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# RACIAL DISPARITIES IN THE ALLOCATION OF STEM CELLS

*Andrea Flynn* \*

## INTRODUCTION

On August 9, 2001, President Bush announced that the federal government would fund research on the 64 stem cell lines that meet certain criteria.<sup>1</sup> These stem cells must come from an embryo that was created for reproductive purposes and was no longer needed for that purpose.<sup>2</sup> A stem cell line is a colony of cells that grows from a single embryo.<sup>3</sup> Federal funding is available for those stem cells that were initiated prior to August 9, 2001 at 9:00 p.m. EST. The companies should have obtained informed consent for the donation of the embryo and the donation must not have involved financial inducements.<sup>4</sup> The Bush administration approved stem cell lines from fertility clinics throughout the world.<sup>5</sup>

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<sup>1</sup> National Institutes of Health, *Update on Existing Human Embryonic Stem Cells*, (August 27, 2001), at <http://www.nih.gov/news/stemcell/082701list.htm>. [hereinafter *NIH Update*].

<sup>2</sup> *Id.*

<sup>3</sup> *Stem Cells: Scientific Progress and Future Research Directions*, DEPARTMENT OF HEALTH AND HUMAN SERVICES (June 2001), at <http://www.nih.gov/news/stemcell/scireport.htm>, at ES-1.

<sup>4</sup> *Id.*

<sup>5</sup> *Id.* The University of Göttenborg has 19 stem cell lines that meet the eligibility criteria. The nineteen lines are in various developmental stages but meet the eligibility criteria. The Wisconsin Alumni Research Foundation owns five stem cell lines. They are licensed through WiCell. Bresa Gen, Inc. in Athens, Georgia has four stem cells. CyThera, Inc. in San Diego, California has nine lines, Karolinska Institute, Stockholm has five lines, Monash University, Melbourne, Australia has six lines; the National Center for Biological Sciences, Bangalore, India has three lines; Reliance Life Sciences, Mumbai, India has seven lines; Technion-Israel

Most of the embryos were harvested at clinics in the United States, Australia, Sweden and Israel where the clinic populations consist primarily of white couples while the other remaining lines were harvested at clinics in Singapore and India.<sup>6</sup> The unintended consequences could have a huge impact.<sup>7</sup> Even if all of these stem cell lines are shown to be viable for research, the lines cover a “very narrow segment of the world’s population and a tiny fraction of what is necessary to ensure genetic diversity in therapies eventually developed from these cells.”<sup>8</sup> Medical geneticists have presented evidence showing that certain diseases are specific to one population.<sup>9</sup> If research is limited to the current stem cell lines then certain drugs may be developed that only work for certain populations.<sup>10</sup>

The health care system is not immune from the social injustices and the various forms of inequality that impact other societal systems. The United States health care industry has and continues to be plagued by racism. During the pre-Civil war, Reconstruction and Jim Crow eras of American history, overt racism was common in medicine. After the Civil Rights Movement, segregation and some of the more blatant manifestations of racism disappeared. However, subtle racism still remains.

This Comment is divided into four sections. The first section provides the reader with an overview of human stem cell research. It provides brief background information of stem cells and their potential uses. The second section examines race discrimination within the American health care system. The third section proposes and analyzes legal and non-legal responses to racial disparities in the allocation of stem cells. The fourth section concludes that minorities should be included in embryonic stem cell research.

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Institute of Technology, Haifa, Israel has four lines, and the University of California, San Francisco, CA has two lines.

<sup>6</sup> Jon Entine and Sally Satel, *Inserting Race into the Stem Cell Debate*, THE WASH. POST, Sept. 9, 2001, at B01.

<sup>7</sup> *Id.*

<sup>8</sup> *Id.*

<sup>9</sup> National Medical Association, *National Colloquium on African American Health*, (July 23-25, 1999), at <http://www.nmanet.org/Policy/05%20Biomed%20srch.pdf>, at 5.

<sup>10</sup> *Id.*

## OVERVIEW

### Background

In vitro fertilization (IVF) is a technique used to impregnate women.<sup>11</sup> IVF involves hormonal stimulation of a women's ovaries that suffer from defective fallopian tubes.<sup>12</sup> Once the eggs are ripened they are mixed with sperm.<sup>13</sup> The fertilized eggs are then put in vitro for a period of time before they are implanted in the women's uterus.<sup>14</sup> Before the eggs are implanted, physicians must decide the number to implant.<sup>15</sup> If there are remaining embryos after implantation the parents as the owners have the right to decide whether they are donated, destroyed, or frozen cryogenically for future use.<sup>16</sup>

### *What are stem cells?*

With the research of human stem cells, physicians hope these stem cells will repair or replace damaged tissues that have been destroyed by diseases and disabilities.<sup>17</sup> If physicians could control stem cells, they could cure diseases such as Alzheimer's, Parkinson's Disease, or even repair spinal cords.<sup>18</sup>

Stem cells are the main cells that have the ability to turn into other types of cells.<sup>19</sup> There are three different sources for stem cells: embryonic stem cells, embryonic germ cells, and adult stem cells.<sup>20</sup> Embryonic stem cells come from the inner cell mass of a blastocyst, a very early embryo.<sup>21</sup> Embryonic stem cells are the cells that are in embryos that have the ability to transform into almost any cell in the

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<sup>11</sup> DOROTHY ROBERTS, *KILLING THE BLACK BODY* 247 (Pantheon Books 1997).

<sup>12</sup> *Id.*

<sup>13</sup> *Id.*

<sup>14</sup> *Id.*

<sup>15</sup> *Id.*

<sup>16</sup> ROBERTS, *supra* note 11, at 247.

<sup>17</sup> *Stem Cells: Scientific Progress and Future Research Directions*, DEPARTMENT OF HEALTH AND HUMAN SERVICES (June 2001), at <http://www.nih.gov/news/stemcell/scireport.htm>, at ES-1.

<sup>18</sup> Seattle Times news services, *Here's What Debate on Stem Cells is All About*, SEATTLE TIMES, Aug. 10, 2001, at A2.

