#### HOW CAN WE FIX THE RACIAL GAP IN INFANT DEATHS?

#### LEGAL APPROACHES AND COMMUNITY BASED SOLUTIONS

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#### **INTRODUCTION**

This paper takes up the issue of the large racial gap in infant mortality in the United States. After citing data that demonstrates such a gap exists, the paper proceeds to explore factors contributing to and the many causes of the problem. Although the causes of the racial disparity in infant mortality may be difficult to determine with certainty due to their interrelatedness, and there may be controversy as to which causes are credible and which are not, we must determine the causes of the problem in order to identify possible remedies.<sup>1</sup>

The scope of this paper is limited. There are disparities in infant mortality in

America across several racial and ethnic lines.<sup>2</sup> But this paper will focus on the gap in

socioeconomic as well as racial gap.<sup>3</sup> Likewise, while there are multiple health measures,

such as cardiovascular health, likelihood of receiving certain medical procedures,

diabetes, and life expectancy, which reveal the gaping disparities in health care provision

<sup>&</sup>lt;sup>1</sup> Some would argue that poor health outcomes are primarily attributable to personal life style choices. Others would argue in response that personal life style choices are in fact influenced and even determined by multiple external factors. *See* ROBERT L. SCHWARTZ, *Life Style, Health Status, and Distributive Justice in* JUSTICE AND HEALTH CARE: COMPARATIVE PERSPECTIVES 225 (Andrew Grubb & Maxwell J. Mehlman eds., 1996).

<sup>&</sup>lt;sup>2</sup> According to the Centers for Disease Control and Prevention, "[N]on-Hispanic black women had the highest infant mortality rate in the United States in 2004 – 13.60 per 1,000 live births compared to 5.66 per 1,000 births among non-Hispanic white women." Other infant mortality rates broken down by race include Cuban (4.55), American Indian (8.45), Puerto Rican (7.82), Mexican (5.47), Asian/Pacific Islander (4.67), and Central/South American (4.65). *See* Press Release, Ctrs. for Disease Control, Overall Infant Mortality Rate in U.S. Largely Unchanged – Rates Among Black Women More Than Twice That of White Women (May 2, 2007), http://www.cdc.gov/nchs/pressroom/07newsreleases/infantmortality.htm.

<sup>&</sup>lt;sup>3</sup> For an extensive explanation of the use of the term "African American," see VERNELLIA L. RANDALL, Racist Health Care: Reforming an Unjust Health Care System to Meet the Needs of African-Americans in JUSTICE AND HEALTH CARE: COMPARATIVE PERSPECTIVES 148 n.5 (1996).

and utilization between European Americans and African Americans in the United States, this paper focuses on infant mortality as an indicator of general population health.<sup>4</sup>

Secondly, what can the law can do, if anything, to mend the gap in infant mortality rates between European Americans and African Americans? Given that the disparity persists despite the present legislative scheme, it is possible that current law and reform efforts actually perpetuate the racial gap in infant deaths or at the least do not address the problem effectively. Lacking a direct legislative fix, what remedies exist to fix the gap? Just as there are likely many causes of the racial gap in infant mortality, there may be many solutions that need to be creative to be effective. While the law can increase access and improve the affordability and quality of health care, it is far from certain that those measures can or will improve health status, let alone close the racial

gap. It is more likely that educational efforts and comprehensive community initiatives will have a positive effect on infant vitality in populations that currently experience a much higher rate of infant mortality than the population as a whole. The law should provide a framework to encourage multifarious, community-based, and diffuse problemsolving.

Lastly, this paper discusses specific community-based approaches that have experienced success in reducing the infant mortality rate and that could and should be applied more broadly.

<sup>&</sup>lt;sup>4</sup> For an overview of racial and ethnic disparities in healthcare across a range of illnesses and services, including cardiovascular care, testing for cancer, and treatment of HIV, *see* UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE 5 (Brian D. Smedley et al. eds., 2003).

#### **II. DEFINING THE PROBLEM AND ITS CAUSES**

#### A. THE UNITED STATES HAS A HIGH INFANT MORTALITY RATE

Infant mortality as a measure of the number of infants who live or die is an important health statistic on its face. But the statistic is also a measure of general population health with ramifications for a particular population decades into the future. According to the Centers for Disease Control's Office of Minority Health & Health Disparities, infant mortality, or the number of infant deaths per 1,000 live births, is a statistic used to evaluate "the health and well-being of populations and within countries."<sup>5</sup> More specifically, infant mortality is "a long-standing general indicator of overall social and economic development, availability, and use of health services, health status of women of childbearing age, and quality of social and physical environment."<sup>6</sup>

Using the infant mortality rate as a metric for the overall health of a population, Manericans, and particularly African Americans, are not faring well compared to the rest in the set of the world.

According to the Centers for Disease Control's National Center for Health Statistics, the United States ranked 30th in infant mortality in the world in 2005, behind most European countries, the Czech Republic, Portugal, Israel, Hungary, Poland, and Cuba, and just ahead of Slovakia.<sup>7</sup> The United States is a wealthy country that spends a tremendous amount on health care, but that wealth and distribution of funds have not

<sup>&</sup>lt;sup>5</sup> Infant Mortality Fact Sheet, Ctrs. for Disease Control and Prevention, http://www.cdc.gov/omhd/amh/factsheets/infant.htm.

<sup>&</sup>lt;sup>6</sup> Timothy LaVeist, Segregation, Poverty, and Empowerment: Health Consequences for African Americans, THE MILBANK QUARTERLY, Vol. 71, No. 1, 41-64 at 49 (1993).

<sup>&</sup>lt;sup>7</sup> Marian F. Macdorman & T.J. Mathews, *Behind International Rankings of Infant Mortality: How the United States Compares with Europe*. NAT'L CTR. FOR HEALTH STATISTICS DATA BRIEF NO. 23. At 1 (Nov. 2009) http://www.cdc.gov/nchs/data/databriefs/db23.pdf.

translated to good health or to a low infant mortality rate in particular.<sup>8</sup> House et al. write, "[D]espite marked growth in medical care spending, the United States's standing on major indicators of population health such as . . . infant mortality . . . has declined relative to other wealthy nations, as well as relative to some much less affluent ones."<sup>9</sup> **Figure 1** shows that the United States has risen in rank over the past fifty years in percentage of GDP spent on health but fallen from being among the top nations in life expectancy and infant mortality to one of the least successful by those markers among the thirty nations of the OECD.<sup>10</sup> The United States' international standing with respect to infant mortality has declined since 1960, when the U.S. ranked 12th in the world.<sup>11</sup> While the infant mortality rate within the United States has improved, the gains in the United States have not kept pace with those in the rest of the world, as the international

ranking of the United States with respect to infant mortality fell throughout the latter half of the twentieth century, ranking 23rd in 1990 and 29th in 2004.<sup>12</sup>

Researchers attribute the relatively high infant mortality rate in the United States to a high percentage of preterm births as compared to the European percentage of preterm births.<sup>13</sup> In 2004, 1 in 8 infants born in the United States was born preterm, compared with 1 in 18 in Ireland and Finland.<sup>14</sup> Preterm infants have higher rates of death or

<sup>8</sup> Although the United States spends more, by percentage of GDP, than any other nation among thirty OECD Developed Nations, the United States ranks 23rd for life expectancy at birth and 27th for infant mortality. *See* JAMES S. HOUSE ET AL., *The Health Effects of Social and Economic Policy: The Promise and Challenge for Research and Policy in* MAKING AMERICANS HEALTHIER: SOCIAL AND ECONOMIC POLICY AS HEALTH POLICY 3-27 at 4 (James S. House et al. eds., 2008).

