DOCUMENT RESUME

ED 376 983 PS 022 876

AUTHOR Irwin, Charles E., Jr., Ed.; And Others

TITLE Health Care Reform: Opportunities for Improving

Adolescent Health.

INSTITUTION National Center for Education in Maternal and Child

Health, Arlington, VA.

SPONS AGENCY Health Resources and Services Administration

(DHHS/PHS), Rockville, MD. Office for Maternal and

Child Health Services.

REPORT NO ISBN-1-57285-007-8

PUB DATE 94

CONTRACT MCU-117007

NOTE 93p.

AVAILABLE FROM National Maternal and Child Health Clearinghouse,

8201 Greensboro Drive, Suite 600, McLean, VA 22102

(single copy, free).

PUB TYPE Reports - Descriptive (141) -- Viewpoints

(Opinion/Position Papers, Essays, etc.) (120)

EDRS PRICE MF01/PC04 Plus Postage.

DESCRIPTORS *Adolescents; *Health; *Health Care Costs; *Health

Promotion; *Health Services; Individual Needs;

Professional Training; Public Health

IDENTIFIERS *Access to Health Care; *Health Care Reform; Health

Delivery Systems; Health Risk Susceptibility

ABSTRACT

Health care reform represents a major step toward achieving the goal of improved preventive and primary care services for all Americans, including children and adolescents. Adolescence is a unique developmental age district from both childhood and adulthood with special vulnerabilities, health concerns, and barriers to accessing health care. It is also an opportune time for prevention. Because adolescents are critical to the future health and well-being of the country, a focus on adolescent care is an important part of health care reform. The essential elements of health care reform for adolescents that should be included in reform legislation and implementation are: (1) ensuring access to care; (2) benefits and cost sharing; (3) attention to the needs of special populations; (4) training to meet the needs of adolescents; and (5) responding to public health needs. The six papers in this report address each of these essential elements. The papers are: (1) "Adolescents, the Health Care Delivery System, and Health Care Reform" (Jonathan D. Klein); (2) "Enhancing Benefits for Adolescents under National Health Reform" (Margaret McManus and Jennifer Dunbar); (3) "Issues for Adolescents Relating to the Financing of Health Care" (Cindy Mann); (4) "Adolescents and Health Care Reform: Protecting Special Populations" (Abigail English); (5) "Training in the Era of Health Care Reform" (Karen Hein); and (6) "Health Care Reform and Adolescent Health: The Anticipated Role and Contribution of Public Health" (Claire Brindis). Most of the papers contain references and four appendices are included. (TJQ)



U.S. DEPARTMENT OF EDUCATION Office of Educations and Improvement EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

This document has been reproduced as received from the person or organization originating it

- Minor changes have been made to improve reproduction quality
- Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

Health Care Reform: Opportunities for Improving Adolescent Health

Adoint Publication of The National Adolescent Health Intokmation Center.

The National Center for Education in Maternal and Child Health, for the Maternal and Child Health Bureau. Health Resources and Services Administration.

Public Health Service, U.S. Department of Health and Human Services.

2 BEST COPY AVAILABLE

Health Care Reform: Opportunities for Improving Adolescent Health

Edited by
Charles E. Irwin, Jr., M.D.
Claire Brindis, Dr.P.H.
Katrina A. Holt, M.S., R.D.
Kristin Langlykke, M.S.N., Ed.M.

A Joint Publication of The National Adolescent Health Information Center,
The National Center for Education in Maternal and Child Health, for the
Maternal and Child Health Bureau, Health Resources and Services Administration,
Public Health Service, U.S. Department of Health and Human Services
Published by National Center for Education in Maternal and Child Health
Arlington, Virginia



Cite as

Irwin, C. E., Brindis, C., Holt, K. A., and Langlykke, K. (Eds.). (1994). *Health Care Reform: Opportunities for Improving Adolescent Health*. Arlington, VA: National Center for Education in Maternal and Child Health.

Health Care Reform: Opportunities for Improving Adolescent Health is not copyrighted. Readers are free to duplicate and use all or part of the information contained in this publication. In accordance with accepted publishing standards, the National Center for Education in Maternal and Child Health (NCEMCH) requests acknowledgment, in print, of any information reproduced in another publication.

The mission of the National Center for Education in Maternal and Child Health (NCEMCH) is to promote and improve the health, education, and well-being of children and families by leading a national effort to collect, develop, and disseminate information and educational materials on maternal and child health; and by collaborating with public agencies, voluntary and professional organizations, research and training programs, policy centers, and others to advance knowledge in programs, service delivery, and policy development. Established in 1982 at Georgetown University, NCEMCH is part of the Graduate Public Policy Program. NCEMCH is funded primarily by the U.S. Department of Health and Human Services through its Maternal and Child Health Bureau.

Library of Congress Catalog Card Number 94-61351 ISBN 1-57285-007-8

Published by:
National Center for Education in Maternal and Child Health
2000 15th Street North, Suite 701
Arlington, Virginia 22201-2617
(703) 524-7802
(703) 524-9335 fax
Internet: ncemch01@gumedlib.dml.georgetown.edu

Single copies of this publication are available at no cost from: National Maternal and Child Health Clearinghouse 8201 Greensboro Drive, Suite 600 McLean, Virginia 22102 (703) 821-8955, exts. 254 or 265 (703) 821-2098 fax

This publication has been produced by the National Center for Education in Maternal and Child Health under its cooperative agreement (MCU-117007) with the Maternal and Child Health Bureau, Health Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services.



Table of Contents

Acknowledgments			
Meet	ing the Challenge	7	
Execu	utive Summary and Recommendations	9	
Intro	duction	15	
I.	Adolescents, the Health Care Delivery System, and Health Care Reform Jonathan Klein	17	
11.	Enhancing Benefits for Adolescents Under National Health Reform Margaret McManus and Jennifer Dunbar	29	
III.	Issues for Adolescents Relating to the Financing of Health Care Cindy Mann	41	
IV.	Adolescents and Health Care Reform: Protecting Special Populations Abigail English	55	
V.	Training in the Era of Health Care Reform Karen Hein	65	
VI.	Health Care Reform and Adolescent Health: The Anticipated Role and Contribution of Public Health Claire Brindis	7 i	
Appo	endices		
	Appendix A: Investing in Preventive Health Services for Adolescents		
	Appendix B: Published Resources on Health Policy and Health Care Reform		
	Appendix C: Organizations Involved in Analysis of Health Policy and Health Care Reform	93	
	Appendix D: Participants and Observers, Working Seminar on Adolescent Health and Health Care Reform, January 10-11, 1994, Washington, DC	99	



Acknowledgments

This collaborative effort provided many of us the opportunity to contribute special knowledge and skill to understanding how a reformed health care system would best meet the health care needs of adolescents. From the initial conceptualization of a working seminar to consider these issues, we have enjoyed the sage guidance of our colleagues, Juanita Evans, Joann Gephart, David Heppel, Woodie Kessel, and Audrey H. Nora of the Maternal and Child Health Bureau, Health Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services. Their support was key to bringing together a panel and participant group with a wide range of expertise in adolescent health and health policy and to publishing this document.

For their special contributions to this project, we are indebted to Robert Blum of the University of Minnesota, Adolescent Health Training Program and the National Center for Youth with Disabilities; Abigail English of the National Center for Youth Law; Michele Solloway of the Center for Health Policy Research; and to David Knopf, Susan Millstein, Elizabeth Ozer, Roy Rodriguez, and Ming Lau of the National Adolescent Health Information Center. Together and individually they assisted in planning the seminar, participated as presenters and respondents, and/or provided us ongoing advice and counsel while we synthesized information from the seminar and developed policy statements for dissemination.

The discussion stimulated by the presenters and respondents during the seminar and the comments offered as we revised these papers have greatly enriched this document. We are grateful for the insight and expertise of Jim Weill of the Children's Defense Fund; Lorraine Klerman of the University of Alabama School of Public Health; Renee Jenkins of the Howard University School of Medicine, Department of Pediatrics and Adolescent Medicine; Harriette Fox of Fox Associates; and Deborah Klein Walker of the Massachusetts Department of Public Health, Bureau of Family and Community Health.

And to the authors—Jonathan Klein of the University of Rochester Department of Adolescent Medicine; Margaret McManus and Jennifer Dunbar of McManus Health Policy; Abigail English of the National Center for Youth Law; Cindy Mann of the Massachusetts Law Reform Institute; and Karen Hein, Robert Wood Johnson Health Policy Fellow with the Senate Finance Committee, on leave from the Albert Einstein College of Medicine Department of Pediatrics—our heartfelt thanks for their thoughtful and thorough analyses of complex policy issues with the potential for long lasting impact on the health of our nation's youth.

Charles Irwin
Claire Brindis

Katrina Holt Kristin Langlykke

National Adolescent Health Information Center

National Center for Education in Maternal and Child Health



5

Meeting the Challenge

There is little doubt that adolescents are a significant underserved segment of our population. The major health risks facing the estimated 34 million adolescents in the United States today are traceable to psychosocial, behavioral, and economic factors. The following statistics illustrate the challenge of meeting adolescent health needs now and in the foreseeable future:

- Unintentional injury is the leading cause of adolescent deaths, and accounts for more deaths than all other causes combined.
- Homicide is the second leading cause of death for adolescents ages 15 through 19.1
- Suicide is the third leading cause of death for adolescents ages 15 through 19.
- Every year, 1 million 15- to 19-year-old adolescent females become pregnant.²
- Every year, 3 million adolescents ages 19 and younger contract a sexually transmitted disease.
- Among 9–12th grade students surveyed in the 1991
 Youth Risk Behavior Surveillance System, 27.5 percent were current smokers, and 51 percent consumed alcohol during the 30 days preceding the survey.
- 1 out of 7 adolescents is without health insurance.

Given these poor health status measures and lack of access to care, it is evident that the medical model of care alone cannot address these issues—what is needed is an interdisciplinary approach to assure comprehensive services to adolescents and their families that responds appropriately to the developmental continuum throughout adolescence and emphasizes prevention and health promotion.

The Maternal and Child Health Bureau (MCHB) supported this forum of experts in the field of adolescent growth and development, service delivery and

financing, and policy development and program implementation to come together and explore how health care in this country can be reformed to respond more effectively to the unmet health needs of adolescents.

Supporting a forum of this kind is typical of the role the Maternal and Child Health Bureau has played from its earliest days . . . and its roots go back to 1912 with the creation of the Children's Bureau. In providing leadership to both the public and private sector to build the infrastructure for the delivery of health care services to all children, adolescents, and families in the nation, the MCHB has often been the catalyst bringing together the most informed experts who can contribute to solving the thorny problems that confront us. This is a gathering, we are pleased to note, of extremely well informed participants.

The Maternal and Child Health (MCH) Services Block Grant is an important resource for building the health care delivery system. The \$600 million of federal funds dispersed to 59 tes and jurisdictions generates well over a billion dollars in total funds available for services to mothers, children, and adolescents at the state and local levels. And its discretionary funds have historically been used to advance knowledge, improve the competence of maternal and child health leadership personnel, test hypotheses, and demonstrate the efficacy of components of models of care. For example, the MCHB supported the first adolescent medicine training grants in the United States with Roswell Gallagher, M.D. These grants were subsequently expanded to an adolescent health focus with a comprehensive interdisciplinary team approach.

In recent years, adolescent health care is becoming a major component of each state's MCH program. Forty-one states, the District of Columbia, and Puerto Rico have designated adolescent health coordinators. This group has created a formal network to communicate among states regarding successful initiatives, to develop strategies for promoting an adolescent health agenda nationally and in each state, and to organize continuing training and opportunities for collaboration for adolescent health professionals. Under MCHB's sponsorship, the State Adolescent Health Coordinators have met annually since 1988 for training, network, and resource sharing.

Under a new discretionary grant initiative in fiscal year 1994—Healthy Schools, Healthy Communities—the MCHB will be collaborating with the Bureau of Primary Health Care in the Health Resources and Services Administration to fund projects for school health staff development and the expansion of school-based health centers as a promising model for comprehensive, interdisciplinary primary health care delivery for children and adolescents.

This year will also see completion of a landmark project—Bright Futures—to develop guidelines for health supervision of infants, children, and adolescents. Bright Futures, which has been supported for almost four years by the MCHB and the Medicaid Bureau, brought together more than 100 experts to review the science and share their wisdom and experience in formulating these important guidelines. Bright Futures gives significant attention to adolescent health needs; its recommendations emphasize primary prevention, early intervention, and an interdisciplinary team approach.

There remain critical areas that still must be examined and reexamined that have significant relevance to any health care reform strategy. President Clinton already has emphasized the health needs of American adolescents in the Health Security Act. The results of this seminar's deliberations will make an important contribution to the continuing dialogue about health care reform.

Juanita Evans, M.S.W., L.C.S.W.
Joann Gephart, R.N., M.S.N.
David Heppel, M.D.
Woodie Kessel, M.D., M.P.H.
Audrey H. Nora, M.D., M.P.H.
Maternal and Child Health Bureau
U.S. Department of Health and Human Services

References

- National Center for Health Statistics. (1994). Unpublished data, prepared by L.A. Fingerhut.
- Alan Guttmacher Institute. (1994). Sex ar '
 America's teenagers. New York, NY: Alan
 Guttmacher Institute.
- 3. Kann, L., Warren, W., Collins, J.L., et al. (1993). Results from the national school-based 1991 Youth Rish Behavior Survey and progress toward achieving related health objectives for the nation. *Public Health Reports*, 108(Supplement 1), 47-55.
- 4. U.S. Congress, Office of Technole, Assessment. (1991). Adolescent health-volume 1: Summary and policy options. Washington, DC: U.S. Government Printing Office.



Health Care Reform: Opportunities for Improving Adolescent Health

Executive Summary and Recommendations

Health care reform represents a major step toward achieving the goal of improved preventive and primary care services for all Americans, including children and adolescents. Adolescence is a unique developmental age distinct from both childhood and adulthood. It is a stage of life with special vulnerabilities, health concerns, and barriers for accessing health care. It is also an opportune time for prevention. Because adolescents are critical to the future health and well-being of the country, a focus on adolescent care must be an important part of health care reform. The following recommendations represent essential elements of health care reform for adolescents and should be included in any reform legislation and implementation.

Ensuring Access To Care

Adolescents need broad community- and school-based preventive strategies that promote healthy lifestyles and ensure access to services that will reduce the prevalence of problems that affect this population, such as sexually transmitted diseases, emotional and behavioral health problems, unintended pregnancy, drug and alcohol abuse, injuries and violence. Despite these problems, adolescents have the lowest utilization rates of health care services of any age group in this country and they are the least likely to seek care through traditional office-based settings. In addition to being uninsured or underinsured, adolescents face behavioral and organizational barriers to receiving health care. Because of developmental characteristics, such as immaturity and a desire for independence, and because of lack of experience in negotiating complex medical systems, adolescents are unlikely to obtain appropriate heaith care services unless they can gain access through multiple entry points. To serve adolescents appropriately, services must be available in a wide range of health care settings, including community-based clinics, school-based and school-linked health clinics, physicians' offices, family planning clinics, health maintenance organizations (HMOs), and hospitals. Adolescents need care not only in diverse settings, but particularly in settings that respond to the special needs of their age group.

Since adolescents depend on and use many care facilities, flexibility and coordination of comprehensive services is essential to ensure quality care. It is important for any health care reform legislation to include procedures, such as guidelines for pre-authorization of care, that would enable adolescents to obtain care at more than one site.

Assurance of confidentiality is an important issue for <u>all</u> patients. For adolescents, it may determine whether they seek treatment. Fear of exposure may cause adolescents to delay or avoid needed care. Thus, confidential services are essential if adolescents are to be assured of <u>access</u> and motivated to assume <u>responsibility</u> for their own health care.

Benefits

Health promotion and prevention through access to preventive care with no cost-sharing represents a major reform in health care. Preventive programs need to be based on recognized standards of care for adolescents, such as: Bright Futures: National Guidelines for Health Supervision of Infants, Children, and Adolescents and



Guidelines for Adolescent Preventive Services (GAPS). Historically, Congress has set a precedent for providing and financing care of children and adolescents at a level that is consistent with professional standards through establishing the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit, the preventive services component of the Medicaid Program for low-income children and youth. All adolescents need access to preventive and primary care services at these established levels. Specifically, the rapid increase in health risk behaviors during the adolescent years makes it imperative that adolescents be seen yearly, so as not to miss opportunities to prevent or diminish these behaviors before they are firmly established.

The lack of preventive status for mental health, substance abuse, family planning and some sexually transmitted diseases screening services presents additional barriers to care for adolescents. For example, the imposition of copayments on services for family planning and sexually transmitted diseases prevention will limit access to services which are clearly preventive in nature, and will result in substantially greater health care costs.

While it is appropriate to place major effort on prevention services, it is also essential to make available to adolescents a comprehensive package of health services to address acute and chronic conditions.

Cost Sharing

Health reform needs to grant adolescents the right to a broad range of health care services through a comprehensive benefit package. Subsidies will be necessary for low-income individuals and families, and there will likely be a need to continue to provide expanded benefits for certain low-income adolescents through the Medicaid Program. While the expansion of Medicaid eligibility for low income women and children in recent years has laid the groundwork for important improvements in access for low-income adolescents,

the gradual phase-in of eligibility for adolescents up to 100 percent of poverty remains problematic. Any health reform legislation should preserve at least the level of access that adolescents currently have and should use this as a base upon which to build and expand.

While it is reasonable to expect individuals and families to share responsibility for financing health care, cost-sharing obligations are particularly burdensome for low and moderate income adolescents and their families, especially for those with chronic illness and disabilities. We are concerned about the annual out-of-pocket costs for low and moderate income families in many of the current proposals. These out-of-pocket expenditures for services covered in a comprehensive benefit package may harm low and moderate income adolescents with a chronic illness or disability.

We are also concerned about the copayment obligation for adolescents. Because health plans may not be permitted to waive copayments, some adolescents will be denied care because of inability to meet cost-sharing obligations. Any link between health care subsidies and cash assistance such as Aid to Families with Dependent Children (AFDC) or Supplemental Security Income (SSI), is counter to welfare reform efforts, and because of state variation in AFDC eligibility levels, will result in different treatment across states for low income adolescents and families.

Special Populations

Problems with access to health care are even greater for certain special population groups of adolescents, whose needs are greater than those of the general population. Special populations of adolescents include those who are poor; those who are living apart from the r families, such as youth in foster care or juvenile justice facilities, and homeless and runaway youth; pregnant and parenting adolescents; gay and lesbian



youth; and adolescents with chronic illness and disability, who require on-going services to maintain or enhance daily life functioning. In addition, another special group, undocumented immigrants, are not eligible for most services under current health care reform proposals. Apart from not meeting individual needs, there are potentially serious public health ramifications of not assuring care for this group.

Training To Meet The Needs Of Adolescents

Most adolescents receive their health care from a variety of health professionals who often lack formal training and specific expertise in the unique needs of adolescents. As a result, they lack the knowledge and skill necessary to feel competent in treating adolescents. Because primary care physicians will be the essential providers of care to adolescents, primary care training should be enhanced to address the unique psychosocial and physical needs of adolescents. A small cohort of health professionals has received advanced training in the primary care of adolescents. The training of this core group of professionals will need to continue in order to both provide quality care and bolster the interdisciplinary training of health care professionals who will have the responsibility of caring for adolescents. The content of this primary care curriculum should be defined by an interdisciplinary group of professionals who are experts in the area of adolescent health.

Public Health

Health care reform involves a commitment not only to improving the health service delivery system, but also to strengthening the role of public health. The responsibility of the public health system is to assess and monitor population-based needs, stimulate and support school and community health promotion efforts, develop policies to protect the health and cafety of the population, and provide assurance of quality and access for all populations. Public health programs respond to the unique needs of adolescents by providing special outreach, counseling, education, and support services that often contribute to adolescents receiving the type of care that they need. Increasingly it assures service equity for special populations and access to important public health and safety services by being a major provider of care.

While many of the current public health service delivery functions may be subsumed under universal health care coverage, existing categorical programs will need to continue until they can be assumed by insurance programs. These programs may extend longer if health reform legislation adopted does not adequarely respond to the services currently provided under the auspices of public health. During this transition period and in the future, it is critical that public health programs continue to play a key role in adolescent health care.

Except for school health education and school related services, no public health initiatives for adolescents have been explicitly articulated within current health care reform proposals. Neither has a specific agency or program been designated to govern personal health and public health services for children and adolescents. For example, what would be the status of Title V of the Social Security Act, which is an established national program of state-based maternal, child, and adolescent health services, enhanced by research and training components, that has helped create a voice for adolescent health at the national and state level.

The public health system has played an important role in the provision of medical services for vulnerable



populations that have often been excluded from mainstream provider settings. At the core of health care reform is a thrust towards a system of care that does not exclude the poor. Until a reformed health system fully integrates all of the population into appropriate care, the public health system will need to continue providing essential services.

Public health functions must be enhanced as an essential component of any health care reform in order to oversee the provision and quality of care, including data collection, monitoring, and quality assurance. Thus, it is essential to include within any health care reform plan a program such as Title V at the federal level and in every state. This program must be adequately funded, appropriately staffed, and have clear mandates to carry out a number of functions including assuring that each state health plan adequately provides for the health of children and adolescents, monitoring and evaluating the impact of health care reform on children and adolescents, and administering school-related health services and comprehensive school health education.

Recommendations

The following is a core set of recommendations made by the authors and seminar participants during the Working Seminar on Adolescent Health and Health Care Reform, convened in Washington, DC on January 10-11, 1994.

Ensuring access to care

 Services must be available in a wide range of health care settings, including community-based centers, school-based and school-linked health centers, physicians' offices, family planning clinics, HMOs, and hospitals.

Benefits

Prevention and primary care services

- Cover clinician visits for adolescents, as preventive health services, to correspond with the frequency recommended by Bright Futures (annual visits with additional visits if needed) and GAPS (annual visits).
- Cover preventive mental health and substance abuse services for children and adolescents who are at risk due to physical health, child abuse, family history, or other biological or environmental risk factors.
- Define family planning and sexually transmitted diseases prevention (i.e., screening for risk and the identification of STDs) as clinical preventive services within a benefit package for both males and females.

Services for mental health, chronic illness, and disability

- Cover outpatient mental health and substance abuse treatment services consistent with child and adolescent mental health care standards. Apply any mental health and substance abuse treatment copayments and co-insurance requirements to annual out-of-pocket limits on cost sharing.
- Cover home health care services, including full-time nursing services and personal care services as well as services included in 1861 (m) of the Social Security Act, for children and adolescents who require this level of care to treat an injury, illness, or chronic condition, consistent with an approved plan of care and subject to a 60 day re-evaluation.
- Cover skilled nursing facility and rehabilitation facility services for children and adolescents who



12 12

require this level of care to treat an injury, illness, or chronic condition, with coverage extending past 100 days only as an alternative to hospitalization.

- Cover occupational and physical therapy, nutrition services, speech pathology services, and respiratory therapy services for children and adolescents to maintain or improve functioning at the maximum age-appropriate level, subject to a 100 day re-evaluation.
- Cover prescribed hearing aids and custom-designed durable medical equipment, including prosthetic devices, orthotic devices, and health-related assistive technology and services for children and adolescents.
- Cover health education and training for families of children and adolescents with special physical, developmental, or emotional needs, consistent with treatment goals.
- Cover multidisciplinary case management for all children and adolescents with intensive or complex health care needs, including those with disabling chronic conditions and those living apart from their families, such as youth in foster care or juvenile justice facilities.

Cost sharing

- Base eligibility for reduced copayments on income level rather than on status as a cash assistance recipient of AFDC or SSI.
- Allow an individual ceiling on out-of-pocket expenditures to apply to an adolescent in a low or moderate income family so that adolescents with particularly high medical needs who live with other

family members are not disadvantaged relative to individuals who live alone.

- Authorize the secretary of HHS to waive or reduce the level of copayments when the imposition of a copayment would contribute to serious limitation or total denial of access.
- Provide premium subsidies for low-income individuals with chronic illness or disability to allow enrollment in fee-for-service plans, and reduce co-insurance and deductible requirements for out-of-plan services.
- Ensure that all adolescents living below the federal poverty level are eligible immediately, rather than on a phase-in-basis, for continued Medicaid coverage or any program of expanded services for lowincome children and adolescents.