<sup>19</sup> *Id.*

<sup>20</sup> Audrey R. Chapman, Mark S. Frankel, and Michele S. Garfinkel, *Stem Cell Research and Applications Monitoring the Frontiers of Biomedical Research*, AMERICAN ASSOCIATION FOR THE ADVANCEMENT OF SCIENCE 1 (November 1999), at <http://www.aaas.org/spp/dspp/sfpl/projects/stem/report.pdf>.

<sup>21</sup> *Id.*

body.<sup>22</sup> Master cells found in embryos generate all the other tissues in the body.<sup>23</sup>

Pluripotent cells have the potential to reproduce into any type of cell.<sup>24</sup> An adult stem cell is found in a specialized tissue such as blood and can reproduce itself for the lifetime of the organ.<sup>25</sup> Scientists have discovered that adult stem cells from one tissue seem to have the ability to develop into stem cells that are characteristic of other tissue.<sup>26</sup> Sources of adult stem cells include bone marrow, blood, the cornea and the retina of the eye, brain, skeletal muscle, dental pulp, liver, skin and pancreas.<sup>27</sup> The fertilized egg is totipotent; it can generate all cells and tissues that are in an embryo.<sup>28</sup> About four days after fertilization the divided cells create a hollow sphere called an early blastocyst.

Human stem cells are pluripotent. The best source of embryonic stem cell research comes from cryogenically frozen human embryos from IVF treatments. An embryonic stem cell is made from a group of cells called the inner cell mass which is part of the early embryo called the blastocyst.<sup>29</sup> Once the cell is separated from the blastocyst, the cells of the inner cell mass can be cultured into embryonic stem cells.<sup>30</sup> These cells are not embryos.<sup>31</sup> Human embryonic cells can be generated into large quantities in the laboratory and can grow in their unspecialized state for a long period of time.<sup>32</sup> According to the National Institute of Health (NIH), these cells do not react in the laboratory than as they would in the developing embryo.<sup>33</sup> Embryonic stem cells are more malleable than adult stem cells.<sup>34</sup>

There are many challenges and misconceptions to embryo stem cells.<sup>35</sup> The lines of unchanged human embryonic stem cells will not be able to be directly used in patients.<sup>36</sup> These lines of unchanged cells

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<sup>22</sup> See SEATTLE TIMES, *supra* note 18.

<sup>23</sup> *Id.*

<sup>24</sup> *Stem Cells: Scientific Progress*, *supra* note 17, at ES-1.

<sup>25</sup> *Id.* at ES-2.

<sup>26</sup> *Id.* at ES-1.

<sup>27</sup> *Id.* at ES-2.

<sup>28</sup> *Id.* at 1.

<sup>29</sup> *Stem Cells: Scientific Progress*, *supra* note 17, at ES-2.

<sup>30</sup> *Id.*

<sup>31</sup> *Id.*

<sup>32</sup> *Id.* at ES-9.

<sup>33</sup> *Id.*

<sup>34</sup> *Stem Cells: Scientific Progress*, *supra* note 17, at ES-9.

<sup>35</sup> *Id.* at ES-5.

<sup>36</sup> *Id.*

will have to be modified in order to be used clinically.<sup>37</sup> Current challenges include the ability to direct embryonic stem cells into specialized stem cell populations and also to maintain control of their development after inserted into patients.<sup>38</sup>

Stem cells have the potential to cure many diseases by replacing cells lost by crippling diseases.<sup>39</sup> One of the major foci of stem cell research is the regeneration of replacement tissues for treating neurological disease.<sup>40</sup> Researchers are currently studying what makes certain cells become abnormal and why they make people get sick.<sup>41</sup>

### ANALYSIS AND IMPACT

The impact of limited stem cell research could be far reaching. For example, Jacob Williams, a thirty-seven year old African American has Parkinson's Disease. Jacob is constantly shaking, unable to walk, loses his balance, and suffers from rigidity in his limbs.<sup>42</sup> He is unable to care for himself. He uses a wheelchair to move. Jacob decides to seek help at the major research university near his hometown. Dr. Hope, the premier researcher on embryo stem cell research, persuades Jacob to seek treatment from the university's medical center for relief from his Parkinson's disease. Dr. Hope assures Jacob that even though he is not a candidate for a pallidotomy, he is an excellent candidate for embryo stem cell research. Prior to the transplant, Dr. Hope explains to Jacob and his family the success the university has had in its transplanting of embryo stem cells for Parkinson's Disease. Dr. Hope reassures Jacob's family that Jacob is an excellent candidate for the embryo stem cell transplant. Jacob becomes excited about being independent and teaching again. Dr. Hope offers him a new life with an embryo stem cell transplant. Despite candid talks with his family, they are still hesitant. Jacob's grandmother, the matriarch of the family, knows of family members that were subjects in the Tuskegee Experiment and strongly expresses her distrust of any medical study. Tammie, Jacob's

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<sup>37</sup> *Id.*

<sup>38</sup> *Id.*

<sup>39</sup> *Id.*

<sup>40</sup> *Stem Cells: Scientific Progress*, *supra* note 17, at ES-4.

<sup>41</sup> *Id.*

<sup>42</sup> Somerset Pharmaceuticals, *What Happens in Parkinson's Disease*, available at [http://www.parkinsonsinfo.com/about\\_parkinsons/whathappens.html](http://www.parkinsonsinfo.com/about_parkinsons/whathappens.html) (1997)

wife, is optimistic and believes that medical science has changed and everyone is treated equally. Other family members have various views.

Dr. Hope is confident about the new life Jacob would experience. Dr. Hope explains that embryo stem cells are funded through research by the federal government, and the tests were very safe and very successful. However, Jacob's body rejects the embryo stem cells. His conditions actually worsen. Disappointed, he and his family question the doctor. Dr. Hope tells Jacob that this is the first time that he has seen such a reaction.

Jacob's wife, Tammie, asks, "How many minorities were actually tested?"

Dr. Hope stammers and tells them none.

"None!? How can the government fund a research program that is supposed to benefit everyone and not test a diverse group of people? That is not fair – nor is it legal."

Dr. Hope is embarrassed and disappointed because he cannot help his patient. Dr. Hope led the research, but he had to admit that he had not thought to include minorities in the study. He had to admit to the Williams family that he did not think that minorities needed to be included in the study.