<sup>9</sup> Id.

<sup>&</sup>lt;sup>10</sup> Id. <sup>11</sup> Id.

<sup>&</sup>lt;sup>12</sup> Macdorman, *supra* note 7, at 2.

<sup>&</sup>lt;sup>13</sup> *Id.* at 5.

 $<sup>^{14}</sup>$  *Id*.

disability ending in death than infants carried to term.<sup>15</sup> The relatively high rate of infant mortality in the United States is reflective of the high number of infants born prematurely, and the increasing percentage of low-birth-weight births in this country mirrors the decreasing ranking of the United States with respect to infant mortality. The percentage of low-birth-weight births in the United States has risen steadily since 1985, while the percentage of low-birth-weight births in Canada, Sweden, and the United Kingdom has remained relatively steady or decreased during the time span 1980-2005.<sup>16</sup> **Figure 2** depicts these trends.

Infant health and infant mortality are representative of population health in part because early health or lack thereof indicates health status for life.<sup>17</sup> Research shows that a preterm infant is not only more likely to die before its first birthday but is also more

Vasandards.<sup>18</sup> Ngton and Lee University

#### **B. INFANT MORTALITY IS A RACE ISSUE**

The infant mortality problem in the United States is a racial problem. In 2005,

infant mortality among African Americans occurred at a rate of 13.63 deaths per 1,000

<sup>&</sup>lt;sup>15</sup> *Id. See also* Marian F. Macdorman & T.J. Mathews, *Recent Trends in Infant Mortality in the United States.* NAT<sup>2</sup>L CTR. FOR HEALTH STATISTICS DATA BRIEF NO. 9 (Oct. 2008) http://www.cdc.gov/nchs/data/databriefs/db09.pdf.

<sup>&</sup>lt;sup>16</sup> Data taken from **Figure 2**, prepared by the Robert E. Lee Scholars for the Washington and Lee University Shepherd Program. March 13, 2010.

<sup>&</sup>lt;sup>17</sup> See A COMMON DESTINY: BLACK AND AMERICAN SOCIETY 393 (Gerald D. Jaynes & Robin M. Williams eds., 1989). (detailing the effect of poor early care and health on individuals. "For example, lack of prenatal care leads to greater likelihood of infant death, neurological damage, or developmental impairment; childhood illnesses and unhealthy conditions can reduce learning potential; adolescent childbearing, substance abuse and injuries cause enormous personal, social and health effects; impaired health or chronic disability in adults contributes to low earning capacity and unemployment; chronic poor health among older adults can lead to premature retirement and loss of ability for self-care and independent living." *Id.*)

 $<sup>^{18}</sup>$  Id.

live births, almost twice the national average of 6.86 deaths per 1,000 live births.<sup>19</sup> Viewed through the lens of the infant mortality rate, African Americans and European Americans live parallel but unequal lives in the United States. European Americans experience an infant mortality rate comparable to that of other industrialized, first world countries, while African Americans sustain infant mortality rates in keeping with poorer, less modernized nations. For example, in 1986, the United States infant mortality rate ranked 17th in the world at 12.1 deaths per 1,000 live births, but when the rate was broken down by race, European Americans ranked twelfth in the world, between Singapore and Canada, at 11.0 deaths per 1,000 live births, and African Americans ranked 26th, after Cuba, with 20 deaths per 1,000 live births.<sup>20</sup> See Figure 3.

Infant mortality is not the only category in which African Americans are

subjectively suffering: African Americans have higher rates of unemployment, illiteracy, unwed and teen births, low birth-weight, and homicide as compared to their European American neighbors.<sup>21</sup> As aforementioned, high rates of preterm births and high infant mortality are linked.<sup>22</sup> Yet African American infant mortality rates are twice as high as those for European American infants, even among normal weight infants.<sup>23</sup>

The racial gap in infant mortality between African Americans and European Americans is, moreover, nothing new. The African American infant mortality rate has been reported to be double the European American rate since the United States began to

<sup>&</sup>lt;sup>19</sup> MacDorman, *supra* note 15.

<sup>&</sup>lt;sup>20</sup> LaVeist, *supra* note 6, at 45.

 $<sup>^{21}</sup>$  *Id.* at 41.

<sup>&</sup>lt;sup>22</sup> See supra text accompanying note 7.

<sup>&</sup>lt;sup>23</sup> Hearst et al., *The Effect of Racial Residential Segregation on Black Infant Mortality*. AM. J. OF EPIDEMIOLOGY 168(11): 1247-1254 at 1247 (2008).

collect race-specific data.<sup>24</sup> Given the disparity and its persistence, we must identify the causes and enact solutions. The racial disparity in infant mortality is at least partly attributable to economic and educational inequality but these inequalities do no not explain the entire disparity. There must be other causes.

## C. THE CAUSES OF INFANT MORTALITY, ALTHOUGH INTERCONNECTED, ARE IDENTIFIABLE

#### **1. INCOME POVERTY**

The causes of infant mortality in the United States are various and interconnected. There are not two or three or four causes of infant mortality, but a tangled knot of contributing factors and interrelated causes. Income poverty is a well-established factor contributing to infant mortality, and the link between income poverty and infant mortality is, many say, undeniable given the quantity of research available.<sup>25</sup>

SThe connection between income poverty and infant mortality does not, however,

explain the large disparity in infant mortality between African Americans and European Americans, although, as Thomas LaVeist writes, "[s]ome scholars have had difficulty distinguishing the line of demarcation between being black and being impoverished."<sup>26</sup> Regardless, "status as an African American is not quite the equivalent of being a low-income white American."<sup>27</sup> Even though poverty is a social risk factor for infant mortality and poverty is more prevalent among African Americans than European

<sup>&</sup>lt;sup>24</sup> LaVeist, *supra* note 6, at 42. The federal government first promulgated standard race categories in 1977 although censuses collected race-specific data prior to 1977. *See* THE AM. SOCIOLOGICAL ASS'N, THE IMPORTANCE OF COLLECTING DATA AND DOING SOCIAL SCIENTIFIC RESEARCH ON RACE 5 (2003) http://www2.asanet.org/media/asa\_race\_statement.pdf.

<sup>&</sup>lt;sup>25</sup> *Id.* at 46. LaVeist writes, "Poverty is the best documented social risk factor for infant mortality . . . The sheer volume of research supporting a link between poverty or low socioeconomic status and infant mortality is impressive."

 $<sup>^{26}</sup>$  *Id.* at 47.

<sup>&</sup>lt;sup>27</sup> *Id.* LaVeist also writes in explanation, "African Americans have cultural values and behaviors; because of racism, they are exposed to potential health risks that sustain race as a determinant of health status, irrespective of social class."

Americans, being African American and being poor are not one and the same.<sup>28</sup> Some would attribute the racial difference in the infant mortality rate to income and educational disparities.<sup>29</sup> But college-educated African Americans experience an infant mortality rate twice that of college-educated European Americans.<sup>30</sup> There must be other contributing factors.

We know that the racial disparity in infant deaths is not solely attributable to income poverty, because researchers have found that European American income poverty is far more strongly associated with infant mortality than African American poverty is with African American infant mortality.<sup>31</sup> While the connection between income poverty and infant mortality persists in the African American black population as it does in the European American population, African American income poverty is less causally related

to infant mortality than European American income poverty is to European American infant mortality. For African Americans, the problem is not just about a lack of financial resources. Lack of education, a lack of access to health care, negative cultural influences, distrust of or alienation from the medical community or outright discrimination may contribute to the African American infant mortality rate in addition to income poverty. **2. SEGREGATION** 

Segregation has also been identified as a contributing factor to infant mortality. The link between racial segregation and health status was first established in 1950 by Yankauer, who observed that infant mortality rates for both African Americans and European Americans were highest in the most segregated African American

<sup>&</sup>lt;sup>28</sup> Id.

