AHA Medical/Scientific Statement

Special Report

Insurability of the Adolescent and Young Adult With Heart Disease

Report From the Fifth Conference on Insurability, October 3–4, 1991, Columbus, Ohio

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Most young adults with a cardiac abnormality require continuing diagnostic or therapeutic cardiovascular care. Their medical expenses incurred as minors were usually covered by a parent's private insurance or a public program such as Crippled Children's Services or Medicaid. However, such private health insurance is usually unavailable for those 19 or older unless the insured is a full-time student. Crippled Children's Services do not fund medical care for patients more than 21 years old. Medicaid coverage may continue, depending on income level.

The problem faced by a young adult with heart disease can be illustrated as follows: A 28-year-old accountant with congenital aortic stenosis has completed college, is married, and has two children. He is excluded from health insurance because of a preexisting condition. He undergoes aortic valve replacement, which costs tens of thousands of dollars. His savings are lost and his family's future financial situation is compromised by debt as a result of the needed operation. He may have been better served if he had no occupation, remained at the poverty level, and used a public program for his medical costs.

The American Heart Association's Council on Cardiovascular Disease in the Young has held several conferences on insurability, but these have focused on life insurance. The council therefore sponsored a conference held October 3–4, 1991, that addressed health insurance because this is a more pressing and pertinent problem for the person with a cardiac abnormality. The goals of the conference were to review the health status, educational data, and employability data of patients with various operated and unoperated lesions; to explore medical resources for such patients; and to develop strategies to provide health-care coverage for this population. The 2-day conference consisted of formal presentations and panel discussions focusing on the health insurability of adolescents and young adults with heart disease.

Population Characteristics

Prevalence data (prevalence = incidence × duration) and extrapolation from the known population of children with a cardiac anomaly suggest that 200,000–300,000 people in the United States between the ages of 21 and 40 have congenital heart disease. By the year 2000, this population will probably consist of more than 500,000 people. Every year, at least 8,500 young people who have undergone surgical repair reach adulthood.

Natural History of Congenital Heart Disease

At this time of assessment and prioritization of health-care expenditures in the United States, knowing the natural history of patients with cardiac malformations becomes important in determining long-term costs of their health care. Understanding the natural history of cardiac malformations is important to the clinician in order to determine the risk–benefit effects of operative interventions. An ongoing multi-institutional study, the Natural History Study of Congenital Heart Disease, has contributed long-term follow-up information since 1958 for 2,408 patients with the relatively simple lesions ventricular septal defect, pulmonary stenosis, or aortic stenosis. In contrast, much of the information about the outcome of complex congenital cardiac defects is from other studies from individual institutions. The Natural History Study data became of interest in the 1990s in a manner that the organizers of the study perhaps did not foresee, because cost–benefit data from the study will be available for future planners of medical care systems.

The Natural History Study of Congenital Heart Disease (NHS-I) was the initial clinical trial funded by the National Heart, Lung, and Blood Institute. This was not purely a natural history study in that surgically repaired patients were also included. Data were collected at six cardiac centers, and the first phase of the study was completed in 1973. All patients had cardiac catheterizations at admission to NHS-I and at completion of NHS-II. Mild, moderate, and severe disease was defined for each of the three lesions and the natural history as well as results of surgery were evaluated carefully. In all categories some patients with moderate disease had only medical follow-up whereas others had surgical intervention. The results of surgery for the more severely affected patients and the progress of patients treated medically were determined. The average follow-up in the first study was 8 years. To determine the long-term status and ultimate prognosis for

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patients in this study, the patients were contacted and studied between 1985 and 1988 in the Second Natural History Study of Congenital Heart Disease (NHS-II).\(^7\) Virtually all patients were children when entered in NHS-I, and the average age at follow-up for NHS-II was just under 30 years, with data obtained from almost 85\% of the NHS-I cohort.

