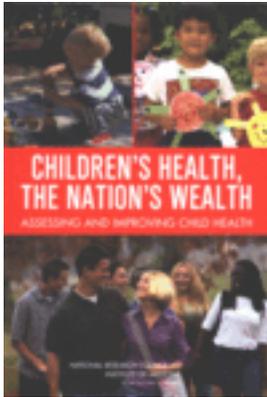


Free Executive Summary



Children's Health, the Nation's Wealth: Assessing and Improving Child Health

Committee on Evaluation of Children's Health, National Research Council

ISBN: 978-0-309-09118-3, 340 pages, 6 x 9, hardback (2004)

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Children's health has clearly improved over the past several decades. Significant and positive gains have been made in lowering rates of infant mortality and morbidity from infectious diseases and accidental causes, improved access to health care, and reduction in the effects of environmental contaminants such as lead. Yet major questions still remain about how to assess the status of children's health, what factors should be monitored, and the appropriate measurement tools that should be used.

Children's Health, the Nation's Wealth: Assessing and Improving Child Health provides a detailed examination of the information about children's health that is needed to help policy makers and program providers at the federal, state, and local levels. In order to improve children's health -- and, thus, the health of future generations -- it is critical to have data that can be used to assess both current conditions and possible future threats to children's health. This compelling book describes what is known about the health of children and what is needed to expand the knowledge. By strategically improving the health of children, we ensure healthier future generations to come.

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Executive Summary

Many things we need can wait. The child cannot. Now is the time his bones are being formed, his blood is being made, his mind is being developed. To him we cannot say tomorrow, his name is today.

Gabriela Mistral

Despite substantial progress in improving children's health, communities vary considerably in the ways they address their collective commitment to children and their health. This results in part from a lack of appreciation of the short- and long-term implications of suboptimal health and in part from the fact that the nation's systems for monitoring and optimizing the health of its children are inadequate. This report seeks to address and remedy those issues.

It is in the national interest to have healthy children. Healthy children are more ready and able to learn and, in the longer term, are more likely to become healthy adults who will contribute as a productive citizenry and workforce to the continued vitality of society. Health surveillance and monitoring systems have evolved largely from models of health based on preventing and treating childhood morbidity and mortality that resulted primarily from infectious diseases, as well as monitoring chronic diseases among adults. Future systems need to incorporate a refined conceptualization of children's health that considers prominent developmental characteristics of children as well as positive aspects of health, and they should include new methods for assessing both children's health and its influences. To ensure healthy children and create a healthy nation, meaningful information must be collected to support a broader conceptualization of health; this information must be used by federal, state, and local decision makers to inform interventions, programs, and policies.

In earlier eras, disease and death in children were due largely to infections. Childhood deaths were common. Childhood mortality and infectious disease rates in America have been radically lowered over the past century. These medical

triumphs are significant, and the medical and public health systems should take pride in what has been accomplished. Despite these accomplishments, however, there are growing numbers of children in the United States with serious chronic diseases, including many emerging disorders that reflect the interaction of genetics, behavior, and the environment. Childhood obesity, diabetes, and asthma rates are among the highest in the world and are increasing rapidly. Intentional and unintentional injuries, mental health disorders, and attention deficit disorder are highly prevalent. Moreover, many of these conditions are not equally distributed across the population; some groups experience substantially higher rates than others. Finally, the long-term consequences of these disorders are significant, because unhealthy children often become unhealthy adults. Health during childhood must be a major concern both because children are important in their own right and because the nation cannot thrive if it has large numbers of unhealthy adults.

THE COMMITTEE STUDY

In response to a congressional request, the Board on Children, Youth, and Families of the National Research Council and the Institute of Medicine formed the Committee on Evaluation of Children's Health: Measures of Risk, Protective, and Promotional Factors for Assessing Child Health in the Community. The committee was directed to review definitions of children's health, factors that influence it, the data and methods used to monitor children's health and the factors that affect it, and how data can be used to inform policy and practice. The committee used the term "children" to refer to the period between birth and 18 years and focused on population-level issues. Although data to monitor population health are often collected at the level of the individual, the committee's focus is on the health of local, state, and national populations of children.

In beginning our work and reviewing the available literature, the committee agreed on six guiding principles:

- children are vital assets of society;
- critical differences between children and adults warrant special attention to children's health;
- children's health has effects that reach far into adulthood;
- the manifestations of health vary for different communities and different cultures; and
- data on children's health and its influences are needed to maximize the health of children and the health of the adults they will become.