<sup>&</sup>lt;sup>29</sup> G.K. Singh & S.M. Yu, Infant Mortality in the United States: Trends, Differentials, and Projections, 1950 through 2010. AM. J. PUB. HEALTH 85(7): 957-964 (July 1995).

<sup>&</sup>lt;sup>30</sup> Id. See also K.C. Schoendorf et al., Mortality Among Infants of Black as Compared with White College-Educated Parents. N. ENGL. J. MED. 326(23): 1522-1526 (1992).

<sup>&</sup>lt;sup>31</sup> LaVeist, *supra* note 6, at 53, *citing* Collins, *supra* note 32.

neighborhoods.<sup>32</sup> Put another way, European Americans living in segregated African American neighborhoods experienced higher infant mortality rates alongside their African American neighbors. This does not mean that segregation itself is the cause of high infant mortality rates, but it does suggest that segregation and high infant mortality are related.

Exactly how segregation informs infant mortality is undetermined. Some have hypothesized that segregation prevents important public health messages from reaching specific communities because of their isolation from the rest of society.<sup>33</sup> It could be that certain behaviors, such as smoking while pregnant, are preserved and reinforced in communities isolated from the mainstream, where such behavior is denigrated. Some have proposed that segregation perpetuates health disparities between African Americans

and European Americans just as it perpetuates social, political and economic disparities.<sup>34</sup> It is not surprising that a neighborhood with lower employment, less education, and a

lower tax base would also experience a higher rate of infant mortality.<sup>35</sup>

Additionally, it is possible that health care is simply scarcer in segregated communities. Research has shown that segregated African American neighborhoods are "less likely to have health care facilities such as hospital and clinics, and have the highest

<sup>&</sup>lt;sup>32</sup> LaVeist, *supra* note 6, at 45-46. *Citing* A. Yankauer, *The Relationship of Fetal and Infant Mortality to* Residential Segregation. AM. SOC. REV. 15:644-8 (1950). LaVeist also documents related research: "The body of research on this topic suggests the prevalence of a variety or problematic social conditions in highly segregated black communities. Previous research has established that segregated black urban communities are highly toxic environments which are not as well served by city services, lack adequate medical service, and have higher housing costs, thus leading to an inflated cost of living." For more recent research documenting the connection between segregation and infant mortality, see D.R. Williams & C. Collins, Racial Residential Segregation: A Fundamental Cause of Racial Disparities in Health. PUB. HEALTH REP. v.116(5), 404-416. (2001).

<sup>&</sup>lt;sup>33</sup> J.W. Collins, Jr. & N. Schulte. Infant Health: Race, Risk, and Residence in NEIGHBORHOODS AND HEALTH (I. Kawachi & L. Berkman eds., 2003).

<sup>&</sup>lt;sup>34</sup> *Id.* <sup>35</sup> *Id.* 

ratio of patients to physicians."<sup>36</sup> Generally, segregated communities do not fare as well as European American or majority communities. LaVeist reports from his own work that "[S]egregation can be viewed primarily as an easily quantifiable summary measure of differences in material living conditions of black and white Americans."<sup>37</sup>

The racial disparity in infant deaths is indicative of more than just income poverty and segregation, though, because rates of infant mortality were found to be unaffected by a city's level of segregation whereas black infant mortality rates were higher in highly segregated cities.<sup>38</sup> In other words, the health status of an African American population suffers in a highly segregated society whereas the health status of European Americans living outside of the isolated or segregated African American community but within the larger society is unaffected. This is further evidence that "separate" is rarely "equal."<sup>39</sup>

One may infer that the isolation of the underprivileged class from the majority is conducive to a high infant mortality rate. That may be because health services and prenatal care are not as readily available in African American neighborhoods, or because negative behaviors are reinforced where lack of resources and minimal education are the status quo. It is possible that neighborhoods of concentrated poverty are more difficult to infiltrate with public health messages than scattered pockets of individuals living at or below the poverty line. At any rate, segregation is not the sole cause of the racial disparity in infant mortality.

The connection between infant mortality and segregation is complicated by more recent findings that segregation has no independent causal effect on excess deaths of

 <sup>&</sup>lt;sup>36</sup> American Sociological Association, *supra* note 24, at 10.
<sup>37</sup> Collins, *supra* note 32.

<sup>&</sup>lt;sup>38</sup> Id.

<sup>&</sup>lt;sup>39</sup> See Plessy v. Ferguson, 163 U.S. 537 (1896) (Justice Harlan, dissenting).

African American infants.<sup>40</sup> Hearst, et al. write, "We do not claim that segregation has no effect on the black infant mortality rate but rather that it is difficult, if not impossible, to disentangle the individual effects from contextual effects."<sup>41</sup> While it is clear that there is some connection between segregation and infant mortality, any causal relationship is unclear and there is certainly not a direct causal relationship.

#### 3. CULTURAL DIFFERENCE, INCLUDING DISCRIMINATION BASED THEREON

Evidence suggests that discrimination or differences in attitudes regarding health care, on the part of both patients and providers, are partly to blame for the racial gap in infant mortality. The Institute of Medicine reported in <u>Unequal Treatment</u> that most studies of racial and ethnic disparities in healthcare find "[Disparities] remain even after adjustment for socioeconomic differences and other healthcare access-related factors.<sup>42</sup>

The National Academy of Social Insurance likewise found in a 2006 report that "[Even] when controlling for factors such as level of income, substandard housing, poor nutrition, **U** etc., racial and ethnic disparities remain . . . <sup>"43</sup> There must be some systemic factor outside of these differences affecting the provision of and access to care for African Americans in the United States.

Professor Timothy Jost identifies provider and patient "attitudes and behaviors" as causal factors that contribute to racial and ethnic disparities in the use of health care services.<sup>44</sup> It is likely that in addition to socioeconomic barriers and the physical

<sup>&</sup>lt;sup>40</sup> Hearst, *supra* note 23.

<sup>&</sup>lt;sup>41</sup> *Id.* at 1252.

 $<sup>^{42}</sup>$  Smedley, *supra* note 4, at 5.

<sup>&</sup>lt;sup>43</sup> National Academy of Social Insurance, *Strengthening Medicare's Role in Reducing Racial and Ethnic Health Disparities*. 8, 15 (Vladeck et al., eds. 2006).

<sup>&</sup>lt;sup>44</sup> Timothy S. Jost, *Racial and Ethnic Disparities in Medicare: What the Department of Health and Human Services and the Center for Medicare and Medicaid Services Can, and Should, Do.* NAT'L. ACAD. OF SOC. INS. At 15. March 2005. Available at: http://www.nasi.org/research/2005/racial-ethnic-disparitiesmedicare-what-department-health. Professor Jost also identifies financial barriers and logistical,

obstacles of segregation, discriminatory attitudes and behaviors on the part of health care providers, whether intentional or not, and culturally informed minority attitudes and behaviors contribute to the racial disparity in infant mortality in the United States.<sup>45</sup> Jost emphasizes in particular patient distrust and a lack of confidence in the system that may be the result of a history of discrimination against and poor treatment of minorities.<sup>46</sup>

At least one localized study has found that systemic racism contributes to barriers

to health care. The Boston Data Report, an effort of the Boston Disparities Project,

found:

[That] socioeconomic factors play a role in health disparities but that the generally lower income and education levels of Black and Latino Bostonians did not explain fully the health disparities. Personal behavior, such as smoking, did not explain disparities. The report concluded that real or perceived racism at a systemic and individual level erected barriers to health care for these populations.<sup>47</sup>

It is sobering to contemplate that racial discrimination alone could have such an effect in society so as to contribute to a higher mortality rate for infants of a particular race. But this cause must be acknowledged alongside others in order to formulate effective solutions.

organizational, or systemic barriers as causal factors contributing to racial and ethnic disparities in the use of health care services.

