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## But Names Will Never Hurt Me: HIV Surveillance & Mandatory Reporting

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# BUT NAMES WILL NEVER HURT ME: HIV SURVEILLANCE & MANDATORY REPORTING

Twenty-year-old Nushawn Williams knew he was infected with the human immunodeficiency virus ("HIV").<sup>1</sup> Still, he had unprotected sex with dozens of women.<sup>2</sup> As a result, he has infected at least ten women with HIV and exposed many more to the deadly virus.<sup>3</sup>

Authorities knew in August 1996 that Williams was infected but could do nothing.<sup>4</sup> New York law prohibits releasing information regarding individuals' HIV status without their consent.<sup>5</sup> In the county where Williams resides, however, officials used a court order to circumvent the law.<sup>6</sup> After pinpointing Williams as the source of a traceable pattern of HIV infections, public health officials invoked an "imminent danger" clause in the law to obtain a judge's permission to reveal Williams' identity.<sup>7</sup>

In 1988, the New York Legislature enacted a law designed to treat HIV tests differently than tests for other sexually transmitted diseases.<sup>8</sup> If individuals test positive for a sexually transmitted disease, such as syphilis, their names are reported to county health agencies.<sup>9</sup> Officials then contact the individuals and urge them to reveal the names of their sexual partners.<sup>10</sup> Without revealing the names of the individuals carrying the disease, the county then attempts to contact their partners and encourages them to be tested.<sup>11</sup>

By contrast, if individuals test positive for HIV, their names are not reported anywhere.<sup>12</sup> Thousands of New Yorkers are tested anonymously at clinics every year; they are assigned numbers so that no one

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<sup>1</sup> See Jeffrey L. Reynolds, *Stop Unsafe Sex, Save Patient's Privacy*, NEWSDAY, Nov. 4, 1997, at A37.

<sup>2</sup> See *id.*

<sup>3</sup> See *id.*

<sup>4</sup> See William F. Buckley, Editorial, *Public Must Know Carriers of HIV*, SAN ANTONIO EXPRESS-NEWS, Oct. 31, 1997, at 5B.

<sup>5</sup> See Reynolds, *supra* note 1, at A37.

<sup>6</sup> See *id.*

<sup>7</sup> See *id.*

<sup>8</sup> See Tom Precious, *State's HIV Confidentiality Policy May Change*, BUFFALO NEWS, Nov. 1, 1997, at A1.

<sup>9</sup> See *id.*

<sup>10</sup> See *id.*

<sup>11</sup> See *id.*

<sup>12</sup> See *id.*

will ever know who they are.<sup>13</sup> Health officials can encourage those who test positive to tell their partners, but there is no formal mechanism through which officials can track down potential HIV victims.<sup>14</sup> Critics say this system of blanket confidentiality must change.<sup>15</sup> Thus, state and federal officials are currently scrutinizing the way the disease is reported.<sup>16</sup>

Every state mandates name-based reporting of acquired immune deficiency syndrome ("AIDS") diagnoses, as opposed to HIV, and public health departments maintain these name-based AIDS case registries.<sup>17</sup> This form of AIDS surveillance has, until recently, formed the cornerstone of the nation's efforts to monitor and characterize HIV.<sup>18</sup> Many public health officials, however, are concerned that existing AIDS surveillance efforts are becoming outdated due to changes in the epidemic.<sup>19</sup> With new treatment options slowing the progression of HIV and the resulting fewer numbers of AIDS cases in the United States, many believe that AIDS surveillance data are less indicative of the actual number and demographics of the HIV-positive population.<sup>20</sup>

States have responded to the need for improved HIV surveillance data with varying HIV reporting systems.<sup>21</sup> A majority of states have taken AIDS case reporting one step further by adopting some form of mandatory HIV name reporting.<sup>22</sup> Under a mandatory name-based reporting system, names of individuals testing HIV-positive are reported to state health departments and compiled in central HIV registries.<sup>23</sup> Concerns about keeping HIV surveillance data confidential, however,

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<sup>13</sup> See Precious, *supra* note 8, at A1.

<sup>14</sup> See *id.*

<sup>15</sup> See *id.*

<sup>16</sup> See Lynda Richardson, *Progress on AIDS Brings Movement for Less Secrecy*, N.Y. TIMES, Aug. 21, 1997, at A1.

<sup>17</sup> See Anna Forbes, *Naming Names*, AIDS POL'Y & L., May 1996, at 1 [hereinafter Forbes, *Naming Names*]. Every state has a statute or regulation requiring laboratories and physicians to report the names of individuals with newly diagnosed AIDS to local and state health departments. See Lawrence O. Gostin et al., *National HIV Case Reporting for the United States—A Defining Moment in the History of the Epidemic*, 337 NEW ENG. J. MED. 1162, 1163 (1997). Case reports follow uniform standards to provide complete, timely and accurate data. See *id.* Reported information includes demographic data, the name of the physician or laboratory making the diagnosis, the patient's risk history, a laboratory analysis, the patient's clinical status and any referrals for treatment or services. See *id.*

<sup>18</sup> See Gostin et al., *supra* note 17, at 1162.

<sup>19</sup> See *First-Ever AIDS Incidence Decline Marks Start of a New Era in Epidemic: Downward Trend Could Change Level of Services, Funding*, AIDS ALERT, Nov. 1, 1997, at 121, available in 1997 WL 8961981 [hereinafter *First-Ever AIDS Incidence Decline*].

<sup>20</sup> See Mark Schoofs, *What's in a Name?* VILLAGE VOICE, Apr. 7, 1998, at 37.

<sup>21</sup> See *First-Ever AIDS Incidence Decline*, *supra* note 19, at 121.

<sup>22</sup> See Forbes, *Naming Names*, *supra* note 17, at 1.

<sup>23</sup> See *Creating an Effective Public Health Response to the Changing Epidemic: Moving to HIV*

have prompted other states to adopt reporting with non-name identifiers.<sup>24</sup> Some states conduct HIV surveillance by a unique identifier system, using numeric codes instead of patient names.<sup>25</sup> Most high-incidence states, however, have not yet adopted an HIV reporting system.<sup>26</sup>

This Note explores the legal and policy considerations surrounding HIV reporting systems. Section I briefly reviews the distinction between AIDS and HIV.<sup>27</sup> Section II discusses the need for HIV surveillance.<sup>28</sup> Section III examines the two main reporting systems, mandatory name reporting and unique identifier reporting.<sup>29</sup> Section IV reviews the current standards courts apply to the constitutional issues that HIV reporting systems raise.<sup>30</sup> Finally, section V discusses the constitutionality of these systems and argues that, although both systems are likely to be constitutional, unique identifier systems are better suited for HIV surveillance than name reporting systems.<sup>31</sup>

## I. DISTINGUISHING AIDS AND HIV

In order to understand the tools used to monitor AIDS and HIV, it is helpful to distinguish between the two conditions. AIDS, first reported in the United States in 1981, is a disease caused by HIV.<sup>32</sup> HIV progressively destroys the body's ability to fight infections by killing or impairing the immune system's cells.<sup>33</sup>

Many individuals do not develop symptoms when they are first infected with HIV.<sup>34</sup> Some, however, develop a flu-like illness within a few months after viral exposure.<sup>35</sup> These symptoms are often mistaken for symptoms of another viral infection because they usually disappear within a week to a month.<sup>36</sup> More severe symptoms may not develop

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*Surveillance by Unique Identifier and Other Non-Name Based Surveillance Systems* (Oct. 1997) <<http://hivinsite.uscf.edu/topics/testing/209.8.347b.html>> [hereinafter *Creating an Effective Public Health Response*].

<sup>24</sup> See *id.*

<sup>25</sup> See *id.* at 2.

<sup>26</sup> See *id.*

<sup>27</sup> See *infra* notes 32–52 and accompanying text.

<sup>28</sup> See *infra* notes 53–116 and accompanying text.

<sup>29</sup> See *infra* notes 117–151 and accompanying text.

<sup>30</sup> See *infra* notes 152–246 and accompanying text.

<sup>31</sup> See *infra* notes 247–405 and accompanying text.

<sup>32</sup> See *AEGIS: HIV Infection and AIDS* (last modified May 1997) <<http://www.aegis.com/topics/whataids.html>> [hereinafter *AEGIS*].

<sup>33</sup> See *id.*

<sup>34</sup> See *id.*

<sup>35</sup> See *id.* Symptoms may include a fever, headache, malaise and enlarged lymph nodes. See *id.*

<sup>36</sup> See *id.*

for ten or more years after HIV exposure to the body.<sup>37</sup> During this period, HIV destroys the immune system's cells.<sup>38</sup> This process is most apparent as a decline in the blood levels of CD4+T cells.<sup>39</sup>

The term AIDS applies to the most advanced stages of HIV infection.<sup>40</sup> The United States Centers for Disease Control and Prevention ("CDC"), the agency responsible for tracking the spread of the disease in the United States, develops the official criteria for the definition of AIDS.<sup>41</sup> In 1993, the CDC revised its definition to include all HIV-infected people who have fewer than 200 CD4+T cells.<sup>42</sup> Additionally, the definition includes twenty-six clinical conditions that affect people with advanced HIV.<sup>43</sup> Most of these conditions ordinarily do not harm healthy individuals.<sup>44</sup> In individuals with AIDS, however, these infections may be fatal because the immune system is weak and the body cannot fight off bacteria and viruses.<sup>45</sup> Many individuals become so debilitated by AIDS symptoms that they can neither hold steady employment nor do household chores.<sup>46</sup> Others experience phases of intense life-threatening illness followed by phases of normal functioning.<sup>47</sup>

Because the early stages of HIV are often unaccompanied by symptoms, the disease is primarily detected by testing an individual's blood for HIV antibodies.<sup>48</sup> These antibodies are generally not detectable until one to three months following infection and may take up to six months to be generated in quantities large enough to appear in standard blood tests.<sup>49</sup> Over the past ten years, therapies have been

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<sup>37</sup> See *AEGIS*, *supra* note 32. This period of "asymptomatic" infection varies considerably from person to person. See *id.*

<sup>38</sup> See *id.*

<sup>39</sup> See *id.* These cells, also called T4 cells, are the immune system's key infection fighters. See *id.*

<sup>40</sup> See *id.*

<sup>41</sup> See *id.*

<sup>42</sup> See *AEGIS*, *supra* note 32. Healthy adults usually have CD4+T cell counts of 1000 or more. See *id.* During the course of HIV infection, many individuals experience a gradual decline in the number of these cells, while others may have abrupt and dramatic drops in the cell counts. See *id.*

<sup>43</sup> See *id.*

<sup>44</sup> See *id.*

<sup>45</sup> See *id.* Opportunistic infections common in people with AIDS cause symptoms such as coughing, shortness of breath, seizures, dementia, severe and persistent diarrhea, fever, vision loss, severe headaches, extreme fatigue, nausea, vomiting, lack of coordination, coma, abdominal cramps or difficult or painful swallowing. See *id.*

<sup>46</sup> See *id.*

<sup>47</sup> See *AEGIS*, *supra* note 32.

<sup>48</sup> See *id.*

<sup>49</sup> See *id.*

developed to fight HIV infection.<sup>50</sup> The Food and Drug Administration has approved several drugs for treatment including reverse transcriptase inhibitors and, more recently, protease inhibitors.<sup>51</sup> Currently available drugs, however, do not cure people of HIV infection or AIDS.<sup>52</sup>

## II. THE NEED FOR HIV SURVEILLANCE

HIV was not discovered until 1983 and testing for HIV antibodies did not become available until the mid-1980s.<sup>53</sup> Since then, there has been much debate about whether the names of HIV-infected individuals should be reported to confidential registries of public health departments.<sup>54</sup> This section describes the conditions that sparked that debate.

### A. *New Treatment & Early Detection*

Current AIDS data indicate that fewer people are dying of AIDS and that the number of AIDS cases per year is declining.<sup>55</sup> In 1996, the incidents of illnesses and deaths due to AIDS declined for the first time in the epidemic's history.<sup>56</sup> According to the CDC, deaths due to AIDS in 1996 decreased 23% and the decline was even greater for certain populations, such as homosexual and bisexual men.<sup>57</sup> Some experts suggest that the effect on these trends will become even more striking as more HIV-infected individuals are treated.<sup>58</sup>

Many health experts insist that successful new drug therapies make early detection and treatment even more crucial.<sup>59</sup> For example,

<sup>50</sup> See *id.*

<sup>51</sup> See *id.* Reverse transcriptase inhibitors interrupt an early stage of virus replication. See *id.* These classes of drugs, including AZT, may slow the spread of HIV in the body and delay the onset of opportunistic infections. See *id.* They do not, however, prevent transmission of HIV to other individuals. See *id.* Protease inhibitors interrupt virus replication at a later step in its life cycle. See *id.* Combination treatment using both types of drugs is necessary to effectively suppress the virus because HIV can become resistant to both. See *id.*

<sup>52</sup> See *AEIGIS*, *supra* note 32. Each of the drugs also have side effects that can be severe. See *id.* For example, AZT may deplete red or white blood cells. See *id.* Protease inhibitors can cause nausea, diarrhea or gastrointestinal symptoms. See *id.*

<sup>53</sup> See *HIV Surveillance and Name Reporting: A Public Health Case for Protecting Civil Liberties* (Oct. 1997) <<http://www.aclu.org/issues/aids/namereport.html#appendix1>> [hereinafter *HIV Surveillance and Name Reporting*].

