



**National Association of
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**VULNERABLE POPULATIONS
AND
HEALTH CARE REFORM**

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Vulnerable Populations and Health Care Reform

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VULNERABLE POPULATIONS AND HEALTH CARE REFORM

EXECUTIVE SUMMARY

This conference focuses on what health care reform can and should mean to vulnerable populations, those most in need of a reformed system. This paper will attempt to structure our thinking today by framing the questions that we must grapple with in examining the extent to which proposals for national health care reform¹ meet their needs.

Although determining just who are the vulnerable populations is difficult, among those that most observers include in the term "vulnerable populations" are the 43 million persons that can be classified as medically underserved for preventive and primary care. The most vulnerable include: 1) homeless persons, 2) migrant farmworkers and their families, 3) persons with HIV and other serious infectious diseases, such as antibiotic-resistant tuberculosis, 4) undocumented persons, and 5) persons with serious physical, developmental, and mental illness requiring special care.

The most vulnerable are those whose socioeconomic profile (e.g., income below the poverty line, ill-housed, minority, non-English-speaking) coexists with poor health status (e.g., chronic mental illness, tuberculosis, hypertension). Thus, in a health care world that places increasing emphasis on the norm, and in reviewing reform proposals also largely concerned with the norm, treatment of those falling outside the norm deserves particular scrutiny. This is especially true when people are outside the norm along multiple dimensions: the vulnerable.

Accordingly, this author's working definition of vulnerable populations is: **those people heretofore facing significant barriers to access appropriate care through our private health care system and/or likely to face continuing barriers to appropriate care.** Note that this definition includes both the people and the system.

HEALTH CARE NEEDS OF THE VULNERABLE

Vulnerable people in this country tend to have the kinds and stages of conditions that require more, not less, health care: diseases such as asthma, hypertension, diabetes, tuberculosis, and cancer; chronic mental illness and substance abuse; violence and unintentional injury; teenage pregnancies; and others. Even conditions that some would judge not serious become so in the

¹Although this paper focuses on national reform proposals, it is applicable to many state efforts, especially those being implemented under the Section 1115 waivers.

context of people's lives: for example, an agricultural worker with lower back strain, a common occurrence, cannot do field labor and thus cannot help support his or her family.

If their needs are to be met, vulnerable people must have a medical "home" that responds to their unique needs, is geographically and physically accessible, culturally and linguistically competent, and available during hours when they can seek care. This home must provide comprehensive primary care and services designed to help people navigate the health care system: transportation, outreach, case management, translation, and others. Moreover, the medical home must be appropriately linked to specialty, secondary, tertiary, subacute, home, and residential care, as well as to related health services such as substance abuse treatment and social services such as food, housing, and jobs programs.

INSURANCE

Most of the major national health reform proposals, with the exception of Wellstone/McDermott, couple private insurance with private providers, or, stated otherwise, financing through a system that has heretofore largely bypassed vulnerable populations and delivery by providers who often have been equally reluctant to serve them.

Does insurance coverage result in reduced financial barriers to accessing care for vulnerable populations? The answer is a qualified "yes"; many studies have shown that insured poor or otherwise vulnerable populations have better access than their uninsured peers, although in few does the gap between the publicly and privately insured disappear. Universal insurance coverage will go a long way to removing a major financial barrier to care.

How can insurance be structured to best meet their needs? What should be the provisions for: 1) eligibility, 2) enrollment mechanisms, 3) security and portability, 4) benefit structure, 5) affordability, 6) consumer choice, 7) incentives to serve vulnerable populations, and 8) accountability to communities and individuals? These questions must be answered about all reform proposals.

Yet universal insurance does not itself equal universal access to the appropriate care that will improve the population's health status. Two major pieces are lacking: 1) the **capacity** to deliver care to vulnerable populations, particularly in vulnerable communities, and 2) the means to lower non-financial access barriers through **enabling services** such as outreach (both individual and community), transportation, translation, cultural competency, case management, and linkages to other parts of the health and social service system.

CAPACITY

While some vulnerable people are found in isolation, more commonly they are clustered in communities lacking the population base and/or economic and social infrastructure to attract and keep health professionals. Providing these populations with appropriate care to meet their special needs will mean investing in the infrastructure of health care in their areas in a three-pronged approach: 1) investments in community-based providers and networks; 2) assuring that community-based providers are adequately funded for services so that they survive;² and 3) investing by "mainstream" managed care plans.

As health care reform is implemented, the need for community-based organizations may fade, the hope of those who fear two-tier medicine. On the other hand, we know for certain very little of the effects of any reform proposal on any population, least of all on the vulnerable. That argues for keeping the safety net strong under the vulnerable and expanding it to include more of them, at least until the effects of reform are known and more-informed decisions can be made.

Most such providers have on paper-thin margins and/or require subsidies to exist, resulting in no reserve for tough financial times. Most also depend on adequate payments from Medicaid to meet their obligations. As we move into a new era where many of the currently uninsured will carry insurance, and where most Medicaid patients will be moved into managed care plans, survival of these providers depends upon: a) successfully participating in managed care arrangements on suitable terms; b) receiving adequate compensation for those who, for whatever reason, are not covered by insurance and for appropriate out-of-plan usage for those who are; and c) adequate payment for non-insured services that are critical to improving both the access and health status of the vulnerable populations.

In light of these issues, how can we best assure that sufficient capacity exists to meet the needs of vulnerable populations? Moreover, what should be the roles of traditional community-based providers? "Mainstream" managed care plans? How can we assure a synergy among them in meeting the needs of vulnerable populations?

ENABLING SERVICES

Vulnerable populations often face access barriers and problems that are only partly relieved through insurance coverage for

²Note that our interest in how well community-based organizations would fare is not in the particular provider but in the development and maintenance of sufficient medical homes for vulnerable people.

medical treatment. Access barriers can include language, culture, distance, lack of transportation, and other factors, exacerbated by poor living conditions (e.g., the homeless), occupational and other safety hazards (e.g., for migrant agricultural workers), chronic substance abuse and/or mental illness, or need for multiple but coordinated services for those with multiple and complex problems (e.g., persons with AIDS).

With rare exceptions, enabling services are not well handled through an insurance mechanism, since they are needed by only a small part of the U.S. population but could be demanded by many if they were made a reimbursable benefit. And they work, not only in reducing barriers to care, but improving health outcomes, which must be the ultimate goal of any health reform proposal.

Thus the question becomes: how should we provide for non-insured essential services under health care reform?

CONCLUSION

In short, how do we structure a system that best meets the needs of the most vulnerable among us, the neediest of the needy, in a community-responsive, effective, and efficient way? That is the ultimate question that any proposal for health care reform must answer to be deserving of the label "reform."

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VULNERABLE POPULATIONS AND HEALTH CARE REFORM

As we would expect from an undertaking as enormous as health care reform, the problems that are identified and addressed, as well as the means of addressing and financing them, are myriad. Unless we are true policy wonks, most of us focus on the areas that are of most professional and personal concern to us, leaving to others both the desire and the expertise to articulate the problems and propose the solutions that we fail to address. Such is the path the sane mind takes to preserve its sanity, or at least its sleep, in these exhilarating but exhausting times.

Those of us participating in this conference have chosen to focus on what health care reform can and should mean to vulnerable populations, that is, those most in need of a reformed system. Some of us choose this concentration on the vulnerable because we are the vulnerable, some because we work with or advocate for vulnerable populations, still others because we believe that our nation as a whole, and health services in particular, must be judged by the way it treats those least able to defend their own interests.¹

This paper will attempt to structure our thinking today about the most vulnerable among us by framing the questions that we must grapple with and then examining the extent to which proposals for national health care reform² satisfactorily answer those questions. The questions that we seek to answer are:

- Who are the vulnerable populations?