**Results of NHS-II**

The results of NHS-II were reported by Drs. Weidman, O'Fallon, Driscoll, and Gersony.

**Pulmonary Stenosis**

Of the original cohort of 592 patients with pulmonary stenosis, 95.7\% were alive 25 years later, a percentage similar to that of the general population. Almost none of the patients with mild pulmonary stenosis (gradient <25 mm Hg) required an operation at an older age, and the results of surgery were excellent for 283 patients who had more severe disease. Approximately 4\% required reoperation. Morbidity was rare, and none of the patients had endocarditis.

**Aortic Stenosis**

Among 462 patients with aortic stenosis, 85\% were alive 25 years later, significantly less than expected for the United States population in 1970. The mortality rate was highest among patients with the most severe disease. Sudden death was unusual and occurred only in the group with severe disease. Reoperation was considerably more common for patients with aortic stenosis than for those with pulmonary stenosis. Nearly two thirds of the patients with aortic stenosis lived for 25 years without requiring a second procedure. Morbidity, including bacterial endocarditis, occurred more frequently in patients with severe stenosis, but complications were infrequent.

**Ventricular Septal Defect**

There were 1,280 patients with ventricular septal defect in NHS-II. Patients with small ventricular septal defects who did not have an operation led normal lives and did not require an operation later in life. Their survival rate was similar to that of the general population. Patients with larger defects who had successful surgical closure also did well over this long follow-up period. Surprisingly, patients with pulmonary vascular obstructive disease (Eisenmenger's complex) had longer and less symptomatic lives than anticipated when the study was organized. More than 40\% of these patients were alive 25 years later.

**Arrhythmias**

Cardiac arrhythmias appeared more frequently than in the general population in all three groups, but their occurrence was assessed by Holter monitor analysis and did not correlate particularly well with the patients' clinical course. Deaths from late arrhythmias were very rare.

**Quality of Life**

Have the results of careful medical evaluation and treatment and surgical intervention helped patients take their place in society as productive citizens? The indicators of quality of life considered in NHS-II included personal assessment of health, interval since last cardiac examination, marriage rate, divorce rate, fertility rate, occurrences of heart disease in offspring, education, employment, and health and life insurance.

**Personal assessment of health.** The patients' perception of their health during NHS-II was no different than the average American's. More than 90\% of the study patients considered their health to be good or excellent, regardless of lesion and degree of severity. Even patients whose medical status was considered poor by their physicians considered their health to be good or excellent.

**Interval since last cardiac examination.** Approximately 40\% of the patients had not seen a cardiologist for an evaluation in more than 10 years, and only one third had been to a cardiac specialist within the last 12 months.

**Marriage, fertility, and occurrence of heart disease in offspring.** Although women with any of the three defects tended to marry later than unaffected women, by the time they reached their late 30s or 40s nearly 80\% were married, a percentage similar to that in the general population. The men married at the same frequency as the general population. Divorce and separation rates were similar to the general population.

The women in the study gave birth to fewer children than the general population average. By the age of 40 years, 60\% had had children compared with about 85\% in the general population. The children of a parent with congenital heart disease were more likely to have a cardiac malformation; the prevalence of congenital heart disease for children of a parent with a ventricular septal defect or with pulmonary stenosis was approximately 30/1,000 compared with 8–10/1,000 for the general population. For aortic stenosis, prevalence was 10/1,000.

**Education.** The patients were generally better educated than the general population. More than 90\% graduated from high school, compared with 80\% in the general population. Of both men and women, approximately 60\% either graduated from or were attending college, compared with 40\% for the general population. Patients had more graduate degrees than the general population average. Those considered to have severe disease and in less than optimal health attained an educational level similar to that of patients with mild disease.

**Employment.** The employment record of these young adults with ventricular septal defect, aortic stenosis, or pulmonary stenosis was similar to that of the general population, with approximately 93\% practicing a profession, holding a job, or still attending college.

