

REPORT OF THE COUNCIL ON MEDICAL SERVICE

CMS Report 2 - I-99

Subject: Insurance Coverage for Adults with Congenital and/or Childhood Diseases
(Resolution 121, I-98)

Presented by: Eugene Ograd, MD, Chair

Referred to: Reference Committee A
(Jerome Bobruff, MD, Chair)

1 At the 1998 Interim Meeting, the House of Delegates referred Resolution 121 to the Board of
2 Trustees. Introduced by the American College of Cardiology, American Society of Hematology,
3 American Society of Anesthesiologists, American Urological Association, American Academy of
4 Family Physicians, American Association of Neurological Surgeons, Congress of Neurological
5 Surgeons, American Academy of Neurology, American Society of Clinical Oncology, American
6 Medical Group Association, American Society of Plastic and Reconstructive Surgeons, American
7 Academy of Dermatology, The Society for Investigative Dermatology, Inc., American Society of
8 Dermatologic Surgery, American College of Emergency Physicians, and American Association of
9 Plastic Surgeons, the resolution calls for the AMA "in collaboration with other state and national
10 medical societies and other interested parties, in the absences of universal health care insurance
11 coverage, to work to pursue an appropriate mechanism for ensuring affordable health insurance
12 coverage for adults with congenital and/or childhood diseases." The Board referred Resolution 121
13 (I-98) to the Council on Medical Service for a report back to the House at the 1999 Interim
14 Meeting.

15
16 This report discusses the prevalence of congenital and/or childhood diseases using the highly
17 visible conditions more precisely identified as birth defects and disabilities; presents available
18 information on the costs of treatment and level of health insurance coverage for this population;
19 summarizes federal laws and pending legislation that have the potential to increase access to health
20 insurance for this population of adults; describes relevant AMA policy; and presents several
21 recommendations.

22 23 PREVALENCE OF BIRTH DEFECTS AND DISABILITIES

24
25 It is difficult to categorize or classify congenital and/or childhood diseases as separate identifiable
26 and distinct groups of conditions. Often, congenital and/or childhood diseases are grouped with or
27 beneath the larger category of birth defects. In other instances, congenital and/or childhood
28 diseases may be viewed as a subset of early onset chronic conditions or disabilities affecting
29 individuals throughout their life. This ambiguity also makes identification of insurance access and
30 coverage for this potentially vulnerable population problematic.

31
32 Birth defects are one of the major causes of childhood and adult disability. There are between
33 3,000 and 5,000 different medical conditions recognized as birth defects. Annually, there are more
34 than 150,000 infants born with birth defects in the United States. Birth defects are currently the

1 leading cause of infant mortality and a major cause of disability in children and young adults
2 accounting for approximately 1 out of every 5 infant deaths. Although 20% of all infant deaths are
3 currently related to birth defects, the rate was cut by more than 50% between 1960 and 1994.

4
5 Congenital heart defects are the most common major birth defect, occurring in approximately 8 in
6 1,000 live births in the United States. This amounts to approximately 30,000 infants born with
7 heart defects each year in the United States. Nearly 25,000 of these infants will require some kind
8 of surgical intervention, including valve repair or prosthetic device implantation, to correct their
9 congenital heart defects. The majority of these infants will survive surgery and, with the
10 appropriate care, reach adulthood. In fact, more than 85% of infants born with congenital heart
11 disease can expect to survive to adulthood. In 1991, it was estimated that there were between
12 400,000 and 500,000 adults over the age of 21 in the United States with congenital heart disease.
13 Fewer than 10% of these individuals were believed to be disabled and the remaining adults were
14 viewed as capable of working. However, despite the recent advances in medical technology
15 associated with surgical repair of congenital heart defects in infants and children, many will
16 encounter complications later in life that may require surgical intervention.