¹A statement of the Union of American Hebrew Congregations cites Malmonides and Jewish tradition to "do justly" to support health care reform.

²Although this paper focuses on national reform proposals, it is applicable to many state efforts, especially those being implemented under the Section 1115 waivers.

- What are their health care needs?
- How and under what circumstances can insurance meet their needs?
- What needs will be left unmet by their access to universal insurance? How can those needs be met?

Because the Clinton Administration's plan is the most comprehensively (at least in size) articulated, most of the examples of approaches will be drawn from its provisions, with comparisons from other legislative proposals as appropriate.

Most of the major national health reform proposals, with the exception of Wellstone/McDermott, rely on mechanisms to couple private insurance with private providers, or, stated otherwise, financing through a system that has heretofore largely bypassed vulnerable populations and delivery by providers who often have been equally reluctant to serve them. Thus these reform proposals invite close scrutiny by those concerned about the vulnerable.

I. WHO ARE THE VULNERABLE POPULATIONS?

Determining just who are the vulnerable populations is difficult, in part because we lack adequate definitions of boundaries (e.g., clearly, not all women and children are high-risk, and yet some need particular services and protections), data (e.g., how many homeless are there in our cities? rural areas?), and their needs (e.g., how many preschoolers lack adequate primary care?). Among those that most observers include in the term "vulnerable populations" are the 43 million persons that can be classified as medically underserved for preventive and primary care.³ The most vulnerable include:

³Daniel Hawkins and Sara Rosenbaum, *Lives in the Balance*, Washington, DC: National Association of Community Health Centers, 1993. See also Lu Ann Aday, *At Risk in America*, San Francisco: Jossey-Bass Publishers, 1993.

- Homeless persons: an estimated 2-3 million people, among whom there is a higher prevalence of many chronic and acute conditions than in the housed population.
- Migrant farmworkers and their families, some 4 million people, whose travels through rural America make their access to care particularly problematic.
- Persons with HIV and other serious infectious diseases, such as antibiotic-resistant tuberculosis. Although they can be found throughout the country, persons with these conditions are disproportionately present in underserved communities.
- Undocumented persons: with estimates ranging from 3 to 10 million and, for many, only tenuous connections with the U.S. health care system.
- Persons with serious physical, developmental, and mental illness requiring special care. Although they, too, are found throughout nation, medically underserved communities have a high incidence of conditions such as infant low birthweight that are associated with some lifelong disabilities like retardation, cerebral palsy, and developmental disabilities.

Each of these groups has a clear claim to being called "vulnerable", and we have no doubt neglected to include some who also have rightful claims. The most vulnerable among them are those whose socioeconomic profile (e.g., income below the poverty line, ill-housed, minority, non-English-speaking) coexists with poor health status (e.g., chronic mental illness, tuberculosis, hypertension). Thus, in a health care financing and delivery world that places increasing emphasis on the norm, and in reviewing reform proposals that are also largely concerned with the norm, treatment of these subpopulation groups that fall outside the norm deserves particular scrutiny. This is especially true when people are outside the norm along multiple dimensions: the vulnerable.

Accordingly, this author's working definition of vulnerable populations is: **those people heretofore facing significant barriers to access appropriate care through our private health care system and/or likely to face continuing barriers to appropriate care.** Note

that this definition includes both the people and the system. In fact, it is somewhat tautological; that is, populations are as "vulnerable" as the policy choices that make them. We can create vulnerable populations by designing systems around premises that may be valid for the great majority of the population (e.g., having a fixed address) but then leave others out (e.g., migrant farmworkers or the homeless), thus making them vulnerable.

II. WHAT ARE THEIR HEALTH CARE NEEDS?

Vulnerable people in this country tend to have the kinds and stages of conditions that require more, not less, health care: diseases such as asthma, hypertension, diabetes, tuberculosis, and cancer; chronic mental illness and substance abuse; violence and unintentional injury; teenage pregnancies; and others. Even conditions that some would judge not serious become so in the context of people's lives: for example, an agricultural worker with lower back strain, a common occurrence, cannot do field labor and thus cannot help support his or her family. Similarly, some dermatological problems that seem minor nuisances to many of us are major threats to the health of people living on the streets.

Thus, if their needs are to be met, vulnerable people must have a medical "home" that responds to their unique needs, is geographically and physically accessible, culturally and linguistically competent, and available during hours when they can seek care. This home must provide comprehensive primary care as well as appropriate services designed to help people navigate the health care system: transportation, outreach, case management, translation, and others. Moreover, the medical home must be appropriately linked to specialty, secondary, tertiary, subacute, home, and residential care, as well as to related health services such as substance abuse treatment and social services such as food, housing, and jobs programs. These social services often directly affect a person's health status. The purpose of access to the

medical home and its related services is to reduce negative health outcomes (e.g., high infant mortality rates) and increase positive health outcomes (e.g., maintaining a diabetic's blood glucose levels under control to prevent side effects).

Some vulnerable people have successfully linked with a medical home: a private physician's office or, more likely, a publicly supported provider such as a migrant health clinic, a homeless health program, a health department, an outpatient department of a public or not-for-profit hospital, or a community health center. Far too many have not, as shown by the explosion in use of emergency rooms by those who could be more appropriately treated in primary care settings.⁴

As would be expected, vulnerable people use far less preventive care such as immunizations, Pap smears, and mammograms, as well as interventions in the early stages of diseases such as cervical cancer or glaucoma,⁵ resulting in eventual need for more

⁴Kevin Grumbach, et al, "Primary Care and Public Emergency Department Crowding," American Journal of Public Health 83,3 (March 1993): 372-7; and United States General Accounting Office, Emergency Departments: Unevenly Affected by Growth and Change in Patient Use, Washington, DC: January 1993.

⁵John Z. Ayanian, et al, "The Relation between Health Insurance Coverage and Clinical Outcomes among Women with Breast Cancer," The New England Journal of Medicine 329, 5 (July 29, 1993):326-31; John Billings, et al, "Impact of Socioeconomic Status on Hospital Use in New York City," Health Affairs, (Spring 1993): 162-73; Robert C. Burack, et al, "Patterns of Use of Mammography among Inner-City Detroit Women," Medical Care 31,4 (1993): 322-34; Jose Escarce et al, "Racial Differences in the Elderly's Use of Medical Procedures and Diagnostic Tests," American Journal of Public Health, 83,7 (July 1993): 948-54; Howard E. Freeman et al, Americans Report on their Access to Health Care, Los Angeles: Institute for Social Science Research, University of California, 1987; Joel C. Kleinman and Ronald W. Wilson, "Are 'Medically Underserved Areas' Medically Underserved?" Health Services Research 12,2 (Summer 1977): 147-62; Barry G. Saver and Nancy Peterfreund, "Insurance, Income, and Access to Ambulatory Care in King County, Washington," American Journal of Public Health, 83,11 (November 1993): 1583-8; Alfred Sommer, et al, "Racial Differences in the Cause-Specific Prevalence of Blindness in East Baltimore," The New England Journal of Medicine, 325, 20 (November 14, 1991): 1412-7; Robert F. St. Peter, et al, "Access to Care for Poor Children: Separate and Unequal?" Journal of the American Medical Association 267, 20 (May 27, 1992): 2760-4; Barbara Wells and John Horn, "Stage at Diagnosis in Breast Cancer: Race and Socioeconomic Factors," American Journal of Public Health, 82,10 (October 1992): 1383-5; Steffie Woolhandler and David

acute and expensive care and in reduced health status. Clearly, their special needs are not being met by the current system.

Moreover, lack of preventive and primary care services for the vulnerable can be a threat to the community at large. For example, diseases that could be prevented through immunizations can be spread throughout a community. Other communicable diseases, such as tuberculosis, while disproportionately prevalent among vulnerable populations, can attack the general population if they are left untreated. In addition, society as a whole pays the steep medical bills for neonatal intensive care for the low birthweight infants born to teenage mothers without adequate prenatal care.