Special populations

Ensure that services that are not included in a universally available guaranteed benefit package but that are essential for special populations of adolescents are available to them either through continued Medicaid coverage or an expanded benefit package as determined by the needs of the specific population.

Training to meet the needs of adolescents

 Designate physicians and other health professionals who have been trained in adolescent medicine as primary care providers to guarantee increased access to care for adolescents. Include interdisciplinary training in adolescent health as a designated component of all primary care disciplines to improve the quality of care received by adolescents. These disciplines include, but are not limited to: nursing, physician assistant, nutrition, psychology, psychiatry, social work, family medicine, internal medicine, pediatrics, and obstetrics and gynecology.

Public health

- Provide sources of financing for the public health infrastructure and core public health functions as a guaranteed set aside. Funding should be ongoing and not dependent on the annual appropriations process.
- Allow school-based health centers to qualify as community providers to provide expanded access for adolescents.
- Create strong mechanisms and incentives to assure that managed care and traditional office-based providers develop collaborative relationships with community-based providers and school-based health centers that serve adolescents.
- Ensure that surveillance and monitoring of health services utilization and outcomes specific to adolescent health are an integral part of a reinvigorated public health system, and are explicitly linked to new governance structures.



14

14

Introduction

The health of our youth is in jeopardy. Adolescents have serious, yet preventable health problems, the resolution of which must become a national priority. One out of every five adolescents has experienced at least e. e critical health problem, such as injuries resulting from a gunshot wound or motor vehicle accident; severe depression leading to suicide attempts; HIV infection; drug, alcohol, and/or tobacco use; or pelvic inflammatory disease; yet too many young people are without affordable and developmentally appropriate health care.

As a developmental stage, the period from 10- to 21-years-old is critical to achieving a healthy, productive adulthood. Through education, counseling, and early intervention and treatment, adequate health care could help adolescents adopt a healthy lifestyle that would endure throughout their lives. The reform of the nation's health care system provides a unique opportunity to address the serious health problems facing young people and to reorganize and redirect health services for youth.

Because many health problems of youth are rooted in behavioral causes and are thus amenable to prevention, adolescents stand to benefit from a health care system which stresses prevention, early intervention, and comprehensive, interdisciplinary services. The current public debate about health care reform has focused on health care costs and financing, universal coverage, and basic benefits packages. These considerations alone will not help adolescents gain access to the health care providers and services that are likely to have positive effects on their health status. Adolescents require specialized affordable health services that respond to their need for confidentiality, flexibility, and coordination. These needs of youth have implications for health care delivery and finance-

ing systems, health care provider training, health

resources allocation, the public health infrastructure, and our traditional beliefs about who should bear the burden of truly comprehensive benefits, especially for children and adolescents with special health needs.

As health care reform moves forward in the legislative process and in implementation both nationally and at the state level, it is essential to look beyond financing issues and to consider the critical health issues and special health care needs of the nation's youth. In order to gather expert opinion and data, debate the issues, and make recommendations on how health care reform could best address the health needs of adolescents, a working seminar was convened in Washington, DC on January 10-11, 1994, coordinated by the National Adolescent Health Information Center (NAHIC) of the University of California, San Francisco: in collaboration with the National Center for Youth Law, San Francisco, California; the Center for Health Policy Research at the George Washington University, Washington, DC; the National Center for Youth with Disabilities at the University of Minnesota, Minneapolis; and the Child and Adolescent Health Policy Center at Johns Hopkins University, Baltimore, Maryland. Through its support of several of these organizations, the Maternal and Child Health Bureau (MCHB) encourages the development of health policy to improve the health of children, adolescents, and families. Also supported by the MCHB, the National Center for Education in Maternal and Child Health (NCEMCH) worked closely with NAHIC and the authors to provide current content, update and verify references. prepare bibliographical and organizational resources, and edit, design, publish, and disseminate this document.

During the working seminar, six papers were presented, and after considerable discussion, seminar participants (Appendix D) developed recommendations



outlining the essential elements needed for health care reform legislation and implementation to improve the health of adolescents. Much of the discussion in these papers focuses on the Administration's Health Security Act because at the time of the meeting it occupied a central place in the debate and contained the most explicit language in terms of benefits, the health of school-age children and adolescents, and the need for a strengthened public health infrastructure. However, the general principles outlined in the papers and the ensuing discussion and final recommendations are applicable to the implementation, monitoring, and improvement of any system of health care financing and service delivery.

The recommendations from the seminar were developed to assist policymakers in the process of planning for national health care reform and to provide guidance for the actual implementation of new structures and systems for adolescent health care delivery. Several similar themes appear in all of the papers and are evident in the final summary of recommendations in regard to adolescent health care:

- Adolescents need a range of choices of health care settings and providers; adolescents living in special circumstances (e.g., homeless, incarcerated, foster care) need services beyond those described in a basic benefits package;
- For prevention to work, adolescents need frequent, repeated messages as well as screening and early intervention when there are suspected high risk behaviors;
- Adolescents have a traditionally unmet need for preventive mental health services and for early intervention when mental health and substance abuse problems are identified;

- Family planning services and sexually transmitted diseases screening and treatment are essential elements of clinical preventive services for adolescents and should be readily available without the barrier of copayments;
- Adolescents with special health needs require additional services such as home health care, case management, skilled nursing and rehabilitation facilities, occupational and physical therapy, nutrition services, speech therapy, respiratory therapy, various durable medical equipment, and training for families and caretakers in special care requirements;
- Copayments and other out-of-pocket expenses are barriers to care for adolescents with low incomes and for those seeking confidential care;
- Public health services need guaranteed funding at a level sufficient to support traditional functions of disease control and prevention and the core functions of assessment, policy development, and assurance; and
- More primary care providers need to be trained and need adolescent health training as part of the basic curriculum and practice, and specialists in adolescent health should be designated as primary care providers.

We are publishing and disseminating these papers in an effort to provide additional resources for the maternal, child, and adolescent health community to use in formulating health care policy, especially at the state level, where in many instances, health care reform is already being implemented. Through wide dissemination of this information, we hope to build a national consensus on the need for new systems of health care for adolescents and a national commitment to their health and well-being.



Adolescents, the Health Care Delivery System, and Health Care Reform

JONATHAN D. KLEIN, M.D., M.P.H. Division of Adolescent Medicine, University of Rochester

601 Elmwood Avenue Rochester, NY 14642 Phone: (716) 275-2964

Fax: (716) 273-1037

The research cited in this paper was supported in part by grant R48-CCR402177 from the Centers for Disease Control and Prevention.



Introduction

The Health Security Act proposes universal coverage through enrollment in health plans offered by regional health alliances. Coverage would be financed through a combination of individual and employer premiums and government assistance. As proposed, the Health Security Act would improve access to health services for those Americans currently uninsured and would increase primary care coverage for all Americans. Because health care reform proposals deal primarily with financial barriers to access, adolescents still will encounter substantial barriers to health services use. Despite the support for primary care and prevention in the Administration's health care reform proposal, specific strategies for the organization of health services still will be needed to ensure access to health care for adolescents.

Adolescents have the lowest rate of primary care use of any age group in the United States. Adolescents and young adults, especially those living in poverty, are more likely to be uninsured than any other age group. Many other adolescents are underinsured, with coverage that does not include preventive care, counseling, substance abuse treatment, or other needed services.

Adolescents also face behavioral and organizational barriers to their receiving health care.' Many insured adolescents are unwilling or unable to use their existing coverage, because they fear loss of confidentiality, they don't know what services are covered or how to file claims, or they can not meet out-of-pocket copayment requirements. Transportation and lack of available services are particularly acute problems in rural settings. A lack of culturally appropriate services often limits the ability of minority youth to use existing health services. Where services are available, they are often fragmented; categorical funding of programs or interagency competition can pose substantial barriers to effective service coordination.^{1,5}

For health services to meet adolescents' needs, either currently or under health care reform, those services must fulfill certain criteria, both for the system of health service delivery and for the specific services provided.* Systems factors, such as program organization, financing, and interorganizational relationships, can interfere with or facilitate adolescents receiving services. Systems also include access to care, specifically availability, affordability, confidentiality, visibility, convenience, flexibility, and coordination. In comparison, services are a measure of the therapeutic interactions between providers and clients; they are a result—an outcome—of the system in place, reflecting service capacity, content, comprehensiveness, quality, and utilization.

Both systems and services factors have an impact on health outcomes for individuals, as well as for programs and providers. This model for describing health services is useful in discussing health care reform, because (1) it helps to clarify the relationship between systems organization, specific service provision, and health outcome; and (2) it makes evaluation of the linkages between these factors a necessary precursor to measuring health outcomes based on either new systems organization or new service availability.

Systems criteria: Access to care

Systems criteria for access to care for adolescents are described in the Society for Adolescent Medicine's position paper which urges that all proposals for improving access to health care for adolescents be evaluated using the following criteria:

Availability: Age-appropriate services and trained health care providers must be present in all communities.



Visibility: Health services for adolescents must be recognizable, convenient, and should not require complex planning by adolescents or their parents.

Quality: A basic level of service must be provided to all youth, and adolescents should be satisfied with the care they receive.

Confidentiality: Adolescents should be encouraged to involve their families in health decisions, but confidentiality must be assured.

Affordability: Public and private insurance programs must provide adolescents with both preventive and other services designed to promote health behaviors and decrease morbidity and mortality.

Flexibility: Services, providers, and delivery sites must consider the developmental, cultural, ethnic, and social diversity among adolescents.

Coordination: Service providers must ensure that comprehensive services are available to adolescents.

Availability/visibility

The preventable health problems of adolescents make the availability and visibility of certain preventive services—including family planning and reproductive health services, diagnosis and treatment of sexually transmitted diseases and HIV infection, mental health counseling and treatment, and substance abuse counseling and treatment—critically important for this age group. But adolescents often do not anticipate or plan for their health needs, so to serve adolescents appropriately, services must be available in a wide range of health care settings, including community-based ado-

lescent health centers, family planning and public health clinics, school-based and school-linked health clinics, physicians' offices, HMOs, and hospitals. Without multiple entry points into care and a diversity of care resources, adolescents are less likely to connect with needed health services.

Quality

One aspect of quality that can be assessed is the capacity for providing appropriate service content. Content guidelines for adolescent preventive services have been recently reviewed by two national scientific panels, Guidelines for Adolescent Preventive Services (GAPS),10 and Bright Futures.11 These groups recommend annual preventive visits to ensure that youth and their families receive health guidance. In contrast, the preventive care periodicity of the benefits package initially proposed in the Health Security Act is inadequate to promote or restore adolescents' health. Even adolescents who receive health care often do not receive adequate preventive counseling, health promotion, or screening. 12.13 Most physicians perform recommended preventive services infrequently; few adolescent visits are for preventive care; and as many as 69 percent of adolescent visits do not include health counseling or guidance.12.14.15

Under the Administration's health care reform proposal many opportunities for effective health promotion and for delivery of clinical preventive services to adolescents would continue to be missed. For example, the Health Security Act provides coverage for annual Pap smears and pelvic exams for sexually active adolescents, but it does not cover screening to identify those adolescents who are having sex (both males and females) nor does it cover periodic health guidance to try to prevent unintended pregnancies and sexually transmitted diseases.



19

Confidentiality/affordability

Adolescents cite confidentiality, cost, and convenience as key determinants of their use of and satisfaction with care. 16.17 Their ability to pay out-of-pocket for services is minimal, and many studies report that the cost of care is a barrier to their use of services. "621 Affordability is a delivery system problem, in that an adolescent's ability to receive health benefits should not depend upon his or her living situation, familial status, or family income. In any health care reform plan, adolescents who are living apart from their families; those who are in foster care, juvenile justice facilities, or other state-supervised care; and those who are homeless should be covered. Similarly, their ability to use insurance benefits should not depend solely on the availability or involvement of their families. To date, neither the federal government nor individual states have allowed presumptive eligibility for insurance based solely on age rather than on status (e.g., pregnancy).

Confidentiality is of highest importance for addressing many types of preventable problems; and fear of disclosure, diagnosis, and treatment can cause adolescents to delay or avoid needed care. 1,67,9,16 In a recent survey, 58 percent of high school students had health concerns they wanted to keep private from their parents; only one third knew they were legally entitled to receive confidential care for specific health issues; and 68 percent had concerns about the confid ntiality of services provided in school-based clinics.²² Although most physicians support providing confidential care to adolescents, many are uncomfortable with the family negotiations that can sometimes surround independent care and decision making, and few routinely arrange alternative billing or other systems for adolescents to facilitate confidentiality. Unfortunately, adolescents and their families do not always agree on their regular source of care.33 To the degree that health care reform relies on managed care gatekeeper mechanisms to control the use of services and to limit expenditures (especially if the adolescent's coverage depends solely on family coverage), reform will promote neither access nor effective use of preventive care services.

Flexibility/coordination

Flexibility of care and coordination of services are also important, and it is in these areas especially that the definition of "access to care" for adolescents differs from that for adults. Adults who have a regular source of primary care use more preventive services and report greater satisfaction with the care they received than did adults without a regular care source.24 Having a regular source of primary care also has been proposed as part of the definition of good access to care for adolescents; however, that definition might not be valid for adolescents who depend on and use multiple sources of care.25 For example, adolescents using a school-based clinic might need a another source of care when the school is closed, and (for 80 percent of school clinic sites) still another for reproductive health services. Thus, the use of multiple sources of care would not necessarily indicate poor access for these adolescents. Both using multiple care sources and being able to identify a source of primary care have significant implications for adolescents' access under health care reform.

Public policy options for meeting adolescents' needs and increasing their access to health care usually emphasize the importance of comprehensive, coordinated, or "integrated" services for adolescents.^{1,5,9}

These services (referred to as "comprehensive" in this paper) imply a broad range of physical and mental health, educational, social, and other services provided in linked, cooperative sites. Although definitions of comprehensiveness are imprecise and criteria for evaluating adolescent services are not always easily determined, explicitly defining the services that must be made available to all adolescents has the greatest



potential for improving adolescents' access to quality care under health care reform. Clinical outcomes increasingly are being used to evaluate health services; but unless the services to effect the outcome are available and used, the desired outcomes cannot occur. Thus, an ability to provide or coordinate a range of services should be mandatory for any health provider, health insurance plan, or health alliance. Similarly, providing or coordinating a specified range of services for adolescents should be required of "essential community providers."

A brief review of what care adolescents actually receive, and from whom, is useful evidence for why these criteria must be applied uniformly. In 1990, a national survey identified approximately 660 programs providing comprehensive health services to adolescents in the United States. Of these, 45 percent were in schools, 22 percent in hospitals, 11 percent in community centers, 9 percent in health centers, 8 percent in health departments, and 5 percent in other sites (e.g., free-standing teen centers, HMOs, etc.). In comparison, in 1990, there were 47,639 family practitioners, 40,893 pediatricians, and 20,649 nurse practitioners in practice, and 1,784 hospitals, 1,419 local health departments, 580 community health centers, and 123 migrant health centers providing primary care services.27.29

Although 80 percent of all adolescents (and 68 percent of adolescents living in poverty) receive care from physicians each year, fewer than 15 percent of all adolescent visits to office-based physician providers and only 13-20 percent of visits to school-based providers are for health supervision or other preventive care. Only 58 percent of Hispanic and 59 percent of African-American adolescents report private doctors or HMOs as their source of routine care, compared with 81 percent of white adolescents. Much of this difference is accounted for by poverty as more poor than nonpoor adolescents report community or hospital clinics or emergency rooms as their regular

source of care.^{29,31} In comparison, "comprehensive" adolescent health programs served only 5.3 percent of all 15 to 19-year-old adolescents in the United States in 1990.²⁶

Although comprehensive programs generally are considered the gold standard for adolescent services, even comprehensive adolescent programs are far from ideal, and evidence from existing programs suggests that it is difficult to provide a truly comprehensive range of services. For example, many school-based programs do not provide reproductive health services on site. In a recent study of comprehensiveness and coordination in 100 school-based clinics, many programs that did not provide reproductive health services or mental health services on site had difficulty coordinating access to these services. Nearly one in three programs reported that their clients have problems accessing mental health services. Programs also report that clients have trouble accessing specialty referrals, dental care, primary care, reproductive health care, and abortion. Unless efforts are made to ensure that school health services are actually comprehensive and/or coordinated, they will not fully meet the needs of adolescents.

A focus on school-based health programs is appropriate for several reasons: the optimism around new funding for school-based primary care; school-based clinics fulfill many access criteria; and the over 600 clinics currently believed to exist do improve care delivery for many adolescents.32 School-based and school-linked programs serve a large proportion of inschool adolescents, many of whom have no other regular source of care. 130,33 The number of states with programs or demonstration projects for school-based or school-linked health programs has grown from 9 in 1991 to 32 in 1993. The Robert Wood Johnson Foundation has just funded a \$23.2 million state-community partnership grant program to increase availability of school-based health services for children and youth with unmet health needs." Additionally, the



Health Security Act contains funding for as many as 3,200 new school health service programs, with special grants targeted toward population groups with the greatest needs. However, unless there is consensus regarding the services that must be available, whether in school-based or in other models for care delivery, it will be difficult to know whether we are in fact meeting adolescents' needs for primary care.

An example of explicit criteria for services that should be provided or coordinated by providers is the normatively defined list of services actually provided by self-defined comprehensive programs in 1990.16 This list is shown in Figure 1, along with the recommendations of previous expert panels and policy reports. Other examples of systems and services criteria include the grantee criteria for community and migrant health centers established by the Bureau of Primary Health Care, and the recently developed Columbia University's School Health Policy Initiative's operating standards for school-based primary care.5 The latter consists of general principles and a checklist of minimum services proposed by a series of expert advisory committees convened to support the institutionalization and expansion of school-based health centers.

By defining specific services, these criteria allow for specificity in evaluating whether and how well appropriate care is being provided. For health care reform, service criteria should be defined based on adolescents' needs, regardless of setting, rather than separately for different service delivery settings.

Policy Issues

The critical health care reform issue for adolescent care delivery is access to care, especially with regard to the effects of managed care reimbursement strategies on confidential, independent access to comprehensive, coordinated care. Access can be promoted in several

ways: by designating comprehensive adolescent health services as essential community providers; by mandating or otherwise ensuring that all eligible health plans (as well as all essential community providers) provide confidential, comprehensive, and coordinated services to the adolescents they serve; and/or by categorically granting adolescents eligibility for insurance coverage on the basis of age alone.

Currently, although family planning services are usually exempt from Medicaid managed-care plans, many school-based clinics and free-standing adolescent health programs report that their reimbursement for both reproductive and other services is restricted, with little or no corresponding change in their patients' needs. 14.58 Designating adolescent health programs as essential community providers under health care reform would ensure both that adolescents could use the services of such programs, and that access would not be solely tied to the family's choice of provider.

Recommendations

Unfortunately, neither the Health Security Act nor any other health care reform proposal identifies a special role for programs that provide comprehensive services to adolescents. In contrast, family planning agencies, community and migrant health centers, certain maternal and child health programs, and school health services would be designated as essential community providers, meaning that qualified health plans must allow them to participate in providing care to the eligible population. What services must actually be provided for school-based or community health centers to be designated as essential providers is not clear. In the case of school-based services, most details are deferred to the secretary of health and human services; however, both capitation and grant funding mechanisms are proposed, with the former to fund enabling services



²³22

FIGURE 1

Criteria for Comprehensive Adolescent Health Services ³⁶					
Operational Standard from Comprehensive Programs					
preventive health care longitudinal care first contact care social work services laboratory services pharmacy services					
STD treatment HIV testing pregnancy testing family planning contraceptives psychologic counseling mental health care health education AIDS education nutrition education outreach					

[Note: Shaded services are included in only one of the definitions]



(i.e., outreach, transportation, etc.) not covered under the basic health plan entitlement.

While many details remain unclear, the lack of essential provider status for free-standing comprehensive adolescent health programs and for community-or hospital-based adolescent health services threatens the viability of many essential programs that are well known to and frequently used by adolescents.

Recommendation 1: Protective language defining comprehensive adolescent health providers as essential community providers should be included in any health care reform proposal.

Mandated guidelines outlining which services must be provided are needed to ensure that America's adolescents have access to appropriate health care. Comprehensive services are the standard for providing effective service for adolescents-at-risk, although, access to comprehensive care, with an emphasis on prevention, is essential for all youth. Thus, a critical element to ensuring access to the range of comprehensive services needed are policies that establish national standards for all delivery systems available to youth. The services that should be provided to adolescents must be explicitly defined so that adolescents have access to appropriate care across all clinical settings (whether in schools or in communities). Although local government, parents, providers, and schools should assume responsibility for developing health scrvices that are available and accessible to adolescents, the federal government should assume responsibility for ensuring that comprehensive, coordinated health services for adolescents are available in all communities. Under health care reform, federal and state financing mandates should be used to ensure that qualified health care providers and health plans make comprehensive, coordinated health services available to adolescents in every community.

Recommendation 2: Comprehensive coordinated adolescent health services, defined by system and service criteria, should be written into health care reform legislation as mandatory components in the description of what is required of all qualified health plans and health care providers.

Ideally, these mandates would specify that health plans be responsible for delivering confidential, high quality care to youth, in flexible, diverse, and visible settings, coordinating and/or providing a specified set of comprehensive services.

Recommendation 3: To assure quality, mandated services should be monitored and evaluated.

The limitations in what even comprehensive programs currently are able to provide and the low frequency at which preventive services are delivered to adolescents suggest that adolescents require multiple points of access to services. Questions, such as whether services are offered and when they are used, will be useful for monitoring both the effect of health care reform on adolescents' access to care and whether health care providers and plans adhere to service mandates and content guidelines. These questions must first be answered before evaluation questions can focus on measurable health outcomes of the care delivered.

For adolescents, access to care is much more than merely having an insurance card. Current efforts to minimize health care expenditures through managed care mechanisms inevitably conflict with efforts to deliver comprehensive preventive services to all adolescents. As health care reform efforts move forward, both careful definition of the services adolescents need and adequate financing for these services are essential. Otherwise, America's adolescents will not have access to appropriate health services.

References

- U.S. Congress, Office of Technology
 Assessment. (1991). Adolescent health—
 volume 1: Summary and policy options.
 Washington, DC: U.S. Government Printing
 Office.
- 2. Newacheck, P. W., and McManus, M. A. (1988). Health insurance status of adolescents in the United States. *Pediatrics*, 84(4), 699-708.
- 3. Children's Defense Fund. (1992). *The state of America's children*. Washington, DC: Children's Defense Fund.
- Carnegie Council on Adolescent
 Development, Task Force on Education of
 Young Adolescents. (1989). Turning points:
 Preparing American youth for the 21st century.
 Washington, DC: Carnegie Council on
 Adolescent Development.
- 5. Jack, M. S., Lear, J. G., and Klerman, L. (1988). Organization of adolescent health services: Study group report. *Journal of Adolescent Health Care*, 9, 33S-35S.
- 6. Brindis, C. D., and Lee, P. R. (1990). Public policy issues affecting the health care delivery system of adolescents. *Journal of Adolescent Health*, 11(5), 387-397.
- Gans, J. E., McManus, M. A., and Newacheck, P. W. (1991). Adolescent health care: Use, costs, and problems of access. Chicago, IL: American Medical Association.
- 8. Klein, J. D., Kotelchuck, M., and DeFriese, G. H. (1990). Critical evaluation of comprehensive multi-service delivery systems for adolescents. Background Paper. Washington, DC: U.S. Congress, Office of Technology Assessment.
- Klein, J. D., Slap, G. B., Elster, A. B., et al. (1992). Access to health care for adolescents. A position paper of the Society for Adolescent

- Medicine. *Journal of Adolescent Health*, 13(2), 162-170.
- Elster, A. B., and Kuznets, N. J. (1994).
 AMA guidelines for adolescent preventive services (GAPS): Recommendations and rationale.
 Baltimore, MD: Williams and Wilkins.
- 11. Green, M. (Ed.). (in preparation). Bright futures: National guidelines for health supervision of infants, children, and adolescents.
- 12. Igra, V., and Millstein, S. G. (1993). Current status and approaches to improving preventive services for adolescents. JAMA, 269(11), 1408-1412.
- 13. Brindis, C. D. (1993). What it will take: Placing adolescents on the American national agenda for the 1990's. *Journal of Adolescent Health*, 14(7), 527-530.
- Lewis, C. E. (1990). Health services research in prevention. In Mayfield, J., and Grady, M. (Eds.). Primary care research: An agenda for the 90s. Rockville, MD: Agency for Health Care Policy and Research, U.S. Department of Health and Human Services.
- Russell, N. K., Boekeloo, B., Rafi, I. Z., et al. (1992). Unannounced simulated patients' observations of physicians STD/HIV prevention activities. *American Journal of Preventive Medicine*, 8(4), 235-40.
- Resnick, M. D., Blum, R. W., and Hedin, D. (1980). The appropriateness of health services for adolescents: Youth's opinions and attitudes. *Journal of Adolescent Health Care*, 1(2), 137-45.
- 17. Klerman, L. V., Kovar, M. G., and Brown, S. S. (1981). Adolescents: Health status and needed services. Report of the select panel for the promotion of child health. Washington, DC: U.S. Department of Health and Human Services.
- 18. Millman, M. (Ed.). (1993). Access to health care in America. Washington, DC: National Academy Press.