**Health and life insurance.** In 1985–1988, 80–85\% of the patients in NHS-II had some form of health insurance, similar to the general population. Sixty percent had group policies or were insured through their parents' policies. It is unknown whether these patients paid higher premiums, whether their policies were cancelled when employment status changed, or whether their coverage was adequate. Patients with any of the three conditions had life insurance coverage at a rate only a few percentage points less than that of the general population. It is unknown to what extent premiums were rated.
Summary of the Second Natural History Study

In summary, the NHS-II indicates that during two decades after their initial evaluation, patients with congenital heart disease felt well. The number of patients married by the age of 35 was similar to that of the population without cardiac disease. The women in this series had fewer children than the general population, but 60% had children. The incidence of congenital heart disease in offspring was 10–30/1,000. The educational level of these patients was higher and the employment rate was equal to those of the general population. Forty percent had not been seen by a cardiologist in more than 10 years, 80% had health coverage of some sort, and 65% had life insurance.

It appears from these data that children in the NHS-I with aortic stenosis, pulmonary stenosis, and ventricular septal defect became, by the time of the NHS-II, productive adults who lead quality lives, are well educated, and achieve employment. They do not appear to be a burden to the health-care or welfare systems.

Other Long-Term Studies in Congenital Heart Disease

Atrial septal defect. Long-term survival of patients after repair of uncomplicated atrial septal defect is similar to that of the general population. Late complications are extremely rare.8  

Complex lesions. Follow-up studies for patients with complex cardiac malformations are less definitive because effective operative procedures have only recently been available. For example, mid-term to long-term follow-up studies of such patients, most of whom have had the Fontan operation, allow only a 5–10-year follow-up. In one large series from the Mayo Clinic,9 352 patients who had a modified Fontan operation before 1985 were evaluated. One-, 5-, and 10-year survival rates were 77%, 70%, and 60%, respectively. Reoperation was necessary for 103 of the 352 patients. Approximately 20% of the patients had postoperative cardiac arrhythmias, and many patients continued to take medications. Whether a successful Fontan procedure increases life expectancy and quality of life is not yet known. At present it is considered a palliative operation.

Murphy and colleagues studied 205 consecutive survivors of repair of tetralogy of Fallot performed between 1956 and 1960. Eighty-six percent of these patients were alive 30 years later. Deaths occurred in patients who were older at the time of operation, had a longer cardiopulmonary bypass time, and a history of congestive cardiac failure (J. Murphy, B. Gersh, D. Mair, V. Fuster, M. McGoon, D. Ilstrup, G. Danielson, unpublished data, 1992).

Ventricular Septal Defect. Data from a long-term follow-up study of 296 survivors of ventricular septal defect surgery at the University of Minnesota showed 80% were still alive 35 years later.10 Deaths occurred among those with elevated pulmonary vascular resistance or heart block. Each of these complications is less of a factor now because the operation is performed when patients are younger, preventing pulmonary vascular obstructive disease, and because more sophisticated surgical techniques are used that avoid conductive tissue damage.

Serial evaluation of 1,000 patients with cardiac anomalies. In a study by Moller and Anderson,11 997 of 1,000 consecutive patients with a cardiac anomaly initially evaluated between 1952 and 1963 showed that 712 were still alive 26–37 years later. Most early deaths were related to complex anomalies such as unoperated transposition or to surgery performed in the early phases of surgical technique development. Late deaths occurred from inoperable conditions, often with pulmonary vascular obstructive disease. Importantly, 89% of the survivors were asymptomatic. The endocarditis risk rate was 12.9/10,000 patient-years, and endocarditis was a particular risk for the aortic valve. In the 712 survivors, only 25 were taking a cardiac medication.