Even when vulnerable people do reach care, there is a substantial body of evidence that suggests that too often they are treated with disdain or indifference and discriminated against through provider choices: for example, Black pregnant women may receive less useful health advice, such as the dangers of smoking during pregnancy, than do White women. In one study, emergency room physicians were significantly less likely to offer analgesics for pain if the patient was Hispanic.⁶

Himmelstein, "Reverse Targeting of Preventive Care due to Lack of Health Insurance," Journal of the American Medical Association 259,19 (May 24, 1988): 2872-4.

⁶Kenneth C. Goldberg, et al, "Racial and Community Factors Influencing Coronary Artery Bypass Graft Surgery Rates for all 1986 Medicare Patients," Journal of the American Medical Association, 267,11 (March 18, 1992): 1473-77; Jennifer S. Haas, et al, "The Effect of Health Coverage for Uninsured Pregnant Women on Maternal Health and the Use of Cesarean Section," Journal of the American Medical Association 270, 1 (July 7, 1993): 61-4; Jack Hadley, et al, "Comparison of Uninsured and Privately Insured Hospital Patients," Journal of the American Medical Association 265,3 (January 16, 1991): 374-9; Bertram L. Ksdidke, et al, "The Effect of Race on Access and Outcome in Transplantation," The New England Journal of Medicine, 324,5 (January 31, 1991): 302-7; Michael D. Kogan, et al, "Racial Disparities in Reported Prenatal Care Advice from Health Care Providers," American Journal of Public Health, 84,1 (January 1994): 82-8; James H Price, et al, "Perceptions of Family Practice Residents Regarding Health Care and Poor Patients," The Journal of Family Practice, 27,6 (1988): 615-21; and Know H. Todd, et al, "Ethnicity as a Risk Factor for Inadequate Emergency Department Analgesia," Journal of the American Medical Association, 269, 12 (March 24/31, 1993): 1537-9.

III. HOW AND UNDER WHAT CIRCUMSTANCES CAN INSURANCE MEET THEIR NEEDS?

Over the past sixty years, the United States has increasingly funded most of its health care through an insurance system⁷, even for the uninsured through shifting their costs onto the bills of the insured. Most Americans have some form of health insurance, which has two major purposes: 1) easing financial barriers to obtaining care, and 2) financially underpinning the providers who serve them. Thus virtually any health care reform is likely to focus on changes in the insurance system rather than, for example, making all health professionals employees of a governmental system.

Does insurance coverage result in reduced financial barriers to accessing care for vulnerable populations? The answer is a qualified "yes".⁸ As cited in lengthy footnote 8, many studies have shown that insured poor or otherwise vulnerable populations have

⁷Notable exceptions are the direct delivery programs of the Departments of Defense and Veterans Affairs, the Indian Health Service, state and local health departments and hospitals, and grant programs of the U.S. Public Health Service.

⁸See Office of Technology Assessment, Does Health Insurance Make a Difference: Background Paper, Washington, DC: 1992; Paula Braveman, et al, "Adverse Outcomes and Lack of Health Insurance among Newborns," The New England Journal of Medicine, 32,8 (August 24, 1989): 508-13; L.J. Cornelius, "Ethnic Minorities and Access to Medical Care," Journal of the Association of Minority Physicians, 4,1 (1993): 16-25; Peter Franks, et al, "Health Insurance and Mortality," Journal of the American Medical Association, 270,6 (August 11, 1993): 737-41; Sylvia Guendelman and Joan Schwalbe, "Medical Care Utilization by Hispanic Children," Medical Care, 24,10 (October 1986): 925-40; Charles N. Oberg, et al, "Prenatal Care Use and Health Insurance Status," Journal of Health Care for the Poor and Underserved, 2,2 (Fall 1991): 270-92; Robert E. Roberts and Eun Sul Lee, "Medical Care Use by Mexican-Americans," Medical Care 18,3 (March 1980): 266-81; Margo L. Rosenbach, "The Impact of Medicaid on Physician Use by Low-Income Children," American Journal of Public Health 79, 9 (September 1989): 1220-6; Joel S. Weissman, et al, "Delayed Access to Health Care: Risk Factors, Reasons, and Consequences," Annals of Internal Medicine, 114,4 (February 15, 1991): 325-31; and Edward H. Yelin, "Is Health Care Use Equivalent across Social Groups? A Diagnosis-Based Study," American Journal of Public Health 73, 5 (May 1983): 563-71.

better access than their uninsured peers, although in few does the gap between the publicly and privately insured disappear.⁹

Under what conditions is health insurance likely to have the largest impact on vulnerable populations? To answer this question, we must separately examine: A) eligibility, B) enrollment, C) security and portability, D) benefits, E) affordability¹⁰, F) consumer choice, G) incentives for plans and providers to serve

⁹See especially Office of Technology Assessment, Does Health Insurance Make a Difference: Background Paper, Washington, DC: 1992; and Nancy E. Adler, et al "Socioeconomic Inequalities in Health," Journal of the American Medical Association, 269,24 (June 23/30, 1993): 3140-5; Ronald Andersen, et al, "Access of Hispanics to Health Care and Cuts in Services," Public Health Reports, 101, 3 (May-June 1986): 238-52; Robert J. Blendon, "Access to Medical Care for Black and White Americans," Journal of the American Medical Association, 261,2 (January 13, 1989): 278-81; Paula Braveman, et al, "Access to Prenatal Care following Major Medicaid Eligibility Expansions," Journal of the American Medical Association, 269, 10 (March 10, 1993): 1285-9; Paula Braveman, et al, "Adverse Outcomes ..."; Llewellyn J. Cornelius, "Barriers to Medical Care for White, Black and Hispanic American Children," Journal of the National Medical Association 85,4 :281-8; James W. Fossett, et al, "Medicaid in the Inner City: The Case of Maternity Care in Chicago," Milbank Quarterly, 68,1 (1990): 111-41; B. Burt Gerstman, et al, "Trends in the Prevalence of Asthma Hospitalization in the 5- to 14-year-old Michigan Medicaid Population: 1980 to 1986," Journal of Allergy and Clinical Immunology, 91 (April, 1993): 838-43; Alan M. Gittelsohn, et al, "Income, Race, and Surgery in Maryland," American Journal of Public Health, 81,11 (November 1991): 1435-41; Guendelman, op cit; Jennifer S. Haas, et al. "The Effect of Providing Health Coverage to Poor Uninsured Pregnant Women in Massachusetts," Journal of the American Medical Association 269, 1 (January 6, 1993):87-91; Rodney A. Hayward, et al, "Inequities in Health Services among Insured Americans," The New England Journal of Medicine, 318, 23 (June 9, 1988): 1507-12; Jonathan C. Javitt, et al, "Undertreatment of Glaucoma among Black Americans," The New England Journal of Medicine, 325,20 (November 14, 1991): 1418-22; Tracy A. Lieu, et al, "Race, Ethnicity, and Access to Ambulatory Care among US Adolescents," American Journal of Public Health, 83,7 (July 1993): 960-5; Paul W. Newacheck, "Characteristics of Children with High and Low Usage of Physician Services," Medical Care 30,1 (January 1992): 30-42; Charles Oberg, op cit; Joyce D. Piper, et al, "Effects of Medicaid Eligibility Expansion on Prenatal Care and Pregnancy Outcomes in Tennessee," Journal of the American Medical Association 264, 17 (November 7, 1990): 2219-65; Steven Shea, et al, "Predisposing Factors for Severe, Uncontrolled Hypertension in an Inner-City Minority Population," The New England Journal of Medicine, 327, 11 (September 10, 1992): 776-81; Suezanne Tangerose, et al, "Differences in Use of Health Services by Children according to Race," Medical Care, 22,9 (September 1984): 848-53; and D. Wolinsky, et al, "Ethnic Differences in the Demand for Physician and Hospital Utilization among Older Adults in Major American Cities," Milbank Quarterly 67 (Fall 1989): 412-49.

