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ABSTRACT

This executive summary presents specific proposals to improve maternal and child health conditions in the United States. Contents of the summary are organized in 13 chapters. Five overriding concerns in the areas of health and health care are identified in Chapter One. Chapter Two focuses on the reduction of environmental risks: Chapter Three explores the relationships between health and behavior; and Chapter Four identifies four ways to improve the nutritional status of mothers and children. Chapter Five focuses mainly on prevention services that typically can be delivered through primary care systems. Chapter Six identifies nine organizational attributes that should be incorporated into all provider arrangements and submits proposals for strengthening existing arrangements. Chapter Seven discusses home visiting, primary mental health care, categorical services, mass screening, hospital care, and regionalization. Chapters Eight and Nine concentrate on organizing services for special populations and financing health services, respectively. Chapter Ten suggests ways to improve program coordination and management. Chapter Eleven discusses federal administration arrangements. The final two chapters suggest new roles for and relationships among health professionals and list domains of special importance on which research is needed. In conclusion, three sets of goals are formulated to clarify relationships among the many recommendations ande. (Author/RH)

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Exec by Summary

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Honorable Patricia R. Harris Honorable Edward M. Kennedy Honorable Henry A. Waxman Page Two

Volume I of our report presents our major findings and recommendations.

Folume II contains specific recommendations for improving five major Federal programs with significant impact on child health:

- -- Title V of the Social Security Act
- -- The Special Supplemental Food Program for Women, Infants and Children
- -- P.L. 94-142: The Education for All Handicapped Children Act
- -- Medicaid and EPSDT
- -- Community Mental Health Centers and Services Systems

Volume III consists of what we believe to be the most comprehensive compilation of data on child health in the U.S. yet to be published.

We also submit a collection of background papers, listed at the end of Volume I, which were prepared for the Panel, and which we believe will be extremely useful to those who wish to become familiar in greater depth with selected aspects of the issues we have analyzed.

Since of our recommendations should be acted on immediately. Other are designed to be considered and implemented over a period of years. All of our recommendations are practical, and as specific and concrete as we have been able to make them.

The goals we set out encompass an extremely broad sweep of issues. In accordance with our congressional mandate we have addressed and analyzed issues and policies pertaining to the physical environment, health behavior, health services organization and financing, and health research. We did not try to go beyond these, although we are fully aware that other aspects of the social environment exercise a powerful influence on health. It is true that if we could eliminate poverty and racism in this country, if high quality preschool programs and community supports for families were more available, if teachers and schools were more effective, if we had full employment and every young person could look forward to productive work, our health indicators would improve significantly. Nevertheless, we have not focused on these issues, both because they are outside the Panel's mandate, and because we wish to help direct public attention to the extensive opportunities to improve child health by improving health policies and programs.





Honorable Patricia R. Harris Honorable Edward M. Kennedy Honorable Henry A. Waxman Page Three

The Panel has asked me to call your attention to an additional problem we faced in defining our mandate. As you know, the legislation that established the Panel asked us to look at the health of "children and expectant mothers." Child health is obviously inseparable from maternal health. The health of the mother during pregnancy is unquestionably a major determinant of child health. But as we looked beyond purely physiological factors in child health, we found that our concern must include fathers as well as mothers, buth in relation to their rule in the decision to conceive a child, and to their continuing conceive a child, and to their continuing the in providing nurturance, support protection, and guidant to their children as they grow. Not only is the family the primary unit for the delivery of health Bervices to infants and Bhildren, but the family environment is probably the greatest influence on a child's health. We wish to be clear that our use ϕ_{ij} the term "maternal and chil health," when we describe and analyze both needs and interventions, is in no way inconsistent with our conviction that fathers as well as mothers are central to raising healthy children.

We are grateful for the opportunity you have given us to engage in this work, and thank you for the help and support we have received from you and your associates in the course of our deliberations. We trust that the value of our efforts will prove to have justified the investment that the American public has made in the creation of this report.

I am sure you share with us the conviction that public policy, no matter how well conceived and carried out, can contribute only modestly to the vigor, grade, and joy we wish to see in our children's lives. But as our report makes clear, public policy and programs can mean the crucial difference, especially in the lives of the most vulnerable of our children.

We hope most profoundly that this report will contribute to shaping public policy in ways that will help all American families and communities to protect and promote the health of all of our nation's children.

Respectfully and sincerely yours,

Lisleth B. Schn

Lisbeth Bamberger Schorr Chairperson

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[†]The Panel members who are representatives of the Department of Health and Human Services wish to commend the Panel as a whole for its thorough information gathering and careful analysis of child health problems. They believe the Panel's report is an extremely useful document. However, the specific programmatic and budget recommendations contained in the report have not yet been formally considered by the Department or by the Executive Office of the President. Thus, participation by Department representatives in the Panel's activities cannot be construed as an Administration endorsement of the recommendations.

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ACKNOWLEDGMENTS

The Panel wishes to express profound appreciation to its highly competent, hard working, and dedicated staff. We are particularly indebted to John Rutler and Sarah Brown for their splendid leadership throughout our 18 months of work. We are also deeply grateful to the members of the Department of Health and Human Services who assisted us, and to the contributors listed in the back of this volume. An extraordinary number of individuals permitted us to disrupt their lives, gave unstintingly of their time and wisdom, tolerated our deadlines, and responded to our requests for help with unwavering understanding, accurate information, and fresh insights. This can only be explained by their deep commitment to the better health of the Nation's children.



SUMMARY

It is a biological fact that human infants and children depend upon others to an extent not found in any other species. In tacit recognition of this fact, all human societies, ancient and modern, have developed elaborate systems of shared family and community responsibility for the young. The makeup of such systems and the precise division of duties where them have varied from one culture to another and from one generation to the next. But the central theme of shared responsibility for the young endures.