Providers of Cardiac Health Care for the Over-21 Population

The over-21 population receives health and cardiac care from many sources. Most health care seems to be episodic and illness-related rather than preventive; for example, many of the NHS-II patients underwent cardiac reevaluation only every 10 years. Sources of care include pediatricians, unless patients have chosen or have been asked to leave that practice. Many patients see a family practitioner, internist, obstetrician/gynecologist, sports medicine specialist, or chiropractor. Some populations may use alternative sources of health care, such as curanderos. Sources of care may be related to the person’s major activity. These sources include nurses, aides, coaches, or athletic trainers. College health centers are often staffed by nurses and physicians from family practice, internal medicine, or obstetrics/gynecology disciplines. Industrial nurses or physicians, who may be expected by industry to protect companies from compensation issues, often give care. In the military, medics and either internal medicine or family practice physicians usually provide care.

Cardiac care is usually provided by either pediatric or internal medicine cardiologists. Many of these patients are transferred to the care of internist cardiologists when they reach a given age, while others continue in the care of a pediatric cardiologist. The most effective programs of care combine the expertise of each cardiologist working as a member of a team.

The rules and regulations of some children’s hospitals do not allow patients older than 21 to be admitted, while others are more lenient. Most pediatric cardiologists are willing to care for the over-21 group, but the upper age limit is unclear and some care is better delivered by an adult cardiologist. Ideally, the internist should have training and understanding of congenital defects, and the pediatric cardiologist should understand adult cardiac disease. Understanding complex cardiac anomalies is not gained from a short rotation during a 3-year internal medicine cardiology training. The opportunity exists in shared clinics for the pediatric cardiologist to provide information to the internal medicine cardiology about complex conditions, natural history, and surgery. Pediatric and adult cardiology fellows who wish to care for young adults with cardiac conditions should receive training in each discipline. They should participate in clinics staffed by cardiologists from both disciplines who are dedicated to this particular age group of patients.
Young adults with a cardiac abnormality have other concerns as well, including sexuality, schooling, physical activity, and development-related problems. They need to be informed about contraception, the ability to carry a pregnancy to term and deliver safely, and the fact that some of their children may have a cardiac anomaly. For such questions, a liaison with an obstetrician is necessary. Although most students with a cardiac problem do well in school, some cannot adapt to a routine school environment. Patients also require guidance about employability, particularly if the condition compromises their ability to function in physically demanding occupations.

Sports and exercise activities are being evaluated for safety and effectiveness in patients with various forms of cardiac malformations. Often people overcompensate by participating in potentially harmful activities. Patients with mild disease can participate in most athletic activities.

Some physicians do not wish to deal with patients with, for example, Down’s syndrome. The impatience of certain practitioners may mitigate their providing care for this population. Communication about and appreciation of the special needs of these patients are necessary.

Projected Costs of Medical Care

Garson and colleagues12 assessed the cost of congenital heart disease by evaluating practice patterns and medical charges in six US cardiac centers. Clinic visits, hospitalizations, medication, and hospital and physician charges were analyzed. There was a wide variation in practice patterns, accounting for 25% of all charges. The average cost of a cardiac malformation from birth through the age of 21, corrected for inflation, was $59,877. The average cost for the age period of 22–40 years was $18,773. Thus, compared with many types of chronic disease, congenital heart disease is comparatively inexpensive to treat, especially in adult survivors.

Garson and Begley13 also outlined a model state program for adults with congenital heart disease. Many people with a cardiac malformation lose insurance coverage upon becoming an adult. Some of these people may be ill-prepared for seeking and keeping appropriate employment. Therefore, they may be employed in entry-level jobs that do not carry insurance benefits, or they may be unemployed. The model program would assist people who are 18 and unemployed; while they are in job training the state would provide their health care. The cost of training would be provided by those who become employed, both from state and local taxes they generate and from a payback plan for their previous training and health care.