Jacob's grandmother, Amelia, says, "That is why I don't trust doctors."<sup>43</sup>

Mr. Williams is a fictitious character, but this scenario shows the possible impact of excluding minorities from stem cell research.

### **Race Discrimination within the Health Care System**

Courts have engaged in the past about health care groups and their access to care. In the past, courts have allowed separation of health care based on race. Courts currently view health care as a right, but there is still unequal care.

African Americans' distrust of the health care system is built out of a history that includes experimentation, the Sickle Cell Screening Initiative, and the participation of the medical system in the justification of racism and discrimination in society.<sup>44</sup> The distrust of

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<sup>43</sup> LAURIE KAYE ABRAHAM, *MAMA MIGHT BE BETTER OFF DEAD* 203 (The University of Chicago Press 1993).

<sup>44</sup> ABRAHAM, at 203.

the American health care system is grounded in the knowledge that the health care system has been built on bodies of African Americans.<sup>45</sup>

### Tuskegee Syphilis Experiment

In July 1932, the United States Public Health Services (PHS) enrolled about 399 men infected with syphilis from Macon County, Alabama, in a public health study.<sup>46</sup> The PHS selected men with late stage syphilis. This showed that the purpose of the study was to determine the impact of untreated syphilis during the final stage of the disease.<sup>47</sup> Most of the men were unaware that they had contracted syphilis.<sup>48</sup> The physicians working for PHS told them that they had “bad blood.”<sup>49</sup> The physicians knew that poor blacks in Macon attributed most ailments to “bad blood.”<sup>50</sup> The physicians did not tell them they could pass the disease to their partners or their unborn children.<sup>51</sup> Most of the men had never received regular health care services and were glad to have regular access to physicians on a regular basis. The PHS used incentives like free meals, physical exams, hot meals on exam dates and burial stipends to encourage participation.<sup>52</sup>

In the early years of the study, mercury and arsenic were used to treat the patients.<sup>53</sup> In 1943, penicillin became an accepted form of treatment for syphilis. In 1943, the Department of Public Health started administering penicillin to syphilitic patients.<sup>54</sup> However, these participants in the Tuskegee study were denied treatment.<sup>55</sup> These men were treated like laboratory animals. The men were not given penicillin, because treatment would have ended the study.<sup>56</sup> For example, men were also given pink-colored aspirin and iron tablets.

Physicians took advantage of the men’s trusting nature and their ignorance. The participants did not understand the purpose of the experiment or the consequences of having syphilis untreated.<sup>57</sup>

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<sup>45</sup> *Id.*

<sup>46</sup> JAMES H. JONES, *BAD BLOOD 1* (The Free Press 1993).

<sup>47</sup> *Id.*

<sup>48</sup> *Id.*

<sup>49</sup> *Id.*

<sup>50</sup> *Id.* at 73. JONES, *supra* note 46 at 73.

<sup>51</sup> JONES, *supra* note 46 at 73.

<sup>52</sup> *Id.* at 5.

<sup>53</sup> JONES, *supra* note 46 at 118.

<sup>54</sup> *Id.* at 178.

<sup>55</sup> *Id.*

<sup>56</sup> *Id.* at 179.

<sup>57</sup> *Id.* at 13.



Without the patients' consent, physicians conducted lumbar spinal taps to test for the effect of syphilis on the central nervous system.<sup>58</sup> The physicians told the patients that they were giving them medicine. One participating doctor justified the treatments by saying, "These Negroes are very ignorant and easily influenced by things that would be of minor significance in a more intelligent group."<sup>59</sup>

Tuskegee participants who agreed to autopsies were given burial stipends to insure that they would continue to participate in the study.<sup>60</sup> This eliminated their worry of burdening their family with expenses after their death.

In July 1972, forty years after the experiment began, the men discovered they had syphilis.<sup>61</sup> In response, the Department of Health, Education, and Welfare (HEW) revamped regulations on human experimentation.<sup>62</sup> However, the damage was already done, and many blacks were distrustful of medical authorities.<sup>63</sup> This study reinforced the distrust African Americans had in the medical system.<sup>64</sup> Tuskegee stood for the need to protect people from experiments that ignored ethical issues.<sup>65</sup>

### Sickle Cell Anemia Screening

Sickle cell anemia is an inherited blood disorder, characterized by chronic anemia and periodic episodes of pain.<sup>66</sup> Sickle cell anemia affects African Americans and people of Mediterranean descent.<sup>67</sup> It is caused by an error in the gene that tells the body how to make hemoglobin.<sup>68</sup> This defective gene tells the body to make the abnormal hemoglobin that results in deformed red blood cells.<sup>69</sup> Children who inherit copies of the defective gene from both parents will have sickle

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<sup>58</sup> *Id.* at 123.

<sup>59</sup> JONES, *supra* note 46, at 123.

<sup>60</sup> *Id.* at 153.

<sup>61</sup> *Id.* at 1.

<sup>62</sup> *Id.* at 214.

<sup>63</sup> *Id.* at 223.

<sup>64</sup> Vernellia L. Randall, *Slavery, Segregation and Racism: Trusting the Health Care System Ain't Always Easy! An African Perspective on Bioethics*, 15 ST. LOUIS, U. PUB. L. REV. 191, 198 (1996).

<sup>65</sup> JONES, *supra* note 46, at 14.

<sup>66</sup> *What is Sickle Cell Anemia?*, American Sickle Cell Anemia Association, at [http://www.ascaa.org/what\\_is.htm](http://www.ascaa.org/what_is.htm). [hereinafter *What is?*].

<sup>67</sup> *What Causes Sickle Cell Anemia?*, American Sickle Cell Anemia Association, at <http://www.ascaa.org/cause.htm>. [hereinafter *What Causes?*].