<sup>54</sup> See Richardson, *supra* note 16, at A1.

<sup>55</sup> See *First-Ever AIDS Incidence Decline*, *supra* note 19, at 121.

<sup>56</sup> See Gostin et al., *supra* note 17, at 1162.

<sup>57</sup> See *id.*

<sup>58</sup> See *id.*

<sup>59</sup> See Richardson, *supra* note 16, at A1.

combination drug therapies with protease inhibitors have dramatically improved the health and prolonged the lives of many HIV-infected individuals.<sup>60</sup> Recent research suggests that a treatment regimen of HIV reverse-transcriptase inhibitors and protease inhibitors reduces mortality and delays disease progression.<sup>61</sup> Individuals who receive this type of regimen have been found to have lower levels of circulating virus, suggesting that treatment not only benefits the patient but also may reduce the risk of transmission.<sup>62</sup> In response to the promise of combination drug therapies and to clinical evidence which suggests that such therapies are more effective when started early in the course of HIV disease, most treatment guidelines now call for early and aggressive intervention.<sup>63</sup> Thus, some believe there are currently more compelling reasons to encourage testing and provide links to treatment than when few effective treatment options existed.<sup>64</sup>

Public health officials also believe that HIV reporting data will become more important as the number of HIV cases increases as a result of improved AIDS treatment.<sup>65</sup> Individuals with HIV infection are generally living longer and progressing to an AIDS diagnosis much more slowly.<sup>66</sup> Thus, AIDS surveillance alone may not provide an accurate view of the extent of the epidemic because those with HIV, but not AIDS, will not be represented.<sup>67</sup> Without comprehensive HIV data, the CDC could have difficulty determining where the epidemic is moving and whether the rate of new HIV cases is slowing.<sup>68</sup> In fact, new HIV infections could be increasing.<sup>69</sup> Without comprehensive HIV reporting data, however, the CDC's ability to monitor the extent of the hypothetical increase or its demographic characteristics is limited.<sup>70</sup> Furthermore, the true impact of prevention efforts is difficult to evaluate without HIV data.<sup>71</sup>

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<sup>60</sup> See *Creating an Effective Public Health Response*, *supra* note 23, at 2.

<sup>61</sup> See Gostin et al., *supra* note 17, at 1162.

<sup>62</sup> See *id.*

<sup>63</sup> See *Creating an Effective Public Health Response*, *supra* note 23, at 3.

<sup>64</sup> See *id.* The New England Journal of Medicine has urged mandatory reporting of HIV infections to state health departments to increase the chances that people will get early treatment. See *Medical Journal Wants Mandatory HIV Reports*, PORTLAND OREGONIAN, Sept. 11, 1997, at A16, available in 1997 WL 13119142.

<sup>65</sup> See *First-Ever AIDS Incidence Decline*, *supra* note 19, at 121.

<sup>66</sup> See *Creating an Effective Public Health Response*, *supra* note 23, at 3.

<sup>67</sup> See *id.*

<sup>68</sup> See *First-Ever AIDS Incidence Decline*, *supra* note 19, at 121.

<sup>69</sup> See *id.*

<sup>70</sup> See *id.*

<sup>71</sup> See *id.*

## B. Funding

Another factor lending support for HIV reporting is that federal funding is allocated based on the epidemic's impact on states, and thus, may be tied to the number of HIV cases and not just AIDS cases.<sup>72</sup> Commentators note that shifts in funding may be made geographically as HIV data reveal new infections increasing in certain regions.<sup>73</sup> They argue that many low to moderate HIV-incidence states have adopted mandatory name-based reporting because of the expected link between HIV name reporting and increased access to federal funds.<sup>74</sup> For instance, the AIDS Action Foundation reports that legislative efforts to implement mandatory name reporting in New Jersey were unsuccessful in 1985.<sup>75</sup> In 1990, however, the legislation passed and was instituted in September 1991, when the state simultaneously received a \$450,000 grant from the CDC for a computer surveillance program.<sup>76</sup> Thus, because federal money is allocated based on the epidemic's impact on states, some state health officials believe that those states which only report AIDS cases, such as New York, may have difficulty adequately describing their share of the AIDS burden.<sup>77</sup> As a result, these states could be at a disadvantage in not having HIV infection data.<sup>78</sup>

## C. The Trend Toward HIV Surveillance

### 1. The CDC

The United States Public Health Service has asked all states to begin monitoring and reporting everyone who tests HIV-positive.<sup>79</sup> Until September 1997, the CDC had only asked states to report cases of full-blown AIDS.<sup>80</sup> Now the CDC says that HIV reporting by states

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<sup>72</sup> See *id.*; Richardson, *supra* note 16, at A1.

<sup>73</sup> See *First-Ever AIDS Incidence Decline*, *supra* note 19, at 121. Before AIDS case data became less reliable, the CDC noted that the epidemic was decreasing in epicenters of the Northwest and West, where it first took hold. See *id.* This, however, has not been the case in the South. See *id.* AIDS incidence decreased only 1% in the South in 1996, compared to 12% in the West and 8% in the Northeast. See *id.*

<sup>74</sup> See Forbes, *Naming Names*, *supra* note 17, at 1.

<sup>75</sup> See *id.*

<sup>76</sup> See *id.*

<sup>77</sup> See Richardson, *supra* note 16, at A1.

<sup>78</sup> See *id.*

<sup>79</sup> See Huntly Collins & Warren King, *U.S. Wants States to Report Those Who Test HIV-Positive*, SEATTLE TIMES, Sept. 19, 1997, at A2.

<sup>80</sup> See *id.* Full-blown AIDS typically develops more than eight years after initial infection with HIV. See *id.*



would help public health officials monitor the course of the AIDS epidemic and target prevention and treatment programs to the most needy populations.<sup>81</sup> Furthermore, the CDC has advised all states not currently requiring name-based HIV reporting to implement "integrated HIV and AIDS surveillance."<sup>82</sup>

## 2. Uses of HIV Surveillance Data

The CDC states that HIV surveillance can "provide a more timely measure of emerging patterns of HIV transmission, a more complete estimate of the number of people with HIV infection and disease, and a better mechanism to evaluate access to HIV testing and medical and prevention services than AIDS surveillance alone."<sup>83</sup> Public health officials are convinced that HIV surveillance data could provide information as to the minimum number of persons known to be infected in a given area for whom services may be required.<sup>84</sup> These officials believe this estimate would provide an appropriate benchmark for distributing federal, state and local funds.<sup>85</sup> These officials further argue that HIV case surveillance could provide more recent data regarding the demographics of those people who have contracted HIV as opposed to those with AIDS.<sup>86</sup>

Health officials also note that HIV case surveillance may provide a basis for offering voluntary referrals to appropriate prevention and treatment programs for HIV-infected individuals.<sup>87</sup> They contend that

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<sup>81</sup> See *id.* The CDC, however, has not estimated the cost of the stepped-up reporting. See *id.*

<sup>82</sup> See Daniel J. DeNoon, *AIDS Testing CDC Recommends Name-Based HIV Surveillance*, AIDS WKLY. PLUS, May 18, 1998. States identified by the CDC as already having "integrated" surveillance programs are those that require name-based reporting. See *id.*

<sup>83</sup> *Creating an Effective Public Health Response*, *supra* note 23, at 3. The CDC Advisory Committee on the Prevention of HIV Infection has thus specified five goals for public health surveillance of HIV and AIDS: (1) target primary and secondary prevention; (2) evaluate the efficacy of prevention activities; (3) determine eligibility for federal, state and local health resources for services for HIV-infected individuals; (4) project future resources needed for care and prevention efforts; and (5) educate the public about the scope and impact of the epidemic. See COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS AND CENTERS FOR DISEASE CONTROL AND PREVENTION, CONSULTATION ON THE FUTURE OF HIV/AIDS SURVEILLANCE, May 21-22, 1997 [hereinafter CSTE & CDC].

<sup>84</sup> See CSTE & CDC, *supra* note 83.

<sup>85</sup> See Richardson, *supra* note 16, at A1.

<sup>86</sup> See CSTE & CDC, *supra* note 83. A higher proportion of persons with HIV, as opposed to AIDS, were women, blacks and 13-24 year-olds in cases reported from 1994 through 1996. See *id.* Although this may partly reflect differences in patterns of HIV, these trends support preliminary findings from other studies which suggest that women and minorities have the highest rates of recently acquired infection. See *id.*

<sup>87</sup> See *id.* Some states, including South Carolina, Missouri, Minnesota and New Jersey, are offering medical and social service referrals for HIV-infected people. See *id.*

early entrance into care slows the development of disease, may lower the spread of infection and results in substantial health care savings for the individual and the community.<sup>88</sup> Additionally, health officials believe that surveillance data may be used to target and evaluate specific HIV prevention interventions, including recommended procedures designed to reduce the risk of perinatal HIV transmission.<sup>89</sup>

Furthermore, public health officials note that HIV reporting would enable public health professionals to help physicians locate and notify patients who do not return for their HIV test results, and thus remain unaware of their infection.<sup>90</sup> These officials also urge using HIV reporting to support voluntary partner notification efforts.<sup>91</sup> The health officials note that the partner notification process increases the chances that women of childbearing age and those who do not perceive a personal risk for infection will become aware of their possible HIV exposure.<sup>92</sup> Thus, these officials contend that partners who are provided information about their at-risk status will be able to access needed early intervention services much sooner.<sup>93</sup>

### 3. Limitations of HIV Case Surveillance Data

Even if all states required HIV reporting, some experts recognize that HIV surveillance data may not represent all HIV cases.<sup>94</sup> They argue that many cases will still go unreported because some at-risk people do not seek testing, some infected people are tested anonymously and variations in testing practices may influence the data.<sup>95</sup> Furthermore, these experts note that states have initiated reporting at different times, thereby potentially influencing the number of HIV cases reported.<sup>96</sup> Using the most conservative estimates, the CDC pro-

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<sup>88</sup> See BUREAU OF HIV AND STD PREVENTION, TEXAS DEP'T OF HEALTH, RECOMMENDATIONS ON HIV INFECTION REPORTING 4 (1998) [hereinafter BUREAU OF HIV AND STD PREVENTION].

<sup>89</sup> See CSTE & CDC, *supra* note 83. A CDC analysis found that by September 1995, HIV surveillance states identified 49% of children who were born to infected mothers in 1993 compared to only 5% identified in states with only AIDS reporting. *See id.* Some experts believe these states can evaluate recommendations for reducing perinatal transmission and voluntary testing of pregnant women. *See id.* Additionally, they believe that changes in rates of perinatal transmission can be monitored in a timely fashion. *See id.*

<sup>90</sup> See BUREAU OF HIV AND STD PREVENTION, *supra* note 88, at 5.

<sup>91</sup> *See id.*

<sup>92</sup> *See id.* Thus, for those who are HIV-infected and pregnant, public health officials contend that timely medical intervention can greatly reduce transmission of the virus to newborns. *See id.*

<sup>93</sup> *See id.*

<sup>94</sup> See CSTE & CDC, *supra* note 83.

<sup>95</sup> *See id.*; *First-Ever AIDS Incidence Decline*, *supra* note 19, at 121.

<sup>96</sup> See CSTE & CDC, *supra* note 83.

jected that states with HIV reporting were picking up only about 25% of infections during the previous year to year-and-a-half.<sup>97</sup> At the same time, however, the CDC estimated that if all states had HIV reporting, approximately two-thirds of all HIV infections in the country already would have been reported.<sup>98</sup>

#### 4. The Federal Government and HIV Surveillance

The "HIV Prevention Act of 1997" proposes mandatory, confidential reporting of HIV infection and mandatory partner notification; it also includes a provision allowing providers to refuse invasive treatment to patients who will not agree to an HIV test.<sup>99</sup> The bill would require states to: report all HIV cases to the CDC; notify partners exposed to HIV (the CDC now requires states to notify partners for AIDS cases only); require HIV testing for people accused of sexual crimes; require insurance companies to provide test results to applicants; and permit parents to know the HIV status of adopted children.<sup>100</sup>

The bill would also force every state to eliminate anonymous HIV testing.<sup>101</sup> Critics argue that people who suspect that they are HIV-positive might delay testing and treatment for fear of being "outed" with HIV to employers and insurance companies.<sup>102</sup> Critics contend that untested individuals could die unnecessarily by not participating in promising new medical treatments available at the incipient stages of the disease.<sup>103</sup>

If states do not comply with the mandatory reporting requirement, the bill would authorize the federal government to withhold that state's portion of its Medicaid dollars.<sup>104</sup> Fifty percent of all Americans with HIV rely upon Medicaid for their health care.<sup>105</sup> Thus, critics argue that any attempt to restrict or withhold Medicaid funding will hurt people with HIV.<sup>106</sup>

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<sup>97</sup> See *First-Ever AIDS Incidence Decline*, *supra* note 19, at 121.

<sup>98</sup> See *id.*

<sup>99</sup> See *HIV Prevention Act Would Require HIV Reporting: AMA's Support of Coburn Bill Called 'Shocking,' AIDS ALERT*, May 1, 1997, at 54, available in 1997 WL 8961937; see also H.R. 1062, 105th Cong. (1997).

<sup>100</sup> See H.R. 1062.

<sup>101</sup> See *id.*; Commentary, *The Downside of the HIV Prevention Act*, TAMPA TRIB., May 18, 1997, at 3.

