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Louise G. Trubek

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### Recommended Citation

Louise G. Trubek, *Searching for a Balance in Universal Health Care Reform: Protection for the Disenfranchised Consumer*, 43 DePaul L. Rev. 1081 (1994)

Available at: <https://via.library.depaul.edu/law-review/vol43/iss4/5>

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# SEARCHING FOR A BALANCE IN UNIVERSAL HEALTH CARE REFORM: PROTECTION FOR THE DISENFRANCHISED CONSUMER

Louise G. Trubek\* & Elizabeth A. Hoffmann\*\*

## INTRODUCTION

The United States is entering into the initial stages of a decade-long project of revamping its health care system to achieve coverage for every citizen. This project has been attempted several times in the last forty years, but with little success.<sup>1</sup> One of the major differences in the recent debate is the strength of disenfranchised consumers. During the thirty years since President Lyndon Johnson's initiation of Medicaid and Medicare,<sup>2</sup> alternative approaches to health care have been proposed and implemented by groups of disadvantaged consumers.<sup>3</sup> Community groups have also grown in strength and expanded their base of support. While some of these institutions and critiques predate the 1960s, their growth in number and funding is relatively recent.<sup>4</sup>

The category of disenfranchised consumers includes those consumers who suffer from a marginalization which prevents them from becoming full members of society.<sup>5</sup> Consumers who are considered disenfranchised in the health care system include persons with Acquired Immune Deficiency Syndrome ("AIDS") or Human Immu-

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\* Clinical Professor of Law, University of Wisconsin Law School.

\*\* Research Assistant, University of Wisconsin Law School.

1. PAUL STARR, *THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE: THE RISE OF A SOVEREIGN PROFESSION AND THE MAKING OF A VAST INDUSTRY* 393-405 (1982).

2. Medicare is a program administered by the Social Security Administration, an agency of the United States Department of Health, Education, and Welfare. 42 U.S.C. § 1395 (1988). Medicaid is administered by individual states in accordance with a state-adopted plan that conforms to federal requirements. *Id.* § 1396.

3. *Id.* at 367-78.

4. Family planning is one such exception. See Joan E. Lynaugh, *Institutionalizing Women's Health Care in Nineteenth- and Twentieth-Century America*, in *WOMEN, HEALTH, AND MEDICINE IN AMERICA: A HISTORICAL HANDBOOK* 247, 266 (Rima D. Apple ed., 1992).

5. The term "disenfranchised consumer" was supplied by the editors of the *DePaul Law Review* in organizing the symposium, and I have used it in this article. Other possible terms that could have been used include "disadvantaged consumers," "marginalized groups," and "subordinated people."

odeficiency Virus ("HIV"), the mentally and physically disabled, women, people of color, the poor, and children.<sup>6</sup>

An ongoing criticism of the American health care system has been the lack of universal coverage, which is essential for the well-being of all consumers. In the present political debate, however, disenfranchised consumers have insisted on special protection to ensure appropriate service, asserting that universal coverage alone will not be sufficient.<sup>7</sup>

The concept of universal coverage is an essential aspect of the health care plan proposed by President Bill Clinton. The requirement that all Americans have access to a basic package of quality health care services is expressed by the proponents of the Clinton plan as its guiding principle. In a recent article on the Clinton plan, the League of Women Voters echoed this point, stating:

It is not only for altruistic reasons that universal access has been so enthusiastically embraced by the nation's health care reformers . . . . [A]ny reform plan that fails to provide access for all Americans to affordable, quality care will only perpetuate what is wrong with the system as it now stands . . . .<sup>8</sup>

Universal coverage is essential for a number of reasons. The two most commonly cited reasons are the high number of uninsured citizens and the escalating cost of health care.<sup>9</sup> There are, however,

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6. The phrase "disenfranchised" distinguishes these consumers from ordinary consumers, who can be weak participants in the health care system because of their inability to organize into interest groups. However, ordinary consumers do not suffer from any additional stigmas. Arthur Snow & Burton A. Weisbrod, *Consumerism, Consumers and Public Interest Law*, in *PUBLIC INTEREST LAW: AN ECONOMIC AND INSTITUTIONAL ANALYSIS* 401-06 (BURTON A. WEISBROD ED., 1978).

7. A perplexing aspect of the case for protection is the role the debate has played in the politics of achieving universal coverage.

There are two stories from my experience that can illuminate that point. In the past several months, as a public interest lawyer and a proponent of universal coverage, I have been told by both the president of a large health care center and by a Wisconsin legislator that universal coverage is not crucial for health care since it would not contribute to better care for children who require specialized prevention programs and culturally-sensitive provider systems. These policy-makers justified their unwillingness to support universal health care reform with this reasoning. These leaders further indicated that they thought my position in favor of universal access was inconsistent with my longstanding advocacy on behalf of disadvantaged consumers.

A second story concerns the difficulty of achieving an alliance to support universal coverage in the state of Wisconsin. Many of the groups, such as maternal and children's health consortia and disability groups, consider the support and funding for their targeted programs to be their priority, and view the substantial political battle to achieve universal coverage as a secondary concern.

8. *Different Communities, Different Needs*, NAT'L VOTER, Dec.-Jan. 1994, at 8.

9. Without universal coverage, society will continue to have people who, for either brief or extended periods of time, cannot pay for their health care. Moreover, without a universal coverage

other significant reasons. In order to have universal coverage, there must be a coordinated system to allocate the resources and ensure that everyone is part of the system. A process of coordinating coverage promotes a social health care system. Such a process does not now exist; rather, we have a series of uncoordinated, fragmented systems which do not interlock. Another possible outcome of universal coverage systems would be the ability of subordinated groups to influence the system. If the process was open and visible, social concern and activism might increase and in turn influence the universal system. The political and community delivery systems could then be made more transparent and open so that the universal system could work for everyone.

Such a comprehensive system also possesses another advantage: the reduction of stigma attached to groups considered to be undesirable. The creation of a system in which all Americans participate would engender a community of health consumers. The disability groups have been particularly interested in "mainstreaming,"<sup>10</sup> so that all health care providers would be accessible to and provide services for disabled consumers. A final reason universal coverage is needed is to engage the traditional hospital and provider system in serving every consumer. This interaction would allow the money in that system to be allocated in the most efficient and equitable way. Thus, in addition to the commonly-mentioned advantages of a universal plan, coverage for all, and cost containment, a universal coverage system also possesses the advantages of democratic community, opportunities for activism, the reduction of stigma, and the appropriate allocation of resources.

Implementation of a universal plan will not eliminate the need to seriously address the critiques of mainstream health care raised by the various disenfranchised consumers' health groups. These provid-

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system that includes standard benefits, essential benefits will continue to remain uncovered.