<sup>68</sup> *Id.*

<sup>69</sup> *Id.*

cell anemia.<sup>70</sup> Children who inherit the defective sickle cell gene from one parent will have the sickle cell trait.<sup>71</sup> People with the sickle cell trait generally have no symptoms, but can pass the sickle cell gene to their children.<sup>72</sup> The trait does provide resistance to malaria, a benefit to people in parts of Africa where the gene is most prevalent.<sup>73</sup>

More than forty states perform a blood test on all newborn infants.<sup>74</sup> These tests are performed at the same time and from the same samples as other routine newborn screening tests.<sup>75</sup> Hemoglobin electrophoresis is the most popular diagnostic test.<sup>76</sup>

In 1972, Congress passed the National Sickle Cell Anemia Control Act.<sup>77</sup> The Sickle Cell Anemia Act provided for research, screening, counseling and education.<sup>78</sup> By 1975, more than 250 screening programs nationwide tested about half a million Blacks for sickle cell anemia. Initially, Congress passed the Act to improve the health of Blacks; however, it soon became a tool for racial discrimination. Fourteen states made testing mandatory for Blacks entering school, obtaining a marriage license or confined in prison.<sup>79</sup>

The excitement over the sickle cell trait led to discrimination against Blacks.<sup>80</sup> The autopsies of four Black army recruits showed severe sickling of their red blood cells.<sup>81</sup> The fact that a sickle carrier's blood cells could possibly sickle at high altitudes was used to justify Blacks' exclusion into the Air Force Academy.<sup>82</sup> Many major airlines fired flight attendants and pilots with the sickle cell trait.<sup>83</sup> Sickle cell carriers were also either charged higher insurance premiums by companies or denied insurance.<sup>84</sup>

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<sup>70</sup> *Id.*

<sup>71</sup> *Id.*

<sup>72</sup> See *What Causes?*, *supra* note 66.

<sup>73</sup> *Id.*

<sup>74</sup> *How is Sickle Cell Anemia Detected?*, American Sickle Cell Anemia Association, at <http://www.ascaa.org/detect.htm>.

<sup>75</sup> *How is Sickle Cell Anemia Detected?*, *supra* note 73.

<sup>76</sup> *Id.*

<sup>77</sup> DOROTHY ROBERTS, *KILLING THE BLACK BODY* 257 (1997).

<sup>78</sup> *Id.*

<sup>79</sup> *Id.*

<sup>80</sup> *Id.*

<sup>81</sup> *Id.*

<sup>82</sup> ROBERTS, *supra* note 76, at 257.

<sup>83</sup> *Id.* at 258.

<sup>84</sup> *Id.*

### **In vitro fertilization**

People are using in vitro fertilization (IVF) to conceive.<sup>85</sup> Even though Blacks have a higher infertility rate than whites, they are not receiving the benefits IVF provides.<sup>86</sup> Blacks have a higher fertility rate due to untreated sexually transmitted diseases and other barriers to health care.<sup>87</sup> Furthermore, the high cost of IVF treatments is too expensive for most Black families.<sup>88</sup> The average cost of IVF treatments is \$8,000.<sup>89</sup> Most insurance plans including Medicaid will not reimburse IVF services.<sup>90</sup> Without some type of additional subsidy, only a small minority of Blacks can afford IVF.<sup>91</sup>

Since few Blacks can afford IVF treatments, they are virtually excluded from stem cell research. Blacks do not have the opportunity to decide if there are remaining embryos after implantation, or to decide whether to donate, destroy or freeze cryogenically their eggs for future use.

## **LEGAL RESPONSES TO RACIAL DISPARITIES IN STEM CELL RESEARCH**

### **Potential Claims Under the Equal Protection Clause of the Fourteenth Amendment to the United States Constitution**

There is the possibility that a plaintiff could bring a claim under the Equal Protection Clause of the Fourteenth Amendment.<sup>92</sup> There is a possibility of pursuing greater racial equality in stem cell research; however, obstacles stand in the way of potential Equal Protection claims. For an effective Equal Protection Claim, the plaintiff must prove state action and an intention to discriminate.<sup>93</sup>

The Supreme Court determines whether the defendant is engaged in a public function, or whether a connection exists between the

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<sup>85</sup> *Id.* at 246.

<sup>86</sup> *Id.* at 252.

<sup>87</sup> ROBERTS, *supra* note 76, at 252.

<sup>88</sup> *Id.* at 253.

<sup>89</sup> *Id.*

<sup>90</sup> *Id.*

<sup>91</sup> *Id.*

<sup>92</sup> U.S. CONST. amend. XIV §1.

<sup>93</sup> *See, e.g.*, Personnel Administrator v. Feeney, 442 U. S. 256 (1979) (discriminatory impact is not enough to prove gender classification; plaintiff must prove a discriminatory purpose); Washington v. Davis, 426 U.S. 229 (1976) *discussed below*.

defendant and the government or whether the government compels the harm caused by defendant.

To win under the Fourteenth amendment, a plaintiff would have to show that the government intended to discriminate against minorities. For example in *Washington v. Davis*, the Supreme Court stated that there must be intentional, purposeful, discrimination to state a claim under the Equal Protection Clause.<sup>94</sup> Discriminatory impact is not enough to establish a prima facie case of a Fourteenth Amendment Equal Protection claim.<sup>95</sup> Plaintiffs may find it difficult to prove that the government used purposeful discrimination. However, a potential plaintiff could argue that even though the stem cells guidelines are not facially discriminatory, the stem cell lines are the equivalent of a racial classification and the Supreme Court is required to evaluate the stem cell lines under strict scrutiny. However, a potential plaintiff would have to prove the significant obstacles of state action and intent to discriminate. An equal protection claim may not be the best legal option for a minority plaintiff.

#### **Title VI of the Civil Rights Act of 1964**

Before the passage of Title VI of the Civil Rights Act, racial discrimination was pervasive. Hospitals and health care facilities openly discriminated.<sup>96</sup> In 1964, Congress enacted Title VI to end discrimination against racial and ethnic minorities.<sup>97</sup> Title VI requires programs receiving federal funds to treat individuals of different races, colors and national origins equally.<sup>98</sup> Title VI curtailed blatant racism in health care facilities.<sup>99</sup> However, subtle racism still prevents African Americans from receiving complete access to federally funded programs and medical facilities. Title VI gives the government the authority to determine how programs are funded.<sup>100</sup>

Anyone receiving federal funding must accept the conditions attached to the receipt of those funds, or they can forego federal

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<sup>94</sup> *Washington*, 426 U.S. at 239.