<sup>102</sup> See *The Downside of the HIV Prevention Act*, *supra* note 101, at 3.

<sup>103</sup> See *id.*

<sup>104</sup> See H.R. 1062; *The Downside of the HIV Prevention Act*, *supra* note 101, at 3.

<sup>105</sup> See *The Downside of the HIV Prevention Act*, *supra* note 101, at 3.

<sup>106</sup> See *id.*

Public response to the bill has been mixed.<sup>107</sup> Comments by CDC officials at the May 1997 meeting of their Advisory Committee for HIV and STD Prevention suggest that they are concerned about the bill.<sup>108</sup> The American Medical Association endorses the bill, but AIDS activists criticize it as punitive and detrimental to existing HIV prevention strategies.<sup>109</sup> Public health agencies opposing the bill include the American Public Health Association and the National Association of County and City Health Officials.<sup>110</sup> The National Alliance of State and Territorial AIDS Directors estimates that the bill would precipitate 265 statutory or regulatory changes with which states would have to comply.<sup>111</sup> Its sister group, the Association of State and Territorial Health Officials, estimates that the bill would cost states \$420 million a year to implement.<sup>112</sup>

## 5. The States and HIV Surveillance

A total of thirty-one states now require reporting of HIV cases, either by name or by unique identifiers.<sup>113</sup> AIDS cases in these states, however, account for less than one-third of the total AIDS cases, and presumably HIV cases, in the country.<sup>114</sup> Many of the states and territories with a higher incidence of HIV and AIDS, such as California, New York, Puerto Rico, Pennsylvania and Massachusetts, do not require HIV surveillance.<sup>115</sup> Other states use anonymous HIV surveil-

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<sup>107</sup> See *New Treatments Give HIV Reporting Added Weight: U.S. at 'Defining Moment' in History of Epidemic*, AIDS ALERT, July 1, 1997, at 80, available in 1997 WL 8961957 [hereinafter *New Treatments Give HIV Reporting Added Weight*].

<sup>108</sup> See *id.*

<sup>109</sup> See *id.*

<sup>110</sup> See *id.*

<sup>111</sup> See *id.*

<sup>112</sup> See *New Treatments Give HIV Reporting Added Weight*, *supra* note 107, at 80.

<sup>113</sup> See *First-Ever AIDS Incidence Decline*, *supra* note 19, at 121. New Mexico and Florida have recently approved legislation adopting mandatory HIV reporting. See *id.* Three of those 31 states—Texas, Connecticut and Oregon—report names of only pediatric HIV cases. See *id.* Among the states reporting HIV cases by name, 20 maintain the option of anonymous HIV testing. See *Creating an Effective Public Health Response*, *supra* note 23, at 2. Eight name reporting states do not have anonymous testing available. See *id.*

<sup>114</sup> See *First-Ever AIDS Incidence Decline*, *supra* note 19, at 121.

<sup>115</sup> See Editorial, *Keeping Track of HIV Cases*, BOSTON GLOBE, Oct. 25, 1997, at A4 [hereinafter *Keeping Track of HIV Cases*]. Of the states with the highest rates of reported AIDS cases in 1996, only Florida, New Jersey and Louisiana require HIV surveillance. See *Creating an Effective Public Health Response*, *supra* note 23, at 2. Massachusetts will be requiring HIV surveillance by unique identifiers as soon as an HIV reporting system is established. See Dolores Kong, *State to Require Reporting of HIV Cases but Massachusetts Breaks Ranks by Using Number Identifiers, Not Names*, BOSTON GLOBE, Feb. 24, 1998, at B4. California lawmakers are debating legislation to create a five-year pilot project to track HIV cases using a unique identifier system. See *California Nearing Decision on Reporting by Coded ID*, AIDS POL'Y & L. (LRP Publications, Horsham, PA), Sept. 4,

lance, thereby reporting only general demographic and exposure data.<sup>116</sup>

### III. THE TWO MAIN REPORTING SYSTEMS

#### A. *Mandatory Name Reporting*

In mandatory name reporting states, the names of individuals are attached to the blood samples which are sent to laboratories for testing.<sup>117</sup> If individuals test positive for HIV, the laboratories report their names to the state health department where their names are entered into an HIV registry.<sup>118</sup> In January 1992, New Jersey became the first high incidence state to adopt name-based HIV reporting.<sup>119</sup> New Jersey's mandatory reporting policy requires doctors to report the names of people diagnosed with HIV to state health officials who are under orders not to disclose these names.<sup>120</sup> According to Douglas Morgan, assistant commissioner in the New Jersey Department of Health and Senior Services, officials do not believe that the policy has deterred anyone from treatment.<sup>121</sup> The state has also established fifteen sites where people can be tested for HIV anonymously.<sup>122</sup> At these sites, people are identified by a number rather than by name.<sup>123</sup> Anonymous sites have identified about 1220 HIV-positive people since 1992, while 21,860 have been identified in doctors' offices, hospitals or clinics.<sup>124</sup>

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1998, at 7. Pennsylvania plans to require HIV surveillance but has not announced whether names or unique identifiers will be used. See *Most States Moving Toward HIV Reporting, but Methods Vary*, AIDS POL'Y & L. (LRP Publications, Horsham, PA), Mar. 20, 1998, at 5. The Governor of New York has signed a partner notification bill that includes name-based reporting of HIV cases. See *New York Governor Signs Bill to Track HIV Cases by Name*, AIDS POL'Y & L. (LRP Publications, Horsham, PA), July 24, 1998, at 1. Additionally, according to a survey completed February 19, 1998 by the National Alliance of State and Territorial AIDS Directors, name-based reporting systems are in various stages of planning in Alaska, Delaware, Georgia, Illinois, Kentucky, Maine and New Hampshire. See *Most States Moving Toward HIV Reporting, but Methods Vary*, *supra*, at 4.

<sup>116</sup> See *Creating an Effective Public Health Response*, *supra* note 23, at 2.

<sup>117</sup> See *AEGIS*, *supra* note 32; CSTE & CDC, *supra* note 83.

<sup>118</sup> See *Creating an Effective Public Health Response*, *supra* note 23, at 5.

<sup>119</sup> See Anna Forbes, *HIV InSite: Name Based HIV Case Reporting Fails in New Jersey—Why Institute It in New York?* (last modified Feb. 1998) <<http://hivinsite.ucsf.edu/topics/testing/2098.38fb.html>>.

<sup>120</sup> See Collins & King, *supra* note 79, at A2.

<sup>121</sup> See *id.*

<sup>122</sup> See *id.*

<sup>123</sup> See *id.*

<sup>124</sup> See *id.*

### B. Unique Identifier Reporting

Unique identifiers are numeric or alpha-numeric codes used to identify individuals.<sup>125</sup> They are used every day in the form of social security numbers, account numbers and drivers' license numbers.<sup>126</sup> For HIV testing, the goal is to create a code that identifies a person and to associate the HIV test result with that code as opposed to the name of that individual.<sup>127</sup> Numbers or letters represent data elements which create a string code with a high degree of uniqueness that theoretically matches only one individual.<sup>128</sup> The unique identifier can then be reported to public health authorities and provide accurate epidemiological data for HIV infection rates along with demographic indicators.<sup>129</sup> The anonymity of the individual is preserved because the code theoretically cannot be traced back to the person tested.<sup>130</sup>

Commentators note that different kinds of unique identifiers afford different levels of privacy protection.<sup>131</sup> The least protective are names and social security numbers.<sup>132</sup> Although everybody has one, names are not private and duplicates certainly exist.<sup>133</sup> Social security numbers were initially created to be a unique identifier solely for use by the Social Security Administration, but now they are used quite commonly, and therefore, offer little privacy.<sup>134</sup>

In response to these privacy concerns, Maryland and Texas have developed an innovative way to report HIV cases.<sup>135</sup> They employ codes comprised of data elements which include the last four digits of a social security number, date of birth, a numeric code for race/ethnicity and a numeric code for gender.<sup>136</sup>

Maryland has used a unique identifier ("UI") system to conduct HIV surveillance since 1994.<sup>137</sup> Its main objectives are to monitor HIV

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<sup>125</sup> See *HIV Surveillance and Name Reporting*, *supra* note 53, at 10.

<sup>126</sup> See *id.*

<sup>127</sup> See *id.*

<sup>128</sup> See Forbes, *Naming Names*, *supra* note 17, at 2-3.

<sup>129</sup> See *HIV Surveillance and Name Reporting*, *supra* note 53, at 10.

<sup>130</sup> See *id.*

<sup>131</sup> See Anna Forbes, *Brief Overview of Some Unique Identifier System Alternatives* (Sept. 18, 1997) <<http://hivinsite.ucsf.edu/topics/testing/2098.33bd.html>> [hereinafter Forbes, *Brief Overview*].

<sup>132</sup> See *id.*

<sup>133</sup> See *id.*

<sup>134</sup> See *id.*

<sup>135</sup> See Gostin et al., *supra* note 17, at 1165.

<sup>136</sup> See Forbes, *Brief Overview*, *supra* note 131. Similarly, New York's system for recording a woman's identity on a Fetal Death Certificate includes first name, maiden name, date of birth, gender and the last four digits of a Social Security number. See *id.*

<sup>137</sup> See Michael Adams, *ACLU AIDS Project: The Maryland Lesson: Conducting Effective HIV*

infection accurately throughout the state and to provide supplemental case identification for AIDS and HIV-positive symptomatic cases.<sup>138</sup> In Maryland, all health care providers requesting HIV or CD4 tests are required to assign unique identifier codes to testees, include the code on the laboratory slip and record it in a surveillance log.<sup>139</sup> The log matches the unique identifier to patient identifiers for purposes of case investigation and follow-up.<sup>140</sup> Only laboratories licensed by Maryland, however, are required to submit HIV reports to the state health department.<sup>141</sup>

In Texas, the reporting of confirmed HIV infections by unique identifier for adolescents and adults began in March 1994.<sup>142</sup> Although Texas and Maryland both use the same data elements in their twelve digit unique identifier codes, the two programs differ.<sup>143</sup> In Texas, the

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*Surveillance with Unique Identifiers* (last modified Dec. 1997) <<http://www.aclu.org/issues/aids/mdnamereport.html>>. This system was implemented after attempts to institute HIV name reporting were defeated in the legislature in 1992 and 1994. *See id.* The Maryland Department of Health and Mental Hygiene established criteria for creating the current unique identifier system. *See* Anna Forbes, *A Brief Overview of the Unique Identifier System Used by the Maryland Department of Health and Mental Hygiene for HIV and CD Reporting*, July 1997, at 1 (on file with author). The system had to be simple to generate (i.e. not require access to a computer, not take more than 90 seconds per code to generate and not require staff to make subjective determinations), have data elements that are immutable, be generated from factual information provided by the client, have a duplication rate no greater than 2%, not be easily "cracked" and not depend on an individual's ability to recall and accurately report a previously assigned code. *See id.*

<sup>138</sup> *See* Adams, *supra* note 137.

<sup>139</sup> *See* CDC, *Evaluation of HIV Case Surveillance Through the Use of Non-Name Unique Identifiers—Maryland and Texas, 1994–1996*, 46 MORBIDITY AND MORTALITY WKLY. REP. 1254, 1255 (1998).

<sup>140</sup> *See id.* The system proceeds through the following steps: (1) the provider orders the laboratory test and creates the unique identifier, which is sent with the laboratory requisition; (2) the laboratory then sends the UI Report Form for positive HIV tests and CD4 counts of fewer than 200 to the State AIDS Administration office or to the local health department and forms sent to the local health department are forwarded to the State AIDS Administration; (3) the AIDS Administration matches each unique identifier received against the State AIDS Registry, which has been coded with unique identifiers using the same 12-digit numbering system; (4) the AIDS Administration then generates a list of non-matches to the State AIDS Registry, thereby creating a list of cases of HIV infection that are not yet reportable as AIDS or HIV-positive symptomatic cases in Maryland; (5) although the surveillance staff calls doctors as necessary to obtain additional patient information, such as clinical status and risk categories, patient names are not given to this staff; (6) if, however, the patient is found to have an AIDS-defining illness or is HIV symptomatic (a reportable condition in Maryland), then the staff will obtain information, including the patient's name, which is used to create an AIDS case report. *See* Adams, *supra* note 137.

<sup>141</sup> *See* CDC, *supra* note 139, at 1255. Non-state residents, people who are tested at anonymous test sites, donors of blood, semen or tissue and participants of certain research projects, are exempted from reporting requirements. *See id.* at 1254.

<sup>142</sup> *See* BUREAU OF HIV AND STD PREVENTION, *supra* note 88, at 7. Confirmed HIV infections in children 12 years of age and younger are reported by name. *See id.* at 7 n.1.