- 19. Ryan, S. A., and Schollenberger, J. (1993). Rural adolescents: Perceived barriers to medical care. *Pediatric Research*, 33(4) part 2, 8A.
- Levenson, P. M., Pfefferbaum, B., and Morrow, J. (1987). Disparities in adolescentphysician views of teen health information concerns. *Journal of Adolescent Health Care*, 8(2), 171-176.
- 21. Malus, M., LaChance, P. A., Lamy, L., et al. (1987). Priorities in adolescent health care: The teenager's viewpoint. *Journal of Family Practice*, 25(2), 159-162.
- 22. Cheng, T. L., Savageau, J. A., Sattler, A. L., et al. (1993). Confidentiality in health care: A survey of knowledge, perceptions, and attitudes among high school students. *JAMA*, 269(11), 1404-1407.
- Kelleher, K. Uruversity of Arkansas. Concordance of health measures, personal communication, May 1993.
- 24. Aday, L. A., Flemming, G. V., and Andersen, R. (1984). Access to medical care in the US: Who has it, who doesn't. Chicago, IL: Center for Health Administration Studies, University of Chicago.
- 25. Starfield, B. (1992). Primary care: Concept, evaluation and policy. New York, NY: Oxford University Press.
- Klein, J. D., Starnes, S. A., Kotelchuck, M., et al. (1992). Comprehensive adolescent health services in the United States, 1990. Carrboro, NC: Center for Early Adolescence, University of North Carolina at Chapel Hill.
- 27. American Medical Association. (1992). *Physician characteristics and distribution in the U. S. 1992.* Chicago, IL: American Medical Association.

- 28. Moses, E. B. (1988). The registered nurse population: Findings from the national sample survey of registered nurses, March 1988.

 Rockville, MD: U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, Bureau of Health Professionals, Division of Nursing.
- Klerman, L. V., Grazier, K. L., and Thomas, K. C. (1990). The role of the public sector in providing children's health care. In Schlesinger, M. J., and Eisenberg, L. (Eds.). Children in a changing health system:
 Assessments and proposals for reform. Baltimore, MD: Johns Hopkins University Press.
- Garfinkel, S. (1993). The answer is at school: Bringing health care to our students.
 Washington, DC: School-Based Adolescent Health Care Program, Robert Wood Johnson Foundation.
- 31. Lieu, T. A., Newacheck, P. W., and McManus, M. A. (1993). Race, ethnicity, and access to ambulatory care among US adolescents. *American Journal of Public Health*, 83(7), 960-965.
- 32. Advocates for Youth. (1994). Support center news. Linkx: The quarterly newsletter of the support center for school-based and school-linked health care, 2(1), 2.
- 33. Dryfoos, J. G. (1990). Adolescents at risk: Prevalence and prevention. New York, NY: Oxford University Press.
- 34. Lear, J., and Brellochs, C. School-Based Adolescent Health Care Program, Robert Wood Johnson Foundation, Washington, DC. Personal communications, May 1993.
- Robert Wood Johnson Foundation. (1993).
 Making the grade. Call for proposals.
 Princeton, NJ: Robert Wood Johnson Foundation.



- Klein, J. D., Starnes, S. A., and Kotelchuck, M. (1993). Adolescent health service "comprehensiveness." *Pediatric Research*, 33(4) part 2, 6A.
- 37. Brellochs, C., and Fothergill, K. (1993). Special report: Defining school-based health center services (Draft). New York, NY: School Health Policy Initiative, Columbia University, School of Public Health.
- 38. Klein, J. D., Slap, G. B., Elster, A. B., et al. (1994). Adolescents and access to health care. *Bulletin of New York Academy of Medicine*, 70(2), 219-235.



Enhancing Benefits for Adolescents Under National Health Reform

MARGARET McMANUS JENNIFER DUNBAR Maternal and Child Health Policy Research Center

2 Wisconsin Circle, Suite 700 Washington, DC 20815 Tel: (202) 686-4797

Fax: (301) 654-1089

Prepared for the Working Seminar on Adolescent Health and Health Care Reform
January 10-11, 1994
Washington, DC



Webster's Dictionary defines a benefit as something that promotes well-being. The purpose of this paper is to determine whether the Health Security Act's definition of benefits is consistent with Webster's definition.

This paper will address three topics: (1) the critical needs of adolescents in the area of benefits, (2) strengths and limitations of the benefits under the Health Security Act and other leading health reform proposals, and (3) recommendations for benefits package for adolescents.

Critical Needs of Adolescents in the Area of Benefits

Developmental, emotional, and behavioral problems are at the root of most of the critical health care needs of adolescents. Recent national survey data reveal that as many as one in four adolescents has experienced a delay in growth or development, a learning disability, or an emotional problem that lasted at least three months or required psychological help.¹

The Office of Technology Assessment summarized the etiology of adolescents' needs for health services:

- prevention of fatal injuries, including accidents, homicide, and suicide;
- family problems, such as maltreatment;
- school problems, such as the potential for dropping out;
- physical problems, such as acute respiratory illness, serious chronic physical illness and disability, and sports injuries;
- · new problems on reaching puberty, such as acne;
- nutritional problems, such as obesity or anorexia;
- dental problems, such as dental minimum inclusion;
- problems associated with unprotected sexual activity, such as pregnancy and sexually transmitted diseases (STDs), including HIV infection;

- mental health and behavioral problems, diagnosable mental disorders, suicide attempts, alcohol abuse, cigarette smoking, and other drug use; and
- · homelessness and associated problems.

Understanding these adolescent needs is essential to evaluate the strengths and limitations of the Health Security Act and other health care reform proposals.

Strengths and Limitations of the Benefits under the Health Security Act

The Administration's Health Security Act offers an array of benefits. First, a standard benefits package would be guaranteed for all Americans. Second, individuals and families would not be subject to limitations in coverage due to preexisting conditions. Third, many of these benefits would represent substantial improvements over what currently exists; for example, several benefits would be added that previously have not been covered by many plans, including clinical preventive services, prescription drugs, mental illness and substance abuse services, vision care, and dental care. The Health Security Act includes several other programs intended to assure access and extend the basic benefits package. Of most relevance to adolescents are the following five programs:

Program for Poverty-Level Children with Special Needs

A federally financed and capped program is proposed for poor children and adolescents under age 19 (ages 0–1, up to 185 percent of the federal poverty level; ages 1–6, up to 133 percent; ages 6–19, up to 100 percent) who are Medicaid eligible. Benefits covered include those in the current Medicaid program that are not covered in the basic benefits plan or in the Program for Home and Community-Based Services.



Program for Home- and Community-Based Services for Individuals with Disabilities

A state-run program is proposed for (a) individuals who require help with daily living, (b) individuals with severe cognitive or mental impairments, (c) individuals with severe or profound mental retardation, and (d) severely disabled children under age six who would require inscitutionalization unless they were provided with personal assistance. Personal assistance services are the only benefit that states would be mandated to cover; additional optional services are case management, homemaker and chore assistance, home modifications, respite services, assistive devices, adult day services, habilitation and rehabilitation, supported employment, home health services, and other services to keep individuals at home.

Comprehensive School Health Education and School-Related Health Services

Two grant programs would be established for (a) state and local education agencies to support K-12 comprehensive school health education, and (b) state health agencies or partnerships (e.g., local health care providers delivering services to adolescents, public schools, and at least one community-based organization) to furnish diagnosis, treatment, referral, and follow-up of minor illness and injury; preventive services; enabling services (i.e., transportation, community and patient outreach, patient education, translation services); and social services, counseling, and referrals, including referrals for mental health and substance abuse. Preference would be given to communities that have the highest level of need among 10- to 19-yearolds, as measured by poverty, medical underservice, and special needs related to disability, pregnancy, STDs, injuries and gang violence, or alcohol and drug abuse. Priority also would be given to those programs demonstrating a link to qualified health plans.

Health Services for Medically Underserved Populations

Grants, contracts, loans, and loan guarantees would be available to develop qualified community health plans and community practice networks in areas with shortages of health professionals or to support those already serving significant numbers of medically underserved clients. Funds would be used to plan the network or health plan, recruit and compensate staff, acquire and expand facilities, and acquire and develop information systems. Grant funds also would be available for enabling services (described above).

Mental Health and Substance Abuse Supplemental Formula Grants

Grants would be available for transportation and translation, patient and community outreach, and patient education to increase access to mental health and substance abuse services. They would be available to improve the capacity of state and local service systems to coordinate and monitor services; enhance information systems; link mental health and substance abuse services and primary care providers and plans; and provide incentives to integrate public and private mental health and substance abuse services. Taken together, these five programs represent important benefit extensions in the areas of school health services, mental health and substance abuse services, and enabling services (transportation, outreach, patient education, and translation services) for adolescents. While all of the benefits in the Health Security Act are important for adolescents, certain benefits require a closer examination in light of adolescents' unique health care needs: clinical preventive services, mental illness and substance abuse services, family planning and pregnancy-related services, home health care, extended care services, outpatient rehabilitation services, durable medical equipment, and dental care.



The Health Security Act's strengths and limitations in each of these eight areas are summarized below.

Clinical preventive services

Strengths: Preventive services are covered, and no costsharing would be required to receive benefits.

Limitations: The new clinical services benefit does not follow an EPSDT standard for preventive care currently existing in Medicaid. Fewer visits are called for than recommended by *Bright Futures* or *Guidelines for Adolescent Preventive Services (GAPS)*.

Mental illness and substance abuse services

Strengths: A wide range of outpatient services would be covered, as well as residential and nonresidential treatment in a variety of settings and programs.

Limitations: Health professionals would not be able to provide treatment for mental illness and substance abuse problems unless the plan in which the adolescent is enrolled determines that such treatment is necessary based on its own criteria. Preventive or early intervention mental health visits would not be available to adolescents suspected of having a mental health or substance abuse problem or to children and adolescents at risk for problems due to physical health, child abuse, or other biological or environmental risk factors. Arbitrary annual limits on visits (i.e., 30) on psychotherapy, collateral services, and substance abuse counseling and relapse prevention would restrict adolescents' access to needed mental health and substance abuse services. Additional visits would be available to individuals only in lieu of a higher level of care. Copayments and coinsurance would not be applied toward any annual out-of-pocket limit on cost sharing, creating substantial financial burdens for families and/or denying access to adolescents seeking confidential services.

Family planning services and pregnancy-related services

This benefit is difficult to judge because services were not specified, except as follows: voluntary family planning services, prescribed contraceptive devices, and services for pregnant women. Copayments would be applied which could limit many adolescents' access to family planning services.

Home health care

Strengths: Home health care would be covered for a limited time only following an illness or injury and as an alternative to more costly inpatient services.

Limitations: Home health care would not be covered as a result of a congenital problem. Full-time nursing services would not be covered; only part-time or intermittent nursing care would be covered. Personal care services would not be covered.

Extended care services

Strengths: Rehabilitation facilities and skilled nursing facilities would be covered only for a limited time as a hospital alternative following an illness or injury.

Limitations: Extended care services wou'd not be covered as a result of a congenital problem.

Outpatient rehabilitation services

Strengths: Occupational therapy, physical therapy, and speech therapy services would be covered for a limited period to restore function or minimize limitations only following an illness or injury.

Limitations: Occupational therapy, physical therapy, and speech therapy would not be covered to improve function as a result of a chronic condition or a developmental problem. Extended outpatient rehabilitation



services would be covered only if function is improving. Respiratory therapy and audiology services would not be covered at all.

Durable medical equipment (DME) and prosthetic and orthotic devices

Strengths: The benefit would cover DME, prosthetics, braces, artificial legs, arms, and eyes.

Limitations: Hearing aids, customized medical devices, and assistive technologies and services would not be covered.

Dental care

Strengths: The benefit would include both emergency dental treatment and prevention, diagnosis, and treatment of dental disease for children and adolescents under age 18. Space maintenance would be covered for children between the ages of 3 and 13.

Limitations: Not until 2001 would interceptive orthodontic treatment be covered for children between the ages of 6 and 12.

In sum, there are clearly many strengths in the benefit package for all adolescents. The limitations are fairly prominent for adolescents with developmental, emotional, and chronic care needs. Consequently, the supplemental programs described earlier are very important.

Strengths and Limitations of Benefits under Other National Health Reform Proposals

Four additional national health reform proposals warrant evaluation in terms of their benefits for children and adolescents. The bills are summarized in Table 1.

Table 2 compares recommended benefits for children and adolescents in three of the proposals. The two remaining bills could not be assessed from a similar benefits perspective. The Cooper/Ereaux bill does not include a benefits package, and instead requires a standard benefit be established by a Health Care Standards Commission, and the Michel/Lott bill would give insurers flexibility to design benefits packages within certain actuarial limits. How do the McDermott/ Wellstone and the Thomas/Chafee bills compare with the Health Security Act in terms of benefits?

The McDermott/Wellstone single-payer plan closely resembles the benefits offered in the Health Security Act, though without as much specificity; the major distinctions are that McDermott/Wellstone includes long-term care as part of the basic benefits package, and illness and injury limits are not placed on rehabilitation, home health, and extended care facilities. The Thomas/Chafee bill benefits plan is far less generous, specifying very few services.

In sum, the Administration's Health Security Act and the McDermott/Wellstone proposal are substantially more complete in their benefits than are the other leading health reform alternatives.

In terms of additional programs offered to enhance or supplement the basic benefits plan, the Health Security Act, of the five plans, offers the widest array of programs related to medically underserved populations, long-term care, children and families living in poverty, school health, and mental health and substance abuse.

Recommendations

Of the health reform proposals evaluated, the Health Security Act is the most comprehensive in both its basic benefits package and its supplemental programs.



32

However, the benefits package under national health care reform should be enhanced for adolescents, particularly for those with developmental, emotional, and chronic care needs, by adding the following:

Clinical preventive services

- Additional preventive health visits, as medically necessary, to provide screening and counseling for and adolescents at risk for physical, emotional, behavioral, and developmental problems or conditions.
- Specified comprehensive family planning s^p ices and services for pregnant adolescents; no copayment for family planning services.

Mental illness and substance abuse services

- Preventive outpatient mental health and substance abuse services, including services for children and adolescents suspected of having a mental health or substance abuse problem or those at risk for mental health problems due to physical health, child abuse, or other biological or environmental risk factors.
- Additional outpatient, inpatient and residential treatment, and intensive nonresidential mental health and substance abuse treatment services, based on reasonable standards of medical practice developed in consultation with recognized medical organizations involved in mental health and substance abuse care.

Home health care

• Home health care services, including full-time nursing services and personal care services, as well as the services included in section 1861 (m) of the Social Security Act, for children and adolescents who require this level of care to treat an injury, illness, or other health condition, consistent with an approved plan of care and subject to a 60-day reevaluation.

Extended care services

 Skilled nursing facility and rehabilitation facility services for children and adolescents who require this level of care to treat an injury, illness, or other health condition, with coverage extending past 100 days only as an alternative to hospitalization.

Outpatient rehabilitation services

· Occupational therapy, physical therapy, speech-language pathology, and audiology services, and respiratory therapy services for children and adolescents to improve or maintain age-appropriate functioning, subject to a 100-day reevaluation.

Durable medical equipment and assistive devices

 Prescribed hearing aids and custom-designed durable medical equipment, including prosthetic devices, orthotic devices, and health-related assistive technology for children and adolescents.

Health education and training

 Health education and training for families of children and adolescents with physical, emotional, behavioral, or developmental conditions who require these services to achieve treatment goals.

Case management

· Multidisciplinary case management for all children and adolescents with severe or chronic health care needs, and those with emotional, biological, or environmental risk factors.

The concluding question on which any proposed health reform plan must be judged is this: Do the proposed benefits and supplemental programs in the plan promote well-being for adolescents?

TABLE 1 Comparison of Selected Features Among Leading National Health Reform Proposals⁵

ISSUE	Health Security Act HR 3600/S 1757 President Clinton/Gephardt/Mitchell	American Health Security Act of 1993 HR 1200/S 491 McDermott /Wellstone
General Approach	Individual entitlement to health coverage secured through enrollment in private health plans offered by private health alliances and financed through a combination of individual and employer premiums and government assistance	Individual entitlement to government-sponsored health insurance secured through enrollment in state-administered programs and financed through various taxes.
Coverage	Universal and mandatory coverage of all US citizens and permanent legal residents by 1998 Excludes undocumented persons Employer mandate to help pay for coverage by paying 80% of the average family premium (divided by the number of workers per family and adjusted by family type) Individual mandate to purchase coverage subsidies for low-income individuals through regional alliances Imposes penalty for noncompliance equal to double cost of average premium	Universal and mandatory coverage for all US citizens and legal residents by 1995 Covers undocumented person if National Board or States expand eligibilty Employers are assessed a payroll tax to pay for program Other revenues used to cover costs of coverage
Benefits	Mandates comprehensive standard benefits package. Includes inpatient and outpatient hospital services, emergency and ambulatory medical services, services of physicians and other health professionals, ambulance services, laboratory and diagnostic services, clinical preventive services, family-planning and pregnancy-related services, home health care, DME, prosthetics and orthotics, extended care services, mental illness and substance abuse services, outpatient rehabilitation services following acute illness, routine vision and hearing, eyeglasses for children under age 18, prescription drugs, routine preventive and emergency dental "are coverage, and health education classes. Initially includes coverage limits on mental health and substance abuse services and age limits on dental prevention and treatment services: by 2001, expands coverage of these and adds orthodontia for children although some limitations still apply. Creates new long term care pregram (non-entitlement) for home-and community-based care through grants to states. Allows the National Health Board to interpret the benefits. Allows individuals to purchase supplementary instrance.	Mandates comprehensing standard benefits package Includes inpatient and outpatimet services, professional services of state-authorized practitioners, community-based primary health services, home and community-based long term care nursing facility services, home health services, chemical dependancy treatment, diagnostic tests, outpatient therapy, home dialysis, emergency ambulance service, prosthetic devices, DME, prescription drugs, and bilogicals. Clarified by National Health Board. Allows states and employers to provide additional benefits at their own risk.



Individual enrichment through mandatory enrollment in qualified health plans offered through parthaining cooperatives, large emplayer plans or a government program of the conditions tax exemptions for coverage or enrollment through individual and employer program assistance. Promise of universal and mandatory coverage of all lawful permentent residents by 205 Eschades undocumented persons laddridual mandator to perchase coverage in long-term, with federal sabsidies for low income individual. Requires employers to offer but not pay for, exceeded and mandatory environment individual. Requires employers to offer but not pay for, exceeded and	Health Equity and Access Reform Today Act of 1993 HR 3704/S 1770 Thomas/Chafee	Managed Competition Act of 1993 HR 3222/S 1579 Cooper/Breaux	Affordable Health Care Now Act of 1993 HR 3080/S 1533 Michel/Lott
 age of all lawful permenent residents by 2005 Excludes undocumented persons Individual mandate to purchase coverage in long-term, with federal subsidies for low-income individuals Requires employers to offer but not pay for, coverage Impasses penalty for individuals failing to obtain coverage equal to 120% of the average yearle premium in a local area (low-income protected from penalties) Mandates standard benefits package or combination of catastrophic benefits package and medical savings account. Includes medical and surgical services and equipment, prescription drugs and biologicals, preventive health services related to an acute care episode, severe mental health services and some substance abuse services. Specific benefits to be clarified by National Expands access to health coverage through insurance coverage through insurance coverage through insurance marketing reforms Ciovernment subsidies available for low-income individuals Allows individuals tax deductions for their share of plan premiums Requires and deductions for their share of plan premiums Requires and deductions for their share of plan premiums Requires standard benefits package to be established by Health Care Standards Commission. Requires standard benefits package to include full range of preventive services with no cost-sharing. Allows plans to offer supplemental benefits as long as they are non-duplicative and offered separately. 	entollment in qualified health plans offered through purchasing cooperatives, large employer plans or a government program • Financed through individual and employer premiums, changes in taxes deductibility	to improve access to affordable health coverage, conditions tax exemptions for coverage on enroll- ment through purchasing cooperatives, provides subsidies for low income individuals and reforms	izes group health insurance sales practices and provides expansion. Medical coverage and low-
nation of catastrophic benefits package and medical savings account. Includes medical and surgical services and equipment, prescription drugs and biologicals, preventive health services, rehabilitation and home health services related to an acute care episode, severe mental health services and some substance abuse services. Specific benefits to be clarified by National package to be established by Health Care Standards Commission. Requires standard benefits package to include full range of preventive services with no cost-sharing. Allows plans to offer supplemental benefits as long as they are non-duplicative and offered separately. Allows plans to offer supplemental benefits as long as they are non-duplicative and offered separately. Medical Savings Accounts must be offered by insurers to create any benefit package that fits within 5 percentage points of the actuarial value Preempts state mandated benefits plackage that fits within 5 percentage points of the actuarial value Medical Savings Accounts must be offered by insurers to small employers.	age of all lawful permenent residents by 2005 Excludes undocumented persons Individual mandate to purchase coverage in long-term, with federal subsidies for low-income individuals Requires employers to offer but not pay for, coverage Imposes penalty for individuals failing to obtain coverage equal to 120% of the average yearly premium in a local area (low-	Expands access to health coverage through insurance reforms Undocumented persons who do not work are excluded Requires employers to offer but not pay for, coverage Government subsidies available for low-income individuals Allows individuals tax deductions for their	 Expands access to health insurance coverage through insurance marketing reforms Silent on coverage of undocumented persons Requires employers to offer but not pay for.
	nation of catastrophic benefits package and medical savings account. Includes medical and surgical services and equipment, prescription drugs and biologicals, preventive health services, rehabilitation and home health services related to an acute care episode, severe mental health services and some substance abuse services. Specific benefits to be clarified by National	package to be established by Health Care Standards Commission. Requires standard benefits package to include full range of preventive services with no cost-sharing. Allows plans to offer supplemental benefits as long as they are non-duplicative and offered sepa-	coverage; allows insurers to create any benefit package that fits within 5 percentage points of the actuarial value Preempts state mandated benefits for group health plans. Medical Savings Accounts must be offered by

TABLE 2 Comparison of Recommended Children's Benefits Among Leading National Health Reform Proposals

Recommended Children's Benefits	President Clinton/ Gephardt/Mitchell HR 3600/S 1757	McDermott/ Wellstone HR 1200/S 491	Thomas/ Chafee HR 3704/S 1770
Hospital services	Yes	Yes	Yes
2. Physician services	Yes	Yes	Yes
3. Services of other health professionals	Yes	Yes	NS
Clinical preventive services	Yes	Yes	Yes
Consistent with pediatric practice guidelines Enriched services for high-risk youth	No NS	No NS	No NS
Emergency and ambulatory medical and surgical services	Yes	Yes	Yes
6. Laboratory, radiology, and diagnostic services	Yes	Yes	Yes
7. Prescription drugs	Yes	Yes	Yes
8. Ambulance services	Yes	Yes	Yes
9. Family planning services and supplies	Yes	Yes	NS
10. Services for pregnant women	Yes	Yes	NS
 Genetic counseling and related services Prenatal care Enriched prenatal care services for high-risk women 	NS NS	NS NS	NS NS
Counseling on pregnancy optionsElective termination of pregnancies	NS NS	NS NS	NS NS
11. Mental health and substance abuse services	Yes	Yes	Limited'
Outpatient treatment	Yes	Yes	NS
Screening and assessment Medical management Substance abuse counseling Crisis services Somatic treatment services Psychotherapy Case management/care coordination Collateral services	Yes Yes Limited ^{1,2,3} Yes Yes Limited ^{1,2,3} Limited ^{1,2,3} Limited ^{1,2,3}	Yes Yes Yes Yes NS Limited ⁵ Limited ¹	NS NS NS NS NS NS
Inpatient and residential treatmentIntensive nonresidential treatment	Limited ¹²³ Limited ¹²³	Limited ²	NS NS



Recommended Children's Benefits	President Clinton/ Gephardt/Mitchell HR 3600/S 1757	McDermott/ Wellstone HR 1200/S 491	Thomas/ Chafee HR 3704/S 1770
 Physical therapy, speech language therapy/pathology services, occupational therapy 	Yes	Yes	Yes
 For chronic care needs Long term care rehabilitation therapy to maximize fur 	No notion No	Yes Yes	No No
13. Respiratory therapy	No	No	NS
 For chronic care needs Long term to promote or maintain functional capacity 	No No	No No	NS NS
14. Home health care	Yes	Yes	Yes
For chronic care needs Long term, full-time nursing care	No No	Limited¹ No	No No
15. Vision and hearing services	Yes	Yes	NS
Hearing aids	No	Limited¹	NS
16. Care coordination/case management	No	No	No
Durable medical equipment and prosthetic and orthotic devices	Yes	Limited ²	NS
Custom designed DMEAssistive technologies	No No	No No	NS NS
18. Extended care inpatient services	Yes	Yes	NS
Chronic care needs Long term rehabilitation or skilled nursing	No	Yes	NS
facility services	Limited ^{2.5}	Limited ^{2 5}	NS
19. Hospice care	Yes	Yes	Yes
20. Dental care	Yes	Yes	No

Limits: 1 Eligibility restrictions

² Day, visit, or service limits

³ Plan discretion

⁴ Services excluded

⁵ Covered only as a hospital alternative

NS = not specified



References

- Zill, N., and Schoenborn, C. A. (1990). Developmental, learning and emotional problems: Health of our nation's children, United States, 1988. Hyattsville, MD: National Center for Health Statistics, U.S. Department of Health and Human Services.
- 3. Green, M. (Ed.). (in preparation). Bright futures: National guidelines for health supervision of infants, children, and adolescents.
- 4. Elster, A. B., and Kuznets, N. J. (1994).

 AMA guidelines for adolescent preventive services
 (GAPS): Recommendations and rationale.
 Baltimore, MD: Williams and Wilkins.
- Kaiser Commission on the Future of Medicaid. (1994). Health reform legislation: A comparison of major proposals. Menlo Park, CA: Henry J. Kaiser Family Foundation.



Issues for Adolescents Relating to the Financing of Health Care

CINDY MANN Massachusetts Law Reform Institute

> 69 Canal Street Boston, MA 02114 Tel: (617) 742-9250

Fax: (617) 742-1983

Prepared for the Working Seminar on Adolescent Health and Health Care Reform, January 10-11, 1994, Washington, DC. Ms. Mann represents the Alliance for Young Families whose staff provided information to aid in the preparation of this paper, and whose comments and concerns have been reflected in this paper.



Financing Obligations Imposed on Individuals and Families

Nationally, about 5 million adolescents 10-18 years old do not have health insurance. This represents 15 percent of the nation's youths, an estimated increase of 10 percent just since 1989. The major reason cited by families for their lack of health insurance is their inability to afford its cost. Families with children are disproportionately poor, and adolescents who live on their own—with or without the responsibility of caring for children—are overwhelmingly low-income. For all children, and for adolescents especially, the question of affordability of health care is a key concern.

Universal access to health care cannot be accomplished unless health care is affordable to all. Studies routinely have shown that children living in low income situations who lack health insurance receive significantly less adequate health care despite having generally greater health care needs.² While it is not unreasonable to expect individuals and families to share responsibility for financing health care, financing obligations must realistically factor in ability to pay and must recognize that people with very limited incomes have no ability to pay. Without this recognition, the central goals of health care reform—assuring universal access, ending cost shifting, and controlling overall costs—cannot be achieved.

The Administration's Health Security Act grants most adolescents the right to a comprehensive range of health care services and recognizes that subsidies are necessary to allow individuals and families with low incomes access to care. Nonetheless, the Act would impose on low-income people—a disproportionate portion of whom are children and adolescents—cost sharing obligations that would be significant relative to their income.

Copayments, Coinsurance, and Deductibles

Overview of cost sharing obligations and subsidies

Under the Health Security Act, all health plans would be required to impose cost-sharing obligations on all enrollees, according to one of three schedules set forth in the bill (sections 1132, 1133, and 1134). The "low cost sharing" plan imposes copayments but no deductibles for most services; the "higher cost sharing" plan imposes deductibles and copayments for most services; and the "combination" plan imposes copayments on most services delivered by plan providers and deductibles and coinsurance requirements on most out-of-plan services. The bill does include two critical cost sharing protections: Plans cannot impose any cost sharing requirements on "preventive services" and providers cannot bill more for services than is allowed under the plan (section 1406(d))."

Because of the significant cost imposed by coinsurance and deductibles, low-income people can be expected to sign up with the "low cost sharing" plan in their area. Even under the low cost plan, however, care is likely to be unaffordable to adolescents and families with low incomes. The bill proposes the following copayments (section 1135):

- \$10 for physician visits, outpatient hospital services, vision care, dental care, and family planning services;
- \$5 for prescription drugs;
- \$25 for certain mental health services, and for each "nonemergency" visit to an emergency room.

Health education and anticipatory guidance are not mandatory components of the comprehensive package. If a plan provides health education classes, the bill authorizes the imposition of unspecified



copayment amounts (section 1127). The National Health Board would appear to have the authority to require that preventive clinical visits include anticipatory guidance for adolescents (see section 1153), in which case no copayment would apply.

Although there is no reduction of cost sharing requirements applicable to all people based on inability to pay, the bill does propose three types of cost sharing limitations:

- For AFDC and SSI cash recipients, copayments would be reduced to 20 percent of the standard copayments requirement, except that no reduction would apply to emergency room visits in which "no emergency medical condition" exists (section 1371(c)).
- Cost sharing for people with incomes below 150 percent of the federal poverty line (fpl) would be available only if "insufficient" combination or low cost sharing plans were available. No definition of insufficiency is included in the bill, and the determination would be made at the discretion of the alliance (section 1371(a)).
- Overall out-of-pocket caps of \$1,500 for individuals and \$3,000 for families apply to all three types of plans (sections 1132 (a)(2), 1133 (a)(7), 1134(a)(1)). Out-of-pocket expenditures for certain mental illness and substance abuse services would not be counted toward these limits (sections 1115(d)(2)(E) and 1115(e)(2)(E)).

Concerns and recommendations regarding cost sharing obligations

In contrast to provisions of the bill addressing premium payments (described below), the bill does not permit plans to waive cost sharing obligations; failure to pay cost sharing obligations results in denial of care. In this respect, the bill contrasts sharply with current Medicaid law, which prohibits copayments for children and pregnant women, limits copayments for all other people to "nominal" amounts, and requires that services be provided if Medicaid recipients state they are unable to afford the fee. Many people with low incomes currently receiving Medicaid would be further disadvantaged under the Health Security Act plan since many would lose supplemental benefits (such as transportation, treatment for mental illness, and coverage of nonprescription medications). At the same time significant additional cost sharing requirements would be imposed for a smaller package of benefits.

The copayments proposed by the Health Security Act would be particularly burdensome to adolescents and their families with low incomes. For those living in poverty, \$10 payments, and certainly \$25 payments are prohibitive—a \$10 payment for a family with median income is comparable to a \$35 payment for a family witl. poverty-level income. Making these copayments could come literally at the expense of paying for other compelling family needs, such as rent, utilities, or food.

For example: A mother of two children, ages three and six, working part-time making \$900 per month, would face the following costs if both children had ear infections, even if she were enrolled in the low cost sharing plan:

2 visits to the doctor for	
each child	\$40 copayments
2 prescriptions	\$10 copayments
Total cost for one	
episode of illness	\$50

These copayments amount to a third of the mother's take-home pay for the week. After paying for rent, utilities, and other necessities, this mother likely has <u>no</u> disposable income with which to meet such obligations.



For adolescents with low incomes, we can expect these cost sharing obligations to result in unintended and undesirable consequences:

- The copayment requirements are particularly problematic for adolescents with chronic illnesses and disabilities.
- People will defer seeking care until their illness degenerates into an emergency, harming their health and risking hospitalization at much higher cost. In Massachusetts, for example, preventable hospitalizations were estimated to have cost \$347 million in 1989 and 1990 for people under age 64. Asthma hospitalizations alone, which primarily affect children, cost over \$46 million during the same time period.⁶
- Limiting protections for cost sharing to AFDC and SSI recipients, arbitrarily distinguishes among people with low incomes and creates new barriers for people who are trying to enter the labor market. Adolescents no longer eligible for cash assistance (e.g., those gainfully employed or who recently turned 18) would be denied protection, regardless of their poverty status. Moreover, because SSI and particularly AFDC levels vary markedly among states, federal subsidies tied to receipt of cash assistance do not treat people fairly on a nationwide basis, even accounting for regional cost-of-living differences.
- People with low incomes who need the limited mental health services covered by the Health Security Act would be particularly disadvantaged. The \$25 copayment, coupled with the frequent interventions that such care often requires, would put these services out of reach for adolescents living in poverty.

- Emergency room copayments would cause many people experiencing true emergencies to delay commencement of care and would impose an unfair premium on people who cannot find linguistically and culturally appropriate primary care except in an emergency room. Such copayments also would prevent access to primary care in communities where the emergency room is the only source of primary care.
- Because no reduction in cost sharing is available except to enrollees in "low cost" plans, people living in poverty would be locked into closed-panel plans, and segregated care is thereby assured. Low income adolescents who require access to out-of-plan specialists available only by paying deductibles and coinsurance would be denied that access solely based on income.
- Copayments would create a significant barrier to adolescents who have no income of their own and who seek confidential care, for example, for family planning services.

Recommendations: Cost sharing limitations should be applied to all individuals and families with low incomes and should not be restricted to those receiving cash assistance. In order to avoid imposing financial barriers to care, copayments must truly be nominal for people with low incomes, and providers should be prohibited from denying services to persons who are unable to pay the fee. No copayments should be imposed for preventive services such as family planning, health education and anticipatory guidance, vision care for children, and preventive dental services, or for emergency room services in communities where culturally or linguistically appropriate primary care services are not available. Some relief from cost sharing beyond copayments also should be made available, at



45

least to people with chronic illnesses and disabilities (e.g., by imposing a monthly limit on out-of-pocket costs).

Premiums

Overview of premium obligations and subsidies

Under the Health Security Act, premiums would be set by each plan within a range established by the alliance. Premium obligations would be the responsibility of a family, rather than a family member, and while penalties will be charged if premiums are not paid, services could not be denied based on nonpayment of premiums.

Basically, if a member of the family is employed full-time, the employer would pay 80 percent of the weighted average premium and the family would pay the remainder, which, depending on the plan they select, would be about 20 percent of the total premium cost." The employer payment would be considered a "credit" against the total premium cost (referred to as the "alliance credit"); families with no qualifying wage earner must "repay" all or part of the credit to the alliance. Some individuals and families, therefore, would be responsible for 100 percent of the premium (sections 1342, 1343 and 6103).

Premium subsidies would be available as follows:"

- Premiums would be <u>paid in full</u>, up to the weighted average premium within the alliance area, for all recipients of AFDC or SSI;
- Premium subsidies for other consumers with low or moderate incomes would be available toward the <u>20</u> <u>percent family share</u> as follows:

A sliding scale subsidy (referred to as the "premium discount") is available to families with "adjusted income" of up to 150 percent of the fpl." No premium is required for individuals or families with annual income below \$1,000; above that amount, payments would increase based on income and the applicable marginal rate. According to the formula, families at 150 percent, of the fpl would be expected to pay 3 percent of their income toward the 20 percent "family share" (section 6104)."

The bill caps premium obligations (relating to the 20 percent share) at 3.9 percent of income for families with adjusted income above 150 percent of the poverty line but below \$40,000 (section 6104(c)(3)(A)(ii)).

An additional subsidy would be available for persons eligible for a premium discount if the alliance determines that the individual or family "is unable to enroll in a lower than average cost plan . . . that services the area." The subsidy would be whatever is required to permit the household to enroll in a plan without having to pay a family share of premium in excess of the premium caps (section 6104(b)(2)).

 Premium subsidies also would be available to individuals and families who must "repay" the alliance credit, i.e., the 80 percent employer share. Individuals and families would be responsible for all or part of the 80 percent employer share when no one in the family is employed by one employer at least 40 hours in a month. This subsidy would be determined on a sliding scale, based on "wageadjusted" income.14 Individuals and families with "wage-adjusted" income below \$1,000 would not pay any of the 80 percent share; individuals and families with "wage-adjusted" income at the poverty level would pay no more than 5.5 percent toward the 80 percent share. The subsidy phases out at 250 percent of "wage-adjusted" income (section 6113).



A special subsidy generally available to small businesses would apply as well to self-employed individuals and families. Under this subsidy, people with low incomes otherwise obligated to repay the alliance credit because they are self-employed would have their 80 percent premium contribution capped at 3.5 percent of income (section 6123).

General concerns regarding premium obligations

The bill provides adequate protection for recipients of cash assistance, but many adolescents and their families with low-incomes who do not receive AFDC or SSI would be responsible for a burdensome and largely unaffordable premium. This is particularly true for individuals and families for whom no employer payments are made, including people who are self-employed or who work sporadically and for multiple employers. Many adolescents would be affected by these burdensome premium payments either as members of a family subject to these payments or as emancipated minors or as parents living on their own with their children.

For example: An 18-year-old pregnant adolescent living apart from her family works two days a week, each day for a different employer, in addition to participating in a job training program. Her total gross monthly income from her wages is \$344—well below the federal poverty line. Because she works a limited number of hours for more than one employer, no employer pays a premium on her behalf. Despite her very low income, her annual premium responsibility, considering available discounts and reductions, would be \$266—more than three-quarters of one month's income.

Recommendation: Premium subsidies should be increased to ensure that health care is affordable for all individuals and families. The scales and premium percentage caps should be revised to provide more relief to families with low incomes, and subsidies should be applied more evenly based on ability to pay rather than on source of wages.

Specific adolescent-related concerns regarding premium obligations

Two additional adolescent specific concerns related to premiums flow from the bill's broad definition of "family." The first concern is that the bill authorizes the National Health Board to require that certain three-generation households be considered one family (i.e., if the grandchild's parent is an adolescent and the adolescent, her baby, and her parent(s) live together; and no one receives AFDC or SSI). In some instances, particularly where the grandparent has other children living at home, this definition might help, or at least not hurt, the family in terms of affordability of payments. However, in most instances, that provision can be expected to make it more difficult for the adolescent and her baby to afford health care.

If the adolescent parent and baby have limited income, which is quite likely, their premium subsidy amount would be greater if they were allowed to participate in the system as a separate family. By grouping the adolescent parent and baby with the grandparent(s), the adolescent would lose her subsidy, and the grandparent's premium payments would likely be higher (depending on the grandparent's income and whether other children were in the home). The option for the adolescent would be to marry (married minors are considered a separate family) or move out. Neither consequence necessarily benefits the health and safety of the adolescent and her baby, and the policy creates a dynamic which is in opposition to many current welfare reform initiatives.



The second concern also relates to family definition rules. Even adolescents living away from home may be considered part of the parent's "family." Like the "grandparent" rule discussed above, this rule would affect different families differently. By considering adolescents living apart from their parent(s) (e.g., an adolescent who moves out of her parent's home because of ongoing disputes and moves in with an older sister or friend) as part of the parent's "family," the adolescent loses the ability to select a plan independently and remains subject to the parent's ability to pay the family premium. From an affordability point of view, this may or may not be harmful to the adolescent; but it seems clear that such a rigid and overly inclusive definition of "family" unduly restricts the ability of adolescents to choose a plan that meets their needs.

Recommendation: Allowing adolescents who are living apart from their parents and pregnant and parenting adolescents living with their families, the choice of whether to participate in the system as part of their family of origin or as a separate household would permit enough flexibility to address various and often complex family situations and extenuating circumstances.

Financing of Adolescent Services

The Health Security Act properly and commendably recognizes that access to health care entails more than conferring the right to universal coverage. Efforts to assure that the delivery of services is sensitive to consumer needs are critically important. In the context of national health care reform, delivery mechanisms that are currently functioning must be safeguarded and secured a place in the new system; and where the current infrastructure fails to meet community needs, new resources and priorities for the delivery of services must be forthcoming.

This is especially true for health care services for adolescents. Adolescents tend to access health care, if at all, in ways which are distinctly different from younger children or adults. Successful models for the delivery of adolescent health services emphasize accessibility, limit gate-keeping barriers, and assure that their service providers are sensitive to the particular needs of adolescents. Fortunately, successful models have blossomed over the past few years in communities throughout the country, but unfortunately, many have been threatened by market forces and managed care models that often do not provide specialized adolescent services nor pay for care at alternative sites.

While the Health Security Act takes a number of steps toward recognizing the importance of specialized services for adolescents, further steps will be required if these and other community-based providers of health care services are to be supported.

Overview of the Health Security Act provisions relating to the financing of adolescent health services

The financing anticipated under the Health Security
Act for community- and school-based providers of
adolescent health services flows from two sources:
(1) payments by alliance health plans for services
otherwise required to be provided by the plans; and
(2) additional federal funding. Both sources of financing depend on community- and school-based
providers having been designated as "essential community provider(s)."

The Health Security Act establishes a process whereby the secretary of health and human services is directed to certify certain providers as "essential community providers," a designation that applies to any of 11 specified categories of providers, including school health service providers, migrant health centers, community health centers, health care for the homeless program providers, and AIDS providers under the Ryan White Act (sections 1581 and 1582).



Adolescent health and mental health service providers outside of the school setting would not be separately designated as essential community providers, but might be certified as such if they receive funds under Title V of the Social Security Act or are part of a "community practice network."

A provider certified as an "essential community provider" can elect to have a formal relationship with each alliance plan serving its region. The Health Security Act provides that, for the first five years of implementation, each regional alliance health plan would be required either to subcontract with or to pay fee-for-service reimbursement to "electing" essential community providers other than providers of school health services (section 1431). Although subcontract agreements must include terms at least as favorable as terms applicable to other plan providers, the Health Security Act would not require plans to pay essential community providers more than others or to safeguard them against additional risk, even though their patient mix would likely have above-average health costs.

Plans that do not subcontract with electing essential community providers must agree to pay such providers on a fee schedule developed by the regional health alliance or based on Medicare rates (the choice of payment schedule is to be made by the community provider). The bill specifically directs that essential community providers that are reimbursed on a fee-forservice basis (i.e., not through a subcontract agreement) shall not be subject to plan gate-keeping requirements; thus, presumably, where community providers subcontract with plans, the plan's gate-keeping rules would apply (section 1431(c)(2)). The choice as to whether to enter into a subcontract with a plan or to establish a fee-for-service reimbursement relationship does not appear to lie exclusively with the community provider.

With respect to plan payments for school health services, the bill simply states that health plans "shall pay to each provider of school health services located in the plan's service area an amount determined by the secretary [of health and human services] for such services furnished to enrollees of the plan" (section 1431(e)).

Financing of community- and school-based adolescent services also would be available potentially through a number of initiatives relating to medically underserved populations, mental health and substance abuse services, and initiatives specifically relating to school-based services (subtitles E, F, and G of Title III of the Act). Funding, however, would not be appropriated or otherwise assured by the Health Security Act, but merely "authorized for appropriation." Programs for promoting health, for serving medically underserved populations, and for paying hospitals that serve vulnerable populations are included among these important initiatives.

Subtitle G of Title III of the Health Security Act is concerned exclusively with "comprehensive school health education and school related health services." State and local community education and health agencies as well as providers working together with local agencies can receive planning grants as well as development and operation grants under the initiatives outlined by the Act. With respect to school-related health services, preferences in funding would be granted to communities with the greatest need among 10-19year-olds with low incomes. The Health Security Act does not specify how the services funded would interrelate with alliance plans, but it does require grant applicants to show how linkage would be arranged. Operating grants for school health service sites may cover, but would not be limited to, services otherwise covered by plans, as well as enabling services (e.g., transportation, outreach, education, and translation), health education, and services to link students to health plans and other services. Significantly, the Health Security Act provides that school health service grantees cannot impose any cost sharing on students or families (section 3685(d)(4)).

Concerns and recommendations regarding the relationship between plans and community- and school-based providers of adolescent services

While the Health Security Act takes several critical steps toward requiring plans to provide financial support for community-based services, school-based services should not be excluded from receiving plan payment. Furthermore, more protection should be afforded to assure that plan funding does not depend on preauthorization of services and cannot be preempted if a plan determines that the community- or school-based services duplicate plan-provided services.

Adolescent health services provided in schools or in other community settings must be able to serve clients in a timely and specialized fashion. While linkages between programs and plans are necessary to assure continuity of care, adolescent health service programs which must first get plan approval before serving clients risk losing the opportunity to serve young people at the critical moment services are sought. Experience around the country overwhelmingly demonstrates that adolescents will lose access to services, and programs that serve adolescents quickly will be squeezed out of existence, if payment for services by plans is subject to preservice authorization and if authorization for payment is conditioned on whether such services are otherwise provided by the plan.

Recommendation: The categories of "essential community providers" should be clarified to assure that community-based adolescent health and mental health services are covered. School-based providers, which are considered essential community providers, should not be excluded from electing to contract with plans as such. Essential community providers should be able to choose whether to affiliate with a plan as a subcontractor or as a fee-for-service provider. In either case, plans should not be allowed to require plan

preauthorization as a condition of payment, although a requirement that the plan receive postservice notification of provision of services in order to assure continuity of care is appropriate. The Act should explicitly provide that payment for services shall not be withheld because the plan otherwise provides the service sought by the plan-enrolled adolescent.

Concerns and recommendations regarding public financing of adolescent health services

Even with established linkages between plans and community- and school-based health services, public financing of adolescent health services would be necessary to assure their continued viability. Communityand school-based services deliver exactly the kind of health care that is critical to promoting health and controlling costs, and they are directed at particularly vulnerable health care consumers who do not always comprehend the rules and who might not or, in some cases, cannot always be expected to follow traditional means of gaining access to care or using services. Moreover, such services should be available to all persons who need health care, including those who might otherwise not be covered by plans due to their immigration status. Finally, unless plan-provided payments are risk-adjusted to account for the generally highly needy populations served by adolescent health care providers, public funds must be sufficient to assure that programs can provide comprehensive services to those adolescents most in need.

The Health Security Act goes far in recognizing and supporting such services; but much of the funding under the Act would be neither steady nor reliable, and without maintenance-of-effort requirements, federal funding through a national health care reform bill might only replace—or worse, not even replace—unds currently made available at the state and local tevels.



Recommendation: The funding for the special access and service initiatives in the Health Security Act, including school health education and school health services, should be guaranteed through appropriations adequate to develop capacity and support the ongoing provision or services. Funding should not be limited to services provided to eligible individuals, and should reflect ris' .djustment factors established by the National Health Board to assure that programs are not discouraged from serving the most disadvantaged adolescents. State maintenance-of-effort requirements should apply to all areas covered by the initiatives.

Endnotes

- Newacheck, P.W., and McManus, M.A. (1988). Health insurance status of adolescents in the United States. *Pediatrics*, 84(4), 699-708.
- 2. Center for the Future of Children (1992). U.S. health care for children. Los Altos, CA: Center for the Future of Children, David and Lucile Packard Foundation.
- 3. No cost sharing can be required for the following preventive services:
 - (1) prevention and diagnosis of dental disease;
 - (2) clinical preventive services (between ages 13 and 19, only three visits are exempt from the cost sharing obligation (section 1114(e)); and
 - (3) clinician visits and "associated services" related to prenatal care or one postpartum visit.

In addition, the "low cost sharing" plan does not impose copayments for durable medical equipment, laboratory services, home health services, and inpatient hospital services (section 1135).

4. It is significant to note that the Health Security Act proposes that all subsidies be so-called "capped entitlements," meaning that, unlike other entitlements such as Medicaid or food stamps, a designated amount of funds would be appropriated and no authority

- would exist to grant subsidies to eligible people if the funds proved to be inadequate and no further appropriation was made.
- 5. While subsidies are determined with reference to the federal poverty line, the bill provides that the normal poverty line household size differentials would not apply. Under the bill, subsidies for single parents with children would be evaluated with reference to the three-person poverty line standard, and subsidies for two-parent families with children would be evaluated with respect to the four-person poverty line standard—in all cases, without regard to actual family size. This creates a disadvantage for families with more than two children. (section 1902 (25)).
- 6. Massachusetts Rate Setting Commission, 1993.
- 7. Section 1011 defines "family" to mean an individual eligible to participate in a plan, the individual's eligible spouse, and the individual's and spouse's eligible children. "Child" is defined as an eligible individual who is under 18 years of age (or under age 24, in the case of a full-time student) and a dependent. State law is used to determine whether a person is a child, but the National Health Board is authorized to establish uniform rules, which, according to the bill, shall define a "child" to include:
 - (1) a step or foster child "living with an adult in a regular parent-child relationship;"
 - (2) certain disabled adult children ("an unmarried dependent eligible individual regardless of age, who is incapable of self-support because of mental or physical disability which existed before age 21"); and
 - (3) the grandchild of the individual, if the parent of the grandchild is under 18 and both the parent and the grandchild are living with the grandparent.

Emancipated minors and married individuals, however, would not be considered children. The



bill authorizes the National Health Board to establish exceptions and special rules for families in which members are not residing in the same area and for the treatment of individuals under age 19 who are not dependents of an eligible individual.

Note that since AFDC and SSI recipients are considered separate families (that is, under the bill, AFDC and non-AFDC or SSI and non-SSI members of a household cannot be combined into one family), adolescents in the home who lose AFDC eligibility based on their age or other program requirement would be required to sign up for a plan on their own and to be responsible tor paying its premium.

- 8. The bill, however, does not bar unfair or inefficient collection methods (section 1344).
- 9. "Full-time" employment is defined as at least 120 hours of employment in a month. People employed for at least 40 but less than 120 hours in a month, are part-time employees, and their employer's premium obligation is determined in proportion to their hours worked (section 1901(b)(2)).
- 10. The subsidies described apply to individuals and families enrolled in regional alliance plans. Different rules apply to individuals and families enrolled through a corporate alliance (section 1311 definition of "corporate alliance"). For workers with annual income below \$15,000, their corporate employer would pay 95 percent of the price of the lowest-cost corporate plan or 80 percent of the average corporate plan premium, whichever is greater; the low income worker would pay the remainder (section 6104(a)(2)).
- 11. "Adjusted income" includes income of all family members and is broadly defined by reference to the "adjusted gross income" section of the Internal Revenue Code, section 62. It includes all wages, student stipends, and certain retirement payments. It does not include normal trade or business expenses, public

- assistance payments, alimony, and income from certain types of retirement accounts. Although additional clarity would be helpful, it appears that the bill adopts the Internal Revenue Code provision whereby social security payments for low to moderate income people are not considered income (section 1372).
- 12. The bill further provides that "in no case" shall families with incomes below 150 percent of the poverty level be required to pay more than 3.9 percent of their income toward the 20 percent family share (section 6104 (c)(3)(A)(i)). All amounts, including the \$1,000 threshold amount, are to be adjusted based on inflation for years following 1994.
- 13. For purposes of determining "wage-adjusted income," wages used to compute any employer premiums paid on behalf of the family (i.e., for part-time or seasonal employees) and income from unemployment insurance benefits are not considered (section 6113(d)).
- 14. The definition of "family" also has significant impact on other matters of importance to adolescents, most notably the ability to choose another provider because of preference, specialty, location, or desire for confidentiality. These important matters are not within the scope of this paper.
- 15. The secretary of health and human services is directed to publish standards for the certification of additional categories of health care providers and organizations, but these additional designations do not appear to be intended to respond to unmet and often unique needs of particular segments of the population (such as adolescents), since they require a determination by the secretary "that health plans operating in the area served by the applicant would not otherwise be able to assure adequate access to items and services included in the comprehensive benefit package..." (section 1583) (emphasis supplied).



43

- 16. By March 2001, the secretary of health and human services would make recommendations to Congress about the continuation of these essential community provider protections. Such recommendations would go into effect unless disapproved by a joint resolution of Congress within 60 days (section 1432).
- 17. There is a state maintenance-of-effort requirement with respect to mental health and substance abuse service initiatives (section 3502(d)), but there does not appear to be any parallel requirement with respect to the other initiatives, including the school health education and services initiatives.



Adolescents and Health Care Reform: Protecting Special Populations

ABIGAIL ENGLISH
National Center for Youth Law

114 Sansome Street, Suite 900 San Francisco, CA 94104 Tel: (415) 543-3307

Fax: (415) 956-9024

Preparation of this paper was supported in part by the David and Lucile Packard Foundation and by the Center for Children with Chronic Illness and Disability, University of Minnesota, under a grant from NIDRR, U.S. Department of Education. The views expressed herein are solely those of the author and not of the funding entities.



Adolescents are uninsured and underinsured at a higher rate than many other age groups; the benefits available under most private health insurance plans and public health care financing programs are not adequate to meet their needs; and the health care delivery system, overall, is not designed for adolescents. These problems are even greater for certain special population groups of adolescents, whose needs vary from those of the general adolescent population.

These special groups include adolescents who are poor; members of racial and ethnic minority groups; those who are living apart from their families, such as runaway and homeless youth, adolescents in foster care, and incarcerated youth; undocumented adolescents; pregnant and parenting adolescents; gay and lesbian youth; and adolescents with chronic illnesses and disabilities. Each group has special needs in relation to the health care system.

Poor. In 1988, more than 8 million adolescents 10-to 18-years-old were living in poor or near-poor families with incomes under 150 percent of the poverty level. The poverty status of adolescents has significance for both their health status and the likelihood that they have adequate insurance or any insurance at all. Poor adolescents are more likely to have a serious chronic illness or condition: In 1988, adolescents whose family incomes were under \$10,000 were more than twice as likely as those whose family incomes were \$35,000 or above to be limited in a major activity as a result of a chronic condition.' They are also more likely to be uninsured and underinsured. Poor, near-poor, and minority adolescents are at the greatest risk among those in their age group for lack of health insurance coverage.

Minority. The proportion of adolescents in the United States who are living in poor or near-poor families varies by race and ethnicity. As is poverty, racial and ethnic minority status is strongly associated both with

lack of adequate insurance coverage and with adverse health status.' For example, black and Latino adolescents are disproportionately represented among adolescent AIDS cases, and Native American adolescents are at high risk for a number of health problems, including suicide, alcohol abuse, mental health problems, and pregnancy.'

Living apart from families. Estimates of the number of runaway and street youth vary from less than 1 million to more than 2 million. In 1985, an estimated 120,000 adolescents were in foster care. And in 1987, there were about 700,000 adolescents confined in public or private juvenile justice facilities, including a disproportionate number of black males. Because these young people experience certain health problems more frequently than other adolescents, they have more intense needs for certain health services such as, for example, mental health services and substance abuse treatment.

Pregnant and parenting. Approximately 1 million adolescents become pregnant each year; about half of these young women have abortions and about half give birth. In 1988, about 65 percent of adolescents who gave birth in the U.S. were unmarried. Many of these young women and girls are not living in a supportive family environment and may, therefore, have difficulty establishing access to both the health care they need and the insurance coverage (public or private) to pay for it.

Gay and leshian. Accurate estimates are not readily available of the numbers of adolescents who are gay, lesbian, or bisexual or who engage in sexual behaviors with members of the same sex. Large scale population-based epidemiologic research on sexual behaviors of all age groups has been limited, and special problems of consent arise in doing research on the sexual behaviors of adolescents who are minors. Nevertheless,

anecdotal evidence based on the experience of those who work with adolescents, as well as data resulting from the HIV epidemic, suggest that a significant number of young people engage in same sex sexual behaviors.* Those adolescents who specifically identify themselves as gay or lesbian experience severe problems of discrimination and ostracism, which contribute to or compound the other health problems they experience.

Chronically ill and disabled. An estimated 5 to 10 percent of adolescents experience a serious chronic health condition that severely limits their activity; and approximately 5 percent are limited in a major activity such as school attendance as a result of such a condition. These conditions include leukemia, severe asthma, cystic fibrosis, traumatic brain injury, cerebral palsy, diabetes, hearing or visual impairment, sickle cell disease, and mental retardation. Significant numbers of adolescents also suffer from serious mental illness.

What Do Adolescents Need from Health Care Reform?

Any health care system that is to meet the needs of most special population groups of adolescents must contain certain key elements, including:

- universal coverage;
- simple enrollment procedures;
- independent access;
- comprehensive benefits;
- · affordable services;
- portable coverage;
- · accessible, age-appropriate sites; and
- access to specialists with expertise in and sensitivity to adolescents' special needs.

These elements are important in meeting the needs of all adolescents and of children generally." The unique social circumstances and psychological and physical needs of special populations of adolescents, however, make these elements even more critical to ensuring the accessibility of health care for these youth. In particular, many of these young people are separated entirely from their families or are unable to depend on them for the adult support they need to gain access to health care.10 11 Moreover, several of the special population groups, particularly those with chronic illnesses and disabilities, need more extensive and intense health care services than do other adolescents. However, these youth also share many of the same characteristics of other adolescents, and therefore, require access to services from health care professionals and at sites with adolescent-specific expertise. Because the existing health care system has fallen far short of meeting the needs of special populations of adolescents in critical respects, a successful health care reform plan will need to change significantly the way the health care financing and service delivery systems operate with respect to adolescents.

How Would the Mitchell/Gephardt (Clinton) Plan Affect these Special Populations?

The Health Security Act, as introduced in Congress on November 22, 1993, embodies President Clinton's proposal for health care reform. It would significantly change and improve the way the health care system now meets the needs of all Americans, including children and adolescents. Most notably, with few exceptions, all individuals would be covered and would be entitled to a uniform set of benefits. Although the Health Security Act contains a number of advantageous provisions, it would need to be modified to fully



meet the needs of special populations of adolescents; for example, one area of concern is the potential impact of the Health Security Act on adolescents in foster care.¹³

Universal coverage. The Health Security Act would provide universal coverage, with at least one major exception: undocumented immigrants would not be covered.11 This would, of course, have a particularly severe impact on certain minority groups such as undocumented Latino adolescents. These young people would continue to be eligible for emergency services through Medicaid¹⁸ and would be able to receive other services through a variety of public health programs and community health centers, to the extent that the funding and infrastructure to provide services in this way conting to exist. Coverage of one additional group of adolescents is somewhat ambiguous in the Acr: Adolescents who are in the juvenile justice system theoretically would be covered, because prisoners (who are excluded from coverage) are defined as individuals who are incarcerated following conviction as adults.16 Nevertheless the Act also specifies that health plans are not required to provide any reimbursement to detention facilities for services performed in the facility."

Simple enrollment procedures. Under the Health Security Act, "enrollment" would involve a variety of procedures and a number of separate steps. For example, in addition to enrolling in a health plan through a regional or corporate alliance, an individual or family would have to establish eligibility for premium subsidies and for entitlement to reduced copayments (20). Adolescents with a chronic illness or disability would have to apply separately for services under the new home- and community-based long-term care program, which would be administered by the states; and low-income adolescents who were AFDC or SS1 recipients or who met financial criteria would have to apply sep-

arately for continued Medicaid coverage or coverage of expanded benefits through a new federal program for low-income children with special needs.^{21 25}

Independent access. The enrollment procedures and process for establishing eligibility for a range of benefits would be particularly problematic for adolescents who need access to health care independent from their families, either because their parents are unwilling or unable to assist them in obtaining health care or because they themselves are unwilling to involve their parents. Some, such as homeless and runaway youth, or gay and lesbian adolescents, might simply go without health care entirely, unless they are able to obtain it independently. Others, such as those in foster care, also might need independent access, if their state care-takers do not enroll them in an appropriate plan or otherwise provide for their care.

Although the Health Security Act provides that each "eligible individual" is to receive a health security card, it specifies no procedures for adolescents to receive their cards separate from their families. The enrollment procedures contained in the Health Security Act assume that children and adolescents will be living with their parents. All members of a family are expected to enroll, through a regional or corporate health alliance, in the same health plan. Some adolescents who live apart from their families might not be enrolled in a plan at all or might be unable to access services from the plan in which they are enrolled. For example, adolescents enrolled in a plan could only have independent access to services if they were able to make copayments or meet coinsurance requirements themselves.26

Even if they were permitted to do so, however, most adolescents would be unable to enroll in a plan separate from their families unless they could establish eligibility for premium subsidies (or for continued Medicaid status, in which case their premiums would be paid by the state) based on their own income. If



adolescents were not enrolled in a plan, they would not be barred from seeking health care services, but their doing so would trigger procedures through a health alliance to determine their enrollment status and to ensure their enrollment. Those procedures almost inevitably would lead to the involvement of their families.

Comprehensive benefits. The Health Security Act would provide for a "comprehensive" benefits package for all eligible individuals, which is one of the major advantages of the Administration's plan.²⁸ Certain benefits, however, are subject to significant limitations, which would fall heavily on some groups of adolescents. For example, limits on outpatient mental health services would be especially troublesome for many of the special population groups, and the limits on outpatient rehabilitation services would adversely affect many adolescents with chronic illnesses or disabilities.^{20 Str.}

Coverage for only three clinical preventive visits for 13- to 19-year-olds is also a significant limitation. This is not frequent enough for adolescents at high risk for a variety of serious health problems, as many of the special populations are. Annual Pap smears are covered for females who are of childbearing age and who are at risk for cancer, and screening for chlamydia and gonorrhea also is provided for females who are of childbearing age and at risk for fertility-related infections, but no comparable coverage is provided for males.

Moreover, services for pregnant women are not defined and, unless abortion services are covered, the half-million pregnant adolescents who choose to terminate their pregnancies each year will be adversely affected." In addition, the absence of coverage for case management, except for substance abuse and mental health services, may be particularly worrisome for special populations of adolescents, who have

complex needs and require a range of diverse health care and related services.

Some adolescents would be able to qualify for expanded benefits based on certain eligibility requirements. For example, home- and community-based services might be available through a new long-term care program.44 However, the eligibility criteria would restrict those services to a very small number of the most severely disabled youth, and states would have virtually complete discretion to determine which services to offer. 55, 56 Expanded benefits (beyond the "comprehensive" benefit package) would be phased in for AFDC and SSI recipients and for adolescents living below the poverty level through either a continuation of Medicaid or a new federal program." " However, not all adolescents in the special population groups would meet these criteria, even though their need for the expanded services might be compelling.

Affordable services. The affordability of services for adolescents under the Health Security Act would depend on several factors: the premium cost for coverage through a health plan; the copayments and coinsurance costs associated with specific services available through the "comprehensive" benefits package or other means; the availability of subsidies for or reductions in these costs for adolescents who are living at or near the poverty level; and the availability of expanded services with little or no cost sharing. "12"

The Act would provide discounts on premiums for AFDC and SSI recipients and for other very low income individuals or families." Reduced copayments would be available in the low-cost plans, but only for AFDC and SSI recipients and individuals or families with incomes below 150 percent of the poverty level." The affordability of services would vary depending on which plan an adolescent was enrolled in, but even the copayments in the low-cost plan—e.g., \$10 for an office visit, \$25 for a psychotherapy visit—would not be affordable for adolescents who need independent



access or who are from low-income families but who do not qualify for reduced copayments.⁴⁵

While there is no charge for clinical preventive services, the three clinician visits covered as preventive services for 13- to 19-year-olds are insufficient in number for adolescents who need frequent monitoring of their health status and who are unable to pay for cost sharing.** Even for adolescents who are eligible for broader services under Medicaid or a new federal program, copayments and coinsurance would apply for services in the comprehensive benefits package. thus creating an affordability problem for the basic services. 15.49 Since many adolescents who are members of special population groups either need services on an independent basis or are from low-income families. and also have extensive health needs, the affordability of services is a significant issue. Even for youth who are in the custody of the state, such as adolescents in foster care, the affordability issue is significant because it is unclear who is responsible for payment in such cases.

Portable coverage. Under the Health Security Act, coverage is portable, in that it cannot be canceled or denied when an individual or family moves to a new job or another geographical area. However, the system assumes that people will not move frequently. Only after three months in a new location would enrollment in a new plan be available. In the interim, only urgent services could be obtained, unless the person is enrolled in a fee-for-service plan or pays for services out of pocket. This is particularly unrealistic for adolescents living apart from their families, either as runaways and homeless youth or in foster care, although the National Health Board would be authorized to make rules concerning children and adolescents who are not residing with their parents.

Accessible, age-appropriate sites. Accessible, age-appropriate sites in some cases might include the regular

health plans available through the health alliances, but many youth in special populations will require care from other providers and at other sites. The extent to which health plans subcontract with "adolescent-friendly" providers could be critically important. Health plans generally are required to contract with "essential community providers," which would include many, but not all, providers who specialize in serving adolescents. It is also possible that some providers who focus on adolescents could receive assistance from alliances to form plans in underserved areas. Without these alternatives, however, many adolescents, and particularly those in special population groups, might not have access to services in age-appropriate and welcoming sites.

Access to specialists. Access to specialists could be a critical issue for these population groups. For youth with chronic illnesses and disabilities access to out-of-plan providers would be available, but only for those adolescents who are able and willing to pay the high coinsurance rates that apply in combination plans or fee-for-service plans or to pay an additional premium to cover out-of-plan services if enrolled in a low-cost plan such as a closed-panel HMO. 55.56 No subsidies are available for this or for the higher cost of enrollment in fee-for-service plans. Certain expertise is scarce enough (e.g., experience in working with gay and lesbian youth or treating rare diseases) that it will be unavailable in many plans.

How Would Other Health Care Reform Proposals Affect these Special Populations?

Many analysts and observers have concluded that the only health care reform plan other than the Administration's plan that would offer significant benefits for children and adolescents is the



McDermott/Wellstone/Conyers plan.` This single-payer plan would provide for universal coverage of preventive, acute, and chronic care for all children and adolescents. It would eliminate most financial barriers to care and would allow individuals and families, regardless of income or employment status, full choice among providers. For special populations of adolescents, this approach would have a number of advantages and would eliminate many of the complexities of other plans.

None of the other five leading health care reform proposals—Gramm/Armey, Thomas/Chafee, Cooper/Breaux, Michel/Lott, or Stearns/Nickles comes as close to meeting the needs of special populations of adolescents as either the Administration's Health Security Act or the McDermott/Wellstone/Convers bill. Significant limitations in these proposals include the absence of a guarantee that all adolescents would have coverage without placing heavy financial burdens on their families, and limiting coverage to "catastrophic" coverage which would take effect only after a \$3,000 deductible has been met. Other limitations include the absence of coverage for preventive care for children and adolescents and prenatal care for all women, including adolescents, and the absence of a guarantee of comprehensive benefits including mental health, dental services, and prescription drugs.

Recommendations

The Health Security Act contains numerous provisions that would greatly benefit adolescents in general and special populations of adolescents in particular. The other leading proposals, with the possible exception of the McDermott/Welistone/Conyers proposal, are seriously deficient in their ability to meet the needs of these groups. Nevertheless, whatever version of a

national health care reform plan ultimately is adopted, certain issues must be addressed in order to assure that the needs of special populations of adolescents are met. The following recommendations address those issues:

Recommendation 1: Design application and enrollment procedures to enable adolescents living apart from their families to establish their entitlement to coverage separately and to qualify for subsidies and reduced cost sharing.

Recommendation 2: Structure subsidies and cost sharing to ensure that special populations of adolescents can obtain health care, including care by appropriate specialists, without incurring costs that are so high that they deter adolescents from using essential services.

Recommendation 3: Provide critically important services, such as clinical preventive services, reproductive health services, mental health services, rehabilitative services, and case management services, in an amount and at a cost appropriate to meet the needs of special populations of adolescents.

Recommendation 4: Ensure that essential services that are not included in a universally available guaranteed benefits package are available to special populations of adolescents through either continued Medicaid coverage or an expanded benefits package which, at minimum, is available to low-income children and adolescents with special needs.

Recommendation 5: Provide sufficient funding and other logistical support to ensure that the health care providers and delivery sites most experienced in providing services to special populations of adolescents are able to continue doing so and that new sites are developed as needed.



References

- U.S. Congress, Office of Technology Assessment. (1991). Adolescent health volume I: Summary and policy options. Washington, DC: U.S. Government Printing Office.
- U.S. Department of Health and Human Services, Public Health Services, Centers for Disease Control, National Center for Health Statistics. (1990). Unpublished data from the 1988 National Health Interview Survey. Hyattsville, MD: National Center for Health Statistics, U.S. Department of Health and Human Services.
- 3. Newacheck, P. W., McManus, M. A., and Gephart, J. (1992). Health insurance coverage of adolescents: A current profile and assessment of trends. *Pediatrics*, 90(4), 589-596.
- 4. U.S. Department of Health and Human Services, Office of Human Development Services, Administration for Children, Youth, and Families. (1985). Runaway youth centers: FY 1984 report to congress. Washington, DC: Administration for Children, Youth, and Families, U.S. Department of Health and Human Services.
- Council on Scientific Affairs, American Medical Association. (1989). Health care needs of homeless and runaway youth. *JAMA*, 262(10), 1358-1361.
- William T. Grant Foundation Commission on Work, Family and Citizenship. (1988). The forgotten half: Pathways to success for America's youth and young families. Washington, DC: William T. Grant Foundation Commission on Work, Family and Citizenship.
- 7. U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics. (1990). Advance report of final natality statistics, 1988. Hyattsville, MD:

- National Center for Health Statistics, U.S. Department of Health and Human Services.
- 8. U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention. (1993). HIV/AIDS Surveillance Reports, 5(3), 10.
- 9. Perkins, J., and English, A. (1993). Evaluating health care reform proposals in the interest of children and adolescents. *Clearinghouse Review*, 25, 428-440.
- 10. Wright, J. D. (1991). Children in and of the streets: Health, social policy, and the homeless young. *American Journal of Diseases of Children*, 145(5), 516-519.
- 11. National Commission on the Role of the School and the Community in Improving Adolescent Health. (1990). *Code blue: Uniting for healthier youth.* Alexandria, VA: National Association of State Boards of Education.
- 12. Health Security Act, H.R. 3600/S. 1757, 103rd Congress 1st Session.
- 13. Halfon, N., English, A., Allen, M., et al. (1994). National health care reform, Medicaid, and children in foster care. *Child Welfare*, 73(2), 99-115.
- 14. S. 1757 §§ 1001(c); 1005(a); 1902(1).
- 15. S. 1757 § 4201(a).
- 16. S. 1757 § 1902(26).
- 17. S. 1757 § 1402 (g).
- 18. S. 1757 § 1002(a)(1).
- 19. S. 1757 §§ 1373 and 6104.
- 20. S. 1757 § 1372.
- 21. S. 1757, Title II, Subtitle B, Part 2, §§ 2101-2109.
- 22. S. 1757 § 4221.
- 23. S. 1757 \$ 4222.
- 24. S. 1757 § 1001(b).



- 25. S. 1757 § 1011(a).
- 26. Mann, C. (1994). Issues for adolescents relating to the financing of health care. In Irwin, C.E., Brindis, C., Holt, K.A., and Langlykke, K. (Eds). *Health care reform:* Opportunities for improving adolescent health. Arlington, VA: National Center for Education in Maternal and Child Health.
- 27. S. 1757 § 1323(b).
- 28. S. 1757 §§ 1101-1128.
- 29. S. 1757 § 1115(e).
- 30. S. 1757 § 1123(b).
- 31. S. 1757 \$ 1114(e)(3).
- 32. S. 1757 § 1114(e)(2).
- 33. S. 1757 § 1116(3).
- 34. S. 1757 § 2104.
- 35. S. 1757 \ 2103.
- 36. S. 1757 § 2104(a)(1).
- 37. S. 1757 § 4221.
- 38. S. 1757 § 4222.
- 39. S. 1757 §§ 6101 and 6102.
- 40. S. 1757 §§ 1131-1135.
- 41. S. 1757 § 1371.
- 42. S. 1757 §§ 4221 and 4222.
- 43. S. 1757 § 6104 (a)(1).
- 44. S. 1757 § 1371(a)(1).
- 45. S. 1757 §§ 1131 and 1135.
- 46. S. 1757 §§ 1114 and 1135.
- 47. S. 1757 § 1114(e)(3).
- 48. S. 1757 § 4221.
- 49. S. 1757 § 4222.
- 50. S. 1757 § 1323(c)(3)(B).
- 51. S. 1757 § 1323(c)(3)(A).
- 52. S. 1757 \$ 1011(f)(1).

- 53. S. 1757 § 1431.
- 54. S. 1757 § 1329(b).
- 55. S. 1757 §§ 1132(a)(4); 1133-1135.
- 56. S. 1757 § 1402(d)(2) and (3).
- 57. American Health Security Act of 1993, H.R. 1200/S. 491, 103rd Congress 1st Session.
- 58. Comprehensive Family Health Access and Savings Act of 1993.
- 59. Health Equity and Access Reform Today Act of 1993, H.R. 3704/S. 1770, 103rd Congress 1st Session.
- 60. Managed Competition Act of 1993, H.R. 3222/S. 1579, 103rd Congress 1st Session.
- 61. Affordable Health Care Now Act of 1993, H.R. 3080/S. 1533, 103rd Congress 1st Session.
- 62. Consumer Choice Health Security Act of 1993, H.R. 3698/S. 1743, 103rd Congress 1st Session.

Training in the Era of Health Care Reform

KAREN HEIN M.D.

Professor of Pediatrics, Epidemiology and Social Medicine Albert Einstein College of Medicine Robert Wood Johnson Health Policy Fellow, Washington, DC

> Montefiore Medical Center 111 East 210th Street Bronx, NY 10467 Tel: (718) 882-0322

Fax: (718) 882-0432

Prepared for the Working Seminar on Adolescent Health and Health Care Reform January 10-11, 1994 Washington, DC



Critical Issues in Adolescent Health Training

Inadequately trained and distributed workforce

The most critical need in the area of adolescent health training is to ensure that sufficient numbers of health care professionals are trained and available to meet the health care needs of adolescents. Unfortunately, this is not the case today, as we enter the era of health care reform. Currently, most adolescents are cared for by professionals with little or no specific training in adolescent health. And among those with training, there is a maldistribution problem, with adolescent medicine divisions or training programs located mostly within large academic health centers, and a smattering of school-based or school-linked services and individual practitioners dispersed throughout the country, without specific consideration or planning regarding regional needs.

Mismatch between location of adolescent training programs and actual care providers

Currently, more than 75 percent of adolescents are cared for by family practitioners, whereas pediatricians account for only 5 percent of adolescent visits to physicians. Yet, few programs in family medicine or internal medicine specifically address the special needs of youth, and even fewer programs systematically expose their trainees to young people in ways that highlight the special developmental aspects of caring for them. In fact, most training programs in adolescent medicine reside in departments of pediatrics, quite separate from the arena in which the bulk of ultimate adolescent health care providers are trained.

Trends in adolescent medicine toward subspecialty certification and identity

For the past decade, there has been a concerted effort by some in the health care field to have adolescent medicine considered a subspecialty. That effort has resulted in the creation of a subspecialty board certification process within the American Boards of Pediatrics and Internal Medicine, and the opportunity for an added certificate of qualification within the Family Practice Board. This trend is out of synch with the current push away from subspecialty care toward primary care that is a basic tenet of all health care reform proposals. Subspecialty training requires additional years of postgraduate work with no clear market for these highly trained physicians in a reformed health care system, except perhaps as trainers, rather than practitioners.

Inadequate numbers and training of nonphysician providers to care for adolescents in community-based health agencies

Currently, a critical shortage exists of nurses, nurse practitioners and other advanced practice nurses, physician assistants, social workers, psychologists, nutritionists, and other health care professionals proficient in caring for adolescents. Yet, within the professional schools, adolescent-specific modules or rotations are nearly nonexistent. The Maternal and Child Health Bureau does fund seven interdisciplinary adolescent health training programs that produce appropriately trained professionals, but in insufficient numbers to address current needs, let alone future needs.



Lack of either current estimates or projections of workforce needs to adequately care for adolescents

Surveys of current use patterns of adolescents exist, but no estimates or projections have been calculated of actual needs to adequately care for adolescents now or in the future. Such projections have been calculated for primary care practitioners in general, and for pediatricians, general internists, and family practitioners specifically, but not for providers for adolescents as an age-specific cohort. Without these data it is impossible to make a case for resources to increase adolescent health training efforts under health care reform.

Health care reform plans and the need for an appropriately trained workforce

The Health Security Act (\$ 1775, \$ 1757, \$ 1779, and HR 3600) contains specific provisions that address the current imbalance of primary care providers versus subspecialists by calling for a 55/45 redistribution of graduating residents. However, given current residency choices, this ratio could not be achieved until 2020 at the earliest, and more likely toward the middle of the next century. To achieve this shift assumes rapid retooling of academic health centers, including changing medical school curricula: shifting postgraduate training sites away from inpatient, tertiary care settings to outpatient and community-based settings; influencing the choices, as well as number and location, of residency training slots; and altering the skills and abilities of the trainers of this new group of primary care trainces.

Adolescent medicine practitioners are specifically mentioned as a primary care discipline (along with geriatrics and preventive medicine) in the Senate Finance Committee proposal. Age-specific components of care appear in the description of preventive health visits and in new initiatives regarding school

related health services. Certainly, a case could be made for including adolescent medicine as part of the basic training of primary care providers, using the generalists criteria put forth in Marc Rivo's recent *JAMA* review.\(^1\) Of note is that the American College of Obstetricians and Gynecologists and others were successful in expanding the original list of primary care providers of pediatricians, general internists, and family practitioners to also include those obstetrics/gynecology practitioners providing primary care to women.

Specific incentives exist in several reform proposals to increase the workforce to include advanced practice nurses and other nonphysician providers, particularly those who could provide primary care. However, there is no indication that the specific needs of adolescents are recognized, nor that they are even considered as a group basic or important enough to include in the training of these providers.

A new category of provider defined in the Health Security Act, the "essential community provider," could be relevant to all adolescent health practitioners, regardless of discipline or training. This category would receive special dispensations from regional health alliances and accountable health plans because providers would serve unique populations, including the traditionally underserved or so called "hard-to-reach" populations. A case could be made that providers caring for homeless youth or school dropouts or other young people not living with families fall into this category.

The major financing mechanism for health care reform is the establishment of a health care premium. The sets of incentives for enrolling adolescents in care could assist those who care for adolescents because nonpaying or low-paying individuals theoretically could provide their accountable health plans with premiums that are currently being covered under uncompensated care. Some accountable health plans might be particularly interested in enrolling adolescents, since



68

they might view this age group as a relatively healthy population requiring few services. However, the link between these plans and training centers regarding adolescents is not specified, except where school-related services are described and special provision for funding demonstration projects is mentioned. Also, the way in which payments for Medicaid recipients are blended into payments by health alliances might affect the desire of accountable health plans to enroll adolescents, and thereby affect training of adolescent health care providers.

Under the current version of the Health Security Act, all youth housed in court-related facilities probably would continue to fall under the category of prison health services, which would not be incorporated into the new system, but would remain both separate and separately funded. This is particularly problematic for incarcerated youth, who frequently are housed in adult facilities or in youth centers or other facilities whose health services are even less adequate than those provided for adult prisoners. Given the other bills in Congress related to youth violence, it is likely that in the future more young people will be incarcerated and kept in prisons for longer periods of time, thereby exacerbating the problem.

The fate of adolescent health training programs probably will be closely linked to the fate of academic health centers. Although specific provisions exist for funding centers of excellence and centers of primary care training, the voice representing the needs of adolescent health care providers in most of the centers is neither strong nor prominent. As academic health centers struggle to survive the difficult transition period ahead, they undoubtedly will be concerned with three key elements: (1) their ability to be part of integrated care networks; (2) their ability to generate revenue through patient care; and (3) their ability to increase the number of primary care providers trained. It is not clear that academic adolescent medicine cen-

ters have yet effectively stated, or will be able to quickly and clearly state, their case for how they will contribute to these critical elements of concern to academic health centers.

Key Recommendations for Adolescent Health Training

- Estimate the number, type (e.g., physician, nurse, physician assistant, social worker, psychologist and other mental health professional, nutritionist, etc.), and distribution of adolescent health care providers needed currently and projected for the next 50 years, based on demographic changes expected and the target of a 55/45 ratio of primary care providers to subspecialists.
- Establish the case for adolescent health care as a primary care component of all disciplines (e.g., pediatrics, general internal medicine, family practice, nursing, etc.). To do this, reconsider the current trend toward certification and board subspecialization and consider, in this era of health care reform, taking active steps toward reversing that trend, particularly in the interim period of the next decade given the current severe shortage of primary care practitioners.
- Consider ways in which training of primary care
 practitioners can occur in outpatient and community-based settings for adolescents. Build a case for
 the benefits of academic health centers improving
 their integrated networks by affiliating with sites
 that care for adolescents. Consider essential community providers and school-related services as sites
 for training.



- Design and distribute a model adolescent health currice tun for undergraduate and postgraduate trainces for all relevant disciplines to be incorporated in suppanded primary care training sites around the country. Consider ways to integrate the curriculum into sites that currently do not have adolescent health training programs. Work with agencies now setting workforce priorities (e.g., American Association of Medical Colleges, Health Resources and Services Administration) to ensure that adolescent health training components are included.
- Target specific members and committees in Congress for action steps to be taken while proposals for health care reform are being considered and rewritten. Examples in the Senate might include the Labor and Human Resources Committee, the Finance Committee, and individual senators who have a track record in legislation regarding issues such as underserved populations, children and youth, academic health centers, and the prevention of youth violence and substance use.

Reference

1. Rivo, M. L., and Satcher, D. (1993). Improving access to health care through physician workforce reform. Directions for the 21st century. *JAMA*, 270(9), 1074-1078.



70

Health Care Reform and Adolescent Health: The Anticipated Role and Contribution of Public Health

CLAIRE BRINDIS, DR.P.H.

Executive Director, National Adolescent Health Information Center

Department of Pediatrics, Division of Adolescent Medicine and Institute for Health Policy Studies University of California, San Fransisco 1388 Sutter Street, 11th Floor San Fransisco, CA 94109

Tel: (415) 476-5256 Fax: (415) 476-0705

Prepared for the Working Seminar on Adolescent Health and Health Care Reform Washington, DC

January 10-11, 1994



Introduction

For national health care reform to fulfill its promise of improving the health of all Americans at an affordable cost, it is likely that far more will be necessary than the mere establishment of new financing mechanisms for medical treatment. An important partner in achieving this goal is a strong, population-based public health system of health promotion and disease prevention. Compelling evidence exists that population-based programs and strategies—such as those aimed at decreasing the incidence of infectious diseases through immunizations; improving sanitation; and through educational efforts, reducing tobacco use, increasing the use of automobile safety restraints, and improving blood pressure control—have contributed dramatically to improving the health status and life expectancy of Americans. The importance of a population-based approach is illustrated by a 1993 Public Health Service study which found that of all deaths among Americans in 1990, nearly half were due to causes that were behavioral in nature and substantially outside the purview of the medical system.\(^1\) Currently, the public health system plays a key role in the assessment of needs, prevention and treatment of disease and injury, development and support of new programs, and in the provision of health services to populations who traditionally have had problems in accessing care. Public health programs respond to the unique needs of adolescents by providing special outreach, counseling, education and support services that often contribute to their receiving the type of care they need. Increasingly the public health system assures service equity for special populations and access to important public health and safety services by providing health care directly.

Of all the proposed health care reform bills under consideration, the Administration's Health Security Act has delineated most clearly a comprehensive, reinvented public health system which would encompass a wide variety of activities to supplement, reinforce, and enhance health care reform strategies. The plan recognizes that mere fiscal reform of the medical care delivery system will not be sufficient to improve the overall health of Americans. Even if reform substantially improves access to care, the need for special public health programs will continue. Even if a system is in place to generate payment, many Americans, including adolescents, will likely need assistance from special outreach and service linkage efforts. That some of today's most pressing health problems are social in nature further defines the boundaries of what financial reform alone can do to solve the health challenges of those Americans most in need. In the past, financial and other barriers often prevented those in greatest need of services from access to care. These populations need additional efforts at outreach, increasing public awareness, and tailoring service delivery to the unique nature of different cultural groups. Such efforts would be best provided through populationbased strategies and programs.

The Administration's health care reform package proposes major shifts in the focus of public health professionals, placing greater emphasis on their role in protecting Americans against preventable diseases; informing and educating consumers and health care providers about their roles in health promotion and the prevention and control of disease and the appropriate use of medical services; and defining and validating new disease prevention and control interventions. The Health Security Act also includes a major commitment to a public health system designed to assess and monitor population-based needs, stimulate and support school and community health promotion efforts through the funding of K-12 comprehensive school health education programs, develop policies to protect and promote the health of the population, and assure quality and access for all

populations. Through these significant changes in the role of the public health system, the proposed health reform agenda may contribute significantly to improving the health of adolescents, particularly if the implementation strategies adopted respond to the unique needs of this population.

This paper outlines some of the problems adolescents face in dealing with the current system of health care, reviews the public health strategies proposed in the Health Security Act and their potential implications for adolescent health, and offers specific recommendations to consider in the health care reform debate. Whatever health care reform program is passed, it is imperative that a strong role for public health be incorporated.

Health Service Delivery Needs of Adolescents

The existing system of care focuses primarily on illness, rather than on health promotion and disease and injury prevention. This perspective is particularly problematic for adolescents who may engage in risk-taking behaviors, which often result in socially-caused morbidity and mortality.

There is a significant mismatch between adolescent health needs and the existing health care delivery system. The existing system of care lacks a consistent and coordinated approach to the problems of adolescents; what health services do exist often are fragmented and oriented toward health "problems," rather than toward health promotion and disease prevention. Financial barriers to care are not insignificant; slightly more than 15 percent of adolescents lack either public or private health insurance coverage. Even when adolescents have insurance available, treatment oriented services rather than preventive services dominate. Coverage restrictions and reimbursement schedules

add to the problem, assuring that relatively few adolescents receive preventive services, particularly in the areas of mental health, substance use, and reproductive services.

In the case of adolescents, universal insurance benefits will likely be insufficient to assure access to care. Special public health oriented initiatives will continue to be needed to respond to the needs of special populations. While a universal system of health insurance would eliminate many of the financial barriers to care that adolescents often experience, adolescents still need a readily identifiable medical home that not only provides primary care but can respond to their unique variety of health and social problems. Currently, even when adolescents are served by the medical care system, few physicians are dealing specifically with the problems known to be prevalent in this age group. Substance use and abuse, sexually transmitted diseases, depression, suicide, sexual and physical abuse, and violence are major adolescent health problems, yet they are not among the most common diagnoses, problems, procedures, or therapies associated with officebased visits. Adolescents who engage in risk-taking behaviors are best served by alternative public-health oriented providers, who sponsor the types of outreach, education, health promotion, and guided counseling services adolescents appear to need. Merely assuring payment is unlikely to result in mainstream providers incorporating into their practice a more adolescentfocused approach to care or in their gaining comfort in providing the type of screening and referral services their adolescent clients need.

Under health care reform, it also will be important to balance adolescents' need for access to care with countervailing efforts to cap health care costs. One important strategy would be a commitment to the reduction of expensive secondary and tertiary care through an emphasis on the provision of primary care, disease and injury prevention, and health promotion.

Public health oriented organizations (e.g., health



departments, community health clinics, migrant health clinics, school-based health clinics) have been at the forefront of creating alternative care delivery models, but they have been limited by critical funding problems, categorical funding streams, and issues of accessibility and "political will."

Services for adolescents currently reflect a categorical and fragmented approach to care, although the consensus increasingly is that adolescents need access to a comprehensive array of services which respond to both the social and the biological aspects of their health problems. Even within the public health "system," health services and programs in the areas of substance abuse; mental health; reproductive health; sexually transmitted diseases, including HIV screening and testing; and maternal and child health have developed largely in isolation from each other. Integrated and comprehensive programs, such as communitybased health clinics and school-based clinics have had a long history of providing free or reduced cost services, without the potential barriers of copayments and deductibles. Such programs also have a long history of providing confidential care to adolescents, particularly in such sensitive areas as reproductive health, mental health, and substance abuse treatment. It will be important to assess how health care reform responds to these important lessons. The challenge also will be to make services more readily available than they have been in the past, when adolescents' exposure to public health programs was often a matter of chance, social class, or area of residence, rather than need.

The Role of Public Health in Health Care Delivery

By default, the public health "system" increasingly has become a health care delivery system, rather than focusing on its other critical roles of assessment, policy development, and assurance.

Safeguarding this country's public health has been the providence of public health agencies since the early days of the 20th century, but the health care crisis has prevented many agencies from carrying out their mandate of prevention and education. As private health care costs have increased, more and more people have been unable to use the private health care system and have sought help from the public sector. As a result, public health has had to devote fewer resources to its missions of assessing community health needs, developing effective policies to meet those needs, and assuring that conditions contributing to good health, including accessible health and social services, prevail for all. It is anticipated that with the availability of a universal, comprehensive, health care system, the majority of individuals would receive their health care from managed care providers, and public health professionals could once again fulfill their traditional mission of promoting and protecting the nation's health. Vulnerable populations such as adolescents, however, would continue to need special outreach, counseling, education, and health services which would be in the purview of public health agencies. Given the current training and experience of many public health professionals, special training would likely be necessary to equip them for their new role expectations.

Broad public health strategies, including health promotion, education, and surveillance, are needed to assure the success of health care reform. For adolescents, these strategies may be particularly important to prevent or modify those behaviors which put them at risk for poor health outcomes.

Consensus is growing that the present health care system is too restricted and too fragmented, and that funds are not made available to respond effectively to the major health problems of adolescents. Because adolescents often seek care through alternative settings in the community, some argue that what's needed are alternative systems which emphasize prevention and outreach and which are consistent with a public health



perspective; school-based clinics are the most frequently mentioned option.

Conventional concepts of medical care, rooted in the biological determinants of disease, do little to address adolescents' serious health problems, many of which are related to patterns of behavior adopted by adolescents in response to their environment. Most adolescent morbidity and mortality is preventable. Evaluations of health service programs indicate that they can reduce the frequency of many conditions and ameliorate the severity of others, even when social factors weigh heavily in the genesis of those conditions.

Proposed Role of Public Health Within the Health Security Act

Many view health care reform as focusing primarily on creating a new system of paying for and delivering care. However, the Health Security Act would build into the new health care system a major shift in emphasis toward health promotion and disease and injury prevention by improving access to preventive and primary care and by making a major commitment to public health. Inherent in the plan is the recognition that access to insurance alone will not guarantee that people will get the health services they need, nor that traditional health care delivery emphasis on illness will reduce overall costs. Health insurance access does not necessarily eliminate discrepancies, such as the lack of a doctor or good facilities near home. Nor does it address language barriers, lack of social support systems, child care or transportation, or fear, any one of which could prevent the newly insured from learning what services they need and how to get them. Many populations of Americans will continue to need special health facilities in their communities, particularly for transient, migrant, central-city, rural, or school-based populations. Further, while the plan recognizes that

employer-based insurance would go a long way toward helping employees, it also emphasizes that without health promotion in the workplace, without safety training, opportunities for exercise, and a smoke-free environment, the cost of health care benefits would not tecrease.

As outlined in the Health Security Act, public health activities are a major strategy to compliment and leverage other proposed health benefits and to reduce the overall cost of health care by improving the health of the public. Traditional public health toolsdata collection and epidemiology, research, outreach, and education—will be required. Under the Administration's plan, public health would be substantially involved in three main functions: assessment, policy development and planning, and quality assurance. This would entail data collection, health surveillance, and outcomes monitoring. Public health would continue to perform many of its traditional roles of protecting the environment, housing, food, and water, as well as investigating and controlling disease and injury and would play a significant role in the provision of public information and education, public health training, policy development, and administration. However, much of this emphasis anticipates that public health's current direct service function, particularly for vulnerable populations, would be performed by health plans.

Several major components of the Administration's health care plan reflect an underlying commitment to public health: either directly, by providing for special funds to support health promotion activities, or more indirectly, by committing to train health providers for rural and inner-city communities, for example. Other areas in the plan which support a strong public health system include specific public health and prevention activities; a special Access Initiative; designation of "essential community providers" to care for underserved and special population groups; and funding of school-related services. It is envisioned that existing



essential community providers, including family planning clinics, community health centers, and programs funded by Title V of the Social Security Act, which have a long- standing history of responding to the special needs of adolescents, would continue to serve them in a number of different sites.

In the new health care system, health plans would be responsible for contracting with essential community providers, on either a fee for service or capitated system for at least a five year period, with the hopes of integrating many of these providers or the services they currently provide into a new "seamless" delivery system. However, that underlying assumption will need to be tested, given previous care patterns and the population-based needs that led to the emergence of these alternative delivery systems. A major question that will require careful monitoring is how will diverse populations of adolescents (different ethnic, social, and cultural groups) be served by mainstream providers. Will providers respond adequately to the unique culture of adolescents?

The Health Security Act also includes plans for major campaigns in the areas of immunizations; adolescent pregnancy; infant health; infectious disease control; violence prevention; and health education and promotion to decrease risk-taking behavior, including certain sexual behaviors, tobacco use, poor diet and use of alcohol and drugs. The plan also calls for investing in epidemiology and testing of new public health strategies, including the application of public health research techniques, for example, to evaluate violent and abusive behavior. Major components of a redefined public health system would be better epidemiological data, crucial in assessing and improving health; data collection systems needed to study outcomes; and new community-based prevention and health promotion programs.

In overall tone, the Health Security Act stresses that the availability of universal health insurance will significantly change the nature of public health's responsibility. Philosophically, the basic principles of the administration's proposed plan call for reexamination of how personal health services would be delivered and how they would relate to a newly reinvigorated public health system. For example, instead of actually immunizing children, the restructured public health system would work through health plans and alliances to set goals and standards, establish a supportive data system, develop indicators for performance monitoring, and develop methods for serving hard-to-reach populations. The new public health system would also be responsible for merging fragmented public health data systems and integrating them into a network of personal health care data sysrems. But weaning public health from personal health service delivery in the inner city and rural areas will not be easy. An important first step under the Health Security Act would be to replenish the supply of practitioners, practice sites, practice networks, and health plans in such underserved areas, while continuing the critical role of delivering care through community and migrant health centers, family planning clinics, and school-based health centers.

A proposed new grant and loan program would unite federally funded providers and other providers in these areas, encourage new practice sites to open, and improve access to specialty care. Another new grant program would supply supplemental services to isolated, culturally and linguistically diverse, hard-to-reach people to help make health care more accessible. These targeted grants would cover outreach and enabling services, such as child care, transportation, and translation, and would complement public health service programs such as the Ryan White Care Act for people with HIV, substance abuse and mental health clinics, maternal and child health programs, and

family planning services. In the case of adolescents, transportation may be a particularly important service.

The Health Security Act reflects a clear commitment to prevention in its proposed school-related services, which include both the provision of care through a network of school-based health centers to be built in medically needy areas and a comprehensive K–12 program of health prom—ion and education. If the health care reform package which is finally adopted includes these components, it could have a significant impact on the health status of children and adolescents. However, out-of-school youth and other youth (who may not live in medically needy areas) would still need comprehensive health care programs.

Such a major agenda for public health raises a number of issues as to the feasibility of providing adequate resources to support it. Another challenge will be how to redirect the existing system of care, with its strong commitment to providing secondary and tertiary care, toward preventive and primary health care.

Next Steps

The new public health agenda contained in the Administration's health care proposal requires skills significantly different from those of the existing cadre of public health professionals now working in the field. Both the levels and types of skills public health professionals would need require a significant investment in professional retraining in order to carry out the proposed public health agenda. Schools of Public Health and other relevant training institutions must be adequately supported in efforts to strengthen their curricula to prepare new cohorts of public health professionals and to develop in-depth continuing education programs to expand the skill base of public health professionals currently working in the field.

The proposed Health Security Act, however, currently does not include provisions for adequate—and

more importantly, secure—funding for public health initiatives, particularly for the special transition-period activities that health care reform likely will require. National expenditures for population-based programs (exclusive of WIC) currently amount to only about 0.9 percent of overall health care expenditures (\$8.4 billion out of approximately \$900 billion expended annually in the U.S. health care system). These funds represent about \$4.1 billion from states and localities, \$1.3 billion from federal grants and contracts to states and localities for public health programs, and \$3 billion from supplemental population-based activities of the U.S. Public Health Service.

Though the Public Health Initiatives were originally incorporated into the Health Security Act, during the health care reform debates they are being treated separately from the health entitlement plan (capped security fund) under debate. This division will require separate authorization for any funds to be allocated to the proposed public health activities. Given how budget allocations can change, the public health budget most likely will have to compete with other pressing priorities.

The public health agenda that has been outlined in the Health Security Act is visionary. However, an anticipated price tag of \$20 billion dollars over five years for all of the proposed public health activities will limit how much of that agenda can be fulfilled. Given an overall health care price tag of close to \$1 trillion dollars, such an uneven investment in public health likely will limit the realization of many of the proposed goals. Priorities will be needed to assure that funds are adequately distributed for public health activities such as screening, outreach, epidemiology, data collection, case management, and health education.

Before public health agencies can begin the transformation from direct service providers to their anticipated new role, adequate assurance is needed that mainstream health providers are capable of and com-



mitted to caring for vulnerable populations, particularly adolescents. Services will need to be closely monitored during the proposed five year transition period to assure adequate care is being provided. A major investment will be required to develop the types of data collection mechanisms and computer systems needed to fulfill the public health functions of data collection, surveillance, and outcomes monitoring.

Finally, as the health care reform debate proceeds. the following recommendations deserve consideration:

- Provide sources of financing for the public health infrastructure and core public health functions as guaranteed set asides. Funding should be ongoing and independent of the annual appropriations process.
- Allow school-based health centers to qualify as
 "essential community providers," whether or not
 they are federally funded, as long as they meet standards of quality adopted by the secretary of health
 and human services.
- Create strong mechanisms and incentives to assure that mainstream providers (i.e., health plans) contract with community-based providers and schoolbased health centers that serve adolescents.
- Ensure that surveillance and monitoring of health services utilization and outcomes specific to adolescent health are an integral part of any reinvigorated public health system, and that they are explicitly linked to any new governance structures (e.g., an alliance of health plans).

Reference

1. Core Function Group, Public Health Service, U.S. Department of Health and Human Services. (1993). Health care reform and public health: A paper on public health population-based core functions. Unpublished manuscript.



APPENDIX A

Investing in Preventive Health Services for Adolescents

The National Adolescent Health Information Center University of California, San Francisco

Several of the major health care reform bills under consideration have incorporated strategies aimed at increasing access to health education and promotion efforts, health screenings, including more frequent clinical preventive health visits, and primary health care for adolescents. Some plans outline a commitment to the delivery of preventive clinical services by health providers on an annual basis.

The following provides a rationale for the investment in services aimed at the prevention and early detection of risk-taking behaviors which have become increasingly prevalent among adolescents and which can be modified by appropriate interventions.

What is known about providing preventive health services?

- Clinical preventive services have been documented to be successful with adults in a wide variety of areas, including smoking cessation, nutrition, weight/loss management, injury prevention, and other health behaviors.¹
- A number of researchers have documented that preventive services provided by physicians can have a significant impact on behavioral change.⁵
- Prevention programs have also been shown to be successful with adolescents in a number of areas including tobacco, drug, and alcohol abuse prevention and adolescent pregnancy prevention.

How effective does a physician-based intervention need to be?

• Preventive services are cost-effective at even low rates of effectiveness. If we assume only five percent effectiveness in preventing the targeted harmful behavior, the delivery of those services would be cost-effective.* For example, the prevention of one case of AIDS infection would save an average of \$38,300 (hospital and medical-related care per patient), which is far more than the costs associated with preventing this condition.

What are we currently spending on health problems resulting from adolescent risk-taking behaviors?

Adolescents engage in a number of risk-taking behaviors for which well-documented interventions exist:

Motor Vehicle and Unintentional Injuries

- In 1990, costs associated with minor, serious, and fatal crash injuries among 10- to 21-year-old youth was \$11.3 billion (or \$13,062,800,000 in 1992 dollars).
- During 1985, there were 1,825,000 15- to 24-year-olds who were injured by falls, 60,000 by firearms, 137,000 by poisoning, 370,000 by fires and burns, 2,000 by drowning, and 8,592,000 by other causes, for a total estimated cost of \$6.2 billion. In 1992 dollars, this would be approximately \$10,378,800,000.



Sexually Transmitted Diseases

• There are approximately 3.8 million reported cases of sexually transmitted diseases among adolescents ages 15- to 19-years-old, including syphilis (16,000 cases), gonorrhea (410,000 cases), chlamydia (an estimated 940,000 cases), pelvic inflammatory disease (PID) (200,000 cases), genital herpes simplex virus (HSV) infection (1,270,000 cases), and human papillomavirus (HPV) infection (1 million cases) among adolescents each year. Based on estimated costs of office visits and laboratory tests of S80 per case, the costs in 1992 dollars would be \$882,028,000.

Prenatal Care

- Hospital and physician costs for live births to mothers 15- to 19-years-old represent another major expenditure. In 1989, the total annual obstetrical costs for adolescents were (82,878 X \$7,186) + (435,111 X \$4,334) = \$2,481,332,382. *** The cost in 1992 dollars would be \$3,133,922,798.
- Hospital costs for treating low birthweight infants are often the result of delayed or inadequate prenatal care. In 1989, there were 517,989 births to women under the age of 20 years. Of these, 9 percent or 46,619 were low birthweight infants. Average hospital costs range from \$11,670 to \$39,420 per low birthweight infant. Therefore, the hospital costs for low birthweight infants of adolescent mothers ranged from \$544 million to \$1.8 billion (or an average of \$1.172 billion). The cost in 1992 dollars would be approximately \$1.5 billion."

Alcohol and Drug Treatment

 Approximately \$185 million was spent in 1987 on adolescent alcohol and drug treatment services—
 \$65 million on alcohol treatment and \$120 million on drug treatment." This includes both inpatient and outpatient treatment, although most adolescents who receive alcohol or drug treatment are seen in outpatient settings (88 percent and 67 percent, respectively). In 1992, costs estimates would rise to \$271,395,000.

How much does it cost to provide clinical preventive services?

• In sum, each year an estimated \$33.4 billion is spent on select adolescent morbidities, approximately \$855 per each of the 39 million youth between the ages of 11- to 21-years of age living in the United States. The cost of clinical preventive services for adolescents ranges from \$57 to \$130 per adolescent per year in a fee-for-service system and from \$72 to \$172 in a capitated system. An average of \$73 to \$120 per adolescent per year, clinical preventive services can be an affordable and cost-effective service.

What evidence exists regarding the cost-benefits of providing preventive services to adolescents?

- Several cost-benefit studies have documented the advantages of investing in increasing access to contraceptive services for women at risk of an unintended pregnancy. Nationally, for every government dollar spent on family planning services, from \$2.90 to \$6.60 (an average of \$4.40) is saved as a result of averting short-term expenditures on medical services, welfare, and nutritional services."
- An estimated 1.2 million to 2.1 million unintended pregnancies are averted every year with the availability of publicly funded reproductive programs.
- In a separate California study, estimated savings in publicly-funded expenditures for services related to



unintended pregnancy ranged between \$3.66 to \$8.03, (an average of \$5.57) for every dollar spent in state and federal dollars on family planning services.³¹

 A cost-benefit analysis conducted in San Francisco, CA showed ratios of \$1.38 to \$2.00 saved for every dollar expended in school-based clinics, based on estimated reductions in use of emergency rooms, fewer pregnancies, early prenatal care, and diagnoses of chlamydia (a sexually transmitted disease)."

Why yearly preventive visits for adolescents make sense?

Adolescent Risk-Taking Behavior
Increases in the incidence of health risk behaviors are dramatic from year to year during adolescence:

- Twenty-one percent of adolescents smoke their first cigarette by sixth grade and an additional 22 percent by eighth grade.
- By eighth grade, 22 percent of adolescents have drunk alcohol; by ninth grade, an additional 24 percent have drunk alcohol; and by tenth grade another 19 percent have begun to use alcohol.
- Serious drinking (getting drunk or very high) is first experienced in ninth grade by 20 percent of adolescents, in tenth grade by another 16 percent, and in eleventh grade by an additional 12 percent.
- There is an approximately 15 percent incremental increase per year in the number of adolescents who are sexually active. By the age of 19, more than 63 percent of females and 86 percent of males have become sexually active.

Because of the significant annual increases in risk behaviors on the part of adolescents, primary prevention efforts will require yearly contacts if they are to take place before behaviors occur. In addition, yearly screening efforts are likely to identify large number of adolescents who can benefit from early intervention.

References

- U.S. Preventive Services Task Force. (1989). *Guide to clinical preventive services*. Baltimore, MD: Williams and Wilkins.
- 2. Kottke, T. E., Battista, R. N. DeFriese, G. H., et al. (1989). Attributes of successful smoking cessation interventions in medical practice: A meta-analysis of 39 controlled trials. *JAMA*, 259(19), 2882-2889.
- 3. Mullen, P. D., Green, L. W., Takak, E., et al. (1989). *Meta-analysis of studies evaluating patient education*. Rockville, MD: The National Center for Health Services Research and Health Care Technology Assessment, U.S. Department of Health and Human Services.
- 4. Janz, N. K., Becker, M. H., Kirscht, J. P., et al. (1987). Evaluation of a minimal-contact smoking cessation intervention in an outpatient setting. *American Journal of Public Health*, 77(7), 805-809.
- 5. Pentz, M. A., Dwyer, J. H., MacKinnon, D.P., et al. (1989). A multicommunity trial for primary prevention of adolescent drug abuse. *JAMA*, 261(22), 3259-3266.
- 6. Zabin, L. S., Hirsch, M. B., and Smith, E. A. (1986). Evaluation of a pregnancy prevention program for urban teenagers. *Family Planning Perspectives*, 18(3), 119-126.
- 7. Vincent, M. L., Clearie, A. E., and Schluchter, M. D. (1987). Reducing adolescent pregnancy through school and community-based education. *JAMA*, 257(24), 3382-3386.

- 8. Downs, S. M., and Klein, J. D. (1992). Clinical preventive services efficacy and adolescent risky behaviors. *American Journal of Diseases of Children*, 146, 488.
- 9. Hellinger, F. J. (1992). Forecasts of the costs of medical care for persons with HIV: 1992-1995. *Inquiry*, 29(3), 356-365.
- Computed by Miller, T., and Blincoe, L. from data In Blincoe, L., and Faigin, B. (1992).
 The economic cost of motor vehicle crashes,
 1990. Washington, DC: National Highway
 Traffic Safety Administration.
- 11. Gans, J. E., Alexander, B., Chu, R., et al. (in preparation). *The cost of comprehensive preventive medical services for adolescents.* Chicago: American Medical Association, Division of Adolescent Medicine.
- 12. Rice, D. M., MacKenzie, E. J., and Associates. (1989). Cost of injury in the United States: A report to Congress. San Francisco, CA: University of California Institute for Health and Aging and Johns Hopkins University Injury Prevention Center.
- 13. Toomey, K. (1994). Centers for Disease Control and Prevention, Atlanta, GA. (Personal communication).
- Health Insurance Association of America.
 Sourcebook of health insurance data, 1990. Washington, DC: Health Insurance Association of America.
- 15. U.S. Department of Health and Human Services, Public Health Service, National Center for Health Statistics. (1992). Advance report of national data from 1989 birth certificates. Hyattsville, MD: National Center for Health Statistics, U.S. Department of Health and Human Services.

- 16. U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics. (1989). Vital statistics of the United States, 1989. Hyattsville, MD: National Center for Health Statistics, U.S. Department of Health and Human Services.
- 17. Hughes, D., Johnson, K., Rosenbaum, S., et al. (1988). *The health of America's children*. Washington, DC: Children's Defense Fund.
- U.S. Congress, Office of Technology
 Assessment. (1987). Neonatal intensive care for low birthweight infants: Costs and effectiveness. Washington, DC: U.S. Government Printing Office.
- 19. Noble, J. (1989). Reimbursement for adolescent alcohol, drug abuse, and mental health treatment. Paper presented at the Conference on Treatment of Adolescents with Alcohol, Drug Abuse, and Mental Health Problems. Alexandria, VA.
- Forrest, J. D., and Singh, S. (1990). Public-sector savings resulting from expenditures for contraceptive services. *Family Planning Perspectives*, 22(1), 6-15.
- 21. Brindis, C., and Korenbrot, C. (1994).

 A study of the cost-effectiveness of the California Office of Family Planning expenditures for reversible contraceptive services. San Francisco, CA: Center for Reproductive Health Policy Research, Institute for Health Policy Studies, University of California.
- 22. Brindis, C., Morales, S., McCarter, V., et al. (1992). An evaluation study of school-based clinics in California: Major findings, 1986-1991. San Francisco, CA: Center for Reproductive Health Policy Research, Institute for Health Policy Studies, University of California.



84

- 23. U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control. (1990). Tobacco use among high school students—United States, 1990. Atlanta, GA: Centers for Disease Control, U.S. Department of Health and Human Services.
- 24. Johnston, L. D., O'Malley, P. M., and Bachman, J. G. (1989). Drug use, drinking and smoking: National survey results from high school, college and young adults populations 1975-1988. Rockville, MD: U.S. Department of Health and Human Services.
- 25. U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control. (1990). Alcohol and other drug use among high school students—United States, 1990. Atlanta, GA: Centers for Disease Control, U.S. Department of Health and Human Services.
- Research Triangle Institute. (1991). National household survey on drug abuse, population estimates 1990. Washington, DC: U.S. Government Printing Office.
- 27. Sonenstein, F. L., Pleck, J. H., and Ku, L. C. (1991). Levels of sexual activity among adolescent males in the United States. *Family Planning Perspectives*, 23(4), 162-167.

APPENDIX B

Published Resources on Health Policy and Health Care Reform

Alan Guttmacher Institute. (1993). Reproductive health and heath care reform: Special considerations. New York, NY: Alan Guttmacher Institute.

American Hospital Association. (1992). National health care reform: Refining and advancing the vision. Chicago, IL: American Hospital Association.

American Nurses Foundation. (1992). Nursing's agenda for health care reform. Kansas City, MO: American Nurses Foundation.

American Public Health Association. (1992). A national health program for all of us: The American Public Health Association's guide to the health care reform debate. Washington, DC: American Public Health Association.

Association of Maternal and Child Health Programs. (1994). Beyond security: The need for a maternal and child health focus and roles for Title V in health care reform. Washington, DC: Association of Maternal and Child Health Programs.

Association of Maternal and Child Health Programs. (1993). Managed care for women, children, adolescents and their families: A discussion paper with recommendations for assuring improved health outcomes and roles for state MCH programs. Washington, DC: Association of Maternal and Child Health Programs.

Association of Maternal and Child Health Programs. (1993). MCH and managed care: Perspectives and experiences from seven state Title V programs: Florida, Kentucky, Maryland, Michigan, Minnesota, New York, Oregon. Washington, DC: Association of Maternal and Child Health Programs.

Association of Maternal and Child Health Programs. (1994). Summary of key components and issues in the Health Security Act of 1993 (H.R.3600/S.1757) from a maternal and child health perspective. Washington, DC: Association of Maternal and Child Health Programs.

Association of State and Territorial Health Officials. (1994). ASTHO priority recommendations for strengthening public health in the Health Security Act. Washington, DC: Association of State and Territorial Health Officials.

Association of State and Territorial Health Officials. (1994). Public health and prevention are essential to health care reform. Washington, DC: Association of State and Territorial Health Officials.

Brecher, C. (1992). Implementation issues and national health care reform. New York, NY: Josiah Macy, Jr. Foundation.

Brown, E. R. (1994). Should single-payer advocates support President Clinton's proposal for health care reform? American Journal of Public Health, 84(2), 182-185.



Brown, S. S. (Ed.). (1992). Including children and pregnant women in health care reform: Summary of two workshops. Washington, DC: National Academy Press.

Center for the Future of Children. (1993). *Health care reform.* Los Altos, CA: Center for the Future of Children, David and Lucile Packard Foundation.

Center for the Future of Children. (1992). *U.S.* health care for children. Los Altos, CA: Center for the Future of Children, David and Lucile Packard Foundation.

Center for the Study of Social Policy. (1993). Financing children's services reform: Redeploy, refinance, reinvest. Washington, DC: Center for the Study of Social Policy.

Child health in 1990: The United States compared to Canada, England and Wales, France, the Netherlands, and Norway. (1990). *Pediatrics*, 86(supplement), 1025-1127.

Children's Defense Fund. (1993). Health care reform: An analysis of President Clinton's health care reform proposal. Washington, DC: Children's Defense Fund.

DeWoody, M. (1994). Health care reform: Meeting the needs of abused and neglected children. Washington, DC: Child Welfare League of America.

Dryfoos, J. G. (1994). Full service schools: A revolution in health and social services for children, youth and families. San Francisco, CA: Jossey-Bass.

Elster, A.B. and Kuznets, N.J. (1994). AMA guidelines for adolescent preventive services (GAPS):
Recommendations and rationale. Baltimore, MD:
Williams and Wilkins.

Epstein, A. M. (1993). Changes in the delivery of care under comprehensive health care reform. *New England Journal of Medicine*, 329, 1672-1676.

Family Voices. (1993). A summary of the Clinton health care reform plan: What it might mean for our children and families—House Resolution 3600 and Senate 1757. Algodones, NM: Family Voices.

Family Voices. (1993). Resources for learning about health care reform. Algodones, NM: Family Voices.

Family Voices. (1993). The American Health Security Act and the voices of families. Algodones, NM: Family Voices.

Field, M. J., Lohr, K. N., and Yordy, K. D. (Eds.). (1993). Assessing health care reform. Washington, DC: National Academy Press.

George Washington University, Center for Health Policy Research. (1994). Health policy and child health: Promoting awareness of mothers and children in state and national health policies and programs.

Washington, DC: Center for Health Policy Research, George Washington University.

George Washington University, Intergovernmental Health Policy Project. (1994). State profiles: Health care reform. Washington, DC: Intergovernmental Health Policy Project, George Washington University.

Green, M. (Ed.). (in preparation). *Bright Futures:* National guidelines for health supervision of infants, children, and adolescents.

Griss, B., and Bergman, A. I. (1993). A disability perspective on health care reform: Evaluation of Clinton health plan based on CCD Health Task Force principles. Washington, DC: United Cerebral Palsy Association.



Hamilton, D. R. (1992). *Economic implications of rising health care costs.* Washington, DC: Congressional Budget Office, U.S. Congress.

Hayes, G. H., Hayes, S. C., and Dykstra, T. (1993). Physicians who have practiced in both the United States and Canada compare the systems. *American Journal of Public Health*, 83, 1544-1548.

Health Affairs Editorial Board. (1993). Managed competition: Health reform, American style? Chevy Chase, MI): *Health Affairs*, 12(Supplement), 1-299.

Iglehart, J. K. (1994). Health policy report: Health care reform: The states. *New England Journal of Medicine*, 330(1), 75-79.

Jacobsen, J. C., Guise, K. D., and Langwell, K. M. (1993). *Trends in health spending: An update.* Washington, DC: Congressional Budget Office, U.S. Congress.

Jewish Healthcare Foundation of Pittsburgh. (1993). *Pennsylvania's vulnerable children: Critical issues in health care reform.* Pittsburgh, PA: Jewish Healthcare Foundation of Pittsburgh.

Kaiser Commission on the Future of Medicaid. (1994). *Health reform legislation: A comparison of committee action*. Menlo Park, CA: Henry J. Kaiser Family Foundation.

Kaiser Commission on the Future of Medicaid. (1994). *Health reform legislation: A comparison of major proposals.* Menlo Park, CA: Henry J. Kaiser Family Foundation.

Kaufman, A., and Waterman, R. E. (Eds.). (1993). Health of the public: A challenge to academic health centers: Strategies for reorienting academic health centers toward community health needs. San Francisco, CA: Health of the Public Program.

Klein, J. D., Slap, G. B., Fister, A. B., et al. (1994). Adolescents and access to health care. *Bulletin of New York Academy of Medicine*, 70(2), 219-235.

Klerman, L. V., Grazier, K. L., and Thomas, K. C. (1990). The role of the public sector in providing children's health care. In Schlesinger, M. J., and Eisenberg, L. (Eds.). *Children in a changing health system: Assessments and proposals for reform.* Baltimore, MD: Johns Hopkins University Press.

Kohrman, A. F. (1994). Financial access to care does not guarantee better care for children. *Pediatrics*, 93(3), 506-508.

Krauss, J. (1993). Health care reform: Essential mental health services. Washington, DC: American Nurses Association.

Leigh, W. A. (1993). Implications of the Clinton health reform proposal for Black Americans.

Washington, DC: Joint Center for Political and Economic Studies.

Lewin-VHI, and MDS Associates. (1993). Health care reform issues: Discussion paper for the Maternal and Child Health Bureau. N.p.: Lewin-VHI.

McManus, M. (1993). *National health reform:* Challenges for Title V. Washington, DC: McManus Health Policy, Inc., Maternal and Child Health Policy Research Center.

Millman, M. (Ed.). (1993). Access to health care in America. Washington, DC: National Academy Press.

National Center for Education in Maternal and Child Health. National Governors' Association, National Conference of State Legislatures, and the Maternal and Child Health Bureau. (1993). Looking forward: The role of state policymakers in promoting healthy families. Arlington, VA: National Center for Education in Maternal and Child Health.

National Council on Disability. (1993). Sharing the risk and ensuring independence: A disability perspective on access to health insurance and health-related services: A report to the President and the Congress of the United States. Washington, DC: National Council on Disability.

National Governors Association. (1994). *State progress in health care reform, 1993.* Washington, DC: National Governors' Association.

New England SERVE. (1992). Assessing the adequacy of national health care reform proposals: An analysis of 3 sample bills based on 'Ensuring access: Family-centered health care financing systems for children with special health needs.' Boston, MA: New England SERVE.

Nicholson, E. (1992). Two become one: Combining the best of the Children's Health Plan and Medical Assistance into a united plan in Minnesota. St. Paul, MN: Children's Defense Fund, Minnesota.

O'Neil, E. H. (1993). Health professions education for the future: Schools in service to the nation. Durham, NC: Pew Health Professions Commission.

Partnership for Prevention. (1994). Prevention is basic to health reform: Model legislative language. Washington, DC: Partnership for Prevention.

Partnership for Prevention. (1993). Prevention is basic to health reform: Recommendations from a conference November 30 to December 1, 1992. Washington, DC: Partnership for Prevention.

Perrin, J. M., Kahn, R. S., Bloom, S. R., et al. (1994). Health care reform and the special needs of children. *Pediatrics*, 93(3), 504-506.

Rosenau, P. V. (Ed.). (1993). *Health care reform in the United States*. Thousand Oaks, CA: Sage Publications.

Rosenberg and Associates. (1994). Financing adolescent school-related health centers under the proposed National Health Security Act. Point Richmon, CA: Rosenberg and Associates.

Rosoff, J. I. (1993). Health care reform: A unique opportunity to provide balance and equity to the provision of reproductive health services. New York, NY and Washington, DC: Alan Guttmacher Institute.

Staines, V. (1993). Managed competition and its potential to reduce health spending. Washington, DC: Congressional Budget Office, U.S. Congress.

Starr, P. (1993). The framework for health care reform. *New England Journal of Medicine*, 329, 1666-1672.

Susser, M. (1994). Health care reform and public health: Weighing the proposals. *American Journal of Public Health*, 84(2), 173-175.

The White House Domestic Policy Council. (1993). *Health security: The President's report to the American people.* Washington, DC: The Executive Office.



U.S. Congress, Office of Technology Assessment. (1991). Adolescent health—volume I: Summary and policy options; volume II: Background and the effectiveness of selected prevention and treatment services; volume III: Crosscutting issues in the delivery of health and related services. Washington, DC: U.S. Government Printing Office.

U.S. Congress, Office of Technology Assessment. (1993). An inconsistent picture: A compilation of analyses of economic impacts of competing approaches to health care reform by experts and stakeholders. Washington, DC: Office of Technology Assessment, U.S. Congress.

U.S. Congress, Office of Technology Assessment. (1993). Benefit design: Patient cost-sharing: Background paper. Washington, DC: U.S. Government Printing Office.

U.S. Congress, Office of Technology Assessment. (1993). *Benefit design: Clinical preventive services: Report number 1.* Washington, DC: U.S. Government Printing Office.

U.S. Department of Health and Human Services, Office of Inspector General. (1993). *School-based health centers and managed care*. Washington, DC: Office of Inspector General, U.S. Department of Health and Human Services.

U.S. Department of Health and Human Services, Office of Inspector General. (1993). School-based health centers and managed care: Examples of coordination. Washington, DC: Office of Inspector General, U.S. Department of Health and Human Services.

U.S. General Accounting Office. (1992). *Health care reform.* Washington, DC: U.S. General Accounting Office.

U.S. General Accounting Office. (1994). Health care reform: School-based health centers can promote access to care. Washington, DC: U.S. General Accounting Office.

U.S. General Accounting Office. (1991). U.S. health care spending: Trends, contributing factors, and proposals for reform. Washington, DC: U.S. General Accounting Office.

Walker, D. K., Butler, J. A., and Bender, A. (1990). Children's health care and the schools. In: Schlesinger, M. J., and Eisenberg, L. (Eds.) *Children in a changing health system*. Baltimore, MD: Johns Hopkins University Press.



APPENDIX C

Organizations Involved in Analysis of Health Policy and Health Care Reform

Advocates for Youth

1025 Vermont Avenue N.W., Suite 200

Washington, DC 20005

(202) 347-5700

Staff: Margaret Pruitt Clark, Ph.D.,

Executive Director

Debra Hauser McKinney, Support Center for

School-based and School-linked Health Care

Alan Guttmacher Institute

1120 Connecticut Avenue N.W., Suite 460

Washington, DC 20036

(202) 296-4012

Staff: Jeannie I. Rosoff, President

Cory Richards, Vice President, Public Policy

American Academy of Pediatrics

141 Northwest Point Boulevard

PO. Box 927

Elk Grove Village, IL 60009-0927

(708) 228-5005, (800) 433-9016

Staff: Joe M. Sanders Jr., M.D., Executive Director

Kathleen Sanabria, Child and Adolescent

Health

American Hospital Association

Section for Maternal and Child Health

840 North Lake Shore Drive

Chicago, IL 60611

(312) 280-4198

Staff: Richard Davidson, President

Bonnie Connors Jellen, Director

American Public Health Association

1015 15th Street N.W.

Washington, DC 20005

(202) 789-5600

Staff: Fernando Trevino, Ph.D., M.P.H., Executive

Director

American Public Welfare Association

810 First Street N.E., Suite 500

Washington, DC 20002

(202) 682-0100

Staff: A. Sidney Johnson, Executive Director

Lee Partridge, Director, Health Policy Unit

Association of Maternal and Child Health Programs

1350 Connecticut Avenue N.W., Suite 803

Washington, DC 20036

(202) 775-0436

Staff: Catherine Hess, M.S.W., Executive Director

Association of State and Territorial Health Officials

415 Second Street N.E., Suite 200

Washington, DC 20002

(202) 546-5400

Staff: Mary McCall

Campaign for Women's Health

730 11th Street N.W., Suite 300

Washington, DC 20001

(202) 783-6686

Staff: Lou Glasse, President

Elizabeth Kahn



Center for Health Policy Research

George Washington University 2021 K Street N.W., Suite 800 Washington, DC 20052

(202) 296-6922

Staff: Peter Budetti, M.D., J.D., Executive Director Michele Solloway, Ph.D.

Center for the Future of Children

David and Lucile Packard Foundation 300 Second Street, Suire 102 Los Altos, CA 94022 (415) 948-3696

Staff: Dick Behrman, M.D., Managing Director

Center on Budget and Policy Priorities

777 North Capitol Street, Suite 705 Washington, DC 20002 (202) 408-1080

Staff: Robert Greenstein, Executive Director

Child and Adolescent Health Policy Center

Johns Hopkins University School of Hygiene and Public Health Department of Maternal and Child Health 624 North Broadway Baltimore, MD 21205 (410) 955-0219

Staff: Bernard Guyer, M.D., M.P.H.,
Principal Investigator
Holly Grason, M.A., Project Director

Child Welfare League of America

440 First Street N.W., Suite 310 Washington, DC 20001-2085 (202) 638-2952

Staff: David S. Liederman, Executive Director

Children's Safety Network

Economics and Insurance Resource Center
National Public Services Research Institute
8201 Corporate Drive, Suite 220
Landover, MD 20785
(301) 731-9891 Ext. 103/108
Staff: Ted Miller, Project Director
Stephanie Butler, Project Administrator

CityMatCH

University of Nebraska Medical Center Section on Child Health Policy Department of Pediatrics 600 South 42nd Street Omaha, NE 68198-2170 (402) 559-8323, (402) 559-4222 TTY/TDD Staff: Magda G. Peck, Sc.D., P.A.,

Staff: Magda G. Peck, Sc.D., P.A., Executive Director

Commonwealth Fund Commission on Women's Health

Harkness House 1 East 75th Street New York, NY 10021-2692 (212) 535-0400

Staff: Keith Kirby, Director Margaret E. Mahoney, President

Congressional Budget Office

Ford House Office Building Second and D Streets S.W. Washington, DC 20515 (202) 226-2621

Staff: Robert Reischauer, Director



Families USA

1334 G Street N.W.

Washington, DC 20005

(202) 628-3030

Staff: F

Ronald F. Pollack, Executive Director

Phyllis Torda

Family Voices

Box 769

Algodones, NM 87001

(505) 867-2368

Staff:

Polly Arango

Julie Beckett

Health Care: We Gotta Have It A Project of MADRE

121 West 27th Street, Suite 1202A

New York, NY 10001

(212) 865-0505

Staff: Marilyn Clement, Executive Director

Health of the Public

National Program Office

University of California

San Francisco, CA 94143-0994

(415) 476-8907

Staff:

Thomas S. Inui, Sc.M., M.D.,

Executive Director

Healthy Mothers, Healthy Babies Coalition

409 12th Street S.W.

Washington, DC 20024-2188

(202) 863-2458, (800) 673-8444 Ext. 2458

Staff:

Lori Cooper, Executive Director

Leslie Dunne

Henry J. Kaiser Family Foundation

Quadrus

2400 Sand Hill Road

Menlo Park, CA 94025

(415) 854-9400

Staff: Drew E. Altman, Ph.D., President

Institute of Medicine

National Research Council

2101 Constitution Avenue

Washington, DC 20418

(202) 334-2138

Staff: Kenneth I. Shine, Executive Director

Intergovernmental Health Policy Project

2021 K Street N.W., Suite 800

Washington, DC 20052

(202) 872-1445

Staff: Richard E. Merritt, Director

Joint Center for Political and Economic Studies

1090 Vermont Avenue N.W., Suite 1100

Washington, DC 20005

(202) 789-3500

Staff: Frederick Leigh, Executive Vice-President

March of Dimes Birth Defects Foundation

1275 Mamaroneck Avenue

White Plains, NY 10605

(914) 428-7100, (202) 659-1800

Staff: Jennifer L. Howse, Ph.D., President

Kay Johnson, Director of Government Affairs



Maternal and Child Health Policy Research Center

Institute for Health Policy Studies 1388 Sutter Street, 11th Floor San Francisco, CA 94109

(415) 476-3896, (202) 686-4797

Paul W. Newacheck, Dr.P.H., Executive Director Margaret McManus, M.H.S

Kaiser Commission on the Future of Medicaid

1450 G Street N.W., Suite 250 Washington, DC 20005 (202) 347-5270

Staff: Diane Rowland, Sc.D., Executive Director David Huddle

National Adolescent Health Information Center

Division of Adolescent Medicine and Institute for Health Policy Studies University of California, San Francisco 400 Parnassus Avenue, Room AC-01 San Francisco, CA 94143-0374 (415) 476-2184

Staff: Charles E. Irwin Jr., M.D., Center Director Claire Brindis, Dr.P.H., Executive Director

National Association of County Health Officials

440 First Street N.W., Suite 500 Washington, DC 20001

(202) 783-5550

Nancy Rawding, M.P.H., Executive Director

National Center for Education in Maternal and Child Health

2000 15th Street North, Suite 701 Arlington, VA 22201-2617 (703) 524-7802

Rochelle Mayer, Ed.D., NCEMCH Director Kristin Langlykke, M.S.N., Ed.M.,

Adolescent Health

National Center for Social Policy and Practice

National Association of Social Workers 750 First Street N.E., Suite 700 Washington, DC 20002 (202) 408-8600

Staff: Vivian Jackson, Director

National Center for Youth Law

114 Sansome Street, Suite 900 San Francisco, CA 94104-3820 (415) 543-3307

Staff: John Francis O'Toole, Director Abigail English

National Center for Youth with Disabilities

University of Minnesota

Box "21

420 Delaware Street S.E.

Minneapolis, MN 55455-0392

(612) 626-2825, (800) 333-6293

(612) 624-3939 TDD

Staff: Robert Blum, M.D., Ph.D., Project Director Nancy Okinow, M.S.W., Executive Director

National Coalition of Hispanic Health and Human Services Organizations

1501 16th Street N.W. Washington, DC 20036-1401 (202) 387-5009

Staff: Jane L. Delgado, Ph.D., President and CEO Mary Thorngren

National Conference of State Legislatures

1560 Broadway, Suite 700 Denver, CO 80202-5140 (303) 830-2200

William Pound, Executive Director Staff: Martha King



National Governors' Association

444 North Capitol Street, Suite 267 Washington, DC 20001-1572 (202) 624-5300

Staff: Raymond C. Scheppach, Executive Director Tracey Orloff

National Health Law Program

2639 South La Cienega Boulevard
Los Angeles, CA 90034
(310) 204-6016
Staff: Laurence M. Lavin, Executive Director
Karen Anthony, Administrator

National Latina Health Organization/Organización Nacional de la Salud de la Mujer Latina

P.O. Box 7567

Oakland, CA 94601

(510) 534-1362

Staff: Luz Martinez, Executive Director

National Leadership Coalition for Health Care Reform

555 13th Street West N.W., Suite 490
Washington, DC 20004
(202) 637-6830
Staff: Margaret M. Rhoades, Executive Director

National School Health Education Coalition

1091 G Street N.W., Suite 400 EastWashington, DC 20001(202) 638-3556Staff: Patrick B. Cooper, Ed.D., Executive Director

National Women's Law Center

1616 P Street N.W., Suite 100 Washington, DC 20036 (202) 328-5160 Staff: Nancy Duff Campbell and Marcia D.

Greenberger, Co-Presidents

Office of Technology Assessment

Congress onal and Public Affairs Publications Order: U.S. Congress Washington, DC 20510-8025 (202) 224-8996

Staff: Roger C. Herdman, Executive Director James Jensen, Congressional Affairs Director

Society for Adolescent Medicine

19401 East U.S. Highway 40, Suite 120 Independence, MO 64055 (816) 795-TEEN Staff: Edie Moore, Administrative Director

United States Conference of Mayors

1620 Eye Street N.W.Washington, DC 20006(202) 293-7330

Staff: J. Thomas Cochran, Executive Director Byron J. Harris, Assistance Executive Director

Washington Business Group on Health

777 North Capitol Street. Suite 800

Washington, DC 20002
(202) 408-9320, (202) 408-9333 TDD
Staff: Mary Jane England, M.D., President
Miriam Jacobson, Director, Prevention
Leadership Forum



APPENDIX D

Participants and Observers, Working Seminar on Adolescent Health and Health Care Reform

January 10-11, 1994 Washington, DC

Lucy Andris, M.S.W.
Senior Policy Analyst
American Academy of Pediatrics
601 13th Street N.W., Suite 400 North
Washington, DC 20005
Tel: (202) 775-0436 Fax: (202) 393-6137

Richard E. Behrman
Managing Director
The David and Lucile Packard Foundation
Center for the Future of Children
300 Second Street, Suite 102
Los Altos, CA 94022
Tel: (415) 948-3696
Fax: (415) 948-6498

Bruce Blehart, J.D.
Director, Division of Federal Legislation
American Medical Association
515 North State Street
Chicago, IL 60610
Tel: (312) 464-4039
Fax: (312) 464-4961

Robert Blum, M.D., Ph.D., M.P.H.
Professor and Director, Division of General Pediatrics and Adolescent Health
Director, National Center for Youth with Disabilities
University of Minnesota
420 Delaware Street S.E.
Minneapolis, MN 55455
Tel: (612) 626-2820
Fax: (612) 626-2134

Claire Brindis, Dr.P.H.
Executive Director
National Adolescent Flealth Information Center
Department of Pediatrics, Division of Adolescent Medicine
and Institute for Health Policy Studies
University of California, San Francisco
1388 Sutter Street, 11th floor
San Francisco, CA 94109
Tel: (415) 476-5255 Fax: (415) 476-0705

Peter Budetti, M.D., J.D.
Director, Center for Health Policy Research
George Washington University
2021 K Street, Suite 800
Washington, DC 20052
Tel: (202) 296-6922
Fax: (202) 785-0114

Susan Campbell, R.N., M.P.H.
Director of Legislative Affairs
Association of Maternal and Child Health Programs
1350 Connecticut Avenue N.W., Suite 803
Washington, DC 20036
Tel: (202) 775-0436
Fax: (202) 775-0061

Margaret Pruitt Clark, Ph.D.
President, Center for Population Options
1025 Vermont Avenue N.W., Suite 200
Washington, DC 20005
Tel: (202) 347-5700 Fax: (202) 347-2263

Christopher DeGraw, M.D., M.P.H. Senior Research Staff Scientist Center for Health Policy Research 2021 K Street, Suite 800 Washington, DC 20052 Tel: (202) 296-6922 Fax: (202) 785-0114

Debra Dunivin (Observer)
Senator Inouye's Office
Hart Senate Building, Suite 722
Washington, DC 20510
Tel: (202) 224-3934
Fax: (202) 224-6747

Arthur Elster, M.D.
Director, Department of Adolescent Health
American Medical Association
515 North State Street
Chicago, IL 60610
Tel: (312) 464-5530 Fas: (312) 464-5842



Abigail English
National Center for Youth Law
114 Sansome Street, Suite 900
San Francisco, CA 94104-3820
Tel: (415) 543-3307 Fax: (415) 956-9024

Harriette Fox, M.S.S.
President, Fox Health Policy Consultants
1747 Pennsylvania N.W., Suite 1200
Washington, DC 20006
Tel: (202) 223-1500 Fax: (202) 785-6687

Joann Gephart, R.N., M.S.N. (Observer)
Deputy Chief, Adolescent Health Branch
Maternal and Child Health Bureau
Parklawn Building, Room 18A-39
5600 Fishers Lane
Rockville, MD 20857
Tel: (301) 443-4026 Lax: (301) 443-1296

Holly Grason, M.A.
Director, Child and Adolescent Health Policy Center Johns Flopkins University
School of Hygiene and Public Health
624 North Broadway, Room 192
Baltimore, MD 21205
Tel: (410) 955-3384
Fax: (410) 955-2303

Bernard Guyer, M.D., M.P.H.
Professor and Chair of Maternal and Child Health
Johns Hopkins University
School of Hygiene and Public Health
624 North Broadway, Room 18
Baltimore, MD 21205
Tel: (410) 955-3384
Fax: (410) 955-2303

David C., Harvey, M.S.W., M.P.H. Coordinator of Public Policy National Pediatrics HIV Resource Center 900 2nd Street N.E., Suite 211 Washington, D.C. 20002 Tel: (202) 289-5970 Fax: (202) 408-9520 Karen Hein, M.D.
Robert Wood Johnson Fellow
3905 Huntington Street N.W. (temporary)
Washington, DC 10015
Tel: (718) 920-6612 Fax: (718) 882-043?
Professor of Pediatrics, Epidemiology, and Social Medicine
Albert Einstein College of Medicine
Montefiore Medical Center
111 East 210th Street
Bronx, NY 10467
Tel: (718) 882-0322 Fax: (718) 882-0432

Karen Hendricks, J.D.
Assistant Director, Department of Government Liaison
American Academy of Pediatrics
601 13th Street N.W., Suite 400 North
Washington, DC 20005
Tel: (202) 347-8600 Fax: (202) 593-6137

David Heppel, M.D. (Observer)
Director, Division of Maternal, Infant, Child
and Adolescent Health
Meternal and Child Health Bureau
Parklawn Building, Room 18A-30
5600 Fishers Lane
Rockville, MD 20857
Tel: (301) 443-2250 Fax: (301) 443-4842

Catherine Hess, M.S.W.
Executive Director
Association of Maternal and Child Health Programs
1350 Connecticut Avenue N.W., Suite 803
Washington, DC 20036
Tel: (202) 775-0436 Fax: (202) 775-0061

Charles E. Irwin, Jr., M.D.
Professor of Pediatrics
Director, Division of Adolescent Medicine
Director, National Adolescent Health Information Center
University of California, San Francisco
400 Parnassus Avenue, AC-01
San Francisco, CA 94143-0574
Tel: (415) 476-2184
Fax (415) 476-6106



Renee Jenkins, M.D.
Associate Professor
Department of Pediatrics and Child Health
Director of Adolescent Medicine
Howard University Hospital
2041 Georgia Avenue N.W.
Washington, DC 20060
Tel: (202) 865-3028 Fax: (202) 865-4558

Mariana Kastrinakis. M.D. (Observer)
Special Consultant to the Surgeon General
Department of Health and Human Services
200 Independence S.W., Room 736E
Washington, DC 20201
Tel: (202) 690-8335
Fax: (202) 690-6498

Woodie Kessel, M.D. (Observer)
Director, Division of Systems, Education and Science
Maternal and Child Health Bureau
Parklawn Building, Room 18A-55
Rockville, MD 20857
Tel: (301) 443-3163
Fax: (301) 443-4842

Jonathan D. Klein, M.D., M.P.H.
Division of Adolescent Medicine
University of Rochester
601 Elmwood Avenue
Rochester, NY 14642
Tel: (716) 275-2964
Fax: (716)273-1037

Lorraine V. Klerman, Dr.P.H.
Professor and Chairperson, Department of Maternal and Child Health
University of Alabama at Birmingham
Room 112, MJH
Birmingham, AL 35294
Tel: (205) 934-7161
Fax. (205) 934-8248

David Knopf, L.C.S.W., M.P.H.
Chief Social Worker
Division of Adolescent Medicine
Special Populations Coordinator
National Adolescent Health Information Center
University of California, San Francisco
400 Parnassus Avenue, AC-OI
San Francisco, CA 94143-0371
Tel: (415) 476-2184
Fax: (415) 476-6106

Lloyd Kolbe, Ph.D. (Observer)
Director, Division of Adolescent and School Health
National Center for Chronic Disease Prevention
and Health Promotion
Centers for Disease Control and Prevention
4770 Buford Highway N.E. (K-32)
Atlanta, GA 30341
Tel: (404) 488-5314
Fax: (404) 488-5972

Julia Lear, Fh.D.

Director, Making the Grade
George Washington University
1350 Connecticut Avenue N.W., Suite 505
Washington, DC 20036
Tel: (202) 466-3396
Fax: (202) 466-3467

Cynthia Mann, J.D.

Massachusetts Law Reform Institute
69 Canal Street
Boston, MA 02114
Tel: (617) 742-9250
Fax: (617) 742-1983

Christine McFetridge
Center for Health Policy Research
2021 K Street N.W., Suite 800
Washington, DC 20052
Tel: (202) 296-6922
Fax: (202) 785-0114

Margaret McManus
President, McManus Health Policy
2 Wisconsin Circle, Suite 700
Washington, DC 20815
Tel: (202) 686-4797 Fax: (301) 654-1089

Merle G. McPherson, M.D. (Observer)
Director, Services for Children with Special Health Needs
Maternal and Child Health Bureau
Parklawn Building, Room 18A-27
5600 Fishers Lane
Rockville, M.D. 20857
Tel: (301) 443-2350
Fax: (301) 443-1797



Susan Millstein, Ph.D.
Associate Professor of Pediatrics, Division of Adolescent Medicine
Associate Director, National Adolescent Health Information Center
University of California, San Francisco
400 Parnassus Avenue, AC-01
San Francisco, CA 94143-0374
Tel: (415) 476-2184

Fax: (415) 476-6106

Freda Mitchem

Associate Director of Development and Research National Association of Community Health Centers 1,330 New Harapshire Avenue N.W., Suite 122 Washington, DC 20036 Tel: (202) 659-8008 Fax: (202) 659-8519

Elena Nightingale, M.D., Ph.D.

Special Advisor to the President/Senior Program Officer.

Carnegie Corporation of New York.

2400 N Street N.W., 6th Floor.

Washington, DC 20037-1153.

Tel: (202) 429-7979.

Fax: (202) 775-0134.

Audrey H. Nora, M.D., M.P.H. (Observer)
Director, Maternal and Child Health Bureau
Parklawn Building, Room 18A-05
5600 Fishers Lane
Rockville, MD 20857
Tel: (301) 443-2170 Fax: (301) 443-1797

Elizabeth Ozer, Ph.D.
Health Psychology Program
University of California, San Francisco
1350 7th Avenue, CSBS-204
San Francisco, CA 94143-0844
Tel: (415) 476-7744
Fax: (415) 476-7744

James J. Papai (Observer)
Chief, Research and Training Services
Maternal and Child Health Bureau
Parklawn Building, Room 18A-55
5600 Fishers Lane
Rockville, MD 20857
Tel: (301) 443-3163
Fax: (301) 443-4842

Barbara Ritchen, R.N., M.A.
Director, Adolescent Health Program
Colorado Department of Health
4300 Cherry Creek Drive South
Denver, CO 80222-1530
Tel: (303) 692-2328
Fax: (303) 782-5576

Jeannie Rosoff
President, Alan Guttmacher Institute
1120 Connecticut Avenue N.W., Suite 460
Washington, DC 20036-3902
Tel: (202) 296-4012
Fax: (202) 223-5756

Beth D. Roy (Observer)
Director, Hemophilia and AIDS Program Branch
Maternal and Child Health Bureau
Parklawn Building, Room 18A-19
5600 Fishers Lane
Rockville, MD 20857
Tel: (301) 443-4842

Paula Sheahan (Observer)
Director of Outreach
National Center for Education in Maternal and Child Health
2000 15th Street North, Suite 701
Arlington, VA 22201-2617
Tel: 703) 524-7802
Fax: (703) 524-9335

Michele Solloway, Ph.D.
Senior Research Staff Scientist
Center for Health Policy Research
George Washington University
2021 K Street, Suite 800
Washington, DC 20052
Tel: (202) 296-6922
Fax: (202) 785-0114

Colleen Sonosky
Center for Health Policy Research
George Washington University
2021 K Street N.W., Suite 800
Washington, DC 20052
Tel: (202) 296-6922
Fax: (202) 785-0114

Robert St. Peter, M.D. (Observer)
Coordinator, Children and School Programs
Office of Disease Prevention and Health Promotion
330 C Street S.W., Room 2132
Washington, DC 20201
Tel: (202) 205-8180 Fax: (202) 205-9478



Shirl Taylor (Observer)
Management Intern
Maternal and Child Health Bureau
Parklawn Building, Room 18A-39
5600 Fishers Lane
Rockville, MD 20857
Tel: (301) 443-4026
Fax: (301) 443-1296

Deborah von Zinkernagel (Observer)
Health Policy Advisor
Committee on Labor and Human Resources
United States Senate
428 Dirksen
Washington, DC 20510-6300
Tel: (202) 224-5880
Fax: (202) 224-3533

Deborah Klein Walker, Ed.D.
Assistant Commissioner
Bureau of Family and Community Health
Massachusetts Department of Public Health
150 Tremont Street, 4th Floor
Boston, MA 02111
Tel: (617) 727-3372
Fax: (617) 727-0880

James Weill G. neral Counsel Children's Defense Fund 25 E Street N.W. Washington, DC 20001