<sup>&</sup>lt;sup>45</sup> *Id.* Professor Jost writes with specificity, "Physicians' expectations or suspicions concerning the ability of minority patients to comply with treatment and about complicating factors such as substance abuse, poor living conditions, or family support, may shape clinical judgments regarding diagnosis and treatment, as may unarticulated assumptions about a minority patient's lack of truthfulness, self-discipline, initiative or intelligence or assumptions about the patient's tolerance for pain." At 20. With respect to minority attitudes and behaviors, Jost writes: "In general, Medicare beneficiaries vary widely in their trust in scientific medicine, their confidence in medical professionals and institutions and in their advice, their tolerance for pain and discomfort, and their attitudes towards the short and long-term trade-offs presented by treatment decisions. At 21.

<sup>&</sup>lt;sup>46</sup> Id.

<sup>&</sup>lt;sup>47</sup> Symposium, *Massachusetts Health Insurance Reform Legislation: An Effective Tool for Addressing Racial and Ethnic Disparities in Health Care?* 29 HAMLINE J. PUB. L. & POL'Y 1, at 36-37 (2007).

#### D. SOCIAL DETERMINANTS OF HEALTH

Three factors related to infant mortality have been identified: income poverty, or socioeconomic and educational isolation; segregation, or physical isolation; and, generally speaking, differences in attitudes and understandings regarding health and health care that could be labeled racial discrimination, but that could also be identified as cultural misunderstanding, patient distrust or some combination thereof. Although these factors are enumerated for the sake of clarity, each informs the other. In many cases it is likely that segregation does not cause high infant mortality but exacerbates other more direct causes, such as income poverty and cultural misunderstandings that sometimes manifest themselves as discrimination, that do "cause" high infant mortality.

I assert that underlying any identifiable distinct factors are social determinants of health that contribute to the racial gap in infant mortality. The World Health Organization defines the social determinants of health as "the conditions in which people" are born, grow, live, work and age . . . shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices.<sup>48</sup> Social determinants are the factors that inform, complicate, and perpetuate the individual behaviors that we readily identify and blame for poor health outcomes.

Some believe that the best health care, the most funding and the best treatment, should go to those who are most "deserving."<sup>49</sup> Robert Schwartz provides three

<sup>&</sup>lt;sup>48</sup> World Health Organization, *Social Determinants of Health*, http://www.who.int/social\_determinants/en/. "[T]he social determinants of health are mostly responsible for health inequities – the unfair and avoidable differences in health status seen within and between countries." The WHO Commission on Social Determinants of Health has released a final report on health inequities and has made three overarching recommendations for their reduction: 1. Improve living conditions, 2. Tackle the inequitable distribution of power, money, and resources, and 3. Measure and understand the problem and assess the impact of action. *Id*.

<sup>&</sup>lt;sup>49</sup> In *Allen v. Mansour*, 681 F. Supp. 1232 (E.D. Mich. 1986), the court held that Medicaid recipients must be treated on the basis of medical necessity and that the state's two-year abstinence from alcohol

commonly invoked justifications for attaching sanctions, such as limiting health care access or giving lower priority to those who engage in risky behavior, to poor health choices:<sup>50</sup> "First, the additional burden deters others from making the same improper life style choices. Second, the burden appropriately punishes the morally wrongful conduct. Third, it is not equitable to distribute scarce health care resources to those who choose to create health risks (and thus who could choose to avoid them)."<sup>51</sup> Schwartz goes on to say that each of the preceding justifications requires an assumption: one, that lifestyle is voluntary; two, that lifestyle is the direct cause of the condition requiring treatment; and three, that the lifestyle in question is not warranted by other social interests.<sup>52</sup>

It is difficult, however, to tease out what is "voluntary" and what is not. Indeed, "it is hard to find a life style 'choice' or a health condition that is not, at least in part, a

consequence of genetics, ethnicity, community, education . . . and . . . wealth.<sup>353</sup> Likewise, it is difficult to find a health behavior that is the sole cause of a health consequence. And occasionally, it is in society's best interests for some individuals to engage in particular behaviors that have health risks, such as undertaking dangerous occupations.<sup>54</sup> Given these constraints, it is not tenable logically or morally to suggest that health care access and quality should be premised on individual merit, however measured, and particularly not in the case of infants, who have no volition of their own. While personal responsibility for one's health is indispensable to good health, poor health behavior is not a sound reason for the denial of health care, particularly not the poor

requirement for those suffering from alcoholic cirrhosis and needing a liver transplant was arbitrary and unreasonable.

<sup>&</sup>lt;sup>50</sup> Schwartz, *supra* note 1.

<sup>&</sup>lt;sup>51</sup> *Id.* at 234.

<sup>&</sup>lt;sup>52</sup> *Id.* at 235.

<sup>&</sup>lt;sup>53</sup> *Id.* at 236.

<sup>&</sup>lt;sup>54</sup> See Norman Daniels, JUST HEALTH CARE: MEETING HEALTH NEEDS FAIRLY (2008). Daniels argues that health is a component of equal opportunity, rather than an outcome that is deserved, merited, or earned.

health behavior of pregnant women and the denial of health and health care to their infants.

Although I have used the word "cause" to describe the relationship between factors such as poverty and infant mortality, the association is not so straightforward. While it is true that poor women are more likely to give birth to infants who will die in the first year of life, it is not true that poverty "causes" infant mortality, just as while it is true that African Americans experience a much higher infant mortality rate than European Americans, it is not true that being African American "causes" poor infant health. A correlation is not a cause. There are other factors.

Some of these factors can be placed under the umbrella of "personal responsibility." I place the term in quotation marks because some, but not all or even

most of the reasons for a high infant mortality rate can be blamed on individual behavior. "Personal responsibility" is often used conceptually to dispel any notion that society owes those who engage in unhealthy behaviors anything more than the bare minimum, or for that matter, anything at all. Dorothy Roberts writes, with reference to politically motivated selective prosecution:

[Shamefully] high black infant death rates are caused by the bad acts of individual mothers. Poor black mothers thus become the scapegoats for the causes of the Black community's ill health. Punishing them assuages any guilt the nation might feel at the plight of an underclass with infant mortality at rates higher than those in some less developed countries.<sup>55</sup>

Some causes of infant mortality are traceable to individuals, i.e., smoking, drug

use, or poor nutrition. Certainly the behavior of a woman who smokes while pregnant is

<sup>&</sup>lt;sup>55</sup> Dorothy Roberts, *Punishing Drug Addicts Who Have Babies: Women of Color, Equality, and the Right of Privacy*, 104 HARV. L. REV. 1436-37 at 1419 (1991).

the cause of her infant's resulting developmental deficiencies.<sup>56</sup> But individual behavior is always, to some extent, socially determined, for either better or worse. An infant's poor health is attributable not only to its mother's poor health behaviors during pregnancy but to its mother's family culture, community culture and circumstances (such as a lack of hospitals and healthcare providers as is often the case in segregated neighborhoods), and the larger society, which may or may not condemn a pregnant woman who engages in poor health behavior and her infant to the lifestyle she "chooses" within that context.