<sup>95</sup> *Id.*

<sup>96</sup> Amy Jurevic, *Disparate Impact Under Title VI: Discrimination, by Any Other Name, Will Still Have The Same Impact*, 15 ST. LOUIS U. PUB. L. REV. 237, 238 (1996).

<sup>97</sup> H.R. REP. NO. 914, at 2355 (1964).

<sup>98</sup> 42 U.S.C. § 2000d (2002).

<sup>99</sup> *Id.* Title VI states: "No person in the United States shall, on the ground of race, color or national origin be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

<sup>100</sup> *Id.*

funding and be free of the legal obligation to treat races equally.<sup>101</sup> The spending of Title VI comes from the spending power of the Constitution and depends on administrative procedures for enforcement. Title VI's enforcement mechanism is administrative.

Yet disparate impact is a constant problem in the health care setting. Disparate impact includes those practices that adversely affect one group more than another regardless of intent.<sup>102</sup> The Supreme Court introduced the theory of disparate impact discrimination in *Griggs v. Duke Power Co.*<sup>103</sup> The Court held that a plaintiff need not necessarily prove intentional discrimination to establish an employer's violation of Title VII of the Civil Rights Act.<sup>104</sup> Although the disparate impact theory was originally created for employment discrimination, courts now apply the theory to claims brought pursuant to Title VI cases.<sup>105</sup>

To prove a Title VI disparate impact, a plaintiff must demonstrate that a facially neutral selection practice has caused a racially disproportionate impact.<sup>106</sup> Second, upon a successful showing by plaintiff, the burden of rebuttal shifts to the defendant, who must show that the selection practice causing the disproportionate effect is justified by an educational "necessity."<sup>107</sup> On rebuttal, the defendant only bears a burden of producing evidence to support its educational necessity.<sup>108</sup> Finally, should the defendant meet its burden of production, plaintiff may nonetheless prevail by: (1) discrediting the asserted educational necessity or (2) proffering an equally effective alternative practice resulting in less disparate impact while still advancing the articulated educational necessity.

The Court reviewed the reach of Title VI in *Guardians Association v. Civil Service Commission*.<sup>109</sup> In *Guardians*, Black and Hispanic police officers filed a class action challenging the use of written examinations to hire entry level officers to the New York City Police Department.<sup>110</sup> Minorities scored lower on the tests.<sup>111</sup> Since

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<sup>101</sup> *Id.*

<sup>102</sup> *Griggs v. Duke Power Co.*, 401 U.S. 424 (1971).

<sup>103</sup> *Id.*

<sup>104</sup> *Id.*

<sup>105</sup> *See Guardians Ass'n. v. Civil Service Commission*, 463 U.S. 582 (1983)

<sup>106</sup> *Id.* at 593.

<sup>107</sup> *Id.* at 598.

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

<sup>109</sup> *Guardians*, 463 U.S. at 582.

<sup>110</sup> *Id.* at 585.

appointments were based on test scores, minorities were hired after Whites.<sup>112</sup> The New York Police Department laid off police officers on a "last-hired, first-fired" basis. The officers with the lowest test scores were laid off first, causing proportionately more Black and Hispanic officers to be fired.<sup>113</sup> The plaintiffs brought a class action alleging that the examinations violated Title VI and Title VII, because they had a disproportionate impact on minority applicants.<sup>114</sup> The district court held that an implied private right of action existed under Title VI and that proof of discriminatory effect was enough to establish a violation of Title VI.<sup>115</sup> It rejected the Police Department's argument that only proof of discriminatory intent was sufficient. The district court found that the same equitable relief available under Title VII should be provided under Title VI.<sup>116</sup> The court awarded constructive seniority, backpay, and back medical and insurance benefits.<sup>117</sup> The Second Circuit affirmed the Title VII relief but reversed as to Title VI.<sup>118</sup>

*Guardians* resolved that private Title VI plaintiffs can prevail upon a showing of disproportionate adverse impact without proof of intent to discriminate as long as they are careful to allege a violation of the Title VI regulations.<sup>119</sup> The case left open, though, the question of the relief available to Title VI plaintiffs.<sup>120</sup>

Yet a different *Guardians* majority than those that coalesced around the intent versus impact issues concluded that both prospective and retrospective equitable relief were available to Title VI plaintiffs who proved either intentional or unintentional discrimination. Justices Stevens, Brennan, Blackmun, and Marshall reasoned that both prospective and retrospective legal and equitable relief were available to all Title VI plaintiffs. Justice O'Connor, concurred that proof of intent was a required element, agreed that both prospective and retrospective equitable relief were available to all Title VI plaintiffs,

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<sup>111</sup> *Id.*

<sup>112</sup> *Id.*

<sup>113</sup> *Id.* at 585.

<sup>114</sup> *Guardians Ass'n*, 463 U.S. at 586.

<sup>115</sup> *Id.* at 587.

<sup>116</sup> *Id.*

<sup>117</sup> *Id.* at 588.

<sup>118</sup> *Id.*

<sup>119</sup> *Guardians Ass'n*, 463 U.S. at 602.

<sup>120</sup> *Id.* at 607.

but reserved judgment on the question of whether there is a private cause of action for damages relief under Title VI.<sup>121</sup>

Since *Guardians*, the Court has not addressed directly the question of whether plaintiffs who prove disproportionate adverse impact discrimination may recover retroactive, equitable relief. However, a unanimous Court has cited *Guardians* saying that "[a] majority of the Court agreed that retroactive relief is available to private plaintiffs for all discrimination, whether intentional or unintentional, that is actionable under Title VI."<sup>122</sup> The Court has not characterized this majority vote as a "holding," although it has so characterized its majority votes on disproportionate adverse impact theory. Thus, the precedential effect of the remedies vote, given the change in Supreme Court personnel since *Guardians*, is unknown. The remedies question is generally of marginal importance only in Title VI health care cases because such actions typically seek prospective injunctive relief rather than any form of retrospective relief. In its tortured way *Guardians* resolved that Title VI plaintiffs could prevail upon a showing of disproportionate adverse impact.<sup>123</sup> Yet because the Supreme Court affirmed the Second Circuit's reversal of the trial court's judgment, *Guardians* did not reach the issue of the parties' evidentiary burdens in a Title VI disproportionate adverse impact discrimination suit. These are important issues. The nature of the defenses available in a Title VI disproportionate adverse impact case -- which party has the burden of producing evidence and who bears the risk of non-persuasion -- can be determinative of the outcome in any Title VI case. These Title VI questions remain unsettled. In *Alexander v. Choate* the Court referred to a majority in *Guardians* as "holding" that Title VI itself, apart from its regulations, reaches only intentional discrimination.<sup>124</sup> The *Alexander* court also referred to *Guardians* as "holding" that the Title VI implementing regulations that prohibit facially neutral policies having an unjustified disparate impact were valid.<sup>125</sup>