<sup>143</sup> *See* BUREAU OF HIV AND STD PREVENTION, *supra* note 88, at 15; CDC, *supra* note 139, at 1255.

reporting system is a dual system, with both physicians and laboratories required to report confirmed HIV infection.<sup>144</sup> In addition to providing unique identifier information, they are also required to report test type, test date, test result, zip code, city and county of residence of the infected individual and name and address of the provider or laboratory reporting the infection.<sup>145</sup> The Texas system, however, does not require physicians to keep a log or its equivalent.<sup>146</sup> Additionally, there are no reporting exemptions.<sup>147</sup>

Commentators argue that the unique identifiers that are most protective of privacy incorporate a private data element into the mix of public data used to produce the code.<sup>148</sup> A couple of these systems have been created in connection with HIV reporting.<sup>149</sup> For example, in 1992, Philadelphia field tested a locally developed system called Client Key.<sup>150</sup> The code, which is created by the service provider, is comprised of the individual's name, date of birth, gender and a key word or phrase selected by the client.<sup>151</sup>

#### IV. CONSTITUTIONAL ISSUES FOR HIV REPORTING SCHEMES

##### A. *The Right to Privacy Claims*

To date, the United States Supreme Court has not specifically addressed the right of privacy vis-à-vis mandatory HIV reporting programs. The Court has addressed, however, the scope of the state's

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<sup>144</sup> See BUREAU OF HIV AND STD PREVENTION, *supra* note 88, at 7. The Texas Department of Health recently reported that an analysis of the state's unique identifier system reveals that the system does not provide reliable and accurate data on the number of HIV-infected individuals in Texas. *See id.* at 14. Because of these shortcomings, the Texas Bureau of HIV and STD Prevention is considering moving to a name-based HIV reporting system. *See id.* at 15.

<sup>145</sup> *See id.* at 7.

<sup>146</sup> See CDC, *supra* note 139, at 1256.

<sup>147</sup> *See id.* at 1254.

<sup>148</sup> See Forbes, *Brief Overview*, *supra* note 131.

<sup>149</sup> *See id.*

<sup>150</sup> *See id.* Another system called DoubleLock was invented in Philadelphia by the creators of Client Key, but has yet to be tested. *See id.* The code, created by the services provider, would be comprised of a name, date of birth, gender and a standardized measurement of hand-size ratio. *See id.* Because the DoubleLock scrambles the public record data elements together with a verifiable, non-public record data element (the hand-size ratio measurement) during the computer encryption process, the risk of client identities later being traced through cross-matching is greatly eliminated. See Forbes, *Naming Names*, *supra* note 17, at 3. The public record data elements cannot be unscrambled or re-isolated without knowledge of the private data element (which is provided with the client's consent and participation only). *See id.* Although it is theoretically possible to learn client identities by cross-matching a list of DoubleLock codes against codes generated by the encryption of a secondary, public record database, this would be extremely difficult and would require great amounts of computer time. *See id.* at 4.

<sup>151</sup> See Forbes, *Brief Overview*, *supra* note 131.



police power to protect the public.<sup>152</sup> In 1905, in *Jacobsen v. Massachusetts*, the Court held that a statute requiring smallpox vaccination of adults did not violate the Fourteenth Amendment of the Constitution.<sup>153</sup> In *Jacobsen*, the plaintiff claimed that a statute's smallpox vaccination requirement violated the preamble to the Constitution, the Fourteenth Amendment and the spirit of the Constitution.<sup>154</sup> The Court recognized the state's authority to enact various quarantine and health laws.<sup>155</sup> The Court also noted the state's need to restrict an individual's liberty to secure the general comfort, health and prosperity of its people.<sup>156</sup> Weighing the state police power to protect the public against the rights of the individual, the Court determined that protecting the public against a potential smallpox epidemic outweighed the individual's right to refuse the vaccination because the vaccination was a reasonable means to prevent the spread of a dangerous epidemic.<sup>157</sup> Thus, the Court upheld the compulsory vaccination statute as constitutional.<sup>158</sup>

In 1965, in *Griswold v. Connecticut*, the United States Supreme Court held that a Connecticut statute which prohibited the use of contraception by a married couple violated their constitutional right of privacy.<sup>159</sup> In *Griswold*, Planned Parenthood League's executive director and medical director, who had been convicted as accessories for informing, instructing and advising married couples on preventing conception, alleged that the Connecticut law forbidding use of contraceptives violated the Fourteenth Amendment.<sup>160</sup> The Court first noted the intimate relationship between a husband and wife and their physician's role in at least one aspect of that relationship.<sup>161</sup> The Court then noted that the association of people is neither mentioned in the Constitution nor the Bill of Rights.<sup>162</sup> The Court reasoned, however, that the First, Third, Fourth, Fifth, Ninth and Fourteenth Amendments created a "penumbra" where privacy is protected from governmental intrusion.<sup>163</sup> Balancing the individual's privacy interest against

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<sup>152</sup> See *Jacobsen v. Massachusetts*, 197 U.S. 11, 25 (1905).

<sup>153</sup> *Id.* at 12, 13, 14, 39.

<sup>154</sup> See *id.* at 13-14.

<sup>155</sup> See *id.* at 25.

<sup>156</sup> See *id.* at 26.

<sup>157</sup> See *Jacobsen*, 197 U.S. at 30-31.

<sup>158</sup> See *id.* at 39.

<sup>159</sup> 381 U.S. 479, 480, 486 (1965).

<sup>160</sup> See *id.* at 480.

<sup>161</sup> See *id.* at 482.

<sup>162</sup> See *id.*

<sup>163</sup> See *id.* at 484-85. Concerning the First Amendment, the Court noted that the right to

the state's police power to invade the marital bedroom, the Court determined that the law was an unjustified governmental intrusion because the law swept unnecessarily into an area of protected freedoms.<sup>164</sup> Thus, the Court held that the Connecticut statute prohibiting the use of contraception by a married couple violated the constitutional right to privacy.<sup>165</sup>

In 1977, in *Whalen v. Roe*, the United States Supreme Court held that a New York statute, which required physicians to identify patients obtaining certain prescription drugs, did not violate the patients' constitutional right to privacy.<sup>166</sup> In *Whalen*, patients and physicians sought to enjoin enforcement of a statute that required physicians to forward copies of prescriptions for certain drugs to the state health department for entry into the state's centralized computer file.<sup>167</sup> The Court determined that the statute was a reasonable exercise of the state's broad police powers by recognizing the state's vital interest in controlling the distribution of dangerous drugs.<sup>168</sup> The Court also noted that there was no basis for assuming that the security provisions of the statute would be improperly administered.<sup>169</sup> Additionally, the Court identified two dimensions of the constitutional right to privacy: the individual interest in avoiding disclosure of personal matters and the interest in making certain kinds of important decisions without governmental interference.<sup>170</sup>

Although the Court acknowledged that some individuals may avoid or postpone needed medical attention due to concerns of privacy and stigmatization, the Court reasoned that disclosing private medical information to state representatives does not automatically amount to

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freedom of speech and press includes not only the right to utter or to print, but also the right to distribute, the right to receive, the right to read, the freedom of inquiry, the freedom of thought and the freedom to teach. *See id.* at 482. The Court reasoned that the right of association, more than merely the right to attend a meeting, includes the right to express one's attitudes or philosophies by membership in a group, by affiliation with such a group or by other lawful means. *See id.* at 483. The Court then noted that the Third Amendment's prohibition against the quartering of soldiers in any house in time of peace without the consent of the owner is another facet of privacy. *See id.* at 484. The Court emphasized that the Fourth and Fifth Amendments have been described as protection against all governmental invasions "of the sanctity of a man's home and the privacies of life." *Id.* The Court also noted that the Ninth Amendment provides that the enumeration of certain rights in the Constitution shall not be construed to deny or disparage other rights retained by the people. *See id.*

<sup>164</sup> *See Griswold*, 381 U.S. at 485.

<sup>165</sup> *See id.* at 480, 486.

<sup>166</sup> 429 U.S. 589, 593, 603-04 (1977).

<sup>167</sup> *See id.* at 591, 595.

<sup>168</sup> *See id.* at 598.

<sup>169</sup> *See id.* at 601.

<sup>170</sup> *See id.* at 598-600.

an impermissible invasion of privacy because patients often disclose this information to their health care providers.<sup>171</sup> The Court recognized, for example, that reporting requirements relating to venereal disease, child abuse, injuries caused by deadly weapons and certifications of fetal death could be justified because disclosing private medical information is often essential to modern medical practice, even though the disclosure could reflect unfavorably on the patient's character.<sup>172</sup> Furthermore, the Court noted that the New York statute did not deprive the public of access to drugs because it neither prohibited the use of the drugs nor conditioned access to the drugs on the consent of any state official.<sup>173</sup> After balancing these issues against the state's interest, the Court determined that the statute's patient-identification requirements did not threaten the patients' privacy rights sufficient to establish a constitutional violation.<sup>174</sup>

The opinion concluded by describing the issues that the Court did not decide.<sup>175</sup> The Court noted that the government's duty to avoid disclosure arguably has its root in the Constitution.<sup>176</sup> The Court also stated that it was not deciding any issue presented by the unwarranted disclosure of accumulated private data, whether intentional or unintentional, or by a system that did not contain comparable security provisions.<sup>177</sup> These considerations notwithstanding, the Court held that the New York statute did not violate the patients' constitutional right to privacy.<sup>178</sup>

In 1980, in *United States v. Westinghouse Electric Corp.*, the United States Court of Appeals for the Third Circuit held that the National Institute for Occupational Safety and Health's ("NIOSH") access to the medical records of certain employees did not violate the employees' constitutional right to privacy.<sup>179</sup> In *Westinghouse*, NIOSH sought access to medical records of Westinghouse employees who were potentially exposed to dangerous chemicals in the plant.<sup>180</sup> Recognizing that information concerning one's body has a special character, the court reasoned that medical records which may contain intimate facts of a

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<sup>171</sup> See *Whalen*, 429 U.S. at 602.

<sup>172</sup> See *id.*

<sup>173</sup> See *id.* at 603.

<sup>174</sup> See *id.* at 600.

<sup>175</sup> See *id.* at 605.

<sup>176</sup> See *Whalen*, 429 U.S. at 605.

<sup>177</sup> See *id.* at 605-06.

<sup>178</sup> See *id.* at 603-04.

<sup>179</sup> 638 F.2d 570, 580 (3d Cir. 1980).

<sup>180</sup> See *id.* at 573.

personal nature fall within a zone of privacy entitled to protection.<sup>181</sup> The court noted, however, that intrusion into the zone of privacy surrounding medical records is permitted if the societal interest in disclosure outweighs the privacy interest at hand.<sup>182</sup> The court identified seven factors to be weighed in deciding whether an intrusion into an individual's privacy is justified: (1) the type of record requested; (2) the information it does or might contain; (3) the potential for harm in any subsequent nonconsensual disclosure; (4) the injury from disclosure to the relationship in which the record was generated; (5) the adequacy of safeguards to prevent unauthorized disclosure; (6) the degree of need for access; and (7) whether there is an express statutory mandate, articulated public policy or other recognizable public interest militating toward access.<sup>183</sup>

After balancing these factors, the court concluded that the strong public interest in occupational safety and health, the fact that the records were reasonably relevant to NIOSH's inquiry and the effective security provisions against subsequent unauthorized disclosure justified the intrusion into the employees' medical records.<sup>184</sup> Thus, the Third Circuit held that NIOSH's access to certain employees' medical records did not violate the employees' constitutional right to privacy.<sup>185</sup>

In 1990, in *Doe v. Borough of Barrington*, the United States District Court for the District of New Jersey held that a police officer's disclosure of an individual's AIDS condition violated the individual's and his family's constitutional right to privacy under the Fourteenth Amendment.<sup>186</sup> In *Borough of Barrington*, the plaintiffs alleged that they suffered harassment, discrimination and humiliation because a police officer disclosed to neighbors that "Mr. Doe" had AIDS.<sup>187</sup> The court noted that the members of the family had a constitutional right to privacy in the information due to its sensitive medical nature.<sup>188</sup> The court reasoned that the privacy interest in one's exposure to AIDS is greater than the privacy interest in other medical records because of the stigma that attaches to the disease.<sup>189</sup> Recognizing that an individual's privacy interest in medical information and records is not abso-

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<sup>181</sup> See *id.* at 577.

<sup>182</sup> See *id.* at 578.

<sup>183</sup> See *id.*

<sup>184</sup> See *Westinghouse*, 638 F.2d at 579, 580.

<sup>185</sup> See *id.* at 580.

<sup>186</sup> 729 F. Supp. 376, 378, 385 (D. N.J. 1990).

<sup>187</sup> See *id.* at 378-79.

<sup>188</sup> See *id.* at 384, 385.

<sup>189</sup> See *id.* at 384.

lute, the court reasoned that the government must show a compelling state interest in breaching that privacy.<sup>190</sup> The court determined that disclosure of Doe's confidential information did not advance a compelling governmental interest in preventing the spread of the disease because there was no risk that the neighbors might be exposed to the HIV virus through casual contact with Doe's wife.<sup>191</sup> Thus, the New Jersey federal court held that the police officer's disclosure about an individual's AIDS condition violated the constitutional right of privacy.<sup>192</sup>

In 1994, in *Doe v. City of New York*, the United States Court of Appeals for the Second Circuit held that individuals have a constitutional right to privacy in their HIV status.<sup>193</sup> In *City of New York*, the plaintiff alleged that his right to privacy was violated when the City of New York publicly revealed details of a discrimination claim settlement against Delta Airlines based on his HIV-positive status.<sup>194</sup> The court reasoned that the right to privacy includes an individual's right to avoid disclosure about his or her health because of its personal nature.<sup>195</sup> The court noted that this is especially true for individuals infected with HIV or AIDS because revealing their HIV status potentially exposes them to discrimination and intolerance.<sup>196</sup> Thus, the Second Circuit held that there is a constitutional right to confidentiality in one's HIV status.<sup>197</sup>

In 1994, in *Doe v. Wigginton*, the United States Court of Appeals for the Sixth Circuit held that the disclosure to corrections officers of a prisoner's HIV status did not violate the prisoner's constitutional right to privacy.<sup>198</sup> In *Wigginton*, a prisoner alleged that his constitutional right to privacy was violated when a prison officer observed a medical file indicating that the prisoner was HIV-positive.<sup>199</sup> The court noted that recognizing a constitutional right of nondisclosure would force courts to balance almost every act of government against its intrusion on a vague concept of privacy.<sup>200</sup> The court also noted that inferring broad constitutional rights where the Constitution does not

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<sup>190</sup> See *id.* at 385.