A pregnant woman living in a segregated neighborhood where mistrust of the health system persists, and in a family with sub-cultural health values may not have the autonomy or capability to change her lifestyle, and she is certainly not able to change overarching cultural attitudes. If the pregnant woman is unable to make changes as an individual, and her culture perpetuates poor health behavior, or even if, accepting the personal responsibility argument, she is able but unwilling, it is society's work to ensure to the extent possible that infants are born to mothers who are empowered to make better health decisions for the benefit of those infants and ultimately for society as a whole. We are well-served to change behavior, and health outcomes, by fostering capability and enabling mothers, rather than by damning them for their individual bad acts. Somehow,

<sup>&</sup>lt;sup>56</sup> Although it is nearly impossible to tell, and we have not developed ways of being able to tell, which developmental deficiencies in an infant are traceable to which behaviors, and to what extent a particular infant's difficulties are due to behavior and to what extent they are due to genetics or any number of other possibilities. *See* Deborah A. Frank et al., *Growth, Development, and Behavior in Early Childhood Following Prenatal Cocaine Exposure*, JAMA 285: 1613-1625 (2001) (finding that popular attitudes and public policies reflect the belief that cocaine is a uniquely dangerous teratogen despite recent studies failing to find catastrophic effects of prenatal cocaine exposure).

Cuba is accepting and handling this particular social responsibility more effectively, if only slightly, than the United States.<sup>57</sup>

Beyond personal responsibility and the idea that one woman's actions are the sole determinant of her infant's health outcomes is the notion of a societal responsibility to educate, empower, and enable women to carry out healthy behaviors, rather than merely telling them that, for example, smoking while pregnant is detrimental to infant health. Some women need more than information; they require the personal capability to quit smoking during pregnancy and the social mobility to build new, positive habits. This is the difference between handing out a brochure in a public health clinic and building personal relationships between healthcare providers, whether doctors, nurses, or laypeople, within which attitudes and behaviors are more likely to change.

Regardless of the beliefs of those who continue to attribute poor health outcomes in specific populations to "personal responsibility," society ignores and perpetuates unhealthy behaviors in the African American populations through an inadequate response. The result is that African Americans experience an unconscionably high rate of infant mortality compared to European Americans.

#### E. A PROPOSED SEA CHANGE

A Centers for Disease Control's Office of Minority Health and Health Disparities webpage declares a goal to "eliminate disparities among racial and ethnic groups with infant mortality rates above the national average" by 2010.<sup>58</sup> The CDC identifies several "promising strategies" for achieving its goal, including "[Focus] on modifying the behaviors, lifestyles, and conditions that affect birth outcomes . . . public health agencies .

<sup>&</sup>lt;sup>57</sup> Macdorman, *supra* note 7.

<sup>&</sup>lt;sup>58</sup> Ctrs. for Disease Control, *supra* note 5.

... must partner to improve the infant mortality rate ....<sup>59</sup> The webpage has not been reviewed by the CDC since June 5, 2007 and clearly, its goal has not been achieved.

In identifying measures the Department of Health and Human Services and Centers for Medicare and Medicaid Services (hereafter CMS) can and should take to reduce racial and ethnic disparities in Medicare, Timothy Jost writes, "The first and most important of these steps is for HHS and CMS to make the elimination of racial and ethnic disparities . . . a top priority."<sup>60</sup> It is 2010 and the CDC's ambitious goal to eliminate disparities among racial and ethnic groups with higher than national average infant mortality rates has not been achieved. Unless eliminating that disparity is made a national priority, much like Professor Jost suggests with respect to HHS and CMS and Medicare, and unless the national priority is backed by specific plans and programs, the disparity will more than likely remain, and African American infants will continue to die

### at a rate twice that of European American infants.

#### II. WHAT THE LAW CAN (OR CANNOT) DO

#### A. GENERALLY: ACCESS

The law can ensure universal access to health care. Title I of the Patient Protection and Affordable Care Act, signed into law on March 23, 2010, is entitled, "Quality, Affordable Health Care For All Americans" and aims to expand and improve coverage.

But universal access to health care may not be sufficient to eliminate the racial gap in infant mortality. For example, Medicare, which provides unfettered access to health care to individuals who qualify, has failed to dispel the disparities seen outside of

<sup>&</sup>lt;sup>59</sup> Id.

<sup>&</sup>lt;sup>60</sup> Jost, *supra* note 44, at 77.

the Medicare realm. Racial and ethnic disparities persist in health care usage and outcomes among Medicare beneficiaries despite equal eligibility for Medicare regardless of race, ethnicity, or class.<sup>61</sup> Furthermore, pregnant women who meet financial requirements already qualify for prenatal care under Medicaid, so the most recent healthcare reform will not expand legal access for these women.<sup>62</sup>

Even so, universal access is not equated with universal or equal usage. Some research has shown that provisions equalizing coverage, standing alone, "[Can] exacerbate disparities because whites and higher-income populations will make greater use of expanded benefits than non-whites and lower-income populations."<sup>63</sup> Some believe that universal insurance alone will have only a small impact on the health status of Americans, and it is unlikely that universal health care access alone will eliminate

existing disparities.<sup>64</sup> A more efficacious approach to reducing the infant mortality gap would address not only technical access, but "true" access that is determined not by statute but by social capability and education. As one health law professor writes, "Although health insurance may be the most important factor in whether or not one may have genuine access to care, a broader understanding of urban health should lead us to consider other factors that contribute to true access or lack thereof."<sup>65</sup> Health insurance and resulting access to care is fundamental, but it is an initial step, not the endgame, as

<sup>62</sup> Virginia Department of Social Services, *Medically Indigent Pregnant Women*, www.dss.virginia.gov/files/division/bp/.../pregnant.../pregnant facts .pdf.

<sup>&</sup>lt;sup>61</sup> Smedley, *supra* note 4, at 78 and 83-85.

<sup>&</sup>lt;sup>63</sup> Barak D. Richman, *Insurance Expansions: Do They Hurt Those They Are Designed For?* HEALTH AFFAIRS 26 no. 5: 1345-1357 at 1348 (2007).

<sup>&</sup>lt;sup>64</sup> Symposium, Ethics of Health Care Law Reform: Making the Case for Socio-Economic Interventions for Low Income Young Adults 12 J. HEALTH CARE L. & POL'Y 17 (2009).

<sup>&</sup>lt;sup>65</sup> Michele Goodwin, *Race & Urban Health: Confronting a New Frontier*, 5 DEPAUL J. HEALTH CARE L. 181 (2002).

far as eliminating the racial disparity in infant mortality is concerned. We must develop a "broader understanding" in order to act accordingly.

#### **B. GENERALLY: AFFORDABILITY AND QUALITY**

Title X of the Patient Protection and Affordable Care Act is entitled, "Strengthening Quality, Affordable Health Care for All Americans," and section 2718 therein is named, "Bringing down the cost of health care coverage."<sup>66</sup> The provision mandates "clear accounting for costs," "providing value for premium patients," and establishing and making public standard hospital charges.<sup>67</sup>

Much like access, however, affordability alone probably will not eliminate health care disparities, because for multiple reasons, the majority is better able to make use of health care, whether universal or not, affordable or not. One study has found that "even when insurance benefits and access are constant, whites and higher-income individuals consume more mental health care services and pharmaceuticals than racial and ethnic minorities and lower-income populations."<sup>68</sup> Those in a better position to attend to their good health are also in a better position to take advantage of the health care services made available to them.

"Quality" is a major component of the Patient Protection and Affordable Care Act, including reporting requirements, a specific provision applying to Medicaid patients and providers, linking quality outcomes to payment in the Medicare program, and the development of quality measures.<sup>69</sup> Certainly "quality" is a worthy aim and one that could benefit both majority and higher-income European Americans and minority and

<sup>&</sup>lt;sup>66</sup> Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 2718 124 Stat. 119 (2010).

<sup>&</sup>lt;sup>67</sup> Id.