17
18 In the United States, there are approximately 250,000 individuals with Down syndrome. Although
19 the percentage of children born with Down syndrome has not changed significantly over the last
20 few decades, the number of children with Down syndrome surviving childhood has improved
21 dramatically due to recent medical advances in treatment of the major health problems associated
22 with Down syndrome such as heart disease. In the 1930s, the estimated life expectancy for a child
23 with Down syndrome was only nine years. Today, a majority of individuals with Down Syndrome
24 live at home or in semi-independent living facilities and work part-time. At present, life
25 expectancy among individuals with Down Syndrome has reached about 55 years of age.

26
27 Cystic fibrosis currently affects approximately 30,000 children and young adults in the United
28 States. In 1995, 35% of the cystic fibrosis population consisted of adults, compared to 8% in 1970.
29 Today, patients with cystic fibrosis have a median survival age of 31 years, and it is estimated that
30 nearly 50% of all patients affected with cystic fibrosis will be adults in the next 10 years. The
31 increased life expectancy can be attributed largely to new drug therapies and improved regimens of
32 care.

33 34 COSTS OF TREATMENT AND LEVEL OF INSURANCE COVERAGE

35
36 Based on a review of the literature, there appears to be limited, recent data available on the
37 aggregate cost of congenital and/or childhood diseases in the United States, as well as on the level
38 of insurance coverage for patients with such diseases. According to a 1994 article, the estimated
39 lifetime costs for infants born with birth defects in the United States totaled \$8 billion in 1992. In
40 accordance with this estimate, the lifetime costs for some of the more significant and long-term
41 birth defects, such as cerebral palsy and Down syndrome, are often in excess of \$450,000 per
42 individual.

43
44 Now that individuals with congenital heart defects and other congenital anomalies are surviving
45 into adulthood, insurability increasingly becomes an important issue. A 1991 study estimated that
46 only 22% of those individuals with the most severe cardiac defects had health insurance.
47 However, another 1991 study reported that only 10% of adult patients with major or complex
48 congenital cardiac defects were uninsured. It also was estimated, in 1991, that the actual cost of

1 congenital heart disease for the age period of 22 to 40 years was roughly \$18,773 per case, or
2 roughly \$1000 per case per year.

3
4 The Cystic Fibrosis Foundation estimated that the total cost in 1995, to treat cystic fibrosis was
5 more than \$900 million, representing a cost of approximately \$39,166 per person. According to
6 the Cystic Fibrosis Foundation's estimates in 1995, more than 34% of people with cystic fibrosis
7 have some type of secondary coverage such as Medicare, Medicaid, SSDI, COBRA, or other
8 programs in addition to their primary coverage. However, individuals with cystic fibrosis may
9 have difficulty in obtaining the type of specialized care they require or may have limited access to
10 the latest medications used to combat the disease.

11
12 Approximately one-sixth of adult, non-elderly Americans with disabilities currently have no health
13 insurance. For the majority of Americans, health insurance is tied to their employment status.
14 Having a severe disability has a large effect on the chances of being employed. According to
15 United States Census data, in 1994-1995, 29 million working age adults (ages 22 to 64) had a
16 disability, while 14 million working age adults had "severe" disabilities. At the same time, 77% of
17 adults with disabilities were employed, compared to 82% of those with no disability, while only
18 26% of adults with severe disabilities worked.

19
20 It has been estimated that over 550,000 severely disabled individuals who are presently employed
21 are uninsured. People with disabilities are less likely to have private health insurance coverage
22 and more likely to have government coverage than people with no disabilities. In general,
23 individuals with non-severe disabilities have insurance coverage patterns similar to those with no
24 disability (expect for a slightly higher percentage of uninsured). However, the mix of public and
25 private insurance coverage as well as the cost of health care is significantly different for disabled
26 individuals, especially severely disabled individuals. In 1994-95, almost 44% of individuals age
27 22 to 64 with severe disabilities had private health insurance, compared to 80% for people of this
28 age group without disabilities. In addition, close to 40% of the people age 22 to 64 with severe
29 disabilities had government coverage, compared to only 3% for people of this age group without
30 disabilities. In 1994, the average Medicaid payment for an adult with a disability was \$8,654,
31 compared to \$2,118 for adults without disabilities. In 1995, the average Medicare payment for an
32 under age 65 adult with a disability was \$5,283, compared to \$4,808 for beneficiaries over age 65.