Universal coverage is also needed to control the resources that are being spent on health care. There is ample documentation of the escalation of health care costs as a percentage of the Gross Domestic Product ("GDP") as well as comparisons with other countries. *E.g.*, *The Future of Health Care in America: Hearings Before the Subcomm. on Education and Health of the Joint Economic Comm.*, 100th Cong., 1st Sess., pt. 1 (1988). A related concern is the cost-shifting between the various payors which results from a lack of universal coverage. For example, Wisconsin hospitals spent \$137 million in 1992 to pay for health care for people unable to pay for their own medical care. This high figure was, in fact, paid for by other payors through higher rates. This cost shifting is especially burdensome for large businesses and government payers.

10. Steven Schwartz, Remarks at the Meeting of the American Association of Law Schools (Jan 8, 1994).

ers and community groups evolved during the 1980s as part of the safety net created to keep some semblance of care for all during the conservative retrenchment. Thus, the debate on the shape of a national health care plan has been transformed by the 1980s safety net system.

Therefore, the Clinton plan of universal coverage must seriously address the programs and protections proposed by the disenfranchised consumers and integrate these in an open and positive fashion. If the plan does not address these needs, it will be unable to provide quality health care for disenfranchised consumers and contribute to the disintegration of community-based and alternative systems.<sup>11</sup>

The concerns of the disenfranchised consumers are clearly articulated and are accompanied by theoretical grounding, legal and regulatory support, a political base, and the support of competent providers. During the many years when mainstream health care institutions failed to meet the needs of disenfranchised consumers and of fiscally-conservative government leadership, a strong alternative health care network developed, and it has convinced many that mainstream medicine is not sufficient.

Without a commitment to the programs and approaches proposed by the advocates for disenfranchised consumers, universal coverage legislation could be in jeopardy.<sup>12</sup> It is essential that a strong com-

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11. An example of the short-sightedness of the proponents of the Clinton plan's universal aspects is an analysis of the plan issued by the Consumers Union. Although the Union lists "25 ways to make a good plan even better," they fail to address additional protections for disenfranchised consumers. CONSUMERS UNION, *THE CLINTON HEALTH CARE ACT: WHAT WILL IT MEAN FOR CONSUMERS?* 5-6 (1993).

The concerns of disenfranchised consumers have become so strong that they can be seen as diminishing the importance of the universal aspect of the Clinton plan. An example of this appeared in a recent article in *The National Voter*, the League of Women Voters's magazine. In the article, representatives of "different communities" addressed the importance of universal coverage, demonstrating *pro forma* support for the concept of universal access, but they also argued for the special needs of their constituency. *Different Communities, Different Needs*, *supra* note 8, at 8. A casual reader of the article would interpret its message as demonstrating the problems, rather than the strengths, of the Clinton plan.

12. One difficulty in enacting the legislation is the challenge of achieving a progressive alliance to ensure that the legislation that is passed provides protection of, and encouragement for, the programs of disenfranchised consumers. In Wisconsin, for example, there has been resistance by the various groups that represent disenfranchised consumers to either plan strategies to enact progressive legislation or to debate how the protections and innovations should work. The attention of the groups has focused on either a continuation of the status quo — in the belief that no legislation at all will be enacted — or to criticize all reform proposals on the basis that they do not sufficiently protect their specific groups' needs and programs. For example, the children's health proponents espoused additional Healthy Start financing, but their proposals did not coincide with

mitment, with financial and regulatory incentives, be advanced to achieve both equality and diversity within the new health system. Since it seems clear that substantial power will be delegated to the states to design their own systems, the federal plan must also require that states take these concerns seriously and then follow through to ensure that the states do just that.

Thus, the challenge facing the Health Security Act ("Act")<sup>13</sup> is to create clear and workable approaches to protect the programs developed by the disenfranchised groups and incorporate these protections in a strong and clear manner. To determine how to achieve this integration, this Article explores the different needs of the various disenfranchised communities: people with AIDS and HIV, the mentally and physically disabled, women, people of color, poor people, and children. It discusses why the proposals of these communities are so powerful and enjoy support from differing aspects of society. The Article then addresses the protections which are contained in the Act, and it closes with a series of suggestions for strengthening the proposals based on the experience of consumer groups in Wisconsin.

### I. THE CASE FOR PROTECTION OF THE DISADVANTAGED CONSUMER

The experience of disenfranchised consumers has made them skeptical of mainstream health care and government policy-makers. While they have expressed the needs of their constituencies, the health care system has resisted meeting these needs. Over a period of time, these consumer groups articulated a series of critiques of mainstream health care and have subsequently developed innovative programs that do meet their needs. This experience has made disenfranchised consumers skeptical of a universal plan's ability to respond to their critiques and to adequately fund the projects that meet their needs. Although a unified system may strengthen institutions unsympathetic to the health needs of the disenfranchised, these groups will resist making a universal plan a top priority until they are convinced that their programs and critiques will be an integral spoke in the national health care wheel.<sup>14</sup>

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the issues under the health care reform debate. Thus, children's health advocates pursued a short-term strategy which may have unsatisfactory results in the long run.

13. The Health Security Act of 1993, H.R. 3600, 103d Cong., 1st Sess. (1993).

14. See *Children, Families and Clinton's Health Care Reform*, CAPITAL COMMENTS, Oct.

### A. *The Programs of Disenfranchised Consumers*

Advocates for the many disenfranchised groups of health care consumers argue that any national health care reform must take special notice of the specific health concerns raised by each group. Each group of disenfranchised consumers has certain unique health-related concerns that they fear will be overlooked in the implementation of a universal health care plan.

#### 1. AIDS

The epidemic of AIDS and HIV, which began to sweep the country in the early 1980s, accompanied the development of strong advocacy groups for gays.<sup>15</sup> This confluence has resulted in strong organizations dedicated to social activism as well as to effecting alternative health care.<sup>16</sup> These groups developed separate outreach programs, provider systems, and research agendas which have been highly successful.<sup>17</sup> The initial hesitancy of the mainstream health care community to realize the importance of the AIDS virus contributed to the development of these specialized services.<sup>18</sup> The hesitancy of traditional physicians and insurance companies contributed to the belief that specialized providers were essential if people with AIDS or HIV were to receive adequate services.<sup>19</sup> These AIDS activists emphasized the importance of providing community health care, such as home-based care, support programs and psychological counseling for patients, as well as the integration of such care into a specialized system.

Advocacy groups stress that health care providers need to be responsive to the concerns of all AIDS patients while realizing that the needs of each individual AIDS patient may be very different from those of any other AIDS patient.<sup>20</sup> They believe that greater input by concerned and knowledgeable parties will create a more effective system of care for people with AIDS and HIV.

The prevention of AIDS is one of the biggest weapons the health

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1993, at 1; Kirk A. Johnson, *The Black Health Crisis*, MILWAUKEE J., Mar. 7, 1994, at D1, D2.

15. Robert A. Padgug & Gerald M. Oppenheimer, *AIDS, Health Insurance, and the Crisis of Community*, 5 NOTRE DAME J.L. ETHICS & PUB. POL'Y 35, 46 (1990).

16. *Id.*

17. *Id.* at 45.

18. *Id.*

19. *Id.* at 45-46.