American Health Care in Crisis

Dr. Joshua M. Wiener, senior fellow at the Brookings Institution, stated that rising health care costs and an increasing population with either inadequate or no health insurance has resulted in the recent crisis in American health care. Twenty percent of people surveyed in a public opinion poll stated that their household had experienced major financial setbacks related to health-care costs. Factors influencing the crisis include increasingly expensive technologies, many of which are needed to provide state-of-the-art care for the increasing population of patients with congenital heart disease, and deterioration of the private health insurance market, resulting in fewer people being insured.

Costs of health care increased from $249 billion in 1980 to $671 billion in 1990, an increase of about 11% per year. In 1990, health-care costs represented 12.2% of the United States’ gross national product, a higher percentage than in any other industrialized country. The increased cost is reflected in health insurance premiums, which have increased 37% in 2 years. There is no sign of this slowing down.

The high cost of medical care has made employers, particularly small companies, unwilling to provide health insurance, especially to employees with a cardiac problem. As a result, people with an underlying medical problem may not be hired. The general population is more concerned about costs of their own care than about coverage for those who are uninsured. Most blame physicians, hospitals, and insurers rather than economic realities.

There is an underlying consensus that the high and rising costs are directly related to technology. Whether the effectiveness and yield of information are worth the costs of devices used to get the information is being questioned. However, if attempts to control these technologies are to be made, Dr. Wiener emphasized “not getting rid of the things that do work.”

An increasing proportion of the population has either limited or no health-care insurance. In 1987, 31–38 million Americans had no coverage, and 48 million had none for at least 1 month of that year. Between 1980 and 1988, 5 million Americans lost their private insurance. Preexisting condition exclusions or no coverage at all for people who, for example, enter young adulthood with congenital heart disease are becoming the norm. This phenomenon raises the question of viability for the health insurance market for small employers. If coverage is provided for employees with preexisting conditions, the employer usually has to pay a higher, often a prohibitively higher, premium. If a patient does have coverage at one job, changing jobs is often impossible—a situation called job lock—because of underinsurability or noninsurability at a place of new employment.

Previously insurance companies determined premiums by community rating (placing all employees in an insurance market in one pool and charging the same premium to everyone). Because employers clamored for lower premiums, the industry has attracted them with lower rates based on claims experience with healthy employees. This policy makes the company’s rates more competitive, and is good for employers with healthy workers, but makes rates prohibitively costly for those who employ persons with a preexisting condition.

The problem is relatively concentrated in small businesses, and insurance companies are aware of the long-term negative impact on the industry if this persists. All agree that something must be done to correct these problems. Possible solutions include community rating, new laws, and new regulations. The public must be willing to accept the concept of health care for the uninsured, which could be influenced by national leadership. Physicians and hospitals must police themselves with respect to health-care costs, and development of standards for cardiac health care is a good first step.
Industry View

John Fisher, chief executive officer of Nationwide Insurance, presented an insurance industry view of the problem. He stated that the current system underserves in some areas and overspends in others. Costs are continually increasing. He suggested development of medical practice guidelines and protocols, criteria to assess new technology, elimination of mandated-benefit laws, development of uniform coding systems, providing data to consumers and payers, and liability reform.

Mr. Fisher suggested that a coalition approach with a partnership of government, health-care providers, and the insurance industry offers the best hope for a system to deliver superior professional service at a manageable cost.

The need to develop practice parameters was discussed by Dr. Nigel Roberts, a pediatric cardiologist with Nationwide Insurance. Professional health organizations can take a lead in this area.

Health Care Provider Views

Dr. Antoinette Parisi Eaton presented suggestions from the American Academy of Pediatrics. She stated that a top priority for the AAP is eliminating financial and nonfinancial barriers to health care. Children First, a legislative proposal, is the first phase of health care reform that would provide for universal access, eliminate barriers, and provide quality comprehensive health care for children and pregnant mothers.

Dr. Eaton stated that the plan is an investment in the future of our country, because it addresses early prevention, early diagnosis, and intervention. There is a need to invest in the young population now because they will make up the elderly population in 2050, by which time they will constitute 20% of the total US population. The AAP’s plan is built on the private insurance system, offering a one-class system supported by the pay-or-play concept.