<sup>&</sup>lt;sup>68</sup> Richman, *supra* note 62, at 1351.

<sup>&</sup>lt;sup>69</sup> Patient Protection and Affordable Care Act, *supra* note 66, at § 931.

lower-income African Americans. But given the causes of the infant mortality gap, it is likely that quality and affordability improvement measures will not precipitate the larger and more fundamental changes that could eliminate the gap. As Nicole Lurie and Tamara Dubowitz report, "[Medical] care makes only a small contribution to health status."<sup>70</sup> Environmental health, community health, education, and income make far larger contributions.

If achieving equity in health status across racial and socioeconomic lines is the goal, alleviating educational disparities is a more effective measure than providing more expensive or comprehensive medical care.<sup>71</sup> Indeed, "the most effective interventions change individual behavior and enable communities and social networks of at-risk persons to provide environmental and normative support for sustained change."<sup>72</sup> The racial disparity in infant mortality is more likely to be alleviated by specific, local, targeted programs than by broad, sweeping provisions such as universal health care and improved healthcare quality. This is not to say that healthcare reform will not have positive outcomes or that the result was not worth the effort, but to suggest that if the goal, as the CDC proclaims, is to "eliminate disparities among racial and ethnic groups,"

then universal access and quality and affordability requirements are fundamental, but not ultimate solutions.

<sup>&</sup>lt;sup>70</sup> Nicole Lurie & Tamara Dubowitz, *Health Disparities and Access to Health*, 297 JAMA 1118, 1118-19 (2007). In fact, the contribution of health care to health status is approximately only 15%. *Id.* at 1119. <sup>71</sup> Woolf et al., *Giving Everyone the Health of the Educated: An Examination of Whether Social Change Would Save More Lives Than Medical Advances*, 97 AM. J. PUB. HEALTH 679, 680 (2007). Woolf et al. estimate that correcting educational disparities would save eight times as many lives as advanced medical technologies and would confer myriad economic benefits.

<sup>&</sup>lt;sup>72</sup> Kathleen J. Sikkema et al., *Outcomes of a Randomized, Controlled Community Level HIV Prevention Intervention for Adolescents in Low-Income Housing Developments*, 19 AIDS 1509, 1510 (2005).

#### C. SPECIFICALLY: MATERNAL AND CHILD HEALTH

The Patient Protection and Affordable Care Act does contain specific provisions that could have positive effects on infant mortality generally and that could possibly narrow the racial gap in infant mortality specifically. One of these provisions, section 2951, establishes a competitive grant program for states to provide maternal, infant, and early childhood home visiting programs.<sup>73</sup> The provision targets "at risk communities" and requires a needs-assessment identifying "communities with concentrations of premature birth, low-birth weight infants, and infant mortality."<sup>74</sup> The grant program establishes three and five-year benchmarks and enumerates goals such as "improvements in prenatal, maternal, and newborn health, including improved pregnancy outcomes."<sup>75</sup> The specificity of the provision is heartening, and it is likely that it could, if carried out as written, narrow the racial gap in infant mortality, although to what extent will not be known for some time.

Research has demonstrated that some home visiting programs improve outcomes for both children and their mothers. The Nurse-Family Partnership, for example, a homevisitation model designed to improve child health and development, reported in a 15-year follow-up that nurse-visited families experienced fewer doctor and hospital visits due to childhood injuries through child age two, a twenty-five percent reduction in cigarette smoking by mothers during pregnancy, and a forty-eight percent lower incidence of child abuse and neglect through child age fifteen.<sup>76</sup> Home visiting programs instituted by the

<sup>&</sup>lt;sup>73</sup> Patient Protection and Affordable Care Act, *supra* note 66, at § 2951.

<sup>&</sup>lt;sup>74</sup> Id. <sup>75</sup> Id.

<sup>&</sup>lt;sup>76</sup> Andy Goodman, Grants Special Report of the Robert Wood Johnson Foundation, *The Story of David Olds and the Nurse Home Visiting Program*, (July 2006)

http://www.rwjf.org/files/publications/DavidOldsSpecialReport0606.pdf. At 6.

Patient Protection and Affordable Care Act will, hopefully, have similarly positive effects.

Additionally, sections 10211-10214 of the Patient Protection and Affordable Care Act create a pregnancy assistance fund of twenty-five million dollars annually for ten years, disbursed through grants to higher education institutions to establish, maintain, or operate pregnant and parenting student services, as well as conduct needs-assessments on campuses and within communities.<sup>77</sup> While the infusion of funding is welcome, increased spending may not be the most effective way to combat a racial gap in infant mortality, as previously discussed. Moreover, these provisions reach pregnant women through institutions of higher education rather than through their communities and families. The provisions do make funding available to eligible high schools and community service centers, but the bulk of the language addresses colleges.<sup>78</sup> Those

SITY most needful of the assistance from these grants are more likely found in their communities and in low-wage occupations than in higher education.

Finally, the Act modifies the Office of Minority Health to "[improve] minority health and the quality of health care minorities receive, and [eliminate] racial and ethnic disparities."<sup>79</sup> The provision authorizes the office to award grants and act within communities to improve the health status of racial and ethnic minorities by supporting community organizations.<sup>80</sup> This provision could have significant and positive effects, but, again, it remains to be seen exactly what those effects will be, and if the language is

<sup>77</sup> Patient Protection and Affordable Care Act, *supra* note 66, at §§ 10211-10214. *See also* The National Campaign to Prevent Teen and Unplanned Pregnancy, Summary of Provisions Related to Teen and Unplanned Pregnancy in H.R. 3590, http://www.summaryprovisions TUO HealthReform.pdf. <sup>78</sup> *Id.* At §§ 10213(b) and (c).

<sup>&</sup>lt;sup>79</sup> *Id.* at § 10334. <sup>80</sup> *Id.* 

aspirational, like that featured on the CDC website previously mentioned, or if it represents a true change in how the Office of Minority Health will operate and what effects it will have.

There are partial remedies for the racial gap in infant mortality within the Patient Protection and Affordable Care Act. Although no provision is devoted entirely to narrowing the racial gap in infant mortality, these specific provisions together may lay the framework and provide initial support for more integrative, community-based solutions discussed below.

#### **III. SOLUTIONS**

Just as there are many causes of and factors contributing to the racial disparity in infant mortality, there are many solutions. Increases in income or funding, non-

discriminatory access to pre-natal care, sanctions on personal behavior, or the denial of societal responsibility are not adequate responses to the racial gap in infant mortality. Since the direct causes of infant mortality and the racial gap in infant mortality are difficult to ascertain and to separate from one another, it is more than likely that several different proposals will need to be explored and implemented to determine which initiatives address the problem most effectively.

In <u>Making Americans Healthier</u>, the editors write, "Most current political and policy analysis related to health in the United States focuses on medical-care and insurance expenditures, incentives, and prices."<sup>81</sup> This observation is borne out by the emphasis given to universal health insurance in the Patient Protection and Affordable Care Act. The editors note that "real opportunities" exist outside those realms. Indeed, "[Economic], social, psychological, behavioral and environmental factors are

<sup>&</sup>lt;sup>81</sup> House et al., *supra* note 8, at 4-5.

increasingly recognized as the major determinants of population health.<sup>352</sup> This recalls the previous observation that medical care makes only a small contribution to health status and that larger environmental and social factors affect the health status of individuals more dramatically.<sup>83</sup> Accordingly, those factors must be accounted for in the design of any initiative with the goal of eliminating the racial disparity in infant mortality.<sup>84</sup> Access to health care is important and affordable health care is important. But social, psychological, and environmental and community health are crucial to reduce racial disparities in infant mortality.