¹⁰Most discussions of out-of-pocket costs are part of those on benefits; however, for vulnerable -- and often low-income -- populations, a separate discussion is warranted.

vulnerable populations, and H) accountability of the system to communities and individuals.

In each of these discussions, we will focus on whether the health reform proposals remove existing barriers to care for vulnerable populations and/or erect new ones. In doing so, we follow in the steps of policymakers who recognize that vulnerable populations must have barrier-free access if they are to truly benefit from apparently available care.¹¹

A. Eligibility

If we are to rely upon insurance to lower financial barriers for the vulnerable populations, then coverage must be universal.¹² Unlike previous insurance expansions that have extended coverage for certain conditions (e.g., end-stage renal disease) or populations (e.g., children under the age of 6 but not their older siblings), the insurance must be available to all Americans, not omitting certain vulnerable populations, such as Washington State's program's initial explicit exclusion of migrant farmworkers.

This guaranteed coverage is at the heart of a reform plan's promise of security: one cannot lose health insurance by becoming unemployed, by changing jobs, by moving, or by having a medical condition that has heretofore been "medically underwritten out." Only the Clinton and Wellstone/McDermott proposals would make this unconditional guarantee of coverage for all eligibles. The other proposed reform measures all would try to make health insurance more affordable and available but offer no guarantees of coverage.

¹¹See, for example, provisions for barrier-free access of the McKinney Act's Health Care for the Homeless program and family planning services under Medicaid.

¹²Note that this discussion focuses on insurance as the mechanism for lowering barriers. Alternative methods, discussed below, include the direct funding of providers rather than, or as a supplement to, insurance.

The Clinton plan would extend such coverage to almost all citizens and residents in a timely fashion, phasing the program in on a state-by-state basis and providing for federal direct management should a state decline to participate. The major exception¹³ would be that of undocumented aliens who are generally excluded from the insurance component except for payment for emergency care. Reflecting their sponsors' sense of public opinion against the expansion of services to undocumented persons, four of the pending major bills (Clinton, Wellstone/McDermott, Chafee/Thomas, and Cooper/Breaux) would have legal-residence requirements, although Cooper/Breaux would apply that test to employees only. Wellstone/McDermott would allow states to include undocumented persons using no federal funds, and it would also provide that the American Health Security Board may override the prohibition if it is in the public interest to do so. The other two major bills are silent on the subject.

The Clinton proposal would also specifically include some sub-populations that have often been neglected by our health insurance system, including step or foster children, disabled adult children, a child who is a mother living with an eligible adult, and adolescents living apart from families.

B. Enrollment

Theoretical universal eligibility for insurance must be translated into enrollment if the insurance is to be real. Unlike the current confused situation, since plans under the Clinton proposal would offer the same benefit package and compete on the bases of price, quality, and consumer satisfaction, then the process of choosing a plan should be simpler. For enrollment to be

¹³Another exception is that of prisoners following convictions as adults, who have traditionally been served under a direct-delivery system of practitioners either hired or contracted by the prison system. Once they return to their communities, they would become eligible for coverage.

accomplished, there will need to be substantial investments in public information campaigns, not just with mainstream methods such as notices in pay envelopes, but also through means that will reach the vulnerable in appropriate ethnic, language, and cultural contexts. The Clinton proposal provides for consumer information and marketing, including an ombudsman, but does not specify that marketing be done in all appropriate languages.

Under the system envisioned in the Clinton plan, there would be multiple enrollment points, including at the point of seeking a medical service. Still, the proposal contains several steps that the vulnerable would have to take before their coverage would be fully operational: 1) enrollment in their regional or corporation alliance, 2) enrollment in a health plan, 3) separate application for premium subsidies and entitlement for reduced co-pays, 4) application for enhanced services, such as those available for children with special needs, and 5) if appropriate, for those with chronic illnesses or limitations in everyday activities, application for home and community-based long-term care.

In addition to positive provisions for appropriate information-sharing and enrollment procedures, there would need to be curbing of marketing abuses, such as falsely assuring new enrollees that they could continue to see their current providers when that is not the case. Marketing abuses are most likely to arise when some insurers sign up as many people as possible without providing sufficient access points for care, thus significantly raising access barriers, not lowering them.

If these procedures are not to serve as a barrier to enrollment, then in areas with high concentrations of vulnerable populations there would need to be: multiple available and accessible enrollment locations in which the vulnerable would feel comfortable; transportation as needed to the application/enrollment points; culturally and linguistically competent outreach,

assistance, and advocacy by people trusted by the vulnerable populations; and special efforts to reach people with no fixed address.

C. Security and Portability

As public opinion polls have shown, even Americans who currently have good health insurance coverage are concerned about losing it as their companies downsize, as they must take early retirement, or as they develop a health condition that makes them undesirable beneficiaries for insurance companies. As the recent Supreme Court decision demonstrated, their employers can change benefit coverage, even if the effect is to deny coverage for people or conditions previously covered, such as AIDS or chronic mental illness. Even worse is the situation of the marginally insured vulnerable person who may regularly cycle through periods of insurance and uninsurance.

Thus a major issue for all Americans, and especially for vulnerable individuals, is that of portability and security: once I am insured, will anything take insurance away from me? Or drastically change the rules so that I am, in reality, uninsured?

The President's bill would assure portability and security through very large health insuring purchasing pools or alliances that would operate under the same rules throughout the country. Wellstone/McDermott would accomplish the same goal through folding Medicare, Medicaid, and all insurance into state single-payer systems. The other legislative proposals would have much more complex rules and far smaller purchasing pools consisting of the unemployed, small employers, and the publicly subsidized. This could mean that vulnerable populations would be segregated into financing mechanisms that are less secure and less portable.

Portability and security may literally be problematic for those whose lives are portable and insecure: the homeless and those who move frequently for purposes of employment, such as migrant agricultural workers and undocumented aliens. Both the President's plan and Wellstone/McDermott would be primarily geographically based systems, which would accommodate movable populations with some difficulty. In most cases, people would be covered for out-of-area (of home-based health plan) only for urgent or emergency needs, the definition to be determined by the National Health Board. Although clearly a major injury or a heart attack would qualify, what about routine prenatal care for a migrant woman away from her home alliance for three months? For ongoing care for an adult chronic patient with diabetes or heart disease? For routine treatment for the chronically mentally ill? Although the Clinton proposal does discuss alternative arrangements for college students who live away from home, it is less complete for other transients.

D. Benefits

To be effective, insurance must cover those benefits that most people need, as well as some that relatively few will require.¹⁴ Both the Clinton and Wellstone/McDermott proposals have explicit lists of comprehensive covered benefits; those of the others have only general categories. Naturally, this allows critics to either complain that critical services are left uncovered in the first two bills, or to attack them as too expensive (bills without lists of benefits cannot, by definition, be costed out, and thus escape the latter charge).

¹⁴This recognizes health insurance's dual role in our society, that is, to cover relatively low-cost predictable events (e.g., well-baby care) as well as rare, high-cost events (e.g., lung transplants); the latter is the purpose of most non-health insurance, which confines itself to paying for infrequent occurrences through spreading the risk over a wide pool. For example, homeowners' insurance pays for the complete rebuilding of a burned-out house, an infrequent and high-cost occurrence, and not for routine furnace maintenance, a frequent and low-cost occurrence.