Dr. James F. Quilty Jr., from the Bureau for Children with Medical Handicaps, discussed the “right” to health care. Quilty emphasized that targeting an unpopular group—physicians—is politically expedient in making Medicaid cuts, even though only 7% of the Medicaid dollar goes to physicians.

Insurance must pay for preventive services. One of the major costs of care in US society is teenage pregnancy. One of 4 women does not receive prenatal care in the first trimester. One of 10 pregnant black women and one of 25 pregnant white women do not receive any care at all. Nationally, about 13–15% of births in the United States are to teenage mothers. These mothers must be brought into a safety net of care. Lack of prenatal care and counseling can increase the incidence of babies born with birth defects, including heart defects.

Health-care providers can work toward changing regulations by meeting with legislators and forming coalitions with organizations that support the needs of children and young adults who have chronic diseases.

The AAP has proposed insurance programs for children to age 21, but people older than 21 often lack such insurance. Susie Truesdell of the University of Rochester School of Medicine reported that 52% of patients over 21 years of age with a congenital cardiovascular malformation were underinsured or uninsured. Patients with the greatest need for comprehensive, preventive health care had the fewest resources available to them.

Dr. Norman Talner reported that over the past 10–15 years the focus of the Council on Cardiovascular Disease in the Young has shifted from life insurability to health insurability for the patient with congenital heart disease. He stated that although data from NHS-II have confirmed the benign nature of most congenital lesions, both in terms of morbidity and mortality, health insurance is being denied to increasing numbers of these patients. The practicing pediatric cardiologist now faces, on a daily basis, patients whose insurance policies are being terminated, patients who transfer jobs and are not reinsured, preexisting condition clauses being invoked to modify patients’ coverage, and bureaucratic roadblocks that stifle appropriate care. To remedy the nationwide problem of health insurance, Talner recommended that the pediatric cardiology community join with the AAP in promoting legislation to provide health care and insurance for all children and pregnant women.

Legislative Views

The Honorable Eliot L. Engel, US Representative from Bronx, New York, stated that although health care is a top priority of American citizens, there is no standing committee on health in the US House of Representatives. He advocated that the medical community and members of Congress with interest and some expertise in health care work closely together. The American Medical Association is addressing health access aggressively and formulating options for medical cost/quality issues.

Many bills have been introduced in the 102nd Congress regarding health insurance, but since the repeal of the catastrophic illness health care law, members of Congress have not been willing to deal extensively with health-care issues. When it comes to funding, political considerations related to anger about costs, especially among senior-citizen constituents, result in less focus on health care reform. Representative Engel stated that the impetus for improvement must come not only from Congress but from the health-care establishment itself.

There is no consensus in Congress to address the problem of health care. One approach is improvement of the current system of coverage by private insurers and the use of government insurance for uninsured people, and another is national health care. Because approximately 37 million Americans lack health-care coverage, as brought out by the Pepper Commission Report, it is important that Congress take a position. The Pepper Commission recommended establishing a pay-or-play insurance system that would require businesses to provide workers with health insurance or pay into a government insurance pool, which would then provide coverage for the uninsured. These recommendations were introduced as legislation by Congressman Waxman in the House of Representatives and Senator Rockefeller in the Senate. The bill would impose pay-or-play requirements on employers and would create a new federal public insurance program for current Medicaid beneficiaries. Provisions to make insurance affordable would include allowing employers to use the public plan.
rates and reimburse providers. Tax credits would be available to small businesses that provide insurance. Major reforms of the private insurance industry would also be included under the terms of this bill. A bill introduced by Senate Majority Leader Mitchell provides similar provisions but differs by giving states a larger role in administration of the program. The Rousseau Bill is oriented toward a form of national health insurance, and the Rostenkowski proposal, which also advocates a complete overhaul of the health-care system, would establish a program similar to the Canadian system. Under this bill there would be universal access to health care through a single publicly administered program. The benefits would include hospital and physician care, dental services, long-term care, prescription drugs, mental health services, and preventive care. The plan would allow patients to continue to choose their own doctors and would have no deductibles or copayments. The proponents of this plan say that it will save $40 billion in health-care costs by substituting a single publicly administered program for the more than 15,000 private insurance plans now in place. A second plan introduced by Congressman Rostenkowski is also based on a pay-or-play concept. In this bill there would be additional benefits for children, including well-child care preventive care, as recommended by the AAP, without deductibles or copayments.