<sup>191</sup> See *Borough of Barrington*, 729 F. Supp. at 385.

<sup>192</sup> See *id.*

<sup>193</sup> 15 F.3d 264, 267 (2d Cir. 1994).

<sup>194</sup> See *id.* at 265-66.

<sup>195</sup> See *id.* at 267.

<sup>196</sup> See *id.*

<sup>197</sup> See *id.*

<sup>198</sup> 21 F.3d 733, 735, 740 (6th Cir. 1994).

<sup>199</sup> See *id.* at 735.

<sup>200</sup> See *id.* at 740.

explicitly mention them is inappropriate for the judiciary.<sup>201</sup> Thus, reasoning that the Constitution does not encompass a general right to nondisclosure of private information, the Sixth Circuit held that there was no violation of the prisoner's constitutional rights.<sup>202</sup>

### B. *Equal Protection Claims*

The Equal Protection Clause of the Fourteenth Amendment mandates that states treat similarly situated people in a similar way.<sup>203</sup> Although the Equal Protection Clause does not prohibit state legislatures from making classifications, it does require that such classifications be based on permissible, and not invidious, grounds.<sup>204</sup> The United States Supreme Court has formulated three standards of review for equal protection claims: strict scrutiny, intermediate scrutiny and a rational basis test.<sup>205</sup> The nature of the allegedly discriminatory classification determines the standard used.<sup>206</sup>

In 1984, in *Palmore v. Sidoti*, the United States Supreme Court held that racial classifications are subject to strict scrutiny and must be narrowly tailored to achieve a compelling governmental interest to comport with the Equal Protection Clause.<sup>207</sup> In *Palmore*, a white man was awarded custody of his three-year-old daughter after the white, natural mother remarried a black man.<sup>208</sup> The Supreme Court noted that the lower court based its custody decision wholly on race because the natural mother is ordinarily allowed to retain custody of her child after a remarriage.<sup>209</sup> The Court determined that the purpose of the Fourteenth Amendment was to abolish the historic discrimination of people based on their race.<sup>210</sup> The Court reasoned that classifying people according to race is more likely to result in a classification based on racial prejudice than on legitimate public concerns because the race, and not the person, dictates the category.<sup>211</sup> Thus, the Court held that private racial biases and their effects are impermissible criteria in

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<sup>201</sup> See *id.*

<sup>202</sup> See *id.*

<sup>203</sup> See *Lindsley v. Natural Carbonic Gas Co.*, 220 U.S. 61, 83 (1911).

<sup>204</sup> See *id.* at 78, 83.

<sup>205</sup> See generally JOHN E. NOWAK & RONALD D. ROTUNDA, CONSTITUTIONAL LAW § 14.3, at 573-90 (4th ed. 1991).

<sup>206</sup> See *id.*

<sup>207</sup> 466 U.S. 429, 432-33 (1984).

<sup>208</sup> See *id.* at 430-31.

<sup>209</sup> See *id.* at 432.

<sup>210</sup> See *id.*

<sup>211</sup> See *id.*

custody decisions.<sup>212</sup> Furthermore, the Supreme Court held that racial classifications are subject to strict scrutiny and must be necessary to the accomplishment of compelling governmental interests.<sup>213</sup>

In 1982, in *Mississippi University for Women v. Hogan*, the United States Supreme Court held that sex classifications are subject to intermediate scrutiny and must substantially relate to important governmental objectives in order to satisfy the Equal Protection Clause.<sup>214</sup> In *Hogan*, Mississippi University's School of Nursing denied admission to a male student because of his sex.<sup>215</sup> The Court reasoned that a heightened level of scrutiny was necessary because gender-based classifications have not only been the product of fixed stereotypes regarding the proper roles and abilities of men and women, but also have resulted in unequal treatment.<sup>216</sup> The Court noted that the single-sex admissions policy neither assisted anyone who was disadvantaged nor offered opportunities to anyone who had faced restrictions based on arbitrary categorizations.<sup>217</sup> Thus, the Supreme Court held that gender-based classifications are subject to intermediate scrutiny and must substantially relate to an important governmental objective.<sup>218</sup>

In 1996, in *Romer v. Evans*, the United States Supreme Court held that a Colorado constitutional amendment prohibiting preferential treatment for homosexuals was subject to a rational basis test and thus, must be rationally related to furthering a legitimate state interest in order to comport with the Equal Protection Clause.<sup>219</sup> In *Romer*, the plaintiffs sought to enjoin enforcement of Amendment Two to the Colorado constitution, which prohibited any legislative, judicial or civil rights protections for homosexuals, claiming that it violated the Equal Protection Clause of the Fourteenth Amendment.<sup>220</sup> The Court noted that, when neither a fundamental right nor a suspect class is implicated, a legislative classification will be upheld if it bears a rational relation to some legitimate state interest.<sup>221</sup> The Court then considered the state's claim that it was protecting its citizens' First Amendment

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<sup>212</sup> See *Palmore*, 466 U.S. at 484.

<sup>213</sup> See *id.* at 432-33.

<sup>214</sup> 456 U.S. 718, 724 (1982).

<sup>215</sup> See *id.* at 720-21.

<sup>216</sup> See *id.* at 725-26. The Court noted that women are not discriminated against in the field of nursing and that the university allowed men to audit classes but prevented them from earning credits. See *id.* at 729, 731.

<sup>217</sup> See *id.* at 728, 729.

<sup>218</sup> See *id.* at 724.

<sup>219</sup> 517 U.S. 620, 624, 631-32 (1996).

<sup>220</sup> See *id.* at 624-25.

<sup>221</sup> See *id.* at 631.

freedoms but determined that the Colorado amendment did not rationally comport with the state's justification.<sup>222</sup> The Court noted that the state's amendment imposed serious disabilities on a single group of citizens, inflicting on them immediate, continuing and real injuries that belied any legitimate justifications.<sup>223</sup> The Court determined, therefore, that the Colorado amendment's rationale could only have been motivated by animosity toward homosexuals.<sup>224</sup> Reasoning that the Constitution does not tolerate mere animus as a rational basis for a law that seeks to disadvantage a political class, the Court held that Amendment Two—in rendering homosexuals unequal to everyone else—violated the Equal Protection Clause.<sup>225</sup>

### C. *Recent Right to Privacy and Equal Protection Claims*

In 1997, in *In re Adams*, the United States Bankruptcy Appellate Panel of the Ninth Circuit held that a bankruptcy statute requiring disclosure of a social security number on court documents did not violate the individual's constitutional right to privacy or equal protection.<sup>226</sup> In *Adams*, the appellant alleged that the bankruptcy code section requiring a bankruptcy petition preparer to disclose a social security number on documents violated her constitutional right to privacy and equal protection.<sup>227</sup> The court first noted that the constitutional right of privacy includes non-disclosure of personal matters.<sup>228</sup> The court then noted that the Ninth Circuit Court of Appeals previously held that the constitutional right of privacy does not prohibit disclosure of unlisted telephone numbers through "Caller ID" service, but that the right of privacy does protect information regarding an individual's HIV status or AIDS diagnoses.<sup>229</sup> The court reasoned that a social security number is more akin to a telephone number than to an HIV or AIDS diagnosis and that revealing a social security number on court documents does not interfere with the most basic decisions about family, parenthood or bodily integrity.<sup>230</sup> Thus, although the court recognized that there were no administrative or statutory safeguards against publicly disseminating a petition preparer's social security num-

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<sup>222</sup> See *id.* at 635.

<sup>223</sup> See *id.*

<sup>224</sup> See *Romer*, 517 U.S. at 632.

<sup>225</sup> See *id.* at 634-35.

<sup>226</sup> 214 B.R. 212, 214, 219 (B.A.P. 9th Cir. 1997).

<sup>227</sup> See *id.* at 214, 215.

<sup>228</sup> See *id.* at 216.

<sup>229</sup> See *id.*

<sup>230</sup> See *id.*



ber, the court held that there is no fundamental privacy right prohibiting disclosure of social security numbers.<sup>231</sup>

The court then addressed appellant's claim that the statute violated the Equal Protection Clause because bankruptcy trustees and debtors' attorneys are not required to use their social security numbers when documenting public records.<sup>232</sup> The court first determined that the bankruptcy statute does not employ an inherently invidious classification scheme because it does not classify by race or gender.<sup>233</sup> The court also reasoned that the statute does not impinge on any fundamental rights because it does not violate the right to privacy and the right to pursue a profession as a bankruptcy petition preparer is not a fundamental right.<sup>234</sup> Therefore, the court concluded that there need only be a rational relation between the classification and legitimate governmental objectives.<sup>235</sup> The court determined that the purpose of the statute—preventing abuse by non-lawyer petition preparers—is legitimate, especially because bankruptcy trustees and attorneys are highly regulated.<sup>236</sup> Thus, the Ninth Circuit Bankruptcy Panel held that the bankruptcy statute requiring disclosure of an individual's social security number did not violate the individual's right to privacy or guarantee of equal protection.<sup>237</sup>

In 1998, in *Middlebrooks v. State Board of Health*, the Supreme Court of Alabama held that Alabama's mandatory name reporting statute for certain diseases and health conditions, including HIV and AIDS, did not violate the individual's right to privacy or the physician's right to equal protection.<sup>238</sup> In *Middlebrooks*, the State Board of Health filed suit against a physician to compel him to disclose the names and addresses of his HIV and AIDS patients, as required by its rules and the reporting statute.<sup>239</sup> The physician argued that the statutory and regulatory scheme violated the Equal Protection Clause of the Fourteenth Amendment because he was required to report the names and addresses of his HIV and AIDS patients, while those who sell confidential HIV-testing kits and out-of-state laboratories that evaluate the test results are not obligated to do the same.<sup>240</sup> Concerning the right of

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<sup>231</sup> See *Adams*, 214 B.R. at 217.

<sup>232</sup> See *id.*

<sup>233</sup> See *id.* at 218.

<sup>234</sup> See *id.*

<sup>235</sup> See *id.*

<sup>236</sup> See *Adams*, 214 B.R. at 218.

<sup>237</sup> See *id.* at 214, 219.

<sup>238</sup> 710 So. 2d 891, 893 (Ala. 1998).

<sup>239</sup> See *id.* at 892.

<sup>240</sup> See *id.*

privacy in medical information relating to HIV and AIDS, the court weighed the *Westinghouse* factors and determined that preventing the spread of HIV and AIDS is a legitimate governmental interest.<sup>241</sup> The court also noted that adequate safeguards existed to protect the medical records from unauthorized disclosure.<sup>242</sup> The court reasoned that the state can require disclosure to state representatives who are responsible for the health of the community, and thus concluded that the statute's disclosure requirements did not impermissibly invade privacy.<sup>243</sup> In addressing the equal protection challenge, the court determined that the state's classification was reasonable because the out-of-state testing labs that analyze the results of the testing kits and vendors of the testing kits are not similarly situated to physicians who regularly treat HIV and AIDS patients.<sup>244</sup> The court emphasized that out-of-state testing labs do not know the identity of the persons being tested and the vendors of the testing kits have no information on whether a particular individual is HIV- or AIDS-positive, whereas physicians do obtain this information.<sup>245</sup> Thus, the Alabama Supreme Court held that Alabama's reporting statute, requiring physicians to disclose the names of their HIV- and AIDS-infected patients to the State Board of Health, did not violate the Equal Protection Clause.<sup>246</sup>

## V. CONSTITUTIONAL ANALYSIS OF HIV REPORTING SCHEMES

### A. *The Right to Privacy in One's HIV Status*

Although it is not explicitly mentioned in the Constitution, the United States Supreme Court has recognized a constitutional right to privacy.<sup>247</sup> The Court has struggled, however, with defining the scope of that right.<sup>248</sup> This is especially true in the area of informational privacy.<sup>249</sup> In *Whalen*, for example, the Supreme Court recognized a right to privacy in personal medical information but never clearly held that the information had explicit constitutional protection.<sup>250</sup> Thus, while some lower courts have embraced the existence of a constitu-

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<sup>241</sup> See *id.* at 892-93.

<sup>242</sup> See *id.* at 893.

<sup>243</sup> See *Middlebrooks*, 710 So. 2d at 893.

<sup>244</sup> See *id.*

<sup>245</sup> See *id.* at 893 n.3.

<sup>246</sup> See *id.* at 893.

<sup>247</sup> See *Griswold v. Connecticut*, 381 U.S. 479, 485 (1965).

<sup>248</sup> See *supra* notes 166-78 and accompanying text.

<sup>249</sup> See *supra* notes 166-78 and accompanying text.