Title VI litigation has not ended health care discrimination caused by these facially neutral policies with a disproportionate impact on minorities. Title VI's implementing regulations proscribe facially neutral policies and practices that, in operation, have the effect of

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<sup>121</sup> *Id.* at 612.

<sup>122</sup> *Consolidated Rail Corp v. Darrone*, 465 U.S. 624, 631 n.9 (1984).

<sup>123</sup> *See Guardians*, 463 U.S. 582.

<sup>124</sup> *Alexander v. Choate*, 105 S. Ct. 712, 716 (1985).

<sup>125</sup> *Id.* at 716.

disproportionately excluding minorities, regardless of the defendant's lack of subjective discriminatory intent. But lower courts have allowed hospitals to defend too easily such policies. In the health care setting, federally funded defendants have been allowed to successfully defend policies with a disproportionate adverse racial impact by showing that the policies are rationally related to any legitimate, non-discriminatory purpose.<sup>126</sup> Thus, Title VI's authors drafted an administrative compliance mechanism empowering the federal agencies that award federal financial assistance to refuse to grant funds and to terminate funding to any recipient found in violation of the Title VI regulations after an opportunity for an administrative hearing.<sup>127</sup> The federal agency does not need to seek a court order, but the funding recipient may seek judicial review of agency action.

Although a federal funding recipient may not discriminate in any of its activities if any part receives federal financial assistance, the administrative sanction for violation of Title VI is termination of federal funds only to the "particular program, or part thereof, in which such noncompliance has been so found."<sup>128</sup> Federal funds specified for a specific purpose are not terminated unless discrimination is found in the use of those funds or the use of those funds is infected by discrimination elsewhere in the operation of the recipient.

Title VI provides expressly only for administrative enforcement. However, the Supreme Court has implied a cause of action for private individuals to sue to enforce both the statute and its implementing regulations.<sup>129</sup> The remedies available to a private plaintiff in a court action do not include termination of federal funding, but a plaintiff who proves intentional discrimination can recover both equitable retrospective and prospective relief, including backpay. The Court has not yet addressed whether such a plaintiff can also recover damages. The Court has also left open the question of the relief available to a Title VI plaintiff who proves disproportionate adverse impact discrimination but who does not prove intent to discriminate. While the Eleventh Amendment prohibits Title VI suits in federal court against a state for compensatory monetary damages, this prohibition

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<sup>126</sup> See, e.g., *Bryan v. Koch*, 627 F.2d 612, 668 (2d Cir. 1980); *NAACP v. Med Ctr. Inc.*, 657 F.2d 1322, 1332 (3d Cir. 1981).

<sup>127</sup> See 42 U.S.C.A. § 2000d, Official Comments (2002).

<sup>128</sup> 42 U.S.C.A. § 2000d (2002).

<sup>129</sup> *Guardians Ass'n*, 463 U.S. at 582.



does not extend to suits against state officials for prospective injunctive relief.

Title VI does not specifically explain discrimination. Rather, it directs each federal administrative agency that provides federal financial assistance to enforce "rules, regulations, or orders of general applicability" effectuating the provisions of Title VI.<sup>130</sup> The Title VI regulations all define prohibited "discrimination" in the same general terms prohibiting, among other things, "criteria or methods of administration which have the effect of subjecting individuals to discrimination because of their race, color, or national origin, or have the effect of defeating or substantially impairing accomplishment of the objectives of the program as respect individuals of a particular race, color, or national origin."<sup>131</sup> While the administrative agencies charged with enforcing Title VI have been unanimous and consistent in concluding that Title VI should prohibit policies and practices that have a disproportionate adverse impact on minorities, the Supreme Court has not been consistent with its rulings.

The Title VI health care cases involve situations that are significantly different from the facts normally analyzed under Title VII. At the appellate level, *Bryan v. Koch*<sup>132</sup> concerns a decision to close a public hospital, while *NAACP v. Medical Center, Inc.*<sup>133</sup> involves a decision to relocate a non-profit hospital. Rather than applying Title VII standards, *Bryan* holds and *NAACP* implies that in the Title VI health care context, a policy with a disparate impact can be justified by showing merely that the policy is rationally related to a legitimate need.

*Bryan* arose when the city of New York decided to close Sydenham Hospital, a public hospital that served a large minority population.<sup>134</sup> Plaintiffs filed a Title VI action alleging that the closing of Sydenham had a disparate impact on Blacks and Hispanics.<sup>135</sup> The court unanimously held that the plaintiffs had established a prima facie

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<sup>130</sup> 42 U.S.C.A. § 2000d-1 (2002) reads: Each federal department and agency which is empowered to extend Federal financial assistance to any program or activity, by way of grant, loan, or contract . . . is authorized and directed to effectuate the provisions of section 2000d of this title with respect to such program or activity by issuing rules, regulations, or orders of general applicability which shall be consistent with achievement of the objectives of the statute authorizing the financial assistance in connection with which the action is taken.

<sup>131</sup> 45 C.F.R. § 80.3(b)(1)(vii)(2) (2002).

<sup>132</sup> *Bryan v. Koch*, 627 F.2d 612, (2d Cir. 1980).

<sup>133</sup> *NAACP v. Med. Ctr. Inc.*, 657 F.2d 1322, (3d Cir. 1981).

<sup>134</sup> *Bryan*, 627 F.2d at 614.