20. Mary Ide et al., *AIDS, HIV Infection and Women*, in *THE NEW OUR BODIES, OURSELVES* 327, 329 (Boston Women's Health Book Collective ed., 1992).

care system presently has to fight the battle against AIDS and HIV. Outreach and education need to be a strong focus of the health care system in order to provide consumers with the information they need to avoid contracting HIV. Health care providers, as well as consumers, must acknowledge accept the fact that AIDS is a behaviorally-transmitted disease, not one that affects only certain types of people. Therefore, AIDS activists stress that outreach needs to be addressed to all groups of people; it must go beyond certain commonly targeted communities. Moreover, health care professionals need to remember that AIDS affects different people in different ways. For years many women died of AIDS, but their conditions went undiagnosed because AIDS often does not display the same classic symptoms in women as it does in men.<sup>21</sup> Without traditional male symptoms, many women were denied access to government support and experimental drugs because they did not qualify as AIDS patients.<sup>22</sup> AIDS prevention efforts also need to start early.<sup>23</sup> Outreach to children, who may or may not be engaging in at-risk behavior, is essential to preventing the spread of HIV and AIDS. The experience of AIDS activists is that the traditional health care system cannot, or will not, provide this kind of outreach.

Prevention, however, is not enough. Many people have already developed AIDS, and many more are HIV-positive but do not show symptoms of the disease.<sup>24</sup> Of those already infected with AIDS, many want access to experimental therapies and drugs.<sup>25</sup> The activists believe that the health care system must give patients the option of using therapies that have not been officially approved. Access to any cure, regardless of how controversial it may be, must be an option for AIDS patients. The final decision as to what treatments to receive must be left to each patient. This also means, of course, that the use of experimental therapies must also never be forced or coerced, but only commenced voluntarily at the patient's request.

Finally, support services must be integrated with medical care in order to provide quality care for AIDS patients.<sup>26</sup> Mental health support for patients with AIDS is necessary for patients to achieve

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21. *Id.*

22. *Id.* at 337-39.

23. *Id.*

24. *Id.* at 334-35.

25. *Id.* at 339.

26. Mireya Navarro, *AIDS Plan for Poor Seen as Model for Other Ills*, N.Y. TIMES, Feb. 22, 1994, at A1.



the highest level of health possible while struggling against the disease.

## 2. *The Mentally and Physically Disabled*

Like AIDS and HIV, disabilities also affect each patient in different ways. Therefore, suitable care for consumers with disabilities demands health care sufficiently tailored to each patient's individual needs and challenges. Advocates for mentally and physically disabled consumers assert that a health care system must provide specialized providers for their specific needs.

For many disabled consumers, the management of chronic health problems is crucial.<sup>27</sup> Health care activists argue that proper ongoing care is essential because it can often prevent a condition from worsening or from creating secondary health complications.<sup>28</sup> Activists for the mentally and physically disabled believe that health care must also recognize that the severity of each patient's condition may fluctuate.<sup>29</sup> Patients with such conditions need the correct care for each of their levels of ability.

Ensuring that consumers have a strong and influential voice in shaping the health care that they receive will benefit all patients.<sup>30</sup> However, according to advocates for the physically and mentally disabled, it will particularly help ensure that disabled consumers have the type of care appropriate to their individual needs.<sup>31</sup> Since each patient's disability or combination of disabilities is very person-specific — and varies with time for each individual — proper health

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27. Bob Griss, *Americans With Disabilities: A Litmus Test for Whether Reform Serves All*, NAT'L VOTER, Dec.-Jan. 1994, at 8.

28. *Id.*

29. Under the current health care system, once a person is deemed "medically recovered" the otherwise disabled person becomes ineligible for medical benefits. This is "another source of fear and anxiety especially true for people with chronic mental illness who experience intermittent disability." *Social Security Health Care for Americans With Disabilities: Testimony Before the House Ways and Means Comm.* (Feb. 23, 1994) (testimony of Gerben de Jong, Director, National Rehabilitation Hospital Research Center), available in LEXIS, News Library, CURNWS File.

30. "A broad base of habilitation, rehabilitation and home health care services is necessary to increase an individual's capacity to prevent deterioration, increase functional skills, and manage chronic disability." *Therapeutic Recreation: Responding to the Challenges of Health Care Reform: Testimony Before the Senate Comm. on Labor* (Feb. 22, 1994) (joint statement of the American Therapeutic Recreation Assoc. and the National Therapeutic Recreation Soc'y), available in LEXIS, News Library, CURNWS File.

31. Wendy Sanford, *Introduction to THE NEW OUR BODIES. OURSELVES* 19 (The Boston Women's Health Book Collective ed., 1992).

care must be keenly sensitive to the unique situations of each patient.<sup>32</sup>

Many patients with disabilities not only require assistance with their disability itself, but also have other health-related special care needs that must be met in order for them to work and live independently.<sup>33</sup> Activists for the needs of the disabled stress that services such as rehabilitation therapy, mental health services, personal assistance services, and care coordination, along with such products as prescription drugs and home care equipment, are often necessary for disabled people to function well.<sup>34</sup> They remind us, however, that many health care coverage programs frequently fail to cover these needs.<sup>35</sup>

### 3. *Women's Health*

The women's health movement asserts that a health care system that promises to provide adequate health services to women must also ensure the protection of a woman's reproductive rights.<sup>36</sup> Reproductive rights include the right to prevent conception and the right to terminate a pregnancy, as well as the right to remain fertile and the right to choose to have a child.<sup>37</sup> Women's health activists emphasize that the choice to conceive and give birth must be protected even when the exercise of such choice can only be accomplished with the help of medical technology, such as artificial insemination and fertility pharmaceuticals. Many women — particularly women of color, poor women, and lesbian women — have been denied the choice to reproduce.<sup>38</sup> Women of color and poor women

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32. See Testimony of Paula Malek, *American Disabled for Attendant Programs Today, Before the Security Subcomm. of the House Ways and Means Committee*, (Feb. 23, 1994) (stressing the need for community-based attendant services in the provision of health care, including assisting the disabled with daily living activities such as bathing, dressing, cooking, and cleaning), available in LEXIS, News Library, CURNWS File.

33. Griss, *supra* note 27, at 8.

34. *Id.*

35. *Id.*

36. WOMEN'S HEALTH: READINGS ON SOCIAL, ECONOMIC, AND POLITICAL ISSUES 135 (Nancy Worcester & Marianne H. Whatley eds., 1988).

37. Edith Butler, *The First National Conference on Black Women's Health Issues*, in WOMEN'S HEALTH: READINGS ON SOCIAL, ECONOMIC, AND POLITICAL ISSUES 39 (Nancy Worcester & Marianne H. Whatley eds., 1988).