<sup>250</sup> See *Whalen v. Roc*, 429 U.S. 589, 599, 605 (1977).

tional right to privacy in personal information, others have rejected or questioned it.<sup>251</sup>

Numerous courts, however, have interpreted *Whalen* as extending the constitutional right to privacy to two interests: (1) the individual interest in avoiding disclosure of personal matters and (2) the interest in making certain kinds of important decisions independently.<sup>252</sup> The privacy interest asserted in mandatory name reporting programs falls within the first category referred to in *Whalen*—the right not to have an individual's private affairs made public by the government.<sup>253</sup> This right of privacy may, therefore, be characterized as a right to confidentiality.<sup>254</sup>

An individual's medical records should fall within the array of materials entitled to privacy protection because information about one's body and state of health is a matter which the individual is ordinarily allowed to retain privately.<sup>255</sup> The status of an individual's health is very personal and there are few matters over which an individual would prefer to maintain control.<sup>256</sup> Therefore, an individual's choice to inform others that he or she has contracted a fatal or incurable disease is one that the individual should be allowed to make.<sup>257</sup> Considering society's moral judgments about high-risk activities associated with AIDS, HIV-related information may be even more personal than other medical conditions.<sup>258</sup> Because HIV-positive individuals are often stereotyped as drug users or homosexuals, revealing HIV status potentially exposes an individual to stigmatization, discrimination and intolerance.<sup>259</sup> Thus, an individual's HIV status is more intimate than the prescription drug usage considered in *Whalen*.<sup>260</sup> Because the Supreme Court in *Whalen* recognized the privacy interest in medical information relating to prescriptions, the right to privacy in one's HIV status should fall within one of the zones of privacy entitled to constitutional protection.<sup>261</sup>

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<sup>251</sup> See, e.g., *Doe v. Wigginton*, 21 F.3d 733, 740 (6th Cir. 1994); *Doe v. City of New York*, 15 F.3d 264, 267 (2d Cir. 1994); *United States v. Westinghouse Elec. Corp.*, 638 F.2d 570, 577 (3d Cir. 1980); *Doe v. Borough of Barrington*, 729 F. Supp. 376, 387 (D. N.J. 1990).

<sup>252</sup> See, e.g., *Whalen*, 429 U.S. at 599-600; *City of New York*, 15 F.3d at 267; *Westinghouse*, 638 F.2d at 577.

<sup>253</sup> See *Whalen*, 429 U.S. at 599.

<sup>254</sup> See *City of New York*, 15 F.3d at 267.

<sup>255</sup> See *Westinghouse*, 638 F.2d at 577.

<sup>256</sup> See *City of New York*, 15 F.3d at 267.

<sup>257</sup> See *id.*

<sup>258</sup> See *id.*; *Borough of Barrington*, 729 F. Supp. at 384.

<sup>259</sup> See *City of New York*, 15 F.3d at 267; *Borough of Barrington*, 729 F. Supp. at 384.

<sup>260</sup> See *Whalen*, 429 U.S. at 599; *supra* notes 256-59 and accompanying text.

<sup>261</sup> See *Whalen*, 429 U.S. at 599; *City of New York*, 15 F.3d at 267; *Westinghouse*, 638 F.2d at 577.

Additionally, although the court in *Wigginton* held that there is no constitutional right to nondisclosure of private information, the case involved a prisoner.<sup>262</sup> Even though the court did not explicitly address privacy in the context of prisoner's rights, *Wigginton* can be factually distinguished because prisoners are afforded fewer privacy rights than the general public.<sup>263</sup> Thus, despite the holding in *Wigginton*, other cases such as *Borough of Barrington* and *City of New York* suggest that the right to privacy in one's HIV status should fall within a constitutional zone of privacy.<sup>264</sup>

Nondisclosure of one's HIV status, however, is not a fundamental right deserving strict scrutiny.<sup>265</sup> The Supreme Court has determined that privacy rights relating to areas of marriage, procreation and child-rearing are fundamental.<sup>266</sup> The Supreme Court in *Whalen*, however, never stated that the privacy interest in medical information is fundamental and did not use a strict scrutiny test.<sup>267</sup> Rather, the *Whalen* Court used a balancing test, thereby implicitly reasoning that the privacy interest at issue was not fundamental.<sup>268</sup> That is, the privacy right in HIV status is not a right "implicit in the concept of ordered liberty" nor a "principle of justice so rooted in the traditions and conscience of our people as to be ranked as fundamental" to the same extent as

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<sup>262</sup> See *Wigginton*, 21 F.3d at 735, 740.

<sup>263</sup> See *id.* at 740; *Doc v. Coughlin*, 697 F. Supp. 1234, 1238 n.10 (N.D.N.Y. 1988).

<sup>264</sup> See *Wigginton*, 21 F.3d at 740; *City of New York*, 15 F.3d at 267; *Borough of Barrington*, 729 F. Supp. at 385. It is possible that a court would not find any constitutional right to privacy in one's HIV status. See *Wigginton*, 21 F.3d at 740. Some courts reject the notion that the Constitution protects against the disclosure of private information. See, e.g., *id.* Because virtually every governmental action could be challenged as interfering with personal privacy to some degree, some courts state that recognizing a right to nondisclosure of private information would compel courts to balance every government action against its intrusion on individual privacy. See *id.* Additionally, some courts might not want to infer very broad constitutional rights where the Constitution does not explicitly provide them, refusing to expand upon the Court's ruling in *Griswold*. See 381 U.S. at 486; *Wigginton*, 21 F.3d at 740. In *Whalen*, the Court indicated that the government's duty to avoid disclosing personal information only arguably has its roots in the Constitution. 429 U.S. at 605. Absent a clear indication from the Supreme Court, courts might not be willing to construe isolated statements in *Whalen* broadly and thus might conclude that there is no general right to nondisclosure of private information. See *id.*; *Wigginton*, 21 F.3d at 740.

<sup>265</sup> See *infra* notes 266-70 and accompanying text.

<sup>266</sup> See, e.g., *Loving v. Virginia*, 388 U.S. 1, 12 (1967) (right to marry); *Skinner v. Oklahoma ex rel. Williamson*, 316 U.S. 535, 541 (1943) (right to procreate); *Pierce v. Society of Sisters*, 268 U.S. 510, 535 (1925) (right to childrearing). In considering equal protection claims, the Supreme Court has also recognized as fundamental the right to vote, the right to travel and the right to access the courts. See, e.g., *Shapiro v. Thompson*, 394 U.S. 618, 629 (1969) (right to travel); *Harper v. Virginia State Bd.*, 383 U.S. 663, 670 (1966) (right to vote); *NAACP v. Button*, 371 U.S. 415, 452 (1963) (right to access courts).

<sup>267</sup> See generally *Whalen*, 429 U.S. at 599-604.

<sup>268</sup> See *id.*

marriage, procreation and childrearing.<sup>269</sup> Given that the Supreme Court has indicated that it will not expand the number of fundamental rights imbedded in the Due Process Clause beyond those currently recognized, nondisclosure of one's HIV status is not a fundamental right.<sup>270</sup>

Although the right to privacy and confidentiality in medical records exists, the right is not absolute.<sup>271</sup> In *Whalen*, the Court established that limited reporting requirements for public health purposes generally will not violate the constitutional right to privacy if the information is reasonably related to a valid public health purpose, if access to the information is limited to public health departments and their officials and if the reporting scheme has strict confidentiality protections.<sup>272</sup> The Court also specified that reporting requirements relating to venereal disease, child abuse, injuries caused by deadly weapons and certifications of fetal death could be justified even though disclosure could reflect unfavorably on the patient's character.<sup>273</sup>

To determine if a right to privacy has been violated, courts have balanced the individual's right to privacy against the government's interest in obtaining personal data and the public's interest in disclosing the information.<sup>274</sup> The *Westinghouse* balancing test is the most appropriate test for determining whether an invasion into an individual's records is justified because the factors enumerated in *Westinghouse* are comprehensive and concretely encompass the reasoning of *Whalen*.<sup>275</sup> Additionally, courts that adopt the *Westinghouse* test will be more consistent in their decisions, thus making it more likely that similar facts will result in similar outcomes.<sup>276</sup> This is crucial in right to informational privacy cases which are, by their nature, quite fact specific.<sup>277</sup> Moreover, the specific nature of the *Westinghouse* factors will allow individuals and legislatures to know what criteria the courts will employ in determining whether there has been a violation and thus

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<sup>269</sup> See *Palko v. Connecticut*, 302 U.S. 319, 325 (1937); *Snyder v. Massachusetts*, 291 U.S. 97, 105 (1934); *City of New York*, 15 F.3d at 267; see also *supra* note 303 and accompanying text.

<sup>270</sup> See *Bowers v. Hardwick*, 478 U.S. 186, 195 (1986).

<sup>271</sup> See, e.g., *Westinghouse*, 638 F.2d at 578; *Borough of Barrington*, 729 F. Supp. at 385.

<sup>272</sup> See *Whalen*, 429 U.S. at 603-04; Mark Barnes, *Confidentiality*, in AIDS LEGAL GUIDE 4-1, 4-2 (2d ed. 1987).

<sup>273</sup> See *Whalen*, 429 U.S. at 602.

<sup>274</sup> See, e.g., *Westinghouse*, 638 F.2d at 578.

<sup>275</sup> See *Whalen*, 429 U.S. at 599-604; *Westinghouse*, 638 F.2d at 578.

<sup>276</sup> See, e.g., *City of New York*, 15 F.3d at 267; *Westinghouse*, 638 F.2d at 578; Middlebrooks v. State Bd. of Health, 710 So. 2d 891, 893 (Ala. 1998).

<sup>277</sup> See, e.g., *Whalen*, 429 U.S. at 605-06.

allow both individuals to gauge their actions and legislatures to assess the constitutionality of proposed laws.<sup>278</sup>

Applying the *Westinghouse* factors, a mandatory name reporting system does not violate an individual's constitutional right to privacy.<sup>279</sup> The first two *Westinghouse* factors involve the type of record requested and the information disclosed.<sup>280</sup> Reports submitted to state health departments under mandatory name reporting programs contain patient identification, by name, for HIV-positive test results.<sup>281</sup> As discussed *infra*, the Constitution protects the confidentiality of this type of medical information.<sup>282</sup>

The third and fourth *Westinghouse* factors are the potential for harm from disclosure and the injury resulting from the disclosure.<sup>283</sup> The disclosure of one's HIV status by mandatory name reporting could result in substantial harm, given the social stigma attached to the disease.<sup>284</sup> This stigma makes the privacy interest in the exposure to the virus greater than one's privacy interest in ordinary medical records.<sup>285</sup> HIV status is information of a most personal nature given society's negative moral judgments about the high-risk activities associated with the disease, including sexual activity and drug use.<sup>286</sup> Thus, the potential for harassment and discrimination increases greatly with disclosure.<sup>287</sup>

Furthermore, the stigma not only attaches to the individual with HIV, but may reach to others around the HIV-positive individual.<sup>288</sup> Disclosure about HIV status violates a family's privacy more than disclosures relating to other aspects of family medical history.<sup>289</sup> Revealing that one's family member is HIV-positive may cause the entire family to be ostracized.<sup>290</sup> Furthermore, because those sharing a household with an infected person suffer from disclosure just as the victim does, the right to privacy in this information may extend to members of the

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<sup>278</sup> See, e.g., *City of New York*, 15 F.3d at 267; *Westinghouse*, 638 F.2d at 578; *Middlebrooks*, 710 So. 2d at 893.

<sup>279</sup> See *Westinghouse*, 638 F.2d at 578; *infra* notes 280-343 and accompanying text.

<sup>280</sup> See *Westinghouse*, 638 F.2d at 578.

<sup>281</sup> See *Creating an Effective Public Health Response*, *supra* note 23, at 2.

<sup>282</sup> See *Westinghouse*, 638 F.2d at 577.

<sup>283</sup> See *id.* at 578.

<sup>284</sup> See *Borough of Barrington*, 729 F. Supp. at 384.

<sup>285</sup> See *id.*

<sup>286</sup> See *id.*

<sup>287</sup> See *id.*

<sup>288</sup> See *id.*

<sup>289</sup> See *Borough of Barrington*, 729 F. Supp. at 385.

<sup>290</sup> See *id.*

infected individual's immediate family.<sup>291</sup> The stigma associated with HIV may even attach to others in contact with HIV-positive individuals, such as doctors, and to those in high-risk groups who do not have the disease.<sup>292</sup>

In *Borough of Barrington*, the court recognized the substantial risks of breaches in confidentiality regarding an individual's AIDS condition.<sup>293</sup> Unauthorized disclosure of HIV status, however, is even more significant than disclosure of AIDS status because an HIV-positive individual is reported earlier in the course of infection, lives longer after being reported and is more likely to be employed.<sup>294</sup> Given that the court in *City of New York* recognized that revealing an individual's HIV status potentially exposes the individual to discrimination and intolerance, a court should find that there is great potential for harm from disclosure in a mandatory name reporting program.<sup>295</sup>

Although the potential for harm from disclosure of HIV status is great, no actual injury may result from the mere collection of HIV surveillance data.<sup>296</sup> The individual interest in protecting the privacy of HIV status seems significantly less important where the information is collected but not publicly disseminated.<sup>297</sup> To date, no court has found a violation of the constitutional right to privacy where information has been collected by the government but not disseminated.<sup>298</sup>

The fifth *Westinghouse* factor involves the adequacy of the safeguards against unauthorized disclosure.<sup>299</sup> With mandatory name reporting, agencies may not be able to control how authorized personnel use the data to which they have access, thereby creating a risk of either inadvertent or intentional breaches of confidentiality.<sup>300</sup> Because federal, state and local public health administrators, HIV-related social service and medical professionals, and field service staff have access to the names of HIV-infected individuals, the reported names could be used for inappropriate purposes.<sup>301</sup> For example, in Florida, a computer disk with the names of 4000 people with AIDS was found in the parking lot of a bar.<sup>302</sup> This disk apparently belonged to an AIDS

<sup>291</sup> See *id.*

<sup>292</sup> See *id.* at 384.