Both the Clinton and Wellstone/McDermott bills contain the benefits found in the plans of major employers: physician and other health professional care, in and outpatient hospital care, hospices, home health, occupational and physical therapy, durable medical equipment, prescription drugs and supplies, and others. Both would offer clinical preventive services with no cost-sharing, as well as vision and dental care for children. The Wellstone/McDermott bill also would include long-term care, while the President would keep services for long-term care or rehabilitation for children with severe disabilities in a separate long-term program for severely disabled children and supplemental Medicaid coverage for services used by low-income children with chronic conditions and disabilities.

All six bills would use the concept of medical necessity to determine whether covered benefits are actually payable in particular cases. None explains what medical necessity is, or how it will be determined. All six bills would also prohibit discriminating on the basis of pre-existing conditions, but Cooper/Breaux, Chafee/Thomas, Michel/Lott, and Nickles/Stearns do allow six-month waiting periods for all but pregnant women and newborns.

How would these benefits fit with those services needed by vulnerable populations? First, we must make it clear that the insurance packages offered in the Clinton and Wellstone/McDermott proposals are more comprehensive than most vulnerable populations have had,¹⁵ and perhaps are broader than those offered many middle class employees. Nonetheless, we have several concerns, particularly about the Clinton plan:

- The periodicity schedules for clinical preventive services, for which there would be no cost-sharing, do

¹⁵A major exception is that of children who have benefited from EPSDT or non-poor children with long-term needs.

not meet those of the relevant professional academies such as the American Academy of Pediatrics and American College of Obstetrics and Gynecology; for children, the preventive and treatment protocols fall short of the current EPSDT requirements. Moreover, family planning is not one of the clinical preventive services with no co-payments; this may be a costly omission.

- The term "medically necessary" is undefined. Presumably, health plans would make that determination, but it is unclear on what bases they would decide, or how the alliance would monitor such decisions.¹⁶ The National Health Board would be authorized to establish regulations regarding the exclusion of items or services that are not medically necessary or appropriate. However, that broad requirement omits the daily decisions that must be made about the medical necessity of a particular service for a particular patient, rather than for classes of patients as a whole. As the technology and dissemination of outcomes research and practice guidelines become more widespread, some of this problem should be eased.
- Medical necessity may be particularly difficult to determine for children if separate pediatric standards are not used. These standards would not only recognize children's different responses to treatments such as prescription drugs, but also the impacts that treatment or non-treatment have on their development.¹⁷ Thus while non-treatment may be a problem for adults' habilitation or rehabilitation, for children the denied treatment may preclude their growth and development to their maximum potential.
- Under the Clinton proposal, a number of home health, rehabilitative, and extended care benefits could be accessed only after injury or illness, and some would require evidence of improvement for their continued use. This leaves open to question services for 1) congenitally disabled children who may not have suffered an obvious, definable illness or injury, and 2) those adults and children, such as HIV/AIDS patients, for whom rehabilitation services can slow the disease's

¹⁶See discussion below on the rights of individuals to appeal the plans' decisions.

¹⁷For a cogent discussion of these issues, see Elizabeth J. Jameson and Elizabeth Wehr, "Drafting National Health Care Reform Legislation to Protect the Health Interests of Children," Stanford Law and Policy Review 5, 1 (Fall 1993):152-76.

progression or ameliorate its effects, but not result in "improvement."

- Primarily in recognition of the costs involved, the Administration's plan would exclude such services as hearing aids for both adults and children, dental services for adults (a great need among vulnerable populations), eyeglasses for adults, and custodial care.
- Similar fiscal caution within the Clinton administration led to limits on mental health and substance abuse benefits:
 - Inpatient care would be limited to 30 days for one admission, unless the person were a clear danger to the life of himself or others; 60-day annual limit.
 - Outpatient mental health would be limited to 30 visits per year, unless a trade-off with hospitalization and extensive day-treatment were used. Moreover, visits could be only for diagnosable mental diseases and would exclude those with suspected problems based on signs, symptoms, and risk factors.
 - The limits would be especially tight for the dually diagnosed, i.e., those with both mental health and substance abuse problems.
- Investigational (experimental) treatments could be covered by plans at their own discretion. In that case, items that are routine care would also be provided. Note that a plan need not include investigational treatments.

Like many decisions in health care today, the choices of covered benefits under the Clinton plan reflect the inevitable trade-off between necessity and costs. While one could argue for the broadest possible benefit package for the entire population, doing so would not recognize the need to restrain costs. On the other hand, vulnerable populations are those least likely to be able to access the uncovered care by other means, unless special and targeted provision is made for them.

E. Affordability

Although insurance can be theoretically available to an entire population, and it can include broad benefits, in reality it will cover people only to the extent that they can afford its out-of-pocket costs: premiums, deductibles, co-insurance and co-payments, including the maximum or catastrophic amount to which a family can be exposed. Unfortunately, during the last decade insurance has become unaffordable even for many employed Americans who are offered it by their employers as premiums have risen, deductibles have multiplied, and there are increased out-of-pocket costs at time of service (e.g., \$20 co-payments for prescribed drugs, even when no generic equivalent is available). In the United States out-of-pocket health expenditures account for more than 22 percent of all personal health care expenditures.

Some argue that increased costs to the consumers have several positive results: 1) greater awareness of the cost of care and thus more shopping for efficient, lower-cost providers; 2) greater consumer questioning of extensive testing, inpatient surgeries, and the like if they have a stake in the total cost; and 3) reduction in the funds required to pay for insurance, in reality a shifting of the costs directly to consumers and away from insurance. However, a recent Office of Technology Assessment study found that cost-sharing leads consumers to not seek health care at all; if they do so, the interventions that they receive are no more appropriate than for those without cost-sharing.¹⁸

For vulnerable populations, even modest cost-sharing may be too high, and either insurance coverage (in the case of premiums) or actual services (in the case of co-payments) will be foregone,

¹⁸U.S. Congress, Office of Technology Assessment, *Benefit Design: Patient Cost-Sharing*, Washington DC (1993).

often to the detriment of the person's health.¹⁹ Moreover, since vulnerable populations tend to be concentrated in vulnerable areas, then their inability to pay affects the economic viability of the providers who serve them. Clearly, some subsidy will be required if both the vulnerable and their providers are to survive.²⁰ Experts have concluded that a family's out-of-pocket costs should not exceed 10 percent of their income, a level which is likely to be far too high for low-income families with high health needs. In premiums alone, the Congressional Budget Office estimates that the average cost for a working family will be \$4,095, clearly unaffordable for most vulnerable families.

All health care reform proposals address the problem of affordability for low-income people, generally through direct subsidies to alliances or plans for their care. The Clinton plan, for example, would offer low-wage workers with income below \$40,000 a contribution toward the premium, so that they would pay a maximum of 3.9 percent of income. Moreover, AFDC and SSI beneficiaries would also receive reductions in cost-sharing (such as having a co-payment for a physician office visit drop to \$2 from the projected \$10 that others would pay).

According to a study recently completed by George Washington University's Center for Health Policy Research for the Kaiser Commission on the Future of Medicaid, the proposed subsidies in the major reform bills differ enormously: for a family of three with a single working parent at 100 percent of the federal poverty income standard, the family's premium costs would be \$357 under Clinton, \$0 under Thomas/Chafee, Cooper/Breaux and McDermott/Will. If,

¹⁹See especially OTA, Benefit Design . . .; S.B. Soumerai, et al, "Payment Restrictions for Prescription Drugs under Medicaid: Effects on Therapy, Cost, and Equity," The New England Journal of Medicine 317, 9:550-56; Soumerai et al, "Effects of Medicaid Drug-Payment Limits on Admissions to Hospitals and Nursing Homes," The New England Journal of Medicine 325, 15: 1072-7.