#### A. COMMUNITY-BASED CARE

One approach is community-based health care tailored to particular communities. In his book, <u>The Community Economic Development Movement</u>, William H. Simon provides two rationales for supporting health-care delivery through community-based public and private organizations in low-income communities. First, "people in lowincome areas seem especially vulnerable to neglect and abuse by for-profit health care providers."<sup>85</sup> This recalls the previous observation that patient and provider attitudes can contribute to health disparities, and that minority populations living separately from the majority population experience higher instances of poor health outcomes.<sup>86</sup>

Second, "limited education and perhaps non-mainstream cultural backgrounds often lead poor people to seek preventive care less often than is desirable."<sup>87</sup> This second rationale of Simon's reflects the previously expressed assertion that lower-income and

<sup>&</sup>lt;sup>82</sup> Id.

<sup>&</sup>lt;sup>83</sup> Lurie, *supra* note 70.

<sup>&</sup>lt;sup>84</sup> House et al., *supra* note 8, at 4-5.

<sup>&</sup>lt;sup>85</sup> William H. Simon, The Community Economic Development Movement: Law, Business, And The New Social Policy, 39 (2001).

<sup>&</sup>lt;sup>86</sup> Jost, *supra* note 45.

<sup>&</sup>lt;sup>87</sup> Simon, *supra* note 75.

minority individuals who live in neighborhoods isolated from the mainstream do not receive either the quality or quantity of health education that individuals in better-situated and socio-economically more advantaged neighborhoods do. Simon goes on to emphasize the importance of education and outreach in addressing the health care needs of poor communities, and points out that "local knowledge" is required to identify needs, design programs, and coordinate efforts between public and private institutions and local institutions.<sup>88</sup>

The Patient Protection and Affordable Care Act incorporates a community-based solution: the "Community-Based Collaborative Care Network Program," to provide "comprehensive coordinated and integrated health care services" for low-income populations.<sup>89</sup> While such a provision is a step in the right direction – it also provides for health outreach using neighborhood health workers and transportation when needed – it does not address some of the root causes of the infant mortality disparity that have been previously identified.<sup>90</sup> It is not apparent that such a program encourages the kind of broad, community-based efforts that would change individual behaviors in a lasting way, because the network focuses on providers of health rather than recipients or participants in the program.

A more successful program would encourage community members to spearhead initiatives and become accountable to one another for healthy behaviors. Simon references the federal government's Community Health Center program, "which provides grants and loan guarantees to nonprofit institutions that provide outpatient care to the

<sup>&</sup>lt;sup>88</sup> Id.

<sup>&</sup>lt;sup>89</sup> Patient Protection and Affordable Care Act, *supra* note 66, at § 10333.

<sup>&</sup>lt;sup>90</sup> Infra at 6-15.

residents of 'medically underserved' geographical area.<sup>91</sup> The Community Health Center program ties its efforts to the community by requiring that qualifying organizations have a governing board that is representative of the service area and in which a majority are patients.<sup>92</sup>

#### **B. ONE COMMUNITY'S SUCCESS STORY**

One community outside of Madison, Wisconsin, has experienced remarkable success in lowering the infant mortality rate in the African American population through a variety of community-based and integrative programs.<sup>93</sup> In Dane County, Wisconsin, the rate of infant deaths among African Americans has decreased from 19 deaths for every 1,000 infants to less than five deaths for every 1,000 infants since the 1990s.<sup>94</sup>

Figure 4 depicts this improvement.<sup>95</sup> In that time, obstetrical services in the area have

not materially changed.<sup>96</sup> Instead, visiting nurses provide transportation to appointments. They also refer and presumably encourage low-income pregnant women at risk for

premature birth to attend anti-smoking and anti-depression groups and other therapies.<sup>97</sup> Because periodontal disease elevates the risk of premature birth due to an increase in levels of a labor-inducing chemical, dental health provides one poignant example of how a referral can have a significant effect on maternal and infant health.<sup>98</sup>

In emphasizing that there is no simple medical explanation for the county's success, a professor of pediatrics is quoted: "... infant mortality is linked to the well-

<sup>&</sup>lt;sup>91</sup> Simon, *supra* note 75, at 40.

<sup>&</sup>lt;sup>92</sup> 42 U.S.C. § 254b(a), (b), (j)(3)(H) (2009).

<sup>&</sup>lt;sup>93</sup> Erik Eckholm, *Trying to Explain a Drop in Infant Mortality*, N.Y. Times, Nov. 27, 2009, at A20. Available at:

http://www.nytimes.com/2009/11/27/us/27infant.html?\_r=1&scp=1&sq=infant%20deaths%20eckholm%2 0madison&st=cse.

<sup>&</sup>lt;sup>94</sup> Id.

<sup>&</sup>lt;sup>95</sup> Id. <sup>96</sup> Id.

<sup>&</sup>lt;sup>97</sup> Id.

 $<sup>^{98}</sup>$  Id.

being of mothers from the time they were in the womb themselves, including physical and mental health; personal behaviors; exposure to stresses, like racism; and their social ties."<sup>99</sup> Dane County's success is probably due at least in part to that perspective, which recalls that of the editors of <u>Making Americans Healthier</u>. Any program that reduces infant mortality and particularly narrows the racial gap in infant mortality must begin with a nuanced organizational understanding of the complexities of the problem and of the larger factors beyond health care that influence health status.

In addition to home-visiting nurses, a federally supported clinic, the Access Community Health Center, serves the uninsured of Dane County by providing lowincome women with nurse-midwives, and a law center, ABC for Health, connects poor women with insurance and medical services.<sup>100</sup> The County Health Director is reported to believe that it is these forms of outreach, that not only provide health care but also enable women and fill the education and capability gap to go above and beyond basic pre-natal care, that deserve credit for so drastically narrowing the infant mortality gap in this one community.

#### C. A LOCAL SOLUTION

Lynchburg, Virginia, is 48.5 miles south and west of Lexington, Virginia. In 1985, of the 176 U.S. cities of 50,000 or more and ten percent black, Lynchburg ranked 142<sup>nd</sup> with respect to infant mortality race disparity.<sup>101</sup> **Figure 5** shows the disparity. The problem increased in severity before any solution was enacted, reaching a high of

<sup>&</sup>lt;sup>99</sup> Id.

 $<sup>^{100}</sup>$  *Id*.

<sup>&</sup>lt;sup>101</sup> LaVeist, *supra* note 6, app. at 60.

29.4 African American infant deaths per 1,000 births in 1999.<sup>102</sup> This rate is comparable to the current infant mortality rate in Indonesia, and is higher than the infant mortality rate in Algeria, many South American countries, and China.<sup>103</sup>

In 2000, a program to teach risk reduction to community residents, called "Community Voice: Taking it to the People," was instituted through a grant from the March of Dimes.<sup>104</sup> The program educated 300 "Lav Health Advisors" through a series of five classes, covering such subjects as SIDS, the effect of tobacco use during pregnancy, and basic prenatal care.<sup>105</sup> The Health Advisors then made "community contacts" to educate and support African American mothers at risk for preterm birth or complications in labor.<sup>106</sup>

"Community Voice" operated for three years and by 2003 the infant mortality rate in the African American population had dropped to 5.5.<sup>107</sup> When funding ran out, the program was concluded, and by 2004 the infant mortality rate had risen to 22.0.<sup>108</sup> The decrease and increase are drastic, and it is possible and likely that some other factors were at work. On the other hand, Lynchburg, Virginia, is a relatively small community, and perhaps a community-based program can expect to have outsized effects within a smaller population. Although there is not concrete evidence linking "Community Voice" to the decrease in African American infant mortality, it is probable that there is a causal

http://apha.confex.com/apha/130am/techprogram/paper\_42079.htm.