FRAMEWORK FOR A CHILDREN'S HEALTH MEASUREMENT SYSTEM

Over the past century, the United States has instituted important health monitoring and surveillance activities. It also has adopted important research

strategies to better understand the influence of various factors on health outcomes. A measurement system for children's health, building on what has already been achieved, should be able to:

- Measure and monitor important trends in health and its influences. These measures would span the developmental stages of childhood and be gathered from important subgroups defined by ethnicity, income, geographic region, and special needs (e.g., children with chronic conditions, in foster care, in special education).
- Provide a surveillance and early warning capacity for the detection of significant changes in health, as well as increase the capacity to forecast the effect of changing influences on children's health and anticipate the need for specific services and interventions.
- Improve understanding of the mechanisms of children's development and determine how changes in behavior, new health practices, and new policy interventions affect children's health.
- Measure the performance of the personal medical care system, relevant community service systems, and the broader public health system and how they affect children's health. Such activities would not only measure the quality of services, but also encourage the improvement of the integration and coordination of personal, community, and public health services.

CONCLUSIONS AND RECOMMENDATIONS

The committee identified five action areas to move toward a comprehensive children's health measurement system:

1. establishing a definition and framework for children's health;
2. establishing children's health as a national priority;
3. improving measurement of children's health;
4. increasing state and local leadership and use of data; and
5. promoting research to better understand children's health and its influences.

This report is intended to provide a foundation and a framework for children's health measurement rather than specific measures to monitor children's health. Appendix B provides a review of the approaches taken by key national surveys, and Appendix C summarizes many of the indicators used in national monitoring efforts.

Definition and Framework

Few existing definitions of health are specific to children, and none accounts fully for issues particularly salient to them: the developmental process; how bio-

logical, behavioral, and environmental influences are embedded in developing biological pathways during sensitive and critical periods of development; the vulnerabilities and sources of resilience of growing children; and the implications for health and health influences in one stage for all subsequent life stages, during both childhood and adulthood. Children interact with their environments in ways different from adults; their body size and behaviors make them more susceptible to some environmental influences; and, particularly in their early years, they are more dependent on their families and communities to meet their needs than adults.

The committee developed a definition of health that builds on the definition adopted by the Ottawa Charter in 1986. While this definition emphasizes health as a positive construct and accounts for the positive attributes, capacities, and reserves that determine how well an individual or population is able to respond to the challenges that life presents, it is more appropriate for adults than for children. The committee modified the Ottawa definition in light of research on developmental processes that affect health, especially for children, and to acknowledge that children's health results from a range of influences.

Recommendation 1: Children's health should be defined as the extent to which individual children or groups of children are able or enabled to (a) develop and realize their potential, (b) satisfy their needs, and (c) develop the capacities that allow them to interact successfully with their biological, physical, and social environments.

Based on current thinking, the committee's expertise, and current research on children's health, the committee further defined three distinct but related domains of health: health conditions, which capture disorders or illnesses of body systems; functioning, which focuses on the manifestation of health on an individual's daily life; and health potential, which captures the development of assets and positive aspects of health, such as competence, capacity, and developmental potential.

There are a variety of potential schemes for classifying health influences. It is generally acknowledged that factors in children's social and physical environments, as well as the services and policy contexts in which they live, affect their health. Research demonstrates that these factors interact with children's own biology and behavior to determine health. One visual model that illustrates the interaction of multiple factors on health is that adopted by the *Healthy People 2010* initiative. The committee refined this model of health to illustrate that multiple influences interact over time and that the relative weight of those influences and interactions changes in relationship to a child's developmental stage. At each stage the previous set of influences and health set the stage for the effects of future influences and health (Figure ES-1).

While much has been learned about children's development and how specific factors influence it and are embedded in biopsychosocial pathways, increased