33 34 AMERICANS WITH DISABILITIES ACT

35
36 The Equal Employment Opportunity Commission (EEOC) has enforcement authority to address
37 the portion of the Americans with Disabilities Act (ADA) that specifically prohibits employment
38 discrimination. The ADA prohibits employers with more than 15 employees from discrimination
39 in employment against any qualified individual with a disability. Specifically, a decision
40 regarding employment may not be motivated by concerns about the impact of an employee's or a
41 prospective employee's disability on the employer's health plan. In addition, an employer may not
42 deny an individual with a disability equal access to health insurance, or require such an individual
43 to have terms and conditions of health insurance different from those of employees without
44 disabilities. However, the equal access requirement does not prevent the employer from offering a
45 health policy that has coverage limitations, such as restricting the number of services and treatment
46 options, and exclusions of certain kinds of coverage that are not "disability-based," including pre-
47 existing conditions. These health plan limitations and pre-existing condition clauses may have a
48 greater adverse impact on the health and well being of certain employees with disabilities, though

1 these restrictions are permissible under the ADA as long as the employer is not using them as a
2 means of evading responsibility under the ADA. Furthermore, the ADA does not require
3 employers to provide health insurance. However, if an employer chooses to offer health insurance
4 to employees, the ADA requirements apply.

5
6 HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT OF 1996

7
8 The Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191) also provides
9 health insurance coverage protection to adults with congenital and/or childhood diseases.
10 Specifically, the Act increases portability of health insurance through restrictions on limitations or
11 exclusions of benefits related to a condition that was present before the date of enrollment for
12 health insurance coverage by group health plans and health insurance issuers offering group health
13 insurance coverage. This restriction on pre-existing condition exclusions allows pre-existing
14 condition limitations in only certain circumstances, and these exclusions are bound by time and
15 coverage constraints. Group health plans or health insurance issuers may exclude certain health
16 benefits and coverage only for conditions for which medical advice, diagnosis, care, or treatment
17 was recommended or received within 6 months prior to enrollment. This exclusion cannot extend
18 beyond 12 months after the enrollment date and the exclusion period may be reduced based on
19 creditable coverage applicable to the participant or beneficiary as of the enrollment date. If an
20 individual with a specific condition had health insurance coverage immediately prior to the
21 enrollment date, that period of coverage is counted against the pre-existing condition exclusionary
22 period.

23
24 FEDERAL AND STATE GOVERNMENT ACTIVITIES

25
26 The Health Care Financing Administration (HCFA) Center for Medicaid and State Operations
27 released the final version of its guide entitled "Key Approaches to the Use of Managed Care
28 System for Persons with Special Health Care Needs" in October 1998. The document provides a
29 framework for states to consider when designing and implementing quality strategies for persons
30 with special health care needs. The guide applies to states planning Medicaid managed care
31 programs for persons with special health care needs under section 1115 and 1915(b) waivers. The
32 document is intended to assist states in identifying and resolving potential problems associated
33 with providing adequate access to quality medical services, assuring an adequate provider network
34 for these populations and addressing social and support needs. States are not mandated, however,
35 to adhere to any of the recommendations of the guide.

36
37 The Balanced Budget Act of 1997 (P.L. 105-33) mandated the Secretary of Health and Human
38 Services to evaluate the safeguards needed to protect individuals with chronic health care needs
39 enrolled in Medicaid managed care. HCFA is presently working on a report that outlines the
40 safeguards needed to protect individuals with special health care needs enrolled in Medicaid
41 managed care programs. It is anticipated that this report will be presented to Congress by the end
42 of 1999.