Representative Engel outlined concerns about the US medical system based on rapidly rising costs of medical coverage. Over the past 30 years, health-care costs have exceeded the annual rate of inflation. Overall, in the decade of the 1980s, there was a 51% real increase in health spending, corrected for inflation. The United States spends almost twice as much as other industrial nations on the administration of health care. Since 1960 US health-care costs have risen from 5.3% of the gross national product to 12.2% in 1990. In 1987 the United States spent 24% of its health-care dollars on administrative costs, compared with 11% by Canada. By bringing administrative costs down to Canada’s level, the United States could have saved $100 billion in 1991 alone. As Representative Engel reiterated, this is money that could have been spent on medical treatment rather than paperwork. Medicaid budgets also increased dramatically during the 1980s. From 1990 to 1991, Medicaid costs rose 22.6%. Reform and cost-containment are clearly required, but Representative Engel believes it is important that the US position as the world leader in medical advances not be compromised. He said that the current major health-care reform bills in Congress do not address the problems of making sure that changes in the health-care financing system do not reduce the availability of important medical technology. This issue must be addressed as reforms in the health-care system are examined. The problems of health-care rationing also must be addressed. Many systems in place in several other countries, although less costly, result in unacceptable waiting times for important medical procedures. Representative Engel described the Oregon plan, in which services are ranked from most beneficial to least beneficial, with the most important services, as assigned by an expert panel, funded first. If funding is insufficient to cover all procedures included in the benefit package, reimbursement is eliminated for services with the lowest priority. Representative Engel expressed opposition to this type of plan and quoted the Children’s Defense Fund, which states that the poorest people in the state are singled out by this program.

Representative Engel concluded his remarks by stating that the problems in the US health-care system must be addressed and that 37 million Americans do not have health insurance. He expressed hope that elected officials in Congress and physicians can work together to implement programs that make sense. Only by working together in partnership can health-care finances and runaway health-care costs be controlled in the context of an effective health-care system.

Senator William S. Cohen of Maine sent the following letter to the conference about access to health insurance:

The problem of access to health insurance is not limited to individuals who cannot afford coverage. Among the uninsured who are the neediest, in a medical sense, are those who are unable to obtain coverage because of their medical histories. Most are willing and able to purchase coverage. However, unless they belong to a particularly generous workplace plan, they are unable to obtain coverage because their health conditions make them unacceptable risks to private insurers.

In response to this problem, at least 24 states, including my home state of Maine, have formed high-risk insurance pools to provide coverage for individuals who are unable to obtain insurance because of a preexisting medical condition. Coverage provided through these risk pools is generally more expensive than the coverage available in the private market. However, the pools have met the acute needs of families in many states, and they do ensure that reasonable coverage is available to those willing and able to pay. Therefore, I have introduced legislation to encourage those states which have not formed high-risk insurance pools to do so.

In addition, there are a number of proposals pending in Congress which would add essential consumer protection standards to the private health insurance market as it relates to small business. As you know, under the current patchwork quilt of state laws, insurers can refuse to sell insurance contracts if they don’t want to accept the employer’s group (for any reason), and can cancel contracts unilaterally. They can selectively deny or restrict coverage for specific employees or an employee’s dependent child (with preexisting medical conditions), or charge prohibitive risk premiums.