<sup>293</sup> See *id.*

<sup>294</sup> See BUREAU OF HIV AND STD PREVENTION, *supra* note 88, at 18.

<sup>295</sup> See *City of New York*, 15 F.3d at 267.

<sup>296</sup> See *id.*; *infra* notes 297-98 and accompanying text.

<sup>297</sup> See *American Fed'n of Gov't Employees, AFL-CIO v. Department of Hous. and Urban Dev.*, 118 F.3d 786, 793 (D.C. Cir. 1997).

<sup>298</sup> See, e.g., *Whalen*, 429 U.S. at 603-04; *American Fed'n of Gov't Employees*, 118 F.3d at 793.

<sup>299</sup> See *Westinghouse*, 638 F.2d at 578.

<sup>300</sup> See *HIV Surveillance and Name Reporting*, *supra* note 53, at 8.

<sup>301</sup> See *id.*

<sup>302</sup> See *id.*

surveillance case worker who misplaced it.<sup>303</sup> In New York, a log with the names of 500 people who were tested for HIV disappeared from a clinic.<sup>304</sup> Similarly, the FBI has admitted using improperly-obtained HIV information, and other law enforcement agencies have both disclosed HIV status to neighbors or prison inmates and have broadcasted the names of HIV-infected individuals over police radios.<sup>305</sup>

Additionally, present legal assurances of confidentiality might not prevent later problems with privacy.<sup>306</sup> State privacy laws are only as strong as the legislature's will to uphold them.<sup>307</sup> A legislature that enacts confidentiality provisions may later create exceptions or revoke protections.<sup>308</sup> Furthermore, health departments could be compelled by legislative or legal mandate to surrender the names of HIV-infected individuals for non-surveillance purposes.<sup>309</sup> For instance, in 1991, Illinois passed a law that directed the Department of Health to identify all HIV-infected health care workers by comparing the state's confidential lists of HIV-positive individuals against records of health care licenses.<sup>310</sup> Patients of health care workers who were infected with HIV and who engaged in invasive medical procedures, including surgery, were to be contacted.<sup>311</sup> Although the law was never implemented, it shows the potentially precarious nature of confidentiality guarantees.<sup>312</sup> Moreover, in Virginia, state HIV registry information was obtained by subpoena and used by a grand jury to bring multiple counts of attempted murder against two female prostitutes in 1993.<sup>313</sup> In Colorado, the names of unlocated HIV-infected individuals are turned over to the Department of Motor Vehicles for assistance in locating them.<sup>314</sup> Furthermore, on September 11, 1997, United States Health and Human Services Secretary Donna Shalala recommended to Congress that po-

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<sup>303</sup> See *id.*

<sup>304</sup> See *id.*

<sup>305</sup> See *HIV Surveillance and Name Reporting*, *supra* note 53, at 8.

<sup>306</sup> See *id.*

<sup>307</sup> See Anna Forbes, *Myths and Facts About HIV Case Reporting By Name Versus By Unique Identifier* (visited Sept. 1997) <<http://hivinsite.ucsf.edu/topics/testing/2098.33bc.html>> [hereinafter Forbes, *Myths & Facts*].

<sup>308</sup> See *HIV Surveillance and Name Reporting*, *supra* note 53, at 9.

<sup>309</sup> See Fred Dillon, *HIV InSite: Primary Arguments Used Against Mandatory Names Reporting* (visited Jan. 4, 1998) <<http://hivinsite.ucsf.edu/topics/testing/2098.33b5.html>>.

<sup>310</sup> See *HIV Surveillance and Name Reporting*, *supra* note 53, at 9.

<sup>311</sup> See *id.*

<sup>312</sup> See *id.*

<sup>313</sup> See Anna Forbes, Address at the National AIDS Update Conference (Mar. 22, 1996). Authorities used positive HIV status to bring attempted murder charges in 1995 against a North Dakota woman after she reported having been raped while unconscious. Since 1988, North Dakota has had mandatory HIV name reporting. See *id.*

<sup>314</sup> See *id.*



lice and other law enforcement officials have access to private medical records on request.<sup>315</sup> If this is passed into law, legal access to name-based HIV registries may be possible.<sup>316</sup>

The United States Supreme Court, however, has recognized that security precautions are never foolproof and does not presume the measures are insufficient if there are reasonable devices in place to secure confidentiality.<sup>317</sup> In *Whalen*, the Court stated that fear of public disclosure could cause some patients to decline prescriptions that were medically necessary.<sup>318</sup> The Court noted, however, that the state had enacted security provisions to protect the patients' privacy and that there was no evidence that the security provisions were inadequate.<sup>319</sup> The Court reasoned that unsubstantiated fear of public disclosure was not sufficient to invalidate the statute.<sup>320</sup> Thus, if there are reasonable devices to secure the confidentiality of records, the Court will not assume that the devices will prove insufficient.<sup>321</sup> As a result, if states take measures to ensure that HIV status reports are maintained under secure conditions, the patients have diminished privacy interests because public dissemination is less likely.<sup>322</sup> Therefore, the fear of unauthorized public disclosure that might discourage some individuals from getting tested will not be sufficient to invalidate mandatory name reporting.<sup>323</sup>

The sixth and seventh *Westinghouse* factors involve the need for access and whether there is statutory authority or public interest favoring access to the information.<sup>324</sup> Disease surveillance plays a vital role in public health because it provides information needed to identify, track and respond to disease trends effectively and timely.<sup>325</sup> Therefore, the availability of accurate, reliable and complete data is critical to protecting and maintaining the health of the community.<sup>326</sup>

Because AIDS reporting does not provide an accurate reflection of HIV cases, the public clearly has a strong interest in further research regarding the epidemic.<sup>327</sup> The advantages of tracking and profiling

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<sup>315</sup> See Forbes, *Myths & Facts*, *supra* note 307, at 1.

<sup>316</sup> See *id.*

<sup>317</sup> See *Whalen*, 429 U.S. at 601-02.

<sup>318</sup> See *id.* at 602.

<sup>319</sup> See *id.* at 601.

<sup>320</sup> See *id.* at 602.

<sup>321</sup> See *id.* at 601-02.

<sup>322</sup> See *Whalen*, 429 U.S. at 601-02.

<sup>323</sup> See *id.* at 602.

<sup>324</sup> See *Westinghouse*, 638 F.2d at 578.

<sup>325</sup> See BUREAU OF HIV AND STD PREVENTION, *supra* note 88, at 4.

<sup>326</sup> See *id.*

<sup>327</sup> See Sophia Kwong, *HIV InSite: Primary Arguments Used in Support of Mandatory Names Reporting* (visited Jan. 4, 1998) <<http://hivinsite.ucsf.edu/topics/testing/2098.33b6.html>>.

HIV are significant because HIV infection marks the beginning of the disease process rather than the end.<sup>328</sup> Due to new treatments which delay the onset of AIDS, states that rely on AIDS surveillance information to target HIV prevention efforts will have a distorted picture of HIV-infected populations.<sup>329</sup> Thus, because HIV reporting programs will increase and improve HIV surveillance efforts and data, the need for HIV surveillance data is virtually undisputed.<sup>330</sup>

Whether obtaining this needed data through name reporting is necessary, however, is hotly debated.<sup>331</sup> Some argue that access to names will enable public health authorities to ensure that information about medical and social services is offered to individuals who test positive.<sup>332</sup> Collecting names, however, will not provide everyone with care when money to pay for the care is not available.<sup>333</sup> From 1996 through early 1997, only twenty-five percent of individuals with CDC-defined AIDS were on any kind of protease inhibitor therapy.<sup>334</sup> The federally funded AIDS Drug Assistance Programs ("ADAP") obtained medication for only fourteen to twenty-eight percent of all ADAP eligible people in 1996.<sup>335</sup>

Some public health officials argue that mandatory name reporting will facilitate partner notification programs and expand access to testing, by allowing public health authorities to contact individuals who test positive and work with them to inform at-risk partners about testing services.<sup>336</sup> It seems, however, that partner notification should not be tied to the issue of mandatory name reporting.<sup>337</sup> The name of the individual who tests positive is not needed to elicit the names of sex and needle-sharing partners for partner notification.<sup>338</sup> Of the HIV-positive people surveyed in the MESH study, those who tested at sites where names were not used supplied the same number of partner names, on average, as those who tested at sites where names were collected.<sup>339</sup> Because it is the partners who are contacted during the

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<sup>328</sup> See BUREAU OF HIV AND STD PREVENTION, *supra* note 88, at 2.

<sup>329</sup> See *id.*

<sup>330</sup> See *Creating an Effective Public Health Response*, *supra* note 23, at 5; Kwong, *supra* note 327.

<sup>331</sup> See Forbes, *Naming Names*, *supra* note 17, at 2.

<sup>332</sup> See Kwong, *supra* note 327.

<sup>333</sup> See Forbes, *Myths & Facts*, *supra* note 307, at 1.

<sup>334</sup> See *id.*

<sup>335</sup> See *id.*

<sup>336</sup> See Kwong, *supra* note 327. About 40% of people at risk for HIV have never been tested. See *id.*

<sup>337</sup> See *infra* notes 338-42 and accompanying text.

<sup>338</sup> See Dillon, *supra* note 309.

<sup>339</sup> See Forbes, *Myths & Facts*, *supra* note 307, at 2.

follow-up in partner notification, the name of the person testing positive is not necessary for effective partner notification.<sup>340</sup> If the individuals give their partners' names to the health department, for example, there is no need to have the initial case reported by name to the government.<sup>341</sup> Furthermore, because partner notification requires the HIV-positive individuals to cooperate, some individuals may be reluctant to provide the names of their partners if they know their own names will be reported to a government entity.<sup>342</sup> Thus, given the strong public interest in and need for HIV surveillance data, and presuming that adequate safeguards are in place to protect a state's centralized HIV registry, the collection of names of HIV-positive individuals in a state's registry will not violate an individual's right to privacy.<sup>343</sup>

Even if name reporting systems were found to be unconstitutional, unique identifier systems would still pass constitutional muster.<sup>344</sup> With unique identifier systems, reports submitted to state health departments link numeric codes to HIV-positive test results.<sup>345</sup> Because individuals are not linked to HIV status by their names, the type of information disclosed in a unique identifier system is not the same type of information disclosed in a name reporting system.<sup>346</sup> Although the Court in *Whalen* recognized a valid privacy interest in medical information relating to prescriptions, patients' names and addresses formed the direct link to the disclosed information.<sup>347</sup> Thus, the facts underlying *Whalen* are less comparable to unique identifier systems than to name reporting systems.<sup>348</sup> Given that the court in *Adams* held that there is no right to privacy prohibiting disclosure of social security numbers, the Constitution does not protect the confidentiality of medical information that is linked to an individual by numeric code only.<sup>349</sup>

Additionally, there is significantly less potential for harm from disclosure and injury resulting from disclosure in a unique identifier system because it uses numeric codes rather than names.<sup>350</sup> This, in

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<sup>340</sup> See *id.*

<sup>341</sup> See Dillon, *supra* note 309.

<sup>342</sup> See *id.*

<sup>343</sup> See *Middlebrooks*, 710 So. 2d at 893.

<sup>344</sup> See *infra* notes 345-53 and accompanying text.

<sup>345</sup> See *Creating an Effective Public Health Response*, *supra* note 23, at 5.

<sup>346</sup> See *id.*

<sup>347</sup> See *Whalen*, 429 U.S. at 593, 599.

<sup>348</sup> See *id.* at 593.

<sup>349</sup> See *In re Adams*, 214 B.R. 212, 216-17 (B.A.P. 9th Cir. 1997); see also *Westinghouse*, 638 F.2d at 577.

<sup>350</sup> See *Creating an Effective Public Health Response*, *supra* note 23, at 5-6, 9.

turn, affects another factor in the *Westinghouse* test: the adequacy of safeguards for the prevention of unauthorized disclosure.<sup>351</sup> Because unauthorized disclosure of codes would result in less harm than that of names, this factor is not as significant.<sup>352</sup> Thus, even though the public's need for access to HIV surveillance data is the same need as in name reporting systems, a unique identifier system will not violate an individual's right to privacy under *Westinghouse's* balancing test.<sup>353</sup>

### B. *The Equal Protection Argument*

Compared to a right of privacy claim, the Equal Protection Clause may provide an even weaker challenge to a mandatory HIV name reporting program.<sup>354</sup> The United States Supreme Court has stated that when the challenged legislation does not restrict a fundamental right or hinder a suspect class, a court merely examines whether there is a rational basis for the law.<sup>355</sup> HIV-positive individuals are not a suspect class because suspect classifications traditionally have been limited to race, gender, alienage, national origin and legitimacy.<sup>356</sup> Furthermore, there is no fundamental right to confidentiality in one's HIV status.<sup>357</sup> Thus, mandatory reporting systems would be reviewed under the rational basis standard and would be upheld if the classification by HIV status rationally relates to a legitimate state purpose.<sup>358</sup> The party claiming discrimination bears the burden of proving that the reporting systems are irrational.<sup>359</sup> Therefore, it would be very difficult for HIV-positive individuals to prevail on an equal protection claim.<sup>360</sup>

Courts have traditionally given great deference to laws and regulations in the public health area, even when they implicate constitutional rights.<sup>361</sup> As demonstrated in *Jacobsen*, states have the authority, through their general police power, to enact and enforce laws to protect people's health, safety and welfare.<sup>362</sup> As a result, states have

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<sup>351</sup> See *Westinghouse*, 638 F.2d at 578.