43
44 In June 1999, the United States Senate voted 99-0 to approve the Work Incentives Improvement
45 Act of 1999 (S.331) that is designed to permit disabled Americans to join the workforce without
46 risking the loss of their federal health benefits. Under current law, if disabled individuals reach a
47 specified level of income, they lose disability benefits and any health insurance that they may have
48 received through Medicaid or Medicare. Without these health benefits, many disabled individuals

1 are unable or unwilling to work. It has been estimated that the proposed bill could help some of the
2 approximately 7.5 million Americans with disabilities join the workforce by discontinuing the
3 practice of eliminating their Medicaid or other federal health insurance benefits. The bill creates
4 several options for states and workers with disabilities, including continuation of Medicare
5 coverage for individuals with disabilities who have returned to work, Medicaid-Buy-In for
6 individuals who become disqualified because of earning limits or because of improvements in their
7 medical conditions, and authorization for state demonstration projects that make available
8 Medicaid benefits to workers who are not presently disabled, but have a specific physical or
9 mental impairment that is “reasonably expected” to become a severe disability. At the time this
10 report was written, the House version of the bill (H.R. 1180) was awaiting mark-up by the Ways
11 and Means Committee Health Subcommittee.

12
13 CURRENT AMA POLICY

14
15 The AMA has established comprehensive policy that, to a large extent, addresses many of the
16 health care access and coverage needs for adults with congenital and/or childhood onset diseases.
17 A number of AMA policies address the issue of insurance portability, pre-existing conditions, and
18 guaranteed renewability (Policies H-165.960, H-165.950, H-165.951, H-165.991, H-185.967 and
19 H-165.920, AMA Policy Compendium). Moreover, Policy H-185.989 opposes any attempt by
20 health insurers to “cancel, reduce, refuse to renew, or increase an individual’s premium for
21 coverage...based on an illness occurring during the time insurance is in force.”

22
23 Policy H-165.920 advocates for individually selected and owned health insurance that could
24 enable people with specialized health care needs, such as individuals with congenital and/or
25 childhood diseases, to choose appropriate health plans that provide access to these specialized and
26 necessary services. This policy further encourages employers to consider the merits of risk
27 adjusting their defined contributions so that higher risk employees would receive a larger
28 contribution, while the lower risk employees would receive a lower contribution. Under this
29 approach, useful risk adjustment measures such as age, sex and family status would be used to
30 provide higher risk employees with a larger contribution.

31
32 The AMA continues to support community rating bands that allow premiums to vary by rating
33 factors such as age, gender, claims experience, and health status, but limit the allowable range in
34 variation from the average premium charged as a realistic and balanced position for ensuring that
35 insurance policies are not priced beyond the means of those who need it most (Policies H-165.920
36 and H-165.882). The AMA also continues to advocate for the establishment of state risk pools
37 to provide adequate health insurance coverage to those individuals unable to obtain insurance
38 elsewhere because of medical considerations or lack of access to group coverage (Policies
39 H-165.915, H-165.995, H-165.920, H-165.991, and H-165.992). Policy H-185.985 “calls upon
40 all third party payors and appropriate federal regulatory agencies to make all guidelines related
41 to patient coverage a matter of public information and easily obtainable by both patients and
42 physicians.” In addition, Policy H-180.964 encourages the health insurance industry to extend
43 parent’s family health coverage to young adults up to the age of 28 who do not otherwise have
44 health insurance coverage.

45
46 Policy H-185.967 states that “treatment of a minor child's congenital or developmental deformity
47 or disorder due to trauma or malignant disease should be covered by all insurers and that such
48 coverage shall include treatment which, in the opinion of the treating physician, is medically

1 necessary to return the patient to a more normal appearance (even if the procedure does not
2 materially affect the function of the body part being treated).” Finally, Policy H-475.992 advocates
3 for the definition of reconstructive surgery that includes surgery that is “generally performed to
4 improve function, but may also be done to approximate a normal appearance” and is “performed
5 on abnormal structures of the body, caused by congenital defects, developmental abnormalities,
6 trauma, infection, tumors or disease.”

7
8 DISCUSSION

9
10 Through medical and technological advances, many children are now surviving childhood diseases
11 that were previously fatal. For example, survival for childhood leukemia/lymphoma has
12 approached 70%. However, these children and, later, these adults, often require ongoing medical
13 care and resources for their complex medical needs.