In the United States today, our system of shared responsibility has contributed much to ensuring the healthy growth of our children. But despite great achievements, we are still falling short of doing what we believe most Americans want to see done to promote the health of all our children. In recognition of this fact, the Congress created a Select Panel for the Promotion of Child Health to assess the status of maternal and child health and to develop, for the first time, "a comprehensive plan to promote the health of children and pregnant women in the United States."

The 17 private citizens and public officials who undertook this task carefully scrutinized existing maternal and child health data, knowledge, and experience. We found widespread consensus about the interventions likely to be effective, about the programs that work well and the obstacles that keep them from working better, about ways to get the most out of the money we are already spending, and about improvements that could be achieved for relatively little more. We have also found that a large proportion of the most burdensome child health problems can be prevented or ameliorated at reasonable and predictable costs through the application of knowledge already at hand The Panel was struck by the contrast between how much we know about promoting the health of pregnant women and children and how little is actually reaching some of the most vulnerable among them. Similarly, we were impressed by the number of highly successful efforts currently underway throughout the country, but discouraged that they have not been systematically built upon and expanded.

Even though we discovered much agreement on what needs to be done, we found the task of developing specific proposals to improve maternal and child health even more formidable than we originally anticipated. It soon became evident that our very mandate was bucking widespread feelings of alienation from Government, and a rising tide of cynicism and hostility toward all social programs.

We believe that it is possible to take account of these currents in our political climate without becoming immobilized by them. We recognized



early in our work that we must be cost-conscious as well as compassionate; incremental but with a clear vision of the long-term goals toward which we aim. We have tried, as Congress asked of us, to be comprehensive, but without being unrealistic. We have made some sweeping but practical proposals. They reflect the broad consensus in the land that even the best public programs and policies can be made to function better when they are more rationally and coherently related to one another.

Perhaps most important in terms of providing a basis for action over the next decade, our proposals are justified by both a human concern for the young and the self-interest of adults. Our recommendations to promote maternal and child health are based on our deep belief—shared, we are convinced, by most Americans—that children matter for themselves, that childhood has its own intrinsic value, and that society has an obligation to enhance the lives of children today, quite apart from whether we can prove later benefits in adulthood.

We do not rest our case solely upon such convictions, however. What we offer is also a prospectus for a sound investment in America's future, in economic as well as social terms. Healthy children represent a major economic asset. As today's children grow to adulthood, they will have to perform increasingly complex tasks, in an age of constant technological change, in order to protect our natural environment, maintain our standard of living, keep our economy competitive with other nations, preserve our defense capabilities, and maintain our humanitarian values. We will tomorrow be dependent upon the very children who today are dependent upon us. Each and every one of them—male and female, rich and poor, black, brown, and white—is both a precious individual and a valuable national resource. Improving the health of today's children not only enhances the quality of their lives immediately, it also expands their potential for significant contributions to the Nation as adults.

We call upon all Americans—public officials and private citizens, parents and professionals, leaders at the local, State, and Federal level—to join in concerted efforts to make certain that policies and programs in the 1980's, in both the public and private sectors, reflect a commitment that does justice to the needs of all of the Nation's children.

CHAPTER SYNOPSIS

Section I—Introduction

Chapter 1: Major Concerns

In the course of our work, five overriding concerns emerged. It is to these concerns that we have addressed our analysis and recommendations:

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(1) Many forms of disease prevention and health promotion are demonstrably effective, especially for children and pregnant women, but still are neither widely available nor adequately used even when available.



- (2) The health status of American children has improved dramatically over the past two decades, but not all groups have shared equally in the progress. Sharp disparities persist in both health status and the use of health services according to family income, ethnic background, parental education, and geographic location.
- (3) The profile of child health needs has changed significantly over the course of this century, partly as a result of success in c mbating infectious disease, partly because new problems have herged. But the organizational, administrative, financial, and professional training aspects of our health care system today have not been adapted to cope with current health problems, which have intertwined psychological, environmental, social, and behavioral components.
- (4) While the family is and will remain the primary source of health care for children, the current health care system insufficiently recognizes or supports this role. Nor has the system acknowledged or adequately responded to the health implications of the changing composition and circumstances of the American family.
- (5) The Nation's increased investment in maternal and child health over the past two decades has spawned many new programs, but they are not working effectively in relation to one another. Public programs have made a significant contribution to improving the health of the Nation's mothers and children, but there remain gaps in and between services; fragmentation and duplication in both programs and services; and conflicts among various levels of government and among a variety of programs.

Section II—Health Protection and Promotion

Many of the strongest influences on child health lie beyond the reach of personal health services. These include the social environment, the physical environment, nutrition, and health-related behavior.

Factors in the social environment such as family income, parental education, opportunities for productive work, minority status, child care arrangements, and the availability of community supports for adolescents and parents of young children all exert a powerful influence on health. We recognize the significance of these influences, but offer no extensive recommendations in this area because it lies beyond the scope of our mandate.

Chapter 2: Reducing Environmental Risks

Hazards in our physical environment can profoundly affect the health of our children both before and after they are born. Our review of the evidence on environmental hazards to mothers and children suggests there are four risks which deserve special attention in the coming decade: accidents of all kinds, with emphasis on motor vehicle accidents and those in the home; chemical and radiation risks, including those posed by toxic



wastes, pesticides, lead and other pollutants; hazards from drugs and foods, with particular focus on substances presenting special risks during pregnancy; and problems caused by inadequate or unhealthful water supplies, with attention to the need for wider fluoridation, potable water in all homes, and adequate sanitation. These four types of risk include old problems which could be prevented through the application of knowledge already in hand, and new or newly discovered problems, which often are complex in causation and less easily understood or addressed.

Accidents, especially motor vehicle accidents, are the leading cause of death and disability among children and adolescents. The United States is second only to Canada among ten Western industrialized nations in its rate of accidental deaths among children. The Panel believes this state of affairs is unacceptable, and can be changed in a Nation as resourceful as ours. A major new national accident prevention strategy should be initiated, with strong participation by private industry, citizen groups, the media, and Government. This strategy should take advantage of both private initiatives and public policy instruments, including technical innovations, regulatory actions, and new approaches to education of children and parents.