<sup>352</sup> See *Creating an Effective Public Health Response*, *supra* note 23, at 6, 9.

<sup>353</sup> See *supra* notes 324-30, 344-52 and accompanying text.

<sup>354</sup> See *infra* notes 355-66 and accompanying text.

<sup>355</sup> See, e.g., *Romer v. Evans*, 517 U.S. 620, 631 (1996).

<sup>356</sup> See *Palmore v. Sidoti*, 466 U.S. 429, 432-33 (1984) (race is a suspect class); *Mississippi Univ. for Women v. Hogan*, 458 U.S. 718, 723-24 (1982) (gender is a suspect class); *Barnes*, *supra* note 272, at 4-4.

<sup>357</sup> See *supra* notes 265-70 and accompanying text.

<sup>358</sup> See *Romer*, 517 U.S. at 631, 632.

<sup>359</sup> See, e.g., *Harrah Indep. Sch. Dist. v. Martin*, 440 U.S. 194, 198 (1979).

<sup>360</sup> See *supra* notes 354-60 and accompanying text.

<sup>361</sup> See *Jacobsen v. Massachusetts*, 197 U.S. 11, 25, 39 (1905).

<sup>362</sup> See *id.* at 25.

the power to regulate HIV surveillance efforts.<sup>363</sup> The purposes of mandatory HIV reporting systems—to accumulate HIV surveillance data and to prevent the spread of HIV and AIDS—are legitimate state goals.<sup>364</sup> Thus, it is unlikely that *Romer* would be used to strike down an HIV reporting scheme because mere animosity toward HIV-positive individuals, even if proven, would not be the main rationale for the program.<sup>365</sup> Given the legitimate public need for HIV surveillance data and the Alabama Supreme Court decision in *Middlebrooks v. State Board of Health*, HIV reporting systems are constitutional.<sup>366</sup>

### C. Unique Identifiers May Be a Better Alternative Than Name Reporting

Although both HIV reporting systems are constitutional, unique identifiers may be more effective from a policy perspective.<sup>367</sup> One of the main criticisms of mandatory name reporting is that individuals will avoid testing due to fear of breaches in confidentiality and the possibility of discrimination or stigmatization.<sup>368</sup> Several studies have indicated that mandatory name reporting would result in fewer individuals being tested.<sup>369</sup> The CDC and the University of Southern California have conducted one of the largest HIV-testing surveys of high-risk populations.<sup>370</sup> In each of nine states, 100 injection drug users on the streets, 100 men in gay bars and 100 heterosexuals in STD clinics

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<sup>363</sup> See *Middlebrooks*, 710 So. 2d at 893.

<sup>364</sup> See *id.*

<sup>365</sup> See *Romer*, 517 U.S. at 632.

<sup>366</sup> 710 So. 2d at 893. Procedural due process may also be useful in challenging mandatory HIV reporting programs. See *Barnes*, *supra* note 272, at 4–5. Such a challenge would rely on the individual's right to notice and a hearing before his or her reputation, honor or integrity is compromised by government action. See *id.* Adding one's name to an HIV registry could constitute such damage to reputation because HIV status is often linked to character traits such as homosexuality or drug addiction, which are often criticized by our society. See *id.* This claim would be particularly effective if a reporting scheme did not include extensive confidentiality precautions, if the list were used for some type of government-sponsored discrimination or if the list were available to law enforcement personnel. See *id.* Even with confidentiality precautions, however, a due process claim would be tenable due to the constant threat of public disclosure of collected names and the potential for both ridicule and discrimination. See *id.* To withstand a due process challenge, a mandatory HIV reporting program arguably should include a confidential administrative mechanism by which an individual could challenge the addition of his name to the HIV registry. See *id.* Procedural due process may also require that a reporting program include a mechanism through which an individual's name could be removed, if his or her HIV status changes at a later date. See *id.* at 4–5 n.20. The strength of any objection based on possible changes in HIV status depends, however, on future medical evidence of the possibility and likelihood of such HIV status changes. See *id.*

<sup>367</sup> See *infra* notes 368–405 and accompanying text.

<sup>368</sup> See *Dillon*, *supra* note 309.

<sup>369</sup> See *id.*

<sup>370</sup> See *First-Ever AIDS Incidence Decline*, *supra* note 19, at 121.

were interviewed about the reason they did or did not seek HIV testing.<sup>371</sup> According to preliminary data, among those who were surveyed, about twenty percent mentioned their names being reported as one of the reasons for not getting tested.<sup>372</sup> Additionally, a 1995 study conducted at Los Angeles-based anonymous and confidential test sites found that approximately eighty-six percent of respondents would not have sought an HIV test if they knew their name was going to be reported to a governmental agency.<sup>373</sup> Individuals will cross state lines, forego needed social services and avoid medical care altogether if they fear being recorded in a name-based registry.<sup>374</sup>

Consequently, by preserving the anonymity of the individual tested, the unique identifier system encourages all individuals to be tested, thereby making it a better alternative to name reporting systems.<sup>375</sup> Because names are not collected in a central registry, unique identifiers may not generate the same fears of stigmatization and discrimination.<sup>376</sup> As a result, individuals are more likely to seek testing because of fewer confidentiality concerns.<sup>377</sup>

Additionally, there will likely be fewer duplication problems with a unique identifier system than with name reporting.<sup>378</sup> An individual will most likely use the same unique identifier code for each test.<sup>379</sup> Thus, a repeat tester can be identified as such and will not be double-counted.<sup>380</sup> In contrast, the accuracy of name-based reporting depends upon whether the testee uses a real name.<sup>381</sup> Evidence suggests that people who must give their name when taking an HIV test will use a pseudonym to protect their identity.<sup>382</sup> If individuals often access testing pseudonymously, this hampers epidemiologists' ability to remove duplicates from name-based records and the provider will be unable to follow up and link individuals to medical care.<sup>383</sup>

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<sup>371</sup> See *id.*

<sup>372</sup> See *id.* In follow-up interviews, however, only 2% of study participants mentioned name reporting as the single reason they avoided testing. See *id.*

<sup>373</sup> See Dillon, *supra* note 309.

<sup>374</sup> See Forbes, *Naming Names*, *supra* note 17, at 2.

<sup>375</sup> See *HIV Surveillance and Name Reporting*, *supra* note 53, at 10.

<sup>376</sup> See *Creating an Effective Public Health Response*, *supra* note 23, at 9-10.

<sup>377</sup> See *id.*

<sup>378</sup> See *HIV Surveillance and Name Reporting*, *supra* note 53, at 10.

<sup>379</sup> See *id.*

<sup>380</sup> See *id.*

<sup>381</sup> See *id.*

<sup>382</sup> See *id.*

<sup>383</sup> See Forbes, *Naming Names*, *supra* note 17, at 4.

Unique identifier systems are not perfect.<sup>384</sup> There can be problems with both the completeness of data and the cross-matching against other registries.<sup>385</sup> Thus, unique identifier systems merit additional study before being implemented in other jurisdictions.<sup>386</sup> The analysis should focus on identifying and correcting any deficiencies in order to avoid repeating some of the problems that Maryland and Texas are experiencing.<sup>387</sup> Although there are still concerns over potential breaches of confidentiality with unique identifier systems when a social security number or other identifying information is requested, the potential for breaches when names are used is much greater.<sup>388</sup> Even though it is possible to decode some unique identifier systems (thereby revealing an individual's identity), name-based reporting systems provide even less protection for HIV-infected individuals.<sup>389</sup>

Furthermore, while unique identifier systems have been criticized as cumbersome and expensive, federal funding could make them more effective and cost-efficient.<sup>390</sup> HIV case reporting costs money to implement regardless of the type of scheme used.<sup>391</sup> Maryland and Texas set up their systems after receiving one-time CDC grants which were allocated to evaluate the systems over three years.<sup>392</sup> In both states, the lack of state funding exacerbated the difficulty of implementing a unique identifier system.<sup>393</sup> Maryland processes 7500 unique identifier-based HIV reports per year with a system that costs about \$100,000 to operate.<sup>394</sup> New York's State Health Department spends a comparable, per-case amount on name-based reporting of low CD4 results.<sup>395</sup> Given the resulting decrease in testing avoidance, the increase in community acceptability and the improved quality of data obtainable through unique identifier systems, Maryland regards the investment as both manageable and worthwhile.<sup>396</sup>

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<sup>384</sup> See BUREAU OF HIV AND STD PREVENTION, *supra* note 88, at 14.

<sup>385</sup> See *id.*

<sup>386</sup> See *HIV Surveillance and Name Reporting*, *supra* note 53, at 11.

<sup>387</sup> See *id.*

<sup>388</sup> See *Creating an Effective Public Health Response*, *supra* note 23, at 5-6.

<sup>389</sup> See *id.*; Forbes, *Myths & Facts*, *supra* note 307, at 3.

<sup>390</sup> See *Creating an Effective Public Health Response*, *supra* note 23, at 12; Gostin et al., *supra* note 17, at 1165.

<sup>391</sup> See Forbes, *Myths & Facts*, *supra* note 307, at 3.

<sup>392</sup> See *id.*

<sup>393</sup> See *id.*

<sup>394</sup> See Anna Forbes, *HIV InSite: An Activist's Guide to Unique Identifiers* (Dec. 1997) <<http://hivinsite.ucsf.edu/topics/testing/2098.351f.html>>.

<sup>395</sup> See *id.*

<sup>396</sup> See Forbes, *Naming Names*, *supra* note 17, at 4.

Although some argue that HIV surveillance by name has been the tradition in many states for years with few complications or leaks in information, most high incidence states still have not implemented a name-based surveillance program.<sup>397</sup> Ultimately, the way the public perceives the system will matter most.<sup>398</sup> If individuals are discouraged from getting tested, the whole purpose of HIV surveillance is completely undermined.<sup>399</sup> Individuals continue to fear unauthorized disclosure of their HIV status and the possibility of misuse of HIV-related data still remains.<sup>400</sup> With unique identifiers, the public health need for HIV information can be fulfilled with less risk to individual confidentiality.<sup>401</sup>

Regardless of which HIV reporting system a state eventually chooses to adopt, anonymous publicly-funded testing should also remain available.<sup>402</sup> Many individuals will continue to need access to anonymity for economic, insurance and personal reasons.<sup>403</sup> Because some individuals would delay testing—or not be tested at all—without remaining anonymous, these sites should be maintained.<sup>404</sup> Although this might slightly skew epidemiological data, it will ensure that no individual is completely prevented from testing because of fears about confidentiality.<sup>405</sup>

## VI. CONCLUSION

With innovative medical treatments delaying the progression of AIDS, HIV data based on AIDS reporting is not sufficient. Thus, there is now an even more compelling need to monitor HIV infection accurately. HIV surveillance systems will provide health officials with more accurate, reliable information about the prevalence, incidence and future direction of HIV.

HIV reporting schemes represent a conflict, however, between an individual's right to privacy and the health of the community. High incidence states are thus currently struggling over whether they should adopt name-based reporting or unique identifiers.

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<sup>397</sup> See *id.* at 1, 4.

<sup>398</sup> See *HIV Surveillance and Name Reporting*, *supra* note 53, at 7.

<sup>399</sup> See *id.* at 16.

<sup>400</sup> See *supra* notes 300–16 and accompanying text.

<sup>401</sup> See *Creating an Effective Public Health Response*, *supra* note 23, at 9.

<sup>402</sup> See *GMHC: HIV Monitoring* (visited Feb. 15, 1998) <<http://www.gmhc.org/aidslib/monitor.html>>.

<sup>403</sup> See *id.*

<sup>404</sup> See *id.*

<sup>405</sup> See *id.*



Both HIV reporting systems are likely to be constitutional as long as strict confidentiality provisions are in place. Although the right to privacy in personal information has not been clearly demarcated by the United States Supreme Court, there is likely a right to privacy in one's HIV status. This right to privacy, however, is likely to be outweighed by other factors, including the strong public interest in HIV surveillance data. An equal protection challenge is also unlikely to succeed because HIV-positive individuals are not a suspect class and keeping HIV status confidential is not a fundamental right.

Although both systems are likely to pass constitutional muster, unique identifier systems provide a comprehensive view of the disease and still maintain confidentiality, thereby not discouraging HIV testing. Even though unique identifier systems need to be further investigated, they remain the most sensible option. For more than twenty years, AIDS and HIV have been the center of bitter controversies. HIV surveillance systems should not be added to this list. Rather, society simply needs to make a sober determination of the policy that best combines solid data collection with privacy—goals that can and should be compatible.<sup>406</sup>

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<sup>406</sup> See *Keeping Track of HIV Cases*, *supra* note 115, at A4.