²⁰See Thomas Rice and Kenneth E. Thorpe, "Income-Related Cost Sharing in Health Insurance," Health Affairs (Spring 1993): 22-39.

however, the family's income rises to 150 percent of the federal poverty level, the family out-of-pocket costs are: \$696 (3.9 percent of total family income) under Clinton; \$103 (0.6 Percent of income) under McDermott/Wellstone; \$1393 (7.8 percent of income) under Thomas/Chaffee, and a whopping \$1950 (10.9 percent of income) for Cooper/Breaux.²¹ A separate program for low-income, high-need children would also be established under the Clinton proposal, but this would, in effect, deny subsidized coverage to moderate-income children who previously have had such coverage.

F. Consumer Choice

Because of the need to contain costs, the Clinton plan calls for premium subsidies only if the person or family enrolls in the low-cost or average health plan, unless those plans are already at capacity. Since these less costly plans would likely be those most aggressively managing utilization and cost, (i.e., most likely to employ barriers to reduce utilization) partly through financial incentives for providers, they are the most likely to be full-risk capitated models. Thus, in effect, vulnerable populations are denied the freedom of choice that other Americans with more resources will continue to have. Furthermore, because some of the more respected managed care plans would be unlikely to market aggressively to vulnerable areas, residents in those areas may be forced into less-than-desirable plans. A less desirable plan might, for example, have excessive waiting times to appointments to discourage utilization.

A further issue in consumer choice is the need that people be well-informed before enrolling in a particular plan. Since managed care, at least in the gatekeeper/capitation model, is relatively

²¹See Sara Rosenbaum and Julie Darnell, Families and National Health Reform: A Comparison of Family Premium Payment Responsibilities under Current Legislative Proposals, Prepared for the Kaiser Commission on the Future of Medicaid and The Commonwealth Fund, Washington DC (February 10, 1994).

unknown among vulnerable populations, a great deal of effort (and resources) will need to be expended if they are to understand what their choices are, as well as the pros and cons of each one (e.g., being able to retain the same provider). Only with such commitment can theoretical consumer choice become actual consumer choice.

G. Incentives for Plans and Providers to Serve Vulnerable Populations

In the past, most private providers have been reluctant to serve vulnerable populations for various reasons: 1) financial losses, since many vulnerable people are currently uninsured and publicly insured (e.g., Medicaid) patients frequently have low payment rates attached to their care; 2) administrative burden on claims submission and other paperwork; 3) providers' perceptions that vulnerable populations are sicker and less likely to comply with the prescribed treatment regimen, particularly if lifestyle changes are required; 4) perception that publicly financed patients are more litigious than the average patient; 5) more churning as enrollees gain and lose eligibility, which makes administration and marketing even more difficult; and 5) covert racism/ethnism, often expressed as "My other patients would be scared away."

Can health care reform change the picture? The various provisions in the Clinton proposal give some promising signals, such as the simplification and automation of claims-filing and payment levels that equal those of other patients. In fact, in most cases vulnerable populations' health insurance cards would appear to be exactly the same as everyone else's. Moreover, the President's plan would provide for premiums paid to the plan at the same level²² for all patients, regardless of whether they are subsidized, even promising risk-adjusted premiums so as not to

²²The plans would be paid through risk-adjusted premiums; however, premiums charged to employers and employees would not be risk-adjusted.

discourage the service of high-risk individuals.²³ Furthermore, the turnover that often now occurs as beneficiaries move on and off plans as they lose or gain third-party financing would be substantially reduced, since their coverage would be seamless, at least for the basic benefit package.

Unfortunately, the Clinton proposal would make some demands that will continue the vulnerable populations' undesirability from a provider perspective. Chief among these is that the plan or its providers would absorb the reduced co-payments paid by AFDC and SSI beneficiaries (e.g., receiving \$2 for a physician visit instead of the \$10 charged to other patients), giving them incentive to avoid areas with large numbers of AFDC and SSI enrollees. Although prohibitions against redlining geographic areas -- i.e., refusing to sell the insurance in certain areas -- are likely to be strict, nonetheless clever plan managers can use other demarketing techniques to either avoid these patients or limit their share. Similarly, many plans are likely to seek to avoid high-risk/high-cost enrollees, such as those with HIV/AIDS.

On the other hand, some managed care plans are learning to serve vulnerable populations successfully, although they have had to make major changes in such things as hours, outreach, transportation, and having bilingual/bicultural staff.²⁴ Some of these "mainstream" HMOs have joined in partnership with providers already based in communities with high concentrations of vulnerable populations.²⁵

²³Two cautions here: 1) the science of risk-adjusting on other than age and sex is not yet well developed; and 2) there is no requirement that the plan also risk-adjust payments to individual providers.

²⁴John E. Ware, et al, "Comparison of Health Outcomes at a Health Maintenance Organization with those of Fee-for-Service Care," The Lancet (May 3, 1986): 1017-21.

²⁵See Lois Simon, et al, Medicaid and Managed Care: Lessons from the Literature, Washington, Dc: Kaiser Commission on the Future of Medicaid (forthcoming).

While respectable managed care plans may approach vulnerable areas gingerly, some not-so-altruistic plans may rush into vulnerable areas for another reason: a quick way to make money is to agree to serve high-risk groups and then, particularly for those individuals who are hardest to tie into the system, make little effort to reach them, and thus be paid for services not delivered.

Therefore, it is likely that, under one or the other versions of health reform, vulnerable populations would become somewhat more attractive to plans and providers, but this situation will require close monitoring to avoid those plans and providers who may take undue advantage of the situation.

H. Accountability of the System to Communities and Individuals

If the Clintons' proposed system is to be held accountable by vulnerable populations and the communities in which they live, then several provisions must be in place:

- The formation of the National Health Board and the alliances must be as inclusive as possible both in their membership and in access to their deliberations.
- The standards against which the plans would be measured (consumer access to services, appropriateness of services provided, outcomes of services and procedures, health promotion, prevention of diseases and disorder, and consumer satisfaction) must be inclusive and specific to vulnerable populations. For example, a requirement that a primary care site be open 40 hours a week would not accommodate low-wage patients without sick leave privileges unless those 40 hours include some clinic time outside regular business hours.
- In the development of the health information systems that will both help plan for services and serve as report cards on the offered plans, there would be a required consultation with representatives of consumers, which should include vulnerable populations.
- In the development and dissemination of practice guidelines, consideration should be given to their

adaptation to meet the needs of vulnerable populations. For example, a medication that requires refrigeration is not a good choice for a homeless person.

- If a patient should be dissatisfied with his/her treatment, then he/she should have the right to disenroll or to pursue the grievance through first an administrative resolution program and then through the courts. This same pathway should be available to those who choose to exercise their private right to enforce responsibilities of Alliances to do their jobs.

The Clinton proposal contains these private-right-of-action provisions, which would be far stronger than reliance on regulatory enforcement alone.²⁶ The latter would be overly dependent on the ideology and resources of the persons administering it, a phenomenon that we observed in many health and social programs in the 1980s.

An undoubtedly more difficult challenge would be to cause Alliances and plans to be responsive to their communities. Community Oriented Primary Care is one such approach.²⁷ Another is the inclusion of community-based providers in any network or plan serving a vulnerable community.²⁸ (See below). In actuality, these two approaches could be combined.

²⁶See Jameson and Wehr for a concise explanation of this issue.

²⁷See Richard A. Wright, "Community-Oriented Primary Care: The Cornerstone of Health Care Reform," Journal of the American Medical Association 269, 19 (May 19, 1993): 2544-7.

²⁸Jon Christianson and Ira Muscovice, "Health Care Reform and Rural Health Network," Health Affairs (Fall 1993):58-75; and Daniel M. Campion et al, "Health Care Reform in Rural Areas," Health Affairs (Fall 1993): 76-80.