38. Chris Anne Raymond, "Ticking Clocks" and Changing Moves, 258 JAMA 2025, 2025 (1987) (quoting Roberta Actenberg, directing attorney of the Lesbian Rights Project in San Francisco: "Many doctors don't want to do inseminations of any kind, and especially not for single women or lesbians."); see also Janet Benshoof, *Planned Parenthood v. Casey: The Impact of the*

have been forcibly sterilized or coerced and misinformed into consenting to unwanted sterilization.<sup>39</sup> Poor women and lesbians are often denied access to fertility and reproductive technology due to the high cost of such procedures, or because some health care providers have policies against inseminating nonmarried or nonheterosexual women.<sup>40</sup>

Women's health care, however, is not limited to reproductive health, and women's health activists demand that other health concerns that effect primarily women — such as breast cancer and menopause — must also be addressed.<sup>41</sup> These activists assert that issues such as domestic violence and gender-specific occupational health concerns also need to be understood and addressed by the health care system.<sup>42</sup> They believe that unique female health issues must also be recognized in areas of health care that are often thought of as gender-neutral, such as mental health, cardiovascular health, and AIDS care.<sup>43</sup>

Women's health care activists believe that quality health care must also include preventive care, and they emphasize the necessity of free access to tests and screenings, such as pap smears and mammographies.<sup>44</sup> They stress the importance of education regarding the prevention of disease, self-detection of warning signs, potential health risks with treatments and behaviors, and strategies to live with various health conditions.<sup>45</sup> Women's health activists argue that for education to be available to all women, information must be dispensed in a way that all women can understand.<sup>46</sup> This means

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*New Undue Burden Standard on Reproductive Health Care*, 269 JAMA 2249 (1993) (discussing how the Supreme Court's "undue burden" standard will limit the reproductive choices of young, poor, minority, and rural women).

39. Butler, *supra* note 37, at 39.

40. See Raymond, *supra* note 38, at 2025 (noting the refusal of doctors to perform artificial insemination on single or lesbian women).

41. See Carolyn M. Clancy & Charles T. Massion, *American Women's Health Care: A Patchwork Quilt With Gaps*, 268 JAMA 1918, 1918 (October 14, 1992) ("Certain women's health problems (e.g., menopause, osteoporosis, breast cancer) have received increased attention and resources.").

42. See Tamar Lewin, *Doctors Consider a Specialty Focusing on Women's Health Issues*, N.Y. TIMES, Nov. 7, 1992, at 1 (noting the development of a medical school curriculum focusing not just on standard topics like women's physiology, but also on issues like sexuality, mental health, and violence and abuse).

43. *Id.*

44. Julia R. Scott, *African Americans: Reform Must Bridge the Gap Between the Races*, NAT'L VOTER, Dec.-Jan. 1994, at 13.

45. *Id.*

46. Tessie Guillermo, *Asians and Pacific Islanders: Cost-Containment Focus Overlooks Funda-*

that educational materials and instruction must be dispensed in a variety of languages other than English.<sup>47</sup> Similarly, health care information must be made available to illiterate women through the use of presentations or individualized instruction.<sup>48</sup>

Patient control over which services are provided and how they are delivered is particularly imperative in the area of women's health, according to women's health activists. A given health condition may have a variety of possible treatments and alternative treatments, each of which may carry different potential risks and benefits. The women's health movement emphasizes that patients need to be able to choose the care which is the most sensitive to their personal identity and with which they feel most comfortable. In addition, patients need to have specialized health care providers who are specifically trained about and oriented to their individual needs.<sup>49</sup> This means that a pregnant woman would have a health care provider who, for example, shares her beliefs in unobtrusive, midwife-assisted delivery and is trained to provide that type of supportive, low-intervention birthing assistance. This could also mean that a Native American woman on a reservation who is fighting tuberculosis would have a health care provider who is familiar with the conditions of her reservation and with the beliefs and customs of her tribe.<sup>50</sup>

#### 4. *People of Color*

Advocates for the health concerns of people of color<sup>51</sup> emphasize that their health care needs differ from those of white patients in several ways. First, minority patients experience health problems of different types and to a different extent than their white counterparts.<sup>52</sup> People of color have a shorter life expectancy due to higher

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*mental Barriers to Care*, NAT'L VOTER, Dec.-Jan. 1994, at 9.

47. See Jane S. Lin-Fu, *Special Health Concerns of Ethnic Minority Women*, 102 PUB. HEALTH REP. 12, 12-14 (1987) (noting that for Asian and Pacific American women, language difficulties and other ethnocultural barriers serve as deterrents to receiving adequate health care).

48. Guillermo, *supra* note 46, at 9.

49. One proponent noted: "To compound the problem, many health care providers are unfamiliar with or insensitive to minority cultures. They are also oblivious of the fact that health services that are not culturally relevant can hardly be effective." Lin-Fu, *supra* note 47, at 12.

50. *Id.*

51. This term is used in this article to discuss people with non-European ancestry.

52. Lin-Fu, *supra* note 47, at 12-14 (noting that "[h]ealth service providers need to be made aware of the special health care needs of minority populations, including genetic disorders and diseases that are particularly prevalent in these populations").

rates of cancer,<sup>53</sup> hypertension,<sup>54</sup> infant mortality,<sup>55</sup> alcohol and drug abuse,<sup>56</sup> cardiovascular disease,<sup>57</sup> and diabetes.<sup>58</sup> In addition to these differences, health care activists argue that people of color also have different cultural, social, religious, and linguistic backgrounds that need to be considered when determining what services and treatments are most appropriate.<sup>59</sup>

Moreover, advocates stress that having providers who are from the communities that they are serving adds a higher level of cultural sensitivity, as well as a keener understanding of issues specific to the community.<sup>60</sup> They believe that the presence of health care providers who are familiar with their patients' concerns and issues helps to create an environment where the greatest amount of patient understanding and comfort can be achieved.

Health activists assert that a quality health care system cannot ignore the mental health needs of the communities it serves. Different communities may demand different types of mental health provisions, and the health care system needs to be responsive to these specific needs. These activists believe that mental health care services need to be available for ongoing mental health maintenance as well as for trauma-induced needs, and that patients must also have access to treatment for drug and alcohol abuse.<sup>61</sup>

### 5. *Poor People*

According to activists for health care for the poor, having quality health care available is useless if patients are unable to travel to the location of the care.<sup>62</sup> For the urban poor, the problem is that health

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53. Johnson, *supra* note 14, at D1.

54. Pamela Sherrod, *Controlling Hypertension*, in *THE BLACK WOMEN'S HEALTH BOOK: SPEAKING FOR OURSELVES* 151, 152 (Evelyn C. White ed., 1990) ("[A]ccording to the American Heart Association, about thirty-nine percent of all adult black females and thirty-eight percent of all adult black males suffer from high blood pressure.").

55. *WOMEN'S HEALTH*, *supra* note 36, at 40.

56. See Sheila Battle, *Moving Targets: Alcohol, Crack and Black Women*, in *THE BLACK WOMEN'S HEALTH BOOK: SPEAKING FOR OURSELVES* 251, 252 (Evelyn C. White ed., 1990) (quoting a recent national study that indicated that 38 percent of black women, but only 11 percent of white women, were found to be heavy drinkers).

