington state, for example, is restructuring care delivery for Medicaid beneficiaries. The state's Medicaid Transformation project will make care coordination and integration mandatory for Medicaid providers by 2021 (Washington State Health Care Authority, 2019). Individual providers are also independently seeking to improve care through their own initiatives which target decreasing emergency department revisits, increasing access to substance use disorder treatment, and more (Schafer, 2019). While individual efforts can make a difference on the local or state level, a coordinated nation-wide effort is required to address the country's need to improve access to care and close gaps in health across racial and ethnic groups.

In response to similar calls for action, in 1999 Congress requested an Institute of Medicine (IOM) study to identify sources of disparities in care and offer intervention strategies to eliminate health disparities (Smedley, Stith, and Nelson, 2003). The resulting study, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, suggests that stereotyping and other forms of inadvertent prejudice on the part of healthcare providers and practitioners may be among the factors that lead to people of color receiving unequal care in this country (Smedley, Stith, and Nelson, 2003). The study reflects a trend on the part of Congress and the United States government to identify racial inequality related to health. In 1999 the IOM released two additional reports confirming that people of color bear a disproportionate burden in terms of instances of cancer and exposure to toxic waste and other harmful agents (Haynes, 1999 and Committee on Environmental Justice, 1999). Indeed, there is ample evidence to support the assertion that people of color bear the brunt of poor health in this country, largely as a result of circumstances that can be altered to undo these inequalities.

The IOM report on unequal treatment in healthcare identifies primary avenues in which providers may, often inadvertently, provide substandard care to people of color. First is clinical uncertainty, which results in assumptions made by physicians about a patient's condition (Smedley, Stith, and Nelson, 2003). Physicians' assumptions about patients couple with observations made in the clinical setting to determine the course of treatment. Clinical uncertainty occurs when a doctor's observations do not clearly provide information needed to establish a course of treatment, causing assumptions about the patient to play a greater role in diagnosis and treatment decisions. These assumptions can be associated with presumed severity of a patient's condition or environmental factors that could impact a patient's condition and are prone to reflecting prejudice on the part of the practitioner.

The implicit nature of stereotypes and outright prejudice are identified as sources of inequality based on race (Smedley, Stith, and Nelson, 2003). While explicit stereotyping may certainly play a role in inequality of care in this country, most healthcare professionals surely see themselves as not being racist and making every effort to provide the best care to every patient, regardless of race. Even the most well-intentioned practitioner, though, can be prone to inadvertent prejudice, which is manifest through expectations and inferences made about the patient by doctors as well as generalized beliefs about individuals of a given race that may explicitly or implicitly play out in clinical settings.

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By addressing unequal treatment with spending, training, and awareness, it is possible to minimize health disparities by targeting shortcomings in the existing health system that we can readily identify. We must, however, first be willing to acknowledge that such inequality exists, and be willing to address it with professional development programs that target race-based assumptions that may inadvertently put patients at risk.

Government Responsibility

State and national governments play a substantial role in determining whether or not access to and quality of healthcare is equal—especially along racial lines. States whose healthcare spending has been decreased due to budget cuts experience far greater inequality than those whose government spending on healthcare is more equally distributed across income levels (Zhu and Clark, 2015). They also find that states with more heterogeneous populations experiences greater disparity in access to and quality of healthcare (Zhu and Clark, 2015).

Given the heterogeneous population of the United States, great care must be taken to prevent health disparity along economic, social, and racial lines. Failure in this country to take such steps have resulted in numerous health and care trends that must be reversed. People of color in the United States, for instance, are hospitalized as a result of preventable conditions at rates that are as much as double that of white Americans (U.S. Department of Health and Human Services, 2016) Much of the burden to reverse health disparity in this country, therefore, falls not only on individual practitioners, researchers, or insurance providers, but government body as a whole. Leadership in and funding from various entities in the United States government will be essential to ensuring that health disparities are reversed. Organizations such as the National Institutes of Health, for example, will be instrumental in establishing protocols and offering training to health professionals that will encourage thoughtful medical practice and appropriately diverse clinical and drug trials.

A World without Disparities

Health disparity is surely a global issue (Moten and Schafer, 2012). As global health advocates work to bring access to care to those underserved worldwide, providing the same in the United States is also crucial. Identifying the triad of need in health disparity—affordability, appropriate clinical trial participant make-up, and unintentional and systemic prejudice—is the first step toward achieving health equality for all Americans.

What makes the issue of health disparity most urgent is the fact that there is a clear correlation between low income and a lack of access to quality healthcare, especially among children (DeNavas-Walt, Semega, and Stringfellow, 2011). Children and people of color in the United States are shockingly underinsured and underserved, resulting in the fact that preventable hospitalizations, diseases, and deaths are significantly higher among people of color and the poor in this country (U.S. Department of Health and Human Services, 2016).

A world without health disparities will be marked by all people having access to prompt and quality care ranging from routine check-ups to treatment from specialists. In order to achieve this, further insurance reform needs to occur beyond the Affordable Care Act, and local care needs to be made more accessible for those in rural, urban, and other areas that underserved. More careful selection must also occur in clinical and drug trials in order for new drugs and treatments to be effective for all populations. Joint efforts between those conducting trials, medical practitioners, the FDA, and potential trial participants, are required for the development of treatment to be more personalized and more effective. With awareness campaigns and efforts aimed toward creating a

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more diverse health profession, inadvertent and systemic prejudices can also be eliminated. Last, with increased funding dedicated to ensuring equal access, disparities can be targeted and addressed.

Health disparities in this country can be eliminated. We have taken the initial steps toward accomplishing this goal, but a concerted effort to continue bringing equitable care, and therefore health, to all Americans must be made to ensure gains to this point will not be lost.

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