IV. WHAT NEEDS WILL BE LEFT UNMET BY THEIR ACCESS TO UNIVERSAL INSURANCE? HOW CAN THOSE NEEDS BE MET?

Universal insurance coverage will go a long way to removing a major financial barrier to care.²⁹ Yet universal insurance does not in and of itself equal universal access to the appropriate care that will improve the population's health status. Two major pieces are lacking: 1) the **capacity** to deliver care to vulnerable populations, particularly in vulnerable communities, and 2) the means to lower non-financial access barriers through **enabling services** such as outreach (both individual and community), transportation, translation, cultural competency, case management, and linkages to other parts of the health and social service system.

A. Capacity

While some vulnerable people are found in isolation, more commonly they are clustered in communities that are lacking the population base and/or economic and social infrastructure that will attract and keep health professionals. To provide these populations with appropriate care to meet their special needs will mean investing in the infrastructure of health care in their areas.

Of the 43 million medically underserved people, some 7-10 million are now being served by publicly funded providers for preventive and primary care, leaving a very large gap. Expanding the capacity to serve the remainder (and even to retain the current infrastructure of the publicly funded providers) will require a three-pronged approach: 1) Investments in community-based providers

²⁹In addition to the citations in footnote 8, see also James Fossett et al, "Public Sector Primary Care and Medicaid: Trading Accessibility for Mainstreaming," Journal of Health Politics, Policy, and Law 14,2 (Summer 1989): 309-25.

and networks; 2) Assuring that community-based providers are adequately funded for services so that they survive; and 3) Investments by "mainstream" managed care plans. Note that our interest in how well these organizations would fare is not in the particular provider per se but in the development and maintenance of sufficient medical homes for vulnerable people.

As health care reform is implemented, it is possible that the need for such organizations will fade, the hope of those who fear two-tier medicine. On the other hand, we know for certain very little of the effects of any reform proposal on any population, least of all on the vulnerable. That very uncertainty argues for keeping the safety net strong under the vulnerable and expanding it to include more of them, at least until the effects of reform are known and more-informed decisions can be made.

1. Investments in community-based providers and networks

Vulnerable populations have long relied on the services provided by public and not-for-profit organizations, many controlled by the communities they serve. These have included full-service acute-care hospitals; comprehensive primary care centers, free clinics, health care for the homeless programs, and health departments; limited-service providers like family planning, school-based programs, and STD clinics; mental health and substance abuse education, intervention, and treatment programs; hospices; and agencies that focus on coordinating health and social services of multiple providers for their clients, such as the Ryan White HIV/AIDS program. Many of the National Health Service Corps' health professionals are placed with these organizations.

But more needs to be done if the promise of health care reform is to become real for vulnerable populations:

- Preventive and primary care health professionals available and deployed to communities where the vulnerable populations live.
- Capital for buildings and equipment for new and expanded programs.
- Capital for planning and start-up.
- Resources to support the development of community-based networks, the funds to be used for contracting/hiring management expertise, telecommunications systems, information systems, etc.

Virtually all the major health reform proposals contain some provision for the investment in the infrastructure to serve underserved and vulnerable populations. The President's proposal would authorize over \$8 billion for six years with Chafee/Thomas authorizing \$5.6 billion over five years. In both cases, the funds would be authorized but with no guarantee of appropriation; in contrast, McDermott/Wellstone allocates a portion of the national health budget for these purposes. The least helpful of the current proposals on this matter is Stearns/Nickles' proposed permission to the states to use Medicaid acute care funds for these purposes.

To produce and deploy more preventive and primary care health professionals, the Clinton proposal would: 1) direct the flow of graduate medical and nurse education training funds to the education programs and not the teaching hospitals; 2) significantly decrease the number of physician specialty training slots and increase primary care opportunities; 3) greatly increase the National Health Service Corps; and 4) authorize more training funds for other badly needed health professionals. In addition, it would provide tax breaks and enhanced Medicare payments for primary care physicians in rural underserved areas.

To develop more preventive and primary care capacity, the Clinton proposal would largely rely on modest increases in current Public Health Service Act grant programs, with a major expansion

for school-based programs. Capital for buildings and equipment would be made available through loans. But most of the Administration's capacity expansions would occur through a new authority³⁰ for community-based networks, with preferences to those that were public-private partnerships, especially with private physicians. Medicaid payments to highly disproportionate-share hospitals would be replaced by Vulnerable Populations Assistance to those hospitals, to be phased out over five years; the Medicare DSH would be retained.

Where such infrastructure exists, it is appropriate to build on current community-based organizations with a track record of successfully serving the vulnerable so as to take advantage of their expertise in reaching what are often hard-to-serve populations with needed services in culturally and linguistically competent ways. For example, community-based organizations serving subpopulations with strong family ties already know that waiting rooms must be larger than "normal" to accommodate the patients' accompanying family members, an insight unlikely to occur to plans or providers used to serving middle class, mainstream populations.

2. **Assuring that community-based providers are adequately funded for services so that they survive to continue serving the vulnerable.**

Most community-based providers for the vulnerable exist on paper-thin margins and/or require public or private subsidies to exist, resulting in no reserve cushion to fall on in tough financial times. Most also depend to an extent on adequate payments from Medicaid to meet their obligations. As we move into a new era where many of the currently uninsured will carry insurance, and where most Medicaid patients will be moved into managed care plans,

³⁰Traditionally, new authorities have grown in funding while older programs stay the same or are reduced.

survival of these community-based providers depends upon: a) successfully participating in managed care arrangements on suitable terms; b) receiving adequate compensation for those who, for whatever reason, are not covered by insurance and for appropriate out-of-plan usage for those who are; and c) adequate payment for non-insured services that are critical to improving both the access and health status of the vulnerable populations.

a. Successfully participating in managed care arrangements on suitable terms

Clearly, the future in health care is likely to be managed care, especially for publicly and newly insured populations, as we have seen in the rapid state movement in this area. Any provider who cannot adjust to managed care is likely doomed. Yet the providers serving vulnerable populations are often avoided by managed care plans who see their sicker, more-expensive patients as difficult to manage and, too often, the providers themselves as unsophisticated and inefficient. In addition, community-based providers seldom have the cash reserves to assume full risk no matter how well managed they are.

To meet this problem head-on, providers to vulnerable populations need:

- The opportunity to contract with managed care plans. The Clinton proposal would offer this opportunity for five years through its required contracting with Essential Community Providers; McDermott/Wellstone would pay community-based providers separately; Chafee/Thomas and Michel would maintain contracting for Federally Qualified Health Centers.
- Payment on a reasonable basis. Under Clinton's proposal, such providers could be paid equal to other providers if they participated in a health plan, but no adjustments would be required for the high-risk/high-cost patients seen by many of these providers. Chafee/Thomas, Cooper/Breaux, Michel, and Stearns/Nickles would all retain the FQHC and RHC payment methods, usually subject to a cap.

- Reasonable acceptance of risk. Funds to establish risk reserves, and special reinsurance and stop-loss arrangements are essential for shallow-pocketed community-based providers to succeed. In most cases, they should be at risk only for the services they directly provide.
- Pass-through of risk adjustments. Under the Clinton proposal, plans would receive risk-adjusted premiums that could, at least in theory, compensate them for the higher costs of caring for vulnerable populations. However, there is no requirement that the plans pass on these adjustments to the providers of these patients. McDermott/Wellstone would require risk-adjusted payments to providers to the medically underserved; the other proposals would not.
- Coverage of unpaid out-of-pocket charges. Except for the very poor categorically eligible, the Clinton proposal would require point-of-service cost-sharing by the beneficiary, charges that many of the most vulnerable would find it hard to pay. Moreover, certain cash-assistance beneficiaries would make reduced co-pays. In both these cases, how would community-based providers be compensated? The same problems would arise under the other proposals except for McDermott/Wellstone.