57. Johnson, *supra* note 14, at D1.

58. *Id.*

59. Wilma Mankiller, *Native Americans: Protecting a Longstanding Right to Government-Provided Care*, *NAT'L VOTER*, Dec.-Jan. 1994, at 12.

60. *Id.*

61. *Id.*

62. *Id.*

care facilities are not often located in their communities.<sup>63</sup> Rather, they are built in more affluent areas or just outside the city limits. For rural poor, the problem is that poor and widely dispersed rural communities rarely attract permanent medical staffs to their area. Therefore, to receive health care, rural patients must travel many miles or they must wait until a visiting health care provider reaches their area.<sup>64</sup> Thus, both rural and urban poor patients are often forced to travel far from their communities to receive care. For many, however, the cost of such traveling is nearly prohibitive. Therefore, health advocates for the needs of the poor argue that health care must be accessible within the poorer communities.<sup>65</sup>

Health care that is located within a community not only remedies the problem of accessibility, but it also addresses the issue of understanding the patient in her or his socio-economic, community, and family context. Health care activists argue that health care workers who provide care within their patients' communities will have a better grasp of the other issues facing their patients.<sup>66</sup> Similarly, activists assert that local health care providers may also have a greater understanding of the relationship between poverty issues, such as lead paint and poor education, and health care issues.<sup>67</sup>

One goal of such health care activists is the dissemination of information in a clear and understandable manner to help patients achieve and maintain good health.<sup>68</sup> They believe that patients must have access to educational materials and instruction in a language with which they feel comfortable,<sup>69</sup> and as a result they argue that information must be available in languages other than English. Also, patients who are not able to read must be able to receive information through nonwritten means, such as the use of presentations or individualized instruction. Furthermore, these activists emphasize that health education cannot be limited to teaching only those patients who actively seek out such information. They believe that a large part of any health education effort must include a strong outreach program.<sup>70</sup>

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63. Scott, *supra* note 44, at 12.

64. Mankiller, *supra* note 59, at 12.

65. Guillermo, *supra* note 46, at 9.

66. Mankiller, *supra* note 59, at 12.

67. Guillermo, *supra* note 46, at 9.

68. Scott, *supra* note 44, at 12.

69. Guillermo, *supra* note 46, at 9.

70. *Id.*

## 6. *Children's Health*

Advocates for children's health assert that, while it is almost universally accepted that dollars spent on prevention often recoup their value many times over in terms of dollars not spent on treatment, the prevention of disease and ill-health in children perhaps illustrates this point most dramatically.<sup>71</sup> Preventive care, including proper nutrition and immunizations, is a key goal of children's health activists because they ensure better health for patients as children and later on as adults.<sup>72</sup>

The children's health movement demands that effective preventive care begin even before the patient is born, and its activists therefore believe that prenatal care must be a high priority in any health care system. These activists emphasize the importance of birth weight and infant health in determining the quality of health that an individual maintains throughout childhood and into adult life.<sup>73</sup>

## 7. *Conclusion*

These consumer groups and their respective programs collectively present an agenda for health care reform. This agenda places an emphasis on prevention, priority to community-based and culturally-sensitive providers, a nonhierarchical arrangement which gives all health care providers status and recognition, maintaining patient health as opposed to curing their diseases, patient control and education, and an understanding of the patient in the socio-economic and family contexts.

### *B. Arguments in Favor of Protections for Disenfranchised Consumers*

These disenfranchised groups have been effective in asserting the advantages of their programs.<sup>74</sup> As a result, support for their programs is wide-spread and varied. Their arguments reinforce the position that special protection is essential and that a universal plan alone will not provide the health care system needed for these citizens. Arguments supporting the stance taken by disenfranchised

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71. *Children, Families and Clinton's Health Care Reform*, CAPITOL COMMENTS, Oct. 1993, at 1.

72. *Id.*

73. *Id.*

74. Public health groups have made their points for a long time but have been historically unsuccessful in influencing mainstream health care. STARR, *supra* note 1, at 373.

consumers include the power of the mainstream health care system, a concern for identity, the competence of alternative providers, the continuation of necessary funding, and client dysfunctionality.

### *1. The Power of the Mainstream Health Care System*

There has been longstanding criticism of the mainstream American health care system, in particular the hegemony of the medical model, an absence of community programs, professional hierarchy, and a concentration on curing medical problems rather than preventing them. The public health community has proposed alternatives to these criticisms but has traditionally been underfunded and marginal in the health care world. In recent years, the growth of corporate medicine has created a health-industrial complex that possesses political and economic power and influence.<sup>75</sup> This power requires countervailing protections for those consumers whose concerns may be in conflict with the interests of the established institutions.<sup>76</sup>

### *2. A Concern for Identity*

The increasing attention paid to race, gender, sexual orientation, and disability as crucial factors in creating identity also increases the strength of the disenfranchised consumer's position. The theories of feminism, critical race, and sexual identity have questioned the ability of providers to adequately understand the health concerns of consumers with whom they do not share the same identity. The concern that a universal system will suppress the interests of marginalized groups through emphasizing a "one-health-care-plan-fits-all" approach is well-taken. The failure of the mainstream health system to respond readily to the real concerns of different communities is notable. Moreover, if a health care system is to maintain the physical and mental well-being of its consumers, it must actively understand and respect the different backgrounds of these patients. These patients must be seriously integrated into the design of the plan.

### *3. Competence of Alternative Providers*

The AIDS clinics, women's health centers, school-based clinics, and parents' disability groups are examples of the innovative and

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75. *Id.* at 428.

76. *Id.*



successful programs that have been set up by alternative providers around the country. In addition, community health centers and public health clinics often provide community-based and family-oriented services that embody the aspirations of the disenfranchised consumer. These programs are often less expensive, reach populations often ignored by mainstream health groups, and involve the participation of the specific communities served. Many of these groups publicized their work during the 1980s, bringing an array of excellent and persuasive descriptions of their successes to the legislature and the media. These providers created strong networks and gained political credibility. They emphasized the uniqueness of their services, their responsiveness to the community, and the low cost of such service. Thus, they revealed an alternative approach to providing health care which both challenged the mainstream medical system and appealed to politicians.

#### 4. *The Continuation of Funding*

Many of the current special needs health programs now have targeted funding and substantial political support. For example, in Wisconsin, Healthy Start — a program for pre-natal care and health care coverage, emphasizing prevention, that covers infants until they reach the age of six — has been described in the media as being cost-effective and preventative.<sup>77</sup> The Wisconsin legislature has appropriated large sums of money for the program. Family planning services have their own funding source, as do support services for disabled children. These government programs often fund alternative providers, thus creating a strong relationship between the politicians who support the programs, the providers, and the community of consumers.<sup>78</sup>

#### 5. *Client Dysfunctionalism*

In the 1960s, the existence of disenfranchised populations was attributed to the unequal distribution of resources and structural failures, such as discrimination against minorities and women.<sup>79</sup> These explanations led to government policies aimed at eliminating the

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77. *Healthy Move For Children*, ST. LOUIS POST DISPATCH, June 23, 1989, at 2b.