The evidence suggests that many kinds of injuries and health problems can be more economically and effectively reduced by changing the environments in which people live, work and play, than by trying to change behavior directly. Thus, for example, safer automobile construction and better passive restraint systems in automobiles may be more effective than increased expenditure on driver education.

Among the most worrisome, pervasive, and complex environmental health hazards are the numerous chemicals and sources of radiation to which Americans are exposed in the home, at work, and in the neighborhood. Toxic chemicals and radiation pose special risks for pregnant women and for children because of the unique susceptibilities early in the life cycle and because effects may be cumulative over the lifespan. The Panel believes the Nation should clean up chemical wastes, establish safe exposure levels for insecticides and pesticides, monitor the use of X-rays, and take other necessary actions to protect the health of current and future generations.

One traditional public health objective which requires no new technology or knowledge is the elimination of obvious contaminants and sources of infectious disease from water systems. Most Americans now benefit from safe and healthy water, but three problems remain: many community water supplies are still not fluoridated, some families still lack indoor plumbing, and certain potentially dangerous chemicals are still found in drinking water.

The Panel believes that effective strategies to reduce environmental risks for children and pregnant women must involve all Americans, and not just the Government. Strategies for health protection should not be automatically equated with regulatory action. But if Federal policy is to continue to play an important role in protecting the health of children and pregnant women, various Federal agencies will need to strengthen considerably their coordination with one another over the coming decade.



Chapter 3: Health and Behavior

Health-relevant beha or is an integral part of lifestyle, which starts forming in infancy. It is influenced by a wide variety of factors including the examples set and instruction given by parents, siblings, peers, schools, religious and community groups, and the media. Socialization—the combined effect of all mese factors—is far more powerful than any single attempt to teach new behaviors. But we now know a good deal about how education in the fancy, schools, the media, the workplace, and the community can exert a significant positive influence on health habits.

A mother's influence on the health of her child begins even before birth, when a number of maternal habits such as smoking, drinking, and drug use can affect the outcome of pregnancy. The Panel believes that prenatal counseling and anticipatory guidance for parents, including preparation for childbirth and education for parenting, should be more widely available from health care providers, private voluntary organizations, and community agencies. Similarly, guidance and support in the period immediately after birth and in the first year of life can help a family cope with issues of infant feeding, how to manage a difficult baby, how to recognize illness, and how to provide a safe and stimulating environment for an infant. The perinatal period also is an opportune time to !ink women and their families with other services and supports to ensure continuity in the availability of primary care.

The rapid increase in numbers of preschoolers attending early education and day care programs oriers a new opportunity for health-related education. Eating habits, dental health practices, and other health behaviors have their roots in early childhood, and the Panel urges that preschools and programs such as Head Start be used as sites for health education and parent counseling as well as early identification of health problems.

Television exerts a powerful influence on formation of behavior from a very early age. The Nation must improve the quality of programming directed at children, particularly with regard to both implicit and explicit health messages; we must also preserve our capacity for regulatory action aimed at mitigating any negative health consequences of television programming and advertising targeted toward children. In addition, parents, policymakers, and community groups should encourage alternatives to excessive television viewing among children. Inordinate time spent watching television diminishes the opportunity for more active ways of learning about life.

Many school health education programs at present are neither sufficiently comprehensive nor sufficiently attuned to the influence of peer culture and other important determinants of youthful behavior to be truly effective in promoting good health habits. The content of school health education should remain a matter for local determination involving active parental participation, but should include sound information and guidance on such topics as eating habits and nutrition, exercise, smoking, alcohol and drug use, driving safety, human sexuality, family development, coping and stress management, and environmental conditions

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affecting health. Physical education programs in particular are an area of vast unrealized potential. These should place new emphasis on lifetime fitness and health maintenance skills as well as competitive team sports.

Because so many forms of behavior with lifetime health consequences are formed or first tried in adolescence, health education activities are especially important for youngsters 10 to 18 years old. Although most adolescents are physically healthy, problems ranging from accidents to substance abuse and uncertain self-esteem and strong peer pressure. Adolescents need more in armation about the effects of their lifestyle on their present and future health, but such information must be presented in ways which are likely to be taken seriously by them. This suggests a special responsibility for those most likely to be heeded by teenagers, including influential teachers and community leaders, sports figures, and television and radio celebrities.

Chapter 4: Improving Nutrition

The critical role that nutrition plays in health has not been adequately recognized by the health community generally, including those whose principal focus is maternal and child health. We share the developing consensus that nutrition is a major, not marginal, component of efforts to promote health and prevent disease, especially during pregnancy, infancy, childhood, and adolescence when the human organism is growing and developing.

While there are still some who lack adequate food, starvation and gross nutritional deficiency diseases are no longer the major problems they once were. Today's nutrition problems are more likely to involve dietary excesses and imbalances which may in turn be implicated in the development of leading chronic degenerative diseases. Adequate nutrition is especially important for some mothers and children who, by virtue of such factors as socioeconomic and minority status, age or cultural background are at special risk of nutrition-related problems.

The Panel identified four ways to improve the nutritional status of mothers and children:

- (1) There must be a new and vigorous commitment in the health system, schools, the media, private industry, and Government to inform and educate families more adequately about health-promoting and risk-reducing diets. The Panel urges the Federal Government to take a major leadership role in developing and disseminating norms for appropriate nutrition. Nutrition-related guidance must take cognizance of our new "nutrition environment," which is characterized by new patterns of eating, a rapidly changing food supply, phenomenal growth in convenience and processed foods, and fast food restaurants.
- (2) Nutrition services must be better integrated into health care. Health care providers should specifically address their patients' nutrition-related needs as part of the full range of health services offered, and should link their practices to nutrition services in their communities.



(3) Existing public food programs also must be strengthened and expanded. Over the long run, the Supplemental Food Program for Women, Infants and Children (WIC) should be enlarged to serve all who are eligible by income and nutritional risk; State and local health care systems which provide the base for the WIC program should be expanded accordingly.

(4) Research is needed to develop a better understanding of children's diets, nutrition, and health status; to identify individual and family nutrition-related behaviors that increase children's risks of disease and to develop ways to help families change such behaviors; and to develop greater understanding of the effects of early feeding patterns and nutritional status on long-term development and adult health status.

Section III—The Content, Organization, and Financing of Health Services

The Panel concluded early in its work that any proposals we might make for changes in the organization and financing of health services should grow out of an assessment of what services children and pregnant women actually need, in addition to an analysis of current patterns of service use and the strengths and shortcomings of existing programs. We focused our attention most heavily on primary care, in the belief that it is the area with the most urgent unsolved problems. Similarly, we directed much of our analysis to the way in which health services for mothers and children are organized and financed, believing that such health system components exert a major influence on health status.

Chapter 5: Needed Services

The task of defining "needed services" was a fundamental first step in the Panel's work and served as the basis for many of our subsequent recommendations, particularly those regarding the organization and financing of health services. Because health problems in this group range from the biomedical to the psychosocial, needed services include services such as counseling, anticipatory guidance, and various information and education activities oriented primarily to psychosocial issues, in addition to traditional medical care.

We focus mainly on services that are preventive in nature and are typically delivered through primary care systems. This orientation stems both from the Panel's mandate and from our belief that many of the strategies most likely to decrease overall mortality and morbidity in mothers and children lie in the domain of preventive services and primary care. This emphasis is accompanied by our conviction that the expansion and improvement of secondary and tertiary services to mothers and children who need such care is also critical and requires more adequate resources and improved coordination between primary care and more specialized services.

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Chapter 5 presents lists of health and health-related services that should be fully available and accessible to women in the reproductive age span, including pregnant women; infants in the first year of life; preschool and school-aged children; and adolescents.

The process of defining needed services led us to three major findings. First and most important is the conclusion that for three broad classes of services, there is such a clear consensus regarding their effectiveness and their importance to good health that it should no longer be considered acceptable that an individual be denied access to them for any reason:

- Prenatal, delivery, and postnatal care
- Comprehensive health care for children from birth through age 5
- Family planning services

A second category of services which merit special attention includes mental health and related psychosocial services, dental services, genetic services, and services that promote access to care. Although each has unique attributes, they have in common not only their importance to health but also the fact that they are not now adequately available, particularly to some of the groups most in need of them, and that they have not been accorded sufficient prominence in current views of the essential components of maternal and child health care services. By singling them out for specific discussion, the Panel hopes to strengthen the national consensus regarding their value in health promotion.

Third, a new mechanism is needed to serve a variety of functions aimed at improving the content, quality, and availability of health services for mothers and children. One reason many services we have identified as needed are unavailable or underutilized is that they are not covered by public and private third-party payment plans, in part because of the nature of the services themselves. They tend to be difficult to define precisely, and—in greater measure than is true for medical services—their effectiveness appears closely related to the circumstances under which they are provided, by whom, and in relation to what other services. To help provide information on such issues, we recommend that a Board on Health Services Standards be created, or existing institutions strengthened and consolidated, to perform the following functions:

- Review and define the health services that should be available to mothers and children in light of new knowledge and changing health problems.
- Provide guidance to third-party payers and purchasers of health insurance regarding the effectiveness and appropriate use of a given service or sets of services, and the circumstances under which such services should be provided and financed.
- Provide information to third-party payers regarding the likely
 effects of their payment policies and practices on the availability
 of needed services, professional personnel, facilities, and other
 health resources.

So that work along these lines can proceed promptly, we recommend that the Secretary of Health and Human Services convene an ad hoc group to propose the precise nature, composition, and authority of the



Board within the broad guidelines we propose, and that the Congress act rapidly to establish the Board or a similar mechanism to perform these important functions.

Chapter 6: Improving the Organization of Health Services

Primary care for children and pregnant women is currently provided under a wide variety of arrangements, which range from private physicians' offices to the public schools, from health department control to community health centers and health maintenant organizations (HMO's).

American communities vary so widely in their needs and resources, as prize so highly the diversity of their own ways of solving problems, that is neither feasible nor wise to attempt to move the Nation toward on standard way of delivering health services to mothers and childre-However, we have identified specific organizational attributes which should be incorporated into all provider arrangements. The effective organization and structuring of services is especially important for families with handicapped, chronically ill, or severely ill children; for pregnant women who for social or medical reasons are at high risk; and for lowincome families, who have greater needs for health and related services and fewer resources to negotiate their way around a complicated maze of fragmented health services. Since these categories of families include perhaps one-fifth of all children and pregnant women at any one time, and one-fourth to one-third over a period of years, the need for more highly organized primary care is not circumscribed, but spread widely throughout the population.

The attributes that we have identified as important components of effective primary care provider arrangements are:

- Comprehensive services
- Accessibility
- Capacity for outreach
- Coordination of services
- Continuity of care
- Appropriate personnel arrangements
- Accountability
- Consumer participation
- Partnership with parents

We have analyzed a number of existing provider arrangements with these attributes in mind, and have made proposals for strengthening them.

We believe that, over the long term, primary care physicians should be encouraged to join in practice with other physicians and with other health professionals. Dentists, too, should be encouraged to join in practice with other dental professionals. Simultaneously, new efforts must be made to develop better links between providers in office-based practice and other sources of care, services, and support in the community.

Hospitals that provide a substantial amount of outpatient care to children and pregnant women must make fundamental changes in their



organizational arrangements by establishing primary care centers, hospital-based group practice, and better linkage with other sources of care in the community. None of this can be accomplished without changes in the financing of hospital outpatient services, and we recommend a number of specific changes toward that end.

Publicly financed comprehensive care settings (including community health centers, migrant health centers, children and youth projects, maternity and infant care projects, some health department programs. Indicated primary care centers) have been highly effective in providing previously unreached populations with needed health services, with subsequent decreases in hospitalization rates, infant mortality rates, and the incidence of preventable diseases in the areas served. They remain a model for the delivery of high-quality care in the Nation's areas of provider scarcity and high health needs.

We believe these programs, along with the deployment of National Health Service Corps personnel, are the best instruments for increasing access to and availability of primary care services for children and pregnant women in underserved areas, and that the Congress should increase its grant support to allow existing comprehensive care centers to serve more clients and to permit their expansion to additional sites.

Because HMO's provide cost and quality controls, the opportunity for collaboration among a variety of health workers, and a system of financing which encourages the provision of primary care and preventive services, the Panel urges that all HMO's expand their ability to provide needed services to children and pregnant women, and that Federal authorities take the steps necessary to make it more attractive for HMO's to enroll low-income mothers and children.

Support for primary care units organized and sponsored by qualified local and State health departments will be even more important during the next decade than in the past. In many areas, no other provider is as likely to offer care at moderate expense to the inner city or rural poor and the medically indigent. We therefore recommend that Federal, State; and local authorities support health department efforts to offer comprehensive primary care, rather than individual components of preventive care.

School-based health services should be considered a desirable way of delivering primary health services to school-aged children, and possibly to preschool children, in those communities where it is possible to utilize schools as the site for the provision of health services rendered under the auspices of an appropriate health agency, and where parents support and actively collaborate in fashioning and maintaining such arrangements. Nonetheless, there are many school systems where it will not seem wise to locate a comprehensive primary care program in the schools. In such instances, professionally qualified nurses should provide health education, counseling and preventive services, work with parents to link children with other health services, and provide professional nursing supervision for children with chronic illness or handicapping conditions. Similarly, we believe a more extensive commitment of resources aimed at improving health services for children in day care, Head Start, and other preschool programs is essential.



Chapter 7: Delivery Problems of Special Concern

In its review of arrangements for the delivery of needed health services to infants, children, adolescents, and pregnant women, the Panel identified a number of special challenges or opportunities in organizing health services that cut across individual provider arrangements. We believe these should be specifically addressed in the formulation of public policy.

Home Visiting

Renewed interest in home visiting services has developed from a growing recognition that many services are best provided outside of large institutions, that traditional sources of support for many pregnant women and new parents are often no longer available, and that efforts to link persons with the services they require are often essential to obtaining good health care. Federal, State, and local authorities should substantially increase their support for home visiting programs. Such increased support should be of sufficient magnitude to: permit a substantial number of States and communities to use home visits by public health nurses or other qualified personnel as one means of ensuring access to the minimum basic health services for children and pregnant women discussed in chapter 5; enable various health care providers to establish or reestablish home visiting programs as a routine component of maternal and child health care; and allow for the evaluation of a wide range of programs.

Primary Mental Health Care

Many health problems which come to the attention of primary care practitioners are either emotional in origin or have important psychosocial components. Furthermore, a significant portion of what might be termed "primary mental health care" is in reality provided in general health care settings and in schools, day care centers, juvenile detention facilities, and other sites by personnel not specifically trained as mental health professionals. These facts must be better recognized in the organization and financing of services, in the training of health professionals, and in arrangements to provide expert mental health support and consultation to parents, general health care providers, teachers, day care workers, social workers, correctional officers, and others who deal with children and their families daily.

The time is ripe for new and systematic efforts to organize and finance primary care—especially for children and pregnant women—in ways which will encourage adequate attention to psychological, social, and behavioral components of care and which encourage referral, consultation, and ease of communication between mental health professionals and primary care providers, and agencies, institutions, and professionals who deal with children, pregnant women, and parents in trouble.

Categorical Services

In the main, primary health services for mothers and children are provided most effectively in settings that offer a comprehensive array of



needed services. But there is persuasive evidence that some services are well provided in settings that are not organized to provide comprehensive care. For example, the Panel recommends that categorical funding for family planning services be expanded to ensure that these services continue to be made available in a variety of settings, and that all persons who wish to make use of family planning services will have access to them.

The potential effectiveness of providing preventive dental services to school-age children through categorical programs has been grossly neglected. Certain basic preventive dental services are so critical to improving the dental health of the Nation that they must be available to all children and in various sites such as public schools, which simplify access and provide substantial economies of scale.

Mass Screening

Screening is useful (a) when performed in the context of individual assessments and continuing care, (b) as a means of detecting a limited number of conditions characterized by simplicity of detection and followup, (c) as a way of linking children to an ongoing source of care, and (d) as a check on the adequacy of care that children are receiving. Developmental assessment is a key component of the health assessment of every child, but developmental assessment of young children is not properly performed as part of a mass screening program, and should be carried out only in the context of a more comprehensive health or educational assessment.

Hospital Care

The operating and staffing policies, environment and design of space, and philosophy of care of all hospitals offering pediatric and obstetrical care should reflect the developmental and psychosocial needs of children and families in health care settings. All hospitals with emergency rooms that treat children should ensure the availability of special pediatric equipment and of medical and nursing staff knowledgeable in the care of critically ill or injured children.

Regionalization

The Panel urges increased support for the regionalization of selected health services for children, newborns, and pregnant women, including further development of regionalized perinatal care networks; genetic services; networks to improve care for serious illness and accidents; backup and referral services for diagnosis and treatment of children with chronic illness, handicaps, or complicated psychosocial problems; and enlarged public and private support of children's hospitals in their role as regional resource centers and providers of specialized care.

Chapter 8: Organizing Services for Special Populations

Four populations of children present special challenges to the effective organization of services: adolescents, chronically impaired children,

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children in foster care or other out-of-home placements, and children with serious access problems as a result of linguistic, cultural, or geographic separation from the mainstream of society.

The health care needs of adolescents require increased attention in existing health services systems, and efforts must be made to develop and refine innovative models for organizing services to meet special health needs arising during this important period in the life cycle. Outreach systems should be targeted to the settings where adolescents spend most of their time; counseling should be a major component of adolescent health care; sensitivity to issues of privacy and confidentiality must be reflected in the design of services for this population; and financial barriers to care must be significantly reduced or eliminated.

Certain basic principles should govern the provision of all health services for chronically impaired children—a group including the chronically ill, physically handicapped, mentally retarded, emotionally disturbed and multiply handicapped. Routine care should be provided in the home or as near to normal settings as possible; hospitals should design systems that maximize use of nearby homelike settings, including hospice care where necessary; primary care needs including mental health, dental care and support services for children and families should not be overlooked; and the hidden costs of care for chronically impaired children should be taken into account in private and public financing of care. Clearer guidelines and specifications are needed in a number of public programs directed at these children. The efforts of maternal and child health authorities in this regard should complement school-based efforts under P.L. 94–142, the Education for All Handicapped Children Act.

Juveniles in confinement and in foster care are often overlooked by the health care system. Detention and correctional facilities have an obligation to meet the health and mental health needs of juvenile offenders, and offenders should not be placed in facilities which lack services to meet their needs. The Panel also recommends that required care plans for children in foster care include thorough periodic assessments, and statements of the children's health needs, the health services being provided, and the agencies or individuals responsible for providing such services.

Migrants and farm workers often have inadequate access to publicly financed health and social service programs, which typically depend on stable residency as a criterion for eligibility. The Migrant Student Record Transfer System, a computerized system enabling education authorities to track migrant children from school to school, should be used to link migrant health service programs so that selected health information can move with the child as families change location. In addition, State health plans should contain explicit provisions for meeting migrant health care needs.

Native American children also have special health care needs. Increased numbers of Native Americans should be helped to enter the health professions; more team care should be available; alcohol abuse and other behavioral problems should be effectively addressed; water and sanitation services should be expanded; and primary care for urban Indians should be improved.



While refugees, "entrants," and illegal immigrants all share common problems in obtaining health services, they are treated quite differently by law and public policy. For refugee children the main problem is the discontinuity which is built in by the 3-year eligibility limit for benefits under the Refugee Act of 1980. No distinction should be made between refugees and "entrants" in determining eligibility for health care for children and pregnant women. In areas where illegal immigrants represent a significant component of medical indigents, means should be sought by the Congress, the Department of Health and Human Services (DHHS) and the States to provide fiscal relief to hospitals and primary care providers requiring such assistance.

Chapter 9: Financing Health Services

The way in which health services are financed is the single most important determinant of how the health care system operates, what services are available, which professionals provide those services, and who will receive them. Current public and private third-party payment systems provide incentives that result in an allocation of physician time, distribution of physicians by speciality are location, and a manner of providing health services that collectively are unresponsive to a significant part of patient needs, especially those of children and pregnant women, and that unnecessarily drive up health care costs. Further, current financing arrangements leave millions of Americans with no public or private health insurance protection whatsoever, and many millions more with grossly inadequate coverage.

Purchasers of health insurance, public and private third-party payers, and health care providers should take steps to modify and create alternatives to prevailing methods of reimbursing health professionals and institutions, including:

- Revision of payment schedules and methods to reflect the value of counseling and other time-intensive aspects of primary care and to decrease inappropriate incentives for performing technical procedures.
- More widespread use of alternatives to fee-for-service payment methods.
- Methods of reimbursement that offer equal incentives for training health professionals in ambulatory care and inpatient settings.

Third-party payers and purchasers of health insurance need better guidance on which services are in fact needed, who is qualified to provide them and under what circumstances. The Board on Health Services Standards recommended in chapter 5 is designed to provide such guidance, and also to provide information regarding the likely effects of third-party payment policies and practices on the availability of needed services. professional personnel, facilities, and other components of the health care system.

Private Health Insurance

The potential of private health insurance plans for advancing maternal



and child health remains to be fulfilled. Toward that end, the Panel recommends that State insurance commissioners review private insurance policies approved for marketing in their States and grant certification to those that meet the health needs of children and pregnant women. In determining which policies merit certification, the States should use criteria advanced by the proposed Board on Health Services Standards.

Medicaid

The Medicaid program has removed economic barriers to needed care for many poor families. However, the adequacy of the program varies greatly among States, and in some instances, restrictive State policies result in tremendous economic hardships and barriers to needed care for millions of families. For example, in 19 States, women who are pregnant for the first time do not qualify for prenatal benefits. Only about two-thirds of all poor children are eligible for Medicaid; and an estimated 7 million children wno meet Federal criteria of poverty cannot receive any Medicaid benefits at all. This is because many States do not allow children of two-parent families to participate in Medicaid, because income standards for eligibility are low in some States, and because many who are eligible during part of the year lose eligibility when family circumstances change.

Many current problems with the program could be ameliorated without changing its basic structure as a Federal-State program focused on the poor. The most important improvements are incorporated in several versions of the Child Health Assurance Program (CHAP) pending before Congress; these improvements should be promptly enacted. Specifically, the Panel recommends immediate action to establish a uniform national income and resources standard and the extension of eligiblity to all children and pregnant women who meet that test, regardless of family status or other conditions; to require coverage of a uniform national package of services; to include all qualified providers; and to provide Federal incentives to the States to expand access to services and encourage continuity of care.

National Health Financing Programs

Even if the improvements we recommend are made in private insurance and Medicaid, some people will remain uncovered by any form of health insurance, public or private, and many parents will still be forced to choose between health care for their children and the purchase of other necessities.

It is the Panel's conviction that the health care needs of children and pregnant women will be best served over the long run by a national health financing program that ensures universal entitlement to health care. If such a plan cannot be put in place relatively soon, the Panel urges enactment of national health insurance for pregnant women and children to 18. If it proves necessary to phase in eligibility even for this population, the Panel recommends starting with a program covering all pregnant women and children through age 5.



Grant Programs

The Panel supports the use of expanded grant programs to:

- Encourage the development of resources in geographic areas where the personnel, facilities, or delivery mechanisms to provide health care services are unavailable, and to finance demonstrations of new and better ways to deliver such services.
- Pay for services that are more appropriately financed through grant programs than through third-party payments, and for those where more information is still needed regarding the most effective methods of payment.
- Pay for comprehensive services for persons such as handicapped children who have health care needs best met through special systems or programs.
- Pay for health services for those persons lacking other sources of payment, such as migrant workers, poor individuals not eligible for Medicaid, and illegal immigrants.

Section IV—Governmental Relationships

The Panel concluded that the interrelationship of local, State, and Federal Government in the area of maternal and child health needs reordering and simplification. Suggested changes pertain not only to agencies that provide or support services directly, but also to those that perform broader functions such as planning, monitoring, and advocacy.

Chapter 10: Structuring the System

The major health and health care objectives the Panel has identified can be attained without creating major new public programs. But it is essential to enhance the complementarity of existing programs, clarify responsibilities for those making policy and administering programs, and achieve improved coordination and program management.

The Panel believes that the current disarray of programs and policies is sufficient to merit a major modification in the Nation's policies and programs for improving the health of mothers and children—equal in significance to the creation of the Children's Bureau in 1912 or the passage of the Title V legislation in 1935. The agenda this time must be to simplify program oversight and management while ensuring the achievement of specific, socially agreed-upon objectives. We propose that various steps be taken to establish more coherent State and Federal administrative structures, to redefine the appropriate relationship between State and Federal authorities responsible for relevant programs, and to improve local service coordination.

Every State should work toward placing authority over all relevant funding streams in an appropriate division of the State health unit, and a strong unification of effort should be promoted around all aspects of care for children and pregnant women, including handicapped children.

While it is difficult to increase both State autonomy and Federal accountability simultaneously in working toward national objectives,

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several steps can be taken that will serve both purposes. These include Federal accountability mechanisms that stress the Federal role in establishing broad performance objectives and standards and the State role in selecting methods for attainment of these; joint applications and reporting forms for all Federal programs related to the health of children and pregnant women; a new set of coordination criteria to be met by all new or continuing legislation and program regulations; and interagency agreements to identify areas of responsibility, define specific steps to be taken, and assign realistic time frames for the attainment of goals.

Title V continues to be an essential element for providing health care services and for increasing the coordination of all State and Federal programs relevant to the health of children and pregnant women. We recommend that Title V be revised and expanded, according to the specifications detailed in volume 11 of the report, to provide the necessary leadership and policy focus.

It is especially at the local level that the efforts of service providers must be simplified and unified in order to provide effective services. At least two types of local initiative have proven successful: the establishment of a single point of service administration and budget control, and the development of improved methods of case management and case advocacy. Each locality should designate a lead agency or publicly appointed body to assess whether the existing network of private and public health care arrangements is sufficient to meet the health care needs of local children and pregnant women, and to recommend changes as needed.

We also urge Federal, State, and local authorities to take a number of steps to better harness existing policy functions applying to all public health programs. These functions include planning, quality assurance, development of information systems, research and demonstrations, technical assistance-consultation, and advocacy.

Chapter 11: Federal Administrative Arrangements

The new national commitment to protect and promote the health of mothers and children which this report advocates can be best advanced at the Federal level through the creation of a Maternal and Child Health Administration (MCHA) within the Public Health Service, to be made up of the existing Office of Maternal and Child Health, the Adolescent Health and Pregnancy Prevention Program authorized by P.L. 95–626, family planning services supported by Title X of the Public Health Services Act, and possibly other programs at some future time.

Maternal and Child Health Administration functions should include (a) operation of these programs; (b) authority to review and comment on major policy issuances, including proposed budgets and legislation, developed by other agencies within DHHS that conduct activities directly related to maternal and child health with a view toward achieving better coordination of programs; (c) assistance to the States on maternal and child health-related topics to help ensure that all mothers and children within their jurisdictions have access to needed services; (d) responsibility for setting national standards by which to assess the adequacy of the



States' progress in ensuring the availability of the minimum set of basic essential services; (e) coordinating the maternal and child health programs of DHHS with related programs in other departments, such as the WIC program of the Department of Agriculture, and the Education for All Handicapped Children activities of the Department of Education; and (f) research and advocacy. The primary value of the MCHA, in the Panel's view, is that it would be an organizational entity of sufficient stature and prestige to mobilize and coordinate programs and sources of funds in many separate agencies in the service of improved maternal and child health.

The Panel decided against recommending that the EPSDT program be moved from the Health Care Financing Administration (HCFA) into the new MCHA. We concluded that its removal from the rest of Medicaid would create delays and disruptions in providing services. More importantly, its relationship to other maternal and child health programs represents a small part of a much larger issue—the relationship of all Public Health Service (PHS) programs to all programs administered by HCFA. A number of steps should be taken to link the service orientation of PHS with the financing and management capacity of HCFA. The establishment of the proposed Board on Health Services Standards could be expected to supplement HCFA's existing expertise in management and cost-containment and thus enable it to perform a broader mission including health promotion and disease prevention. We recommend that the Secretary of DHHS give urgent consideration to other possible steps in this direction, such as making both PHS and HCFA responsible to a new Under Secretary for Health.

The Panel also proposes the creation of a National Commission on Maternal and Child Health, appointed by the Secretary of DHHS to report every 3 years on the health status and unmet service needs of mothers and children; to recommend policy changes in Federal maternal and child health programs, especially to improve their effectiveness and to enhance coordination among programs; and to serve as an advocate, particularly in Congress, for the health needs of mothers and children.

We also recommend joint oversight hearings by the appropriate committees of House and Senate to increase the coordination of maternal and child health programs that fall within the responsibilities of different committees.

Section V-Manpower and Research

Many of the Panel's recommendations suggest new roles and relationships among the health professionals who provide care to children and pregnant women, and underscore the importance of continued and expanded research.

Chapter 12: Health Professionals

Many of the views and recommendations presented in this report contain major policy implications regarding the training and deployment of professionals in maternal and child health. These include:

 The changing profile of primary care needed by mothers and children, with its emphasis on health promotion and disease



prevention activities, requires new components in the training of all primary care providers.

 Meeting the health needs of pregnant women, children, and adolescents will increasingly require a team approach to the delivery of primary care.

• The anticipated increase in the overall supply of primary health care providers in the coming decade makes possible, but does not by itself ensure, better access to health care for those most in need. Improved distribution of services will depend, among other things, on alterations in the deployment of National Health Service Corps personnel and on creative use of providers with different levels of training and expertise.

 Training of maternal and child health personnel involved in program administration and policymaking at the Federal, State, or local level must be modified to equip such professionals with the broad range of skills required for management roles in complex, interrelated service systems and to bridge the worlds of maternal and child health, obstetrics, and pediatrics.

Chapter 13: Research

The Panel emphasizes the importance of research directed toward increasing understanding of the biomedical, behavioral, and environmental determinants of health and disease, and toward the improvement of our health delivery system. A wide array of scientific disciplines, pursued at both the fundamental and the applied levels, must be employed—biomedical, behavioral, and social research, the population-based health sciences, health services research, and related disciplines.

The Panel vigorously supports the pluralism of research orientations and agencies currently supported by the Federal Government, but recognizes such diversity of effort requires broad-scale research planning and coordination. We recommend that the Assistant Secretary for Health undertake periodic and careful review of the activities of Federal agencies supporting health research, and of the relationship of current research priorities to the evolving needs of mothers and children, to minimize the risk of significant gaps developing in the total research effort.

We call attention to several research domains of special importance: epidemiology, prevention, social and behavioral aspects of health, health policy, evaluation research, and research on environmental risks to health. We also recommend strongly that support for fundamental research in the health sciences be sustained and increased as opportunities emerge and resources allow, and that special efforts be made to ensure that support for new or neglected areas of research not be made at the expense of fundamental research.

To support many of the research needs we identify and to improve the content, organization, and financing of health services, a more adequate pool of statistical and survey data is needed on a great variety of maternal and child health issues. We stress simultaneously that massive amounts of data already in hand are inadequately analyzed and reported.

Because a well trained, steady supply of researchers is a cornerstone of any national strategy to prevent disease and promote health, we view the



current trend toward erosion of training support with great concern. Also, in order to further stimulate research on the health issues and interventions which are particularly important in primary care and to maternal and child health, the Panel recommends that research training opportunities be increased in ambulatory primary care settings and other settings oriented to health promotion and disease prevention.

PLAN FOR ACTION

The Panel views the spectacular improvements in child health achieved by this nation in the past half century as providing a firm foundation on which to build for the future. We have identified the areas in which major problems persist and further improvements are urgently needed.

To clarify the interrelationship among the many recommendations we make throughout the report, we propose three sets of goals.

- (1) The first set of goals is directed at ensuring that all needed health and health-related services are available and accessible to all infants, children, adolescents, and pregnant women:
 - First, to ensure universal access to three sets of minimum basic services: prenatal, delivery, and postnatal care; comprehensive care for children through age 5; and family planning services.
 - Second, to bring about the more effective operation of governmental activities aimed at improving maternal and child health.
 - Third, to improve the organization of health services to reach those population groups with special needs or at special risk, including adolescents, chronically impaired children, children in institutions and foster care, and children in the families of migrant and farm workers, Native Americans, refugees, and illegal immigrants.
 - Fourth, to ensure that a family's economic status shall not be a bar to the receipt of needed health services or determine the nature and source of such services, and that the use of such services shall never reduce a family to penury.
 - Fifth, to ensure that every child from birth to age 18 and every pregnant woman has access to a source of continuing primary care.
 - Sixth, to ensure that every family, child, and pregnant woman has access to all services identified as "needed," not merely those basic minimal services which are part of our first goal. This includes genetic, dental, and mental health services and services to respond to health problems with major social and behavioral components.
- (2) The second set of goals we propose addresses the influences on maternal and child health which lie beyond the reach of personal health services:
 - First, to encourage all efforts aimed at reducing accidents and risks in the physical environment, and to bring about greater recognition of the particular vulnerability of children and pregnant women to environmental risks.



- Second, to promote greater understanding and acceptance of the critical role of nutrition by private industry, Government, the media, the schools, and community groups as well as by the health system.
- Third, to enlist the schools, the media, industry, and voluntary associations, as well as the health system, in far more vigorous efforts to help individuals adopt and sustain behaviors that enhance health and well being.
- (3) The third set of goals we propose is directed at building the knowledge base necessary to further enhance maternal and child health:
 - First, to encourage both the public and private sector to pursue a wide range of research spanning not only the biomedical and behavioral sciences, but also the population-based sciences and health service research.
 - Second, to recognize that fundamental research remains the cornerstone of many past and future advances in health.
 - Third, to ensure that an adequate portion of research support is directed to the special health problems of mothers and children.

It is clear that progress toward achieving these goals will require integrated and coherent action. We recognize the difficulties involved in achieving such action, especially if the necessary steps involve any fundamental change. With an eye to constraints on both available public funds and advocacy energies, we suggest that many changes can be made incrementally without diminishing their effectiveness, as long as there is a clear vision of long-term goals. We urge policymakers and advocates, in adopting such an approach, not to lose sight of the relationships among the parts.

Progress toward these goals will also require considerable attention to detail. For this reason, we devote the second volume of our report to spelling out the implications of our recommendations for immediate action to improve five Federal programs with a major impact on child health: Medicaid and EPSDT, the WIC Supplemental Food Program, Title V (Maternal and Child Health and Crippled Children's Programs) of the Social Security Act, the Education for All Handicapped Children Act (P.L. 94–142), and Community Mental Health Centers and Service Systems. In volume III the Panel also presents a compendium of background data on various aspects of maternal and child health, and in volume IV a series of relevant background papers. Both are intended to provide additional information to assist policymakers and the public to arrive at informed judgments in their efforts to improve child health.