If we want to facilitate the expansion of private insurance coverage, we must act to stabilize this market. Therefore, Congress is considering reform proposals that would 1) guarantee issue of policies; 2) limit or eliminate insurers’ ability to impose coverage restrictions due to preexisting conditions; 3) guarantee renewability of policies; and 4) place restrictions on experience rating and limits on annual increases in premiums.

Although it is highly unlikely that Congress will enact sweeping health care reform legislation this year [1991–1992 session] the prospects for enactment of such reforms in the small-group insurance market are very good. Enactment of such legislation will not solve all of the problems of financial access to health care for the uninsured. However, it is a big step in
the right direction as we work to ensure access to affordable health-care services for all Americans.

Summary and Conclusions

By the mid-1990s there will be more than 500,000 young adults in the United States over the age of 21 with a cardiac malformation. Presently more than half of this population is denied insurance coverage entirely or in part because of their preexisting condition.14 Because some did not have coverage and because of uncertainty about whom to see for their cardiology care, patients assessed in NHS-II who were evaluated by their physician on an annual basis before the age of 21 were seen by a cardiologist only every 10 years after the age of 21. However, they have been shown by NHS-II to be well-educated, productive in the workplace, and to share an equal place in society with the general population. Their health-care costs are decidedly lower after the age of 21 than before.

This group represents a microcosm of a general society of more than 37 million Americans who, for various reasons, are not insured. Dr. Wiener described an American health-care system in crisis. Smaller companies are no longer able to afford health insurance for all their employees, especially for those with preexisting conditions, because of an industry pricing concept based on a claims-experience standard rather than a community standard.

The insurance industry, the government, and patients are demanding medical cost-containment. Health-care costs, 12.2% of the gross national product in 1990, are climbing, and no end to this increase is presently in sight. At the same time the need for some form of universal health-care coverage, whether from industry, the public sector, or various arenas of organized medicine, is thought to be necessary. Representatives from each sector felt that solutions to these problems would be best achieved through cooperation rather than by individual or governmental mandate.

Several recommendations emerged from the conference.

1. Standards for care must be established by pediatric cardiologists. These standards could provide a template against which costs and quality of care could be judged.
2. The insurance industry should reestablish community rating.
3. A high-risk pool, national health plan, or other mechanism should be developed to provide coverage for the uninsured.
4. A uniform coding system would streamline health-care funding.
5. Preventive services should be funded, especially for pregnant women because this may decrease the number of offspring with congenital heart disease.
6. The public should accept the concept of insuring not only themselves but others.
7. Costs of medical care should be contained but the expensive technologies that have so dramatically improved the diagnosis and management of heart disease should not be abandoned if they are effective.
8. Technologies should be continually assessed and costs controlled.
9. Malpractice reform would curtail rising costs that are passed on to the public and the insurance industry.
10. Internal medicine cardiologists and pediatric cardiologists should develop strategies to provide care for young adults with heart disease and modify training programs to prepare cardiologists to provide the health-care needs of this population.

The population of young adults over the age of 21 with a congenital cardiac malformation is a reflection of the greater population whose health-care needs must be met. Cooperation between industry, government, society, and medicine for cost-containment and innovative thinking are necessary for timely, adequate solutions to the health-care and health cost problems of these young adults, whose societal productiveness could then develop and progress without their being preoccupied by concerns related to their cardiac condition.

Appendix

Conference Participants

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David J. Driscoll, MD
Antoinette Parisi Eaton, MD
The Honorable Eliot L. Engel
John E. Fisher
Arthur Garson Jr., MD
Welton M. Gersony, MD
James H. Moller, MD
William M. O'Fallon, PhD
James F. Quilty Jr., MD
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Norman S. Talner, MD
Kathryn A. Taubert, PhD
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William H. Weidman, MD
Joshua M. Wiener, PhD

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