78. Examples include Title X family planning monies and public health monies for children with special care needs.

79. Peter B. Edelman, *Toward a Comprehensive Antipoverty Strategy: Getting Beyond the Silver Bullet*, 81 GEO L.J. 1697, 1698 (1993).

subordination of such groups through government transfer programs and anti-discrimination laws appear to be potential solutions.<sup>80</sup>

In the 1980s, however, these explanations regarding the existence of certain disadvantaged groups were attacked. A new explanation was developed by conservative thinkers and researchers, based on the pathology of group members. The development of the "victim" theory — the theory that women are unable to participate in society without special attention being paid to their psychological issues — was accepted by many as the reason that women needed special attention.<sup>81</sup> In the poverty discourse, the conservative writers and researchers argued that the personal limitations of poor people contributed to or even caused their impoverished condition.<sup>82</sup> These developments have contributed to the support for special programs for the disadvantaged which are tailored to their needs. While the proponents of the "pathological" or "victim" schools are often criticized by progressive leaders, the contribution of this rhetoric in helping to legitimize the arguments of the progressive proponents of multi-dimensional programs is considerable.

## II. THE HEALTH SECURITY ACT: TECHNIQUES FOR PROTECTION<sup>83</sup>

The disenfranchised community has been surprisingly strong in arguing for its approach to health care, thus challenging the advocates for a universal health care plan. Protection of their programs and responding to their critiques requires modification of any universal health reform plans.

The Health Security Act<sup>84</sup> as proposed by the Clinton Administration does have several sections that acknowledge the needs of

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80. *Id.* at 1717; see generally NAOMI WOLF, FIRE WITH FIRE: THE NEW FEMALE POWER AND HOW IT WILL CHANGE THE 21ST CENTURY (1993); Lynn Darling, *Feminism in Wolf's Clothing*, HARPER'S BAZAAR, Nov. 1993, at 182 (both discussing discrimination against women and the effectiveness of solutions such as government regulation).

81. WOLF, *supra* note 80, at 135-42; Darling, *supra* note 80, at 185.

82. Edelman, *supra* note 79, at 1697, 1698.

83. Vernellia R. Randall recently wrote an article which states that the Clinton health reform proposal is structurally and ideologically flawed. She advances the view that the proposal cannot serve the interests of ethnic Americans and the poor. See Vernellia R. Randall, *Health Care Reform: Does Clinton's Health Care Reform Proposal Ensure (E)qual(ity) of Health Care for Ethnic Americans and the Poor?*, 60 BROOK. L. REV. (forthcoming 1994). This Article takes the position that the Clinton proposal, with substantial modifications, could provide health care that would substantially improve the health status and overall well-being of such disenfranchised consumers. I greatly respect, however, the opinion of Professor Randall.

84. Health Security Act of 1993, H.R. 3600, 103d Cong., 1st Sess (1993).

these communities.<sup>85</sup> The Clinton proposal demonstrates a significant understanding of disenfranchised consumers which may reflect the diverse group of individuals who contributed to the original conceptualization of the plan. The protections include funding for special needs providers as well as antidiscrimination provisions.<sup>86</sup> However, the proposal, as it stands now, remains insufficient. The present version expresses no overall commitment to disadvantaged consumers, does not adequately integrate the protections it provides with universal coverage, and fails to assign monitoring responsibility to the states.

The purpose section of the plan has no reference to the goal of providing adequate health care for disenfranchised communities.<sup>87</sup> Such an addition to the Act is essential, as it should recognize that "consumers are not identical and the health care system must be responsive to the needs of disenfranchised consumers."<sup>88</sup>

Examining the list of protections and programs developed by the disenfranchised groups is a useful approach to analyzing the limits and possibilities of the legislation. These requirements are: (1) the maintenance of special needs providers; (2) outreach and consumer education programs; (3) participation in the quality of health care; and (4) coordination with other providers.

#### A. *Maintaining Special Need Providers*

The type of providers that serve these populations range from the longstanding family planning services to the newer clinics that assist HIV-positive persons. The drafters of the Clinton plan were aware of the strength and number of these agencies, and the Act contains a section entitled "Requirements Relating to Essential Community

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85. *Id.* §§ 1431-32.

86. *Id.* § 1328.

87. *Id.* § 3. The Health Security Act is intended:

- (1) To guarantee comprehensive and secure health care coverage.
- (2) To simplify the health care system for consumers and health care professionals.
- (3) To control the cost of health care for employers, employees, and others who pay for health care coverage.
- (4) To promote individual choice among health plans and health care providers.
- (5) To ensure high quality health care.
- (6) To encourage all individuals to take responsibility for their health care coverage.

*Id.*

88. A group of providers and consumers in Madison, Wisconsin, developed such a statement. See MADISON REGIONAL HEALTH COALITION, POLICY STATEMENT ON HEALTH CARE REFORM (1994) (on file with author).

Providers.”<sup>89</sup> This section requires each health plan to enter into agreements with such essential community providers,<sup>90</sup> and the goal of this important and creative section is to ensure that alternative providers will be part of, and supported by, the mainstream health care system. This approach may assist those alternative providers who wish to, or must, eventually become part of a mainstream system.

The Wisconsin experience may be instructive. In the early 1980s, the Wisconsin Medicaid program required Aid to Families with Dependent Children (“AFDC”) recipients in Milwaukee to enroll in HMOs. The HMOs initially ignored the existing alternative providers, resulting in a decline in quality of service and the subsequent financial failure of the alternative providers. This experience demonstrated that these alternative providers could not survive without contracts with the mainstream HMOs. It also showed that the HMOs were not able to adequately serve the disenfranchised consumer.<sup>91</sup>

Over the last few years, several programs have been created to encourage HMO providers to contract with special needs providers. These include additional requirements in the bidding process for and funding of alternative providers by both the HMOs and the state.

The Federal Act relies on both a regulatory approach and financial incentives to encourage mainstream providers to enter into contracts with alternative providers. The remedies section of the Act allows lawsuits based on the actions of mainstream providers, thus encouraging them to contract with alternate providers.<sup>92</sup> Financial incentives are included in the section on underserved populations, thus providing extra dollars to those who serve that population.<sup>93</sup> There are no sections, however, that directly encourage the funding of alternative providers. The Wisconsin experience demonstrates that every approach — regulation, financial incentives, and direct

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89. H.R. 3600, § 1431. There has been recent public debate on the essential community provider section. Representative John Lewis (D-Ga.) stated in a letter published in the *New York Times*: “Essential community providers are exactly what the name implies. They are individual or institutional health care providers that are essential to the community. Without them, the poor in inner cities and rural areas would not have health care.” John Lewis, Letter, *Health Reform “Providers” Would Aid the Poor*, N.Y. TIMES, Apr. 21, 1994, at A18.