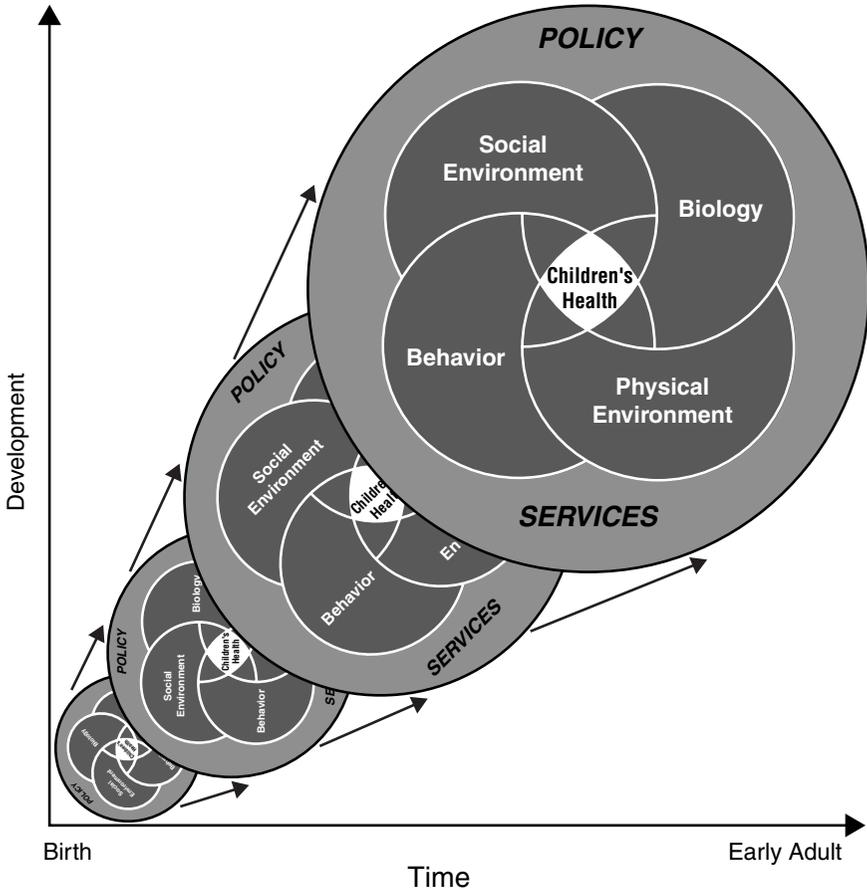


FIGURE ES-1 A new model of children's health and its influences.

understanding is important if cost-effective programs and policy interventions are to be developed, targeted, and implemented to support healthy children.

A National Priority

It is necessary for a single federal-level agency to take lead responsibility for measuring and monitoring children's health and its influences. The majority of relevant data is collected by offices in the Department of Health and Human Services (HHS), the lead federal agency on health issues. This includes the Maternal and Child Health Bureau in the Health Resources and Services Administration, the National Center for Health Statistics and other offices in the Centers for

Disease Control and Prevention, the Agency for Healthcare Research and Quality, the Office of Disease Prevention and Health Promotion and the Office of the Assistant Secretary for Planning and Evaluation in the Office of the Secretary, the National Institute for Child Health and Human Development and other units in the National Institutes of Health, and the Administration for Children and Families. Coordination among these agencies and with the other federal departments who collect data and fund services or research that affect children's health is essential to minimize duplication, increase efficiency, and ensure that data collection focuses on the most important variables.

Recommendation 2: The secretary of the U.S. Department of Health and Human Services (HHS) should designate a specific HHS unit with a focus on children to address development, coordination, standardization, and validation of data across the multiple HHS data collection agencies, to support state-level use of data, and to facilitate coordination across federal departments. The designated agency's long-term mission should be to:

- **monitor each of the domains of children's health (i.e., health conditions, functioning, and health potential) and its influences over time;**
- **develop the means to track children's health and identify patterns (e.g., trajectories) in it over time, both for individual children and for populations and subpopulations of children; and**
- **understand the interaction and relative effects of multiple influences on children's health over time.**

The designated unit should (1) translate recommendations on domains, subdomains, and dimensions of health and its influences into improved data collection strategies; (2) identify duplication and gaps in data collection efforts and develop recommendations to make data collection efforts more economical and standardized; (3) ensure that necessary data validation efforts are carried out; (4) ensure that as many data collection activities as possible are usable at the state and substate levels; (5) ensure that thoroughly documented data are released on as timely a basis as possible; (6) develop a process for assessing the potential effect of key policy changes on children's health; and (7) facilitate continued research, particularly longitudinal research, on children's health and its influences.

Improving Children's Health Measurement

Although numerous national surveys collect relevant data on children's health, serious gaps remain. Health is not measured in sufficient detail to distinguish the special developmental issues of infants and toddlers (ages 0–3 years), preschool children (4–5), school-age children (6–11), early adolescents (12–14), and older adolescents (15–18). Data on children between toddlerhood and adolescence are especially lacking. Surveys usually do not capture information on

multiple individual and environmental influences necessary to improve understanding of the interactive nature of health influences