<sup>103</sup> Central Intelligence Agency, The World Factbook: Infant Mortality,

https://www.cia.gov/library/publications/the-world-factbook/rankorder/2091rank.html. <sup>104</sup> A. Scott & K. Wesley, Community Voice: Taking it to the People to Reduce African American Infant Death, http://cdc.confex.com/cdc/pcs2007/techprogram/P13615.HTM (2007).

 $^{105}$  *Id*.  $^{106}$  Id.

<sup>108</sup> *Id*.

<sup>&</sup>lt;sup>102</sup> American Public Health Association. Community Voice: A Program to Reduce Infant Mortality by Taking the Problem to the People. Nov. 13, 2002.

 $<sup>^{107}</sup>$  *Id*.

effect, and it is clear that the community-based effort, which did not require more primary care physicians, a new hospital, universal health insurance or welfare assistance, was successful.

**Appendix 1**, in a separate, attached document, specifies several best practices in infant mortality compiled by the Kansas Blue Ribbon Panel on Infant Mortality.

#### **IV. CONCLUSION**

The racial gap in infant mortality in the United States persists despite extravagant healthcare spending and copious data documenting the problem. The blame for this issue should not lie with individuals. It is a societal problem meriting a societal response.

The Patient Protection and Affordable Care Act recently signed into law contains some provisions that could narrow the infant mortality gap, particularly in funding for

home visiting programs and through the reorganization and empowerment of the Office

of Minority Health. These changes, as well as the universal care provided by the Act, may have a positive effect on the disparity and on infant mortality more generally, since even the European American infant mortality rate in the United States is not a rate to which most developed countries would aspire. The Act could provide the framework and support for community-based programs run not by doctors and hospitals or with a health care emphasis per se, but with the assistance of lay health advisors such as those used in Lynchburg, Virginia, and through a network of services and diverse support like that available in Dane County, Wisconsin.

Regardless of the specific remedies used to narrow the gap in infant mortality, we must shift our understanding of health and the goals of policy reform to include factors beyond medical care. We must perceive health as the result of broader societal forces. We must work within communities to encourage integrated programs that promote

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capability first and individual health as one outcome of that newfound capability. This must be done for the sake of society's most vulnerable and for the sake of society itself.

# Washington and Lee University

#### Making Americans Healthier

Year	U.S. Rank on Life Expectancy at Birth	U.S. Rank on Infant Mortality	Percentage of GDP Spent on Health			
			United States Rank	United States Spending	Average Spending Amo All Other OECD Countri	
1960	15.5	12	2	5.1%	3.7%	
1970	19	14	3, tied	7.0	5.0	
1980	14	18	1	8.8	6.7	
1990	18	21	1	11.9	6.8	
2000	22	25	1	13.3	7.6	
2003	23	27	1	15.2	8.6	

US Rank Among Thirty OECD Developed Nations on Indicators

# Washington and Lee University

#### Figure 1 Source: House, Schoeni, Kaplan, and Pollack from OECD Health Statistics (2006).

#### Sagragation, Poverty. and Entpowerment

45

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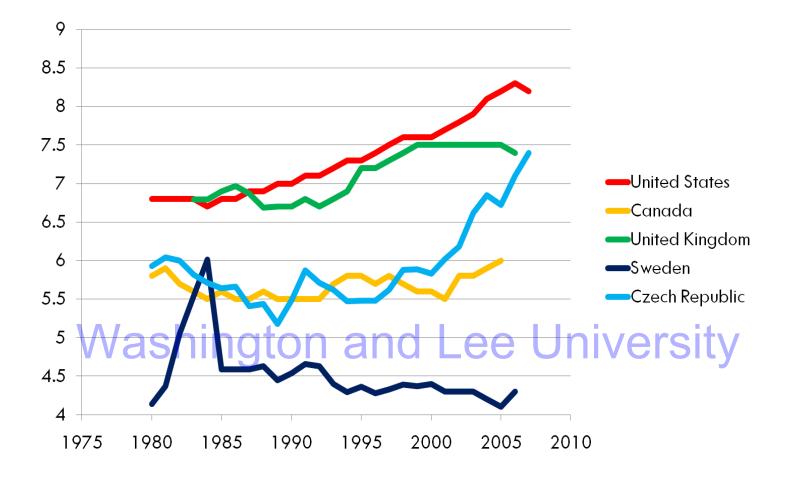
Тпсеглах	TABLE : ional Computisons of Infunt Mortality	Kates, 1986	
	< Country	IMR.	
1	Sweden	7.0	—
2	Japan	7.1	
}	Fieland	7,6	
4	Norway	8,3	
,	Netherlands	8.2	
\$	Denmark	8.4	
7	Swetzerland	8,5	
8	Australia	9.6	
9	France	9.6	
10	Spain	10.3	
11	Slegapote	10.8	
12	United States-white	22.0	
12	Canada	11.0	
13	Pelgium	11.7	
14	Austria	15.9	
14	New Zealand	11.9	
17	United States-total	12.1	
18	German Democratic Republic	12.3	
19	Tederal Republic of Germany	12.6	
20	Italy_	14.5	
21	Israel	15.1	
. 22	Jamaka	16.2	
23	Cacchoslovakia	16.8	
Machinatab	Greece	17.9	
Washington	Cuhe	18.5	University
	United States-black	20.0	

Addreadation: JMD., infact modality mat.

#### Figure 2

Source: Timothy LaVeist, *Segregation, Poverty, and Empowerment*, The Milbank Quarterly, Vol. 71, No. 1, 41-64 at 49. (1993).

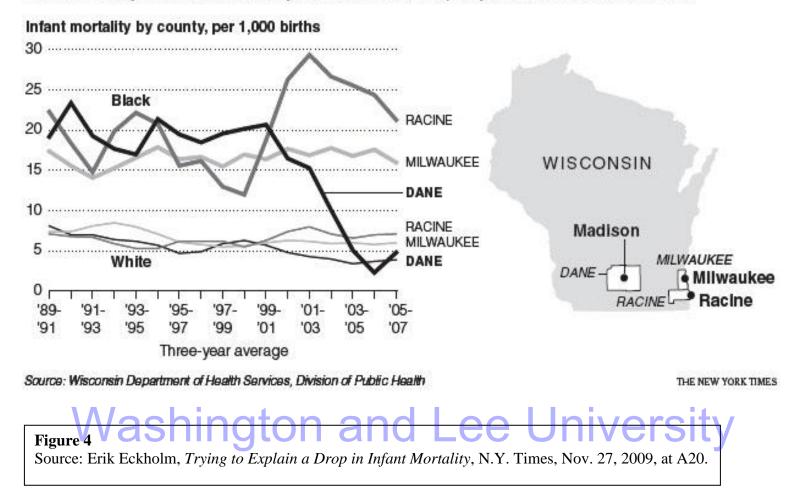




**Figure 3** Prepared by the Robert E. Lee Scholars for the Shepherd Program

### **Closing the Infant Mortality Gap**

In Dane County, Wis., infant mortality rates have reached parity between blacks and whites.



City Ratings in Five-Year Infant Mortality Race Disparity for All U.S. Cities of 50,000 or More and Ten Percent Black, 1981-1985

		Population		Infant Mortality (/1000 births)		
Rank	City	Total	Black	White	Black	Ratio
142	Lynchburg, VA	66, 743	15, 791	8.8	18.8	2.14

Washington and Lee University

#### Figure 5

Source: Timothy LaVeist, *Segregation, Poverty, and Empowerment*, The Milbank Quarterly, Vol. 71, No. 1. Appendix 1. (1993).