If these provisions can be put in place, then providers of care to the vulnerable have an acceptable chance of survival; if not, we will see almost a century of social and health investment drain away.

- b. **Receiving adequate compensation for those who, for whatever reason, are not covered by insurance and for appropriate out-of-plan usage for those who are**

Since community-based providers have traditionally (and sometimes by law) served vulnerable populations regardless of ability to pay, they attract those people who feel that they have nowhere else to go or who have not yet adjusted to their new managed care plan. Under health care reform, this is likely to include undocumented aliens [who are specifically excluded from the Clinton, Chafee/Thomas, and Cooper/Breaux (for non-workers) proposals], migrant agricultural workers away from their home

areas, other transients, the chronically mentally ill, ex-prisoners, and other vulnerable people. These are people whom it is difficult to fit into any managed care system, even a system with a commitment to provide care for difficult-to-serve persons.³¹ In addition, there would likely be people who are confused by the enrollment and provider-assignment processes and who would therefore seek care where they felt they belonged.³²

Community-based providers would find it difficult, if not impossible, to turn these people away, and so a means must be found to pay for their care. For the most seriously impacted hospitals, under the Clinton proposal there would be diminishing Vulnerable Population Assistance payments for this care; other providers would need to rely on discretionary grants to cover these costs. Unlike the other major proposals, the Clinton bill would not permit development funds (primarily for community-based, multi-provider networks) to also be used for post-developmental operations. The McDermott/Wellstone proposal would be the only one with guaranteed funding to cover such costs as a proportion of the national health care budget.

c. Adequate payment for non-insured services that are critical to improving both the access and health status of the vulnerable populations

As discussed below, the non-insured "enabling services" such as outreach, transportation, translation, case management, and referral are critical if vulnerable populations are to access the health care system and improve or ameliorate their health status. Since these services are labor-intensive, community-based providers would need a flow of funds to pay for them.

³¹Managed care plans without such a commitment would respond only to the financial incentives for underservice.

³²The amount of confusion -- and thus the size of this problem -- would be exacerbated if start-up were rapid, as shown by the extreme confusion among both clients and managers under rapidly implemented state plans.

3. Investments by "mainstream" managed care plans

In some areas, community-based providers will be able to band together to offer their own managed care plans to at least the newly insured and previously publicly insured vulnerable populations. In other areas, they may lack sufficient expertise or, more likely, capital to endure through the intense effort and expense of the start-up period. Or, there may be insufficient population to spread the risk broadly enough for a stand-alone managed care plan to succeed. In all these cases, mainstream managed care plans may be suitable partners for community-based providers, lending their managed care expertise and capital in exchange for access points and providers knowledgeable about and able to serve their communities, including the most vulnerable populations among them. If conditions are right (see above), we can expect to see successful arrangements between mainstream managed care plans and networks of community-based providers.³³

Unfortunately, the managed care plans attracted to vulnerable populations and areas are also likely to include those for whom the primary motivation is financial, easily realized with vulnerable enrollees through underservice or only nominally accessible services. While it is difficult to foresee a motivation test imposed to assure that plans have noble intentions, any health care reform plan could require evidence of accommodation to vulnerable populations, such as through extended hours for primary care, as well as process measures (e.g., required immunization rates) and outcomes (e.g., low infant mortality rates). Furthermore, the oversight methods and mechanisms could explicitly include members of vulnerable populations in decision-making roles. In none of the proposed national health reform proposals is the oversight function

³³The Clinton proposal, as noted above, would provide a workable framework. Unfortunately, many of the state health care reform efforts offer few such assurances.

articulated sufficiently so that we could be certain that such factors would be included in the certification and evaluation of managed care plans.

B. Enabling Services

Most of the emphasis in health care reform, whether state or national, is really on medical care reform; indeed, this paper has acceded to that emphasis in speaking of the need for a medical home for the vulnerable populations. While most proposals offer special treatment for clinical preventive services, such as mammograms, that are often omitted from current insurance plans, nonetheless they exclude other health and social services from the insurance package.

Yet vulnerable populations often face access barriers and problems that are only partly relieved through insurance coverage for medical treatment. Access barriers can include language, culture, distance, lack of transportation, and other factors, exacerbated by poor living conditions (e.g., the homeless), occupational and other safety hazards (e.g., for migrant agricultural workers), chronic substance abuse and/or mental illness, or need for multiple but coordinated services for those with multiple and complex problems (e.g., persons with AIDS).³⁴

With rare exceptions, services such as outreach, transportation, translation, day care for other family members, and case management are not well handled through an insurance mechanism, since they are needed by only a small part of the U.S. population but could be demanded by many if they were made a

³⁴See, for example, Lorraine V. Klerman, "Nonfinancial Barriers to the Receipt of Medical Care," The Future of Children (Winter 1992):171-85; and G.M. Quesada, "Language and Communication Barriers for Health Delivery to a Minority Group," Social Science and Medicine 10,6 (June 1976): 323-7.

reimbursable benefit. This potential demand, often called the "woodwork factor," would make their coverage prohibitively expensive if they were part of a general insurance package. But they are critical to the wellbeing of vulnerable populations. In other words, some vulnerable people are unable to reach sources of care without transportation; however, it makes little economic sense to have "transportation" as a covered benefit for middle-class parents taking their children to the pediatrician for routine check-ups. Thus such services are best handled through non-insurance mechanisms.

And they work, not only in reducing barriers to care, but improving health outcomes, which must be the ultimate goal of any health reform proposal.³⁵

The Clinton proposal would pay for these "enabling services" through two mechanisms: a new grant program for community-based networks (not individual provider organizations) and traditional grant programs, such as for Health Care for the Homeless and Ryan White. Although the services would be authorized but would need to compete with other priorities for actual funding, the Clinton proposal is the only major national plan to specifically include these services for vulnerable populations. With the exception of Stearns/Nickels, the other major national proposals would implicitly include enabling services in increased funding for existing and new community-based organizations.

³⁵Paul A. Buescher and Nancy I. Ward, "A Comparison of Low Birth Weight among Medicaid Patients of Public Health Departments and other Providers of Prenatal Care in North Carolina and Kentucky," Public Health Reports 107, 1 (January-February 1992): 54-65; P.A. Buescher, et al, "Source of Prenatal Care and Infant Birth Weight," American Journal of Obstetrics and Gynecology, 156 (1987): 204-10; and J. Athole Lennie, "Low-birth-weight Rate Reduced by the Obstetrical Access Project," Health Care Financing Review, 8,3 (Spring 1987): 83-6.

V. CONCLUSION

As we have seen above, expansion of health (actually medical) insurance will significantly lower financial access barriers for many vulnerable people. But questions remain about even an expanded and reformed insurance mechanism's ability to substantially improve the health of the neediest of our fellow Americans. How can insurance be structured to best meet their needs? What should be the provisions for:

- Eligibility
- Enrollment mechanisms
- Security and portability
- Benefit structure
- Affordability
- Consumer choice
- Incentives to serve vulnerable populations
- Accountability to communities and individuals?

But insurance, no matter how well structured, will likely leave significant problems untouched, particularly those access problems that are not largely caused by individuals' financial barriers. Vulnerable populations tend to be concentrated in communities that both insurance companies and also private providers have heretofore shunned, which raises further questions:

- How can we best assure that sufficient capacity exists to meet the needs of vulnerable populations?
- How should we provide for non-insured essential services?
- What should be the roles of traditional community-based providers? "Mainstream" managed care plans? How can we assure a synergy among them in meeting the needs of vulnerable populations?

In short, how do we structure a system that best meets the needs of the most vulnerable among us, the neediest of the needy, in a community-responsive, effective, and efficient way? For to me,

that is the ultimate question that any proposal for health care reform must answer to be deserving of the label "reform."