14
15 It is possible that many adults with congenital and/or childhood diseases are facing the common
16 difficulty of obtaining health insurance coverage. In some cases, even if health insurance is
17 obtained, it may not cover certain conditions that develop later because they may be viewed as pre-
18 existing or not “medically necessary” to the health and well-being of the individual. In fact, health
19 insurers have increasingly drawn a line between payment for medical procedures that are
20 “medically necessary” and allow people to function, and services that provide for increased
21 freedom of function or the ability to live a more productive life.

22
23 Continued improvements in the early diagnosis and management of patients with congenital and/or
24 childhood diseases, as well as advances in medical technology, will likely result in the sustained
25 growth in the number of adults with congenital and/or childhood diseases. A review of the current
26 literature, however, reveals that it is extremely difficult to identify accurately the number of
27 individuals with congenital and/or childhood diseases, let alone what percent of this population is
28 insured, underinsured, has access to appropriate and necessary health care services, or has reached
29 their lifetime caps on coverage. In addition, repeated requests for additional information from the
30 17 co-sponsors of Resolution 121 (I-98) produced little additional data on the size of this
31 population, their specific health insurance needs, or the current status of their health insurance
32 coverage.

33
34 Given the fact that there are no definitive data to verify the perceived lack of health insurance
35 coverage for this potentially vulnerable population, the Council believes that it is necessary to
36 advocate for a study by the federal government of the present insurability of this population and
37 the potential costs associated with enhancing such coverage. At the same time, the Council
38 believes that the AMA’s existing policies related to individually selected and owned health
39 insurance, portability, pre-existing conditions, guaranteed renewability, state risk pools, and
40 community rating bands continue to serve as vehicles to increase awareness of the health care
41 needs of adults with congenital and/or childhood diseases, as well as effectively promote greater
42 health care access and quality for this potentially vulnerable population.

43
44 An increasing percentage of health care services for adults with congenital and/or childhood
45 disease is being provided in community care and home settings, with the family playing an ever-
46 increasing role in care planning and care giving. However, the out-of-pocket expenses for families
47 who care for adults with congenital and/or childhood diseases are not well documented. The
48 Council is concerned that the cost burden associated with the health care of adults with congenital

1 and/or childhood diseases could be shifted more profoundly to the individual or family if insurance
2 coverage that provides adequate access to needed health care services, including ancillary and
3 support services, supplies and prescription drugs, is not available. The Council also believes that
4 while the family should play a large role in the development of a care plan, it should not bear the
5 full burden of the costs associated with the health care regimen.

6
7 The unspecified magnitude of this population, their specialized health care needs, and their
8 seeming disproportionate use of resources may necessitate a change in treatment regimens and a
9 reformation in health insurance coverage policies. Individually-selected and owned health
10 insurance may, in fact, provide the best option. The Council on Medical Service believes that
11 continuity of care can only be achieved for this population through health insurance coverage that
12 permits and encourages access to health care services and health care professionals specialized in
13 the care of children and adults with congenital and/or childhood diseases. The Council also
14 believes that health insurance coverage for adults with congenital and/or childhood diseases must
15 be able to respond to both the routine and the unique medical needs of this apparently sizeable and
16 exceedingly diverse population.

17
18 RECOMMENDATIONS

19
20 The Council on Medical Service recommends that the following be adopted in lieu of Resolution
21 121, (I-98), and the remainder of the report filed:

- 22
23 1. That the AMA work with the Federation and other interested parties to encourage federal
24 and state governmental agencies to develop a comprehensive population profile of adults
25 with congenital and/or childhood diseases, their health care service needs, and their level
26 of health insurance coverage.
27
28 2. That the AMA work with the Federation and other interested parties to encourage federal
29 and state governmental agencies to identify any barriers of access to primary and specialty
30 health care services.
31
32 3. That the AMA urge public and private third-party payors to increase access to health
33 insurance products for adults with congenital and/or childhood diseases that are designed
34 for the unique needs of this population.
35
36 4. That the AMA emphasize that any health insurance product designed for adults with
37 congenital and/or childhood diseases include the availability of specialized treatment
38 options, medical services, medical equipment and pharmaceuticals, as well as the
39 accessibility of an adequate number of physicians specializing in the care of this unique
40 population.