90. H.R. 3600, § 1431(a).

91. See WISCONSIN DEP’T OF SOCIAL SERVS., AN EVALUATION OF THE MEDICAL HEALTH MAINTENANCE ORGANIZATION PROGRAM: 1989-91 (1992).

92. H.R. 3600, §§ 5201-43.

93. *Id.* §§ 3401-84.

funding — is needed. The Act should support a linking of the three approaches and encourage the states to implement them together.

### *B. Consumer Information and Outreach*

Consumer information that enables patient autonomy, access, and participation in their own health care requires cultural sensitivity, appropriate language, and outreach. The Clinton plan requires the regional alliances to make consumer information available in a usable form.<sup>94</sup> However, the relevant section describes this information as focusing on costs rather than on access, an understanding of the system, or the availability of redress mechanisms.<sup>95</sup> In addition, this information section is not tied to the outreach section. Although an outreach section — which includes immunizations<sup>96</sup> — is included in the Act's benefit requirements, it does not develop any community-based programs for hard-to-reach populations.<sup>97</sup>

In order to have successful consumer access to and use of health care services, especially in managed care systems, face-to-face services are essential. Furthermore, these individualized programs should be provided by the community groups who work with and represent these consumers. The health plans and alliances should work closely with organizations that have experience in dealing with disadvantaged consumer groups, such as low-income consumers and patients with HIV.<sup>98</sup>

The experience in Milwaukee, where Medicaid recipients were mandatorily enrolled in HMOs, demonstrates that when these face-to-face, community-based techniques are used, Medicaid recipients' appropriate use of HMOs are greatly improved.<sup>99</sup> The outreach sections in the Act should be rewritten to require education and outreach using the techniques of funding for advocacy groups, regulation to mandate such programs, and financial incentives for creating these programs. The section on increased reimbursement for enroll-

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94. *Id.* § 1325.

95. *Id.*

96. *Id.* § 1114. (addressing outreach and clinical services).

97. The health education classes provided for in § 1127 are listed only as wellness-type services such as smoking cessation, nutrition counseling, stress management, and physical training; not the type of services which are high priorities for the various disenfranchised populations. *Id.* § 1127.

98. Interview with Tom Korpady, Administrator, State Employee Trust Fund, in Madison, Wis. (Nov. 9, 1993).

99. David R. Riemer, Remarks at the Panel Discussion on Managed Competition and Underserved Populations, White House Task Force on Health Care Reform 7 (Feb. 24, 1993) (transcript on file with author).

ing underserved populations should be accompanied by regulations that require enrollment areas to include disenfranchised populations and prohibit the designing of plans for the purpose of excluding certain groups of people. In addition, the health plans and alliances must be required to contract with community-based groups to provide appropriate information and outreach to disenfranchised populations. Section 1203 would allow the states to provide incentives, such as a risk-adjusted methodology and payment for special services — including transportation, interpreting, and outreach services — to ensure access for populations that face barriers to access because of geographic location, low income levels, physical disabilities, or racial or cultural differences.<sup>100</sup> While a financial incentive is included in the legislation,<sup>101</sup> the funding of community-based programs to provide such services is not required.

Affirmative action in staffing health plans should be required to encourage the employment of disadvantaged groups within the health care system. This requirement should affect all levels, including professionals and managers. In Milwaukee, for example, the HMO Initiative resulted in the loss of many inner-city minority health care providers. Affirmative action requirements may encourage health care plans to seek diverse providers at the early stages of health care reform.<sup>102</sup>

### *C. Participation in Decisions on the Quality of Health Care*

The approach of the Clinton health care plan consists of a series of integrated networks and a reliance on managed care systems. Disenfranchised consumers may be particularly disadvantaged in these systems, which envision consumers who are able to speak out on their own behalf. Managed care systems deliberately create obstacles to consumer choice, often by maximizing cost controls.

For example, when the Medicaid HMO mandate went into effect in Milwaukee, there was significant confusion about how to access HMO services since the new system contained significantly more

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100. H.R. 3600, § 1203.

101. *Id.*

102. The request for bids for the Medicaid HMO program has been revised to reflect the need for minority providers. There are two sections that address this concern. The first is the "Affirmative Action Plan," found on page 8 of the Policies Section. The second is the "Minority Business Enterprise," found both in the Policies Section on page 14, and under the Technical Specifications Section on page 31. See WISCONSIN DEP'T. OF SOCIAL SERVS., DIV. OF HEALTH, REQUEST FOR BIDS: MA/HMO PROGRAM (1993).

roadblocks to obtaining services than the previous fee-for-service system had contained. There were complaints about cumbersome grievance procedures, lack of culturally sensitive providers, and poor preventative services.<sup>103</sup>

Milwaukee advocates for the poor and for people of color proposed three mechanisms to rectify such service underutilization. The first was the creation of an HMO Ombudsman to represent complaints on behalf of the consumers. Two nonprofit organizations, long-time representatives of the poor in Milwaukee, received the contract to provide this service.<sup>104</sup>

This, however, was not sufficient. The Medicaid Bureau, at the request of the Milwaukee-based Black Health Coalition, required all HMOs to hire an HMO Advocate to assist patients in understanding the system and in accessing services. The Medicaid bureau considers both programs to be successful, and they have also been supported by the disenfranchised consumer community.<sup>105</sup> In addition to the ombudsman and the advocates, groups of providers and community groups, as well as the state agency and local governments, regularly meet to discuss continuing problems. These groups then either correct the problem themselves or require changes in the contract agreement between the HMO and the Medicaid bureau.<sup>106</sup>

The Clinton plan would require an ombudsman at the health alliance level to handle complaints from consumers.<sup>107</sup> This is far short of the system in Wisconsin, which has evolved over the ten years since managed care first came to the state. An ombudsman or advocate should be required at the health plan level as well. Moreover, funding for community groups who wish to be involved in the representation of their constituencies' concerns should be created in every state under the authority of the Act. This program would allow disenfranchised groups to gain more from the health care system through greater participation in the system. In addition, the Act should contain a regulatory section that would require every health

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103. Interview with Neva Kaye, Department of Health and Human Services, Bureau of Health Care Financing, in Madison, Wis. (Apr. 8, 1994); Interview with Shirin Cabraal, Attorney, Legal Action of Wisconsin, in Madison, Wis. (Nov. 17, 1993).

104. Interview with Neva Kaye, Department of Health and Human Services, Bureau of Health Care Financing, in Madison, Wis. (Apr. 8, 1994); Interview with Shirin Cabraal, Attorney, Legal Action of Wisconsin, in Madison, Wis. (Nov. 17, 1993).

105. Interview with Ruth Belshaw (Cabraal), Administrator with the Bureau of Health Care Financing, Milwaukee, Wisconsin, in Madison, Wis. (Jan. 13, 1994).