<sup>135</sup> *Id.* at 614.

case of disparate impact.<sup>136</sup> The court inquired instead whether the decision to close Sydenham was rationally related to a legitimate objective.<sup>137</sup> New York City's reasoning for closing Sydenham was that the closure would reduce total hospital expenditures and would increase efficiency within the municipal hospital system.<sup>138</sup> The court found that the city's goal of saving money and increasing efficiency was obviously a legitimate objective.<sup>139</sup> The court then reviewed whether the criteria used to decide which hospital to close were reasonably related to reducing expenditures and increasing efficiency and whether the decision to close Sydenham was justified according to these criteria.<sup>140</sup> Since the plaintiffs did not disagree that Sydenham was the appropriate hospital to close if New York had to close, the court found that the city's decision to close Sydenham withstood this rational relationship scrutiny.<sup>141</sup> Plaintiffs argued that the city could save just as much money and increase hospital efficiency with less impact on minorities by regionalizing hospital services, merging hospitals or increasing Sydenham's services to make it more profitable to operate rather than closing Sydenham or any public hospital.<sup>142</sup> The court feared that an alternative inquiry that went beyond the question of which hospital to close would impinge upon elected officials' discretion to run their city government.

The second Title VI health care decision to address the defendant's burden of justification arose in the context of a hospital site controversy. *NAACP* involved a proposed hospital reorganization and relocation from the predominately Black inner city of Wilmington, Delaware, to a predominately white suburb.<sup>143</sup> First plaintiffs alleged that the relocation plan violated Title VI because the Medical Center's remaining urban facility would become a "ghetto hospital" serving primarily minorities, the poor, elderly and handicapped, while the proposed suburban hospital would treat only the more affluent, white population.<sup>144</sup> Second, the plaintiffs alleged that the relocation of certain acute care services exclusively to the new suburban hospital

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<sup>136</sup> *Id.*

<sup>137</sup> *Id.* at 620.

<sup>138</sup> *Id.* at 618.

<sup>139</sup> *Bryan*, 627 F.2d at 620.

<sup>140</sup> *Id.* at 617.

<sup>141</sup> *Id.* at 620.

<sup>142</sup> *Id.*

<sup>143</sup> *NAACP*, 657 F.2d 1322.

<sup>144</sup> *Id.* at 1324.

would make them virtually inaccessible to many handicapped and minority residents.<sup>145</sup>

The Third Circuit, sitting en banc, assumed that the plaintiffs had established a prima facie case of disparate impact but affirmed the district court's finding that the defendant had met its burden of justification.<sup>146</sup> The court held that the Title VI plaintiff bore the risk of non-persuasion on the defendant's justification in a Title VI case.<sup>147</sup>

The court affirmed the district court's analysis that the defendant had met its burden of justification. The district court had required that the relocation serve a legitimate bona fide interest and that there be no less discriminatory alternative. In affirming, a plurality characterized the district court's standard as more stringent than a rational relationship test and "more than adequately served Title VI aims," while suggesting that the appropriate standard for judging a Title VI defendant's justification was a rational relationship test required by the Constitution.<sup>148</sup>

The rational relationship test articulated in *Bryan* and *NAACP* is so undemanding that a decision to use the standard is tantamount to holding that the challenged policy is valid. Rational relationship scrutiny merely inquires whether there is any relationship between the challenged practice and any legitimate goal. It strikes down only classifications that are arbitrary because they fail to advance any legitimate goal. Rational relationship scrutiny does not require any degree of correlation; it asks merely if there is any relationship.

Any disproportionate adverse impact should require a heavier burden of justification than mere rational relationship. For example in *Washington v. Davis*, the Supreme Court held that the Constitution did not prohibit policies and practices with a disproportionate adverse racial impact, but required merely that such policies, like all governmental classifications, be justified as at least bearing a rational relationship to some legitimate governmental goal.<sup>149</sup> The Title VI regulations forbidding facially neutral policies that impact disproportionately on minorities reach beyond this constitutional prohibition to forbid facially neutral policies that can be justified under a rational relationship test. By definition, a prohibition on

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<sup>145</sup> *Id.* at 1326.

<sup>146</sup> *Id.* at 1336.

<sup>147</sup> *Id.*

<sup>148</sup> *See id.* at 1337 n.18.

<sup>149</sup> *Washington*, 426 U.S. at 239.

disproportionate adverse impact discrimination requires a more stringent justification than the mere rational relationship required by the Constitution.

Title VI allows private parties to file legal complaints alleging a Title VI violation.<sup>150</sup> In response to racial discrimination in the health care sector, plaintiffs have used Title VI in attempts to prevent hospitals geographically placed in predominantly black communities from closing or relocating to white neighborhoods.<sup>151</sup> The Supreme Court has recognized that Title VI applies when there is disproportionate adverse impact discrimination, without proof of intent to discriminate as long as the plaintiff alleges a violation of Title VI's implementing regulations. In *Alexander v. Choate*, the Court held that Title VI applies only to intentional discrimination.<sup>152</sup> In *Alexander*, Medicaid recipients brought a class action for declaratory judgment and injunctive relief against the state of Tennessee Medicaid's reduction of inpatient hospital days.<sup>153</sup> Second, respondents argued that any limitation was likely to disadvantage the handicapped disproportionately.<sup>154</sup> Respondents argued that the change from 20 to 14 days of Medicaid coverage would have a disproportionate effect on the handicapped and was discriminatory.<sup>155</sup> The court added that Title VI plaintiffs could state a claim by showing a disproportionate adverse impact without proof of intent to discriminate as long as the plaintiff alleged a violation of Title VI implementing regulations.

A federally funded health care defendant should do more than merely assert that the policy furthers an important purpose. It should introduce some empirical evidence establishing that the challenged practice is, in fact, effective in furthering an important program need. The higher the disproportionate adverse impact the more effective the challenged practice needs to be to justify its continued use. For example, if a policy excluded almost all minority patients while only incrementally improving the quality of patient care, the policy would not "significantly" further the important, legitimate objective of non-discriminatory, high-quality care. In effect, the requirement of a "significant" relationship creates a balancing test. However, the

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<sup>150</sup> 42 U.S.C. § 2000d (2002).

<sup>151</sup> *Alexander v. Choate*, 469 U.S.287, 293. (1985).

<sup>152</sup> *Id.*

<sup>153</sup> *Id.* at 289.

<sup>154</sup> *Id.* at 290.

<sup>155</sup> *Id.* at 715.

purpose of the proposed Title VI standard is to create nondiscriminatory alternatives. Rather than inquiring directly into the strength of the relationship between the policy chosen and the goal sought, evidence of less discriminatory alternatives provides a framework for evaluating a health care provider's need for a facially neutral practice that disparately impacts minorities. In *Alexander*, the existence of workable alternatives proves that the challenged policy is insufficiently related to the hospital's asserted goal or that the hospital's interests advanced by a particular policy are not important enough to justify use of the policy in light of its disparate racial impact.<sup>156</sup>

Nevertheless, minorities still do not get the health care services they need nor are they fully integrated into the mainstream of American health care. Longstanding hospital policies, such as private physician rules and pre-admission deposits, still operate to exclude minority patients from federally funded health care.

Courts should not be reluctant to scrutinize the operation of federally funded programs. Title VI is a spending power statute.<sup>157</sup> It does not regulate, but places conditions on the expenditure of federal money.<sup>158</sup> As a condition of receipt of federal Medicaid and Medicare money, hospitals and other health care providers guarantee that they will not use policies and practices that have the effect of excluding minority patients. Courts should hold health care providers to their promise.<sup>159</sup>

It is highly likely that under embryonic stem cell research, a minority plaintiff could bring a case against Health and Human Services. First, the federal financial assistance requirement is met. The companies that are participating are receiving federal funding. Second, the plaintiff would have to show that Title VI implementing regulations that forbid organizations receiving federal funding from using "criteria or methods of administration which have the effect of subjecting individuals to discrimination because of their race, colors or national origin, or have the effect of defeating or substantially impairing the accomplishments of the objects of the program as respect individuals of a particular race, color, or national origin.

Stem cell research policies are "facially neutral policies that have a disproportionate adverse impact." They are "facially neutral" because

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<sup>156</sup> *Alexander*, 105 S. Ct. at 715.

<sup>157</sup> *See Guardians Ass'n*, 463 U.S. at 599.

<sup>158</sup> *Id.*

<sup>159</sup> *Id.*

they may not have been enacted with the subjective intent of discriminating. Their impact is disproportionate because they hit the poor and minorities harder than other groups. Their effect is adverse because in the health care context such exclusionary policies can be deadly.

Stem cell research is supposed to be for the community. The government has an obligation to preserve and save lives. The federal government's role is to ensure that basic research occurs.<sup>160</sup> The state has an obligation to protect and keep the community safe.<sup>161</sup> Stem cell research is an example of a policy of mixed moral considerations and obligations. The state has an obligation to preserve the lives and the health of its members. However, not every member of the country is equally represented in the stem cell research project. The National Institute of Health (NIH) justifies its current number of stem cells. NIH argues that it is currently too early to determine benefits, and it will only know with considerable future research.<sup>162</sup> However, if minorities are not included in the basic research, how can they be certain they will benefit from cures once they are discovered? Secretary Thompson argued that research has been conducted on mice using only five stem cell lines.

## CONCLUSION

The federal government has made a significant financial commitment to healthcare. Health care spending is one of the largest components of the federal budget, accounting for 193 billion federal dollars in 2002.<sup>163</sup> Federal money, primarily Medicaid and Medicare, pays for approximately 30% of the total costs of health care in the United States.<sup>164</sup> The federal government's role is greatest in the health care sector, where federal dollars pay for 43% of the care provided, but

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<sup>160</sup> Tommy G. Thompson, Speech to Senate Health, Education Labor and Pensions Committee: *Embryonic Stem Cell Research* (Sept. 5, 2001, available at <http://www.hhs.gov.news/speech/2001/010905.html>).

<sup>161</sup> Michelle Goodwin, *Deconstructing Legislative Consent Law: Organ Taking, Racial Profiling and Distributive Justice*, 6 VA. J.L. & TECH. 2 (Spring 2001).

<sup>162</sup> NIH Update, *supra* note 1.

<sup>163</sup> Budget of the United States Government 97 (2002).

<sup>164</sup> *Hispanic and Black Americans Still More Likely than Whites to be Uninsured*, AGENCY FOR HEALTH CARE RESEARCH AND QUALITY PRESS RELEASE, available at, <http://www.ahrq.gov/news/press/pr2000/meps98r.htm> (Aug. 2, 2000)

federal money also pays for 24% of doctors' fees and 27% of nursing home costs.<sup>165</sup>

However, minority Americans are still in worse health and receive less health care than white Americans. Although Blacks are generally in worse health than Whites, they receive fewer services from doctors and hospitals. Blacks have a lower percentage of usual sources of medical care than Whites.<sup>166</sup> A disproportionate number of Blacks rely on hospital emergency rooms and outpatient clinics for primary care.<sup>167</sup>

If minorities are ever to gain full access to America's health care system, judges must stringently scrutinize facially neutral policies that exclude a disproportionate number of minority patients. Title VI's implementing regulations specifically prohibit facially neutral policies that have the effect of discriminating against minorities, and courts should strictly construe the regulations. Companies testing embryo stem cells bear a heavy burden to justify such policies and to show that there are no less discriminatory alternatives available. Business as usual is not delivering health care to minority Americans.

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<sup>165</sup> *Id.*

<sup>166</sup> J.L. Hargraves, P.J. Cunningham, and R.G. Hughes, *Racial Disparities in Access to Care Pervasive in Managed Care Plans*, ROBERT WOOD JOHNSON FOUNDATION, available at [http://www.rwjf.org/publications/advances/2002\\_Issue\\_1/abridge1jhtml](http://www.rwjf.org/publications/advances/2002_Issue_1/abridge1jhtml) (2002).  
[Rwjf.org/publications/advances/2002\\_Issue\\_1/abridge1jhtml](http://www.rwjf.org/publications/advances/2002_Issue_1/abridge1jhtml).

<sup>167</sup> *Id.*