106. *Id.*

107. H.R. 3600, § 1326.

care plan to have an advocate or patient representative with the special responsibility of serving disadvantaged consumers. The funding for those positions should come from the health plan itself.<sup>108</sup>

The concern about experimental therapies is a major issue facing disenfranchised consumers, particularly for persons with AIDS and for the mentally and physically disabled. In the Act, the health plans are given the authority to review denials of experimental therapies. The health plans have a disincentive to pay for these therapies, and thus should not possess this authority. The alliance or state agency should have such review authority.<sup>109</sup>

The Health Security Act has several sections which would enable consumers to use the courts for resolving discrimination claims.<sup>110</sup> A common theme among disenfranchised consumers is the need for protection against discrimination within the health care system. These remedies sections should be clarified and strengthened to ensure that they can be effectively utilized.<sup>111</sup>

#### D. Coordination With Other Providers

The benefits section of the Act provides for case management to allow reimbursements for services that assist individuals in gaining access to necessary medical, social, educational, and other services.<sup>112</sup> This section would allow a greater commitment by health care plans to integrated social services, although it is clear that such services are not to be paid for under the health care plan.

In Milwaukee, two programs have been developed to coordinate the activities of providers with the health care needs of disenfranchised consumers. The first is the HMO Advocate program, where each HMO that serves the AFDC population must employ an advocate to assist low-income women and children who participate in the Medicaid program.<sup>113</sup> Upon discovering a lack of access to dental care for that community, these advocates organized a series

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108. See Rand E. Rosenblatt, *On Access to Justice, Discrimination and Health Care Reform: Testimony Before the Health and Environment Subcomm. of the House Comm. on Energy and Commerce* (Jan. 31, 1994) (on file with author).

109. CONSUMERS UNION, *supra* note 11, at 15 (suggesting that in order to avoid the imposition of different budget constraints on different segments of the population, the plan should create an integrated global budget).

110. *E.g.*, H.R. 3600, § 1402(c); *Id.* § 5238.

111. Rosenblatt, *supra* note 108, at 32-42.

112. H.R. 3600, §§ 1111-28.

113. See WISCONSIN DEP'T. OF SOCIAL SERVS., CONTRACT FOR SERVICES (1992).



of meetings with dental care providers to encourage recipients to use, and the providers to deliver, dental services.<sup>114</sup> The second involves a contract that Wisconsin has entered into with a women's health center, called the HMO Partnership. Under this program, mental health providers and HMO advocates meet on a monthly basis to discuss how to better serve women who are pregnant and who have alcohol or drug abuse problems.<sup>115</sup>

Again, a combination of financial incentives, regulatory approaches, and the utilization of community-based groups has contributed to the integration of other providers in the mainstream health care system. In Wisconsin, payment for coordination, the Medicaid requirement to use HMO Advocates, and HMO contracts with community-based providers are creating a network of services.<sup>116</sup>

### *E. Coordinating State and Federal Approaches*

Another way of viewing the concerns of disenfranchised consumers is to consider the level of delivery and regulation. The Clinton plan gives the states substantial discretion to design their own version of the plan. All indications are that this discretion will be even greater in the final version of the plan that will eventually be passed.

Disadvantaged consumers, however, will have difficulty organizing separately in every state to lobby for their positions. These groups will have more influence if they can concentrate their efforts on a single source. For example, one key attraction of Medicare is that elderly groups can direct their advocacy and lobbying activities specifically at Congress and the President. Yet that is clearly not the direction that the health care plan is taking.

Thus, disadvantaged consumers are reluctant to wholeheartedly back the plan because they are uncertain of their status in a state-federal system. A health-financing system where authority is exercised by both the states and Washington can weaken the position of consumers who wish to speak out. It is crucial that any legislation include provisions for the funding of consumer advocacy at the state

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114. Interview with Ruth Belshaw, Administrator with the Bureau of Health Care Financing, Milwaukee, Wisconsin, in Madison, Wis. (Jan. 13, 1994). These services were required under the Medicaid Act, but due to minimal reimbursement, the services were not being used.

115. Interview with Neva Kaye, Department of Health and Human Services, Bureau of Health Care Financing, in Madison, Wis. (Apr. 8, 1994).

116. *Id.*

level. The Health Care Act should include a plan for the funding of community groups who wish to advocate health care issues on behalf of disenfranchised consumers at the state level.<sup>117</sup> The legislation should encourage disenfranchised consumers to form such coalitions by making such funding available.

The federal legislation should require that the states include the approaches listed above before certifying their plan as an approved system. A state should be given several options, but these options must include a variation of the theme of protecting the disadvantaged consumer. Evaluations of state approaches indicate that the most successful state-federal system would give the states a limited number of options from which to choose.<sup>118</sup> This approach would also provide some reassurance that a reasonable state plan will emerge.<sup>119</sup>

### CONCLUSION

President Clinton's proposed health care reform plan is a dramatic step towards universal coverage. The drafters of the plan realized that the reorganization of health care financing and delivery required to achieve such a comprehensive system could jeopardize the programs and protections required by disenfranchised consumers.

The Clinton proposal contains innovative approaches toward the goals of ensuring that people of color, poor people, women, disabled persons, people who are HIV-positive, and children will receive quality health care. The concerns of these disenfranchised consumers can be integrated into the health care system by offering financial incentives to and imposing regulatory requirements on mainstream providers, as well as the funding of community-based groups and alternative providers. The utilization of financial incentives would be effective, since money is the motivating force in a competition-based approach. Regulatory requirements should serve to discourage discriminatory actions or practices on the part of the health

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117. There are two excellent programs that currently require and provide funding for consumer advocacy in every state. The developmentally disabled are protected through the Developmentally Disabled Assistance Act and Bill of Rights, 42 U.S.C. §§ 6001-81. Nursing home residents are protected under an ombudsman program which is required in every state. Older Americans Act of 1965, 42 U.S.C. §§ 3001-58 (West. Supp. 1994).

118. Michael Sparer, *Evaluation of State-Federal Approaches*, 60 BROOK. L. REV. (forthcoming 1994).

119. *Id.*

care plans, states, or alliances.<sup>120</sup> This would include enforcement by private attorneys with private rights of action as well as government enforcement.<sup>121</sup> Funding for disadvantaged consumer representatives is currently found only in the Essential Provider section;<sup>122</sup> the plan contains no requirement for group action or system advocacy, such as those included in the Advocate and Partnership programs in Milwaukee. Funding for such programs, however, was presented by a group of law professors in Washington to a Congressional committee,<sup>123</sup> as such programs are essential to a plan that purportedly strives to achieve universal health care coverage for everyone.

The strength of an approach to health care that places a high priority on client needs is surprising and heartening. A clear, positive commitment should be expressed in the Clinton legislation. Even more crucial will be specific, focused mechanisms and participatory spaces spelled out in the Act. Consumers require protections that will amplify their voices, provide them with access to justice, and encourage providers to address client needs.

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120. The Health Security Act includes a substantial series of remedies, such as suits on behalf of essential providers as well as consumers who believe they have been unfairly treated. H.R. 3600, §§ 5231-43.

121. *Id.*

122. *Id.* § 1431.

123. Rosenblatt, *supra* note 108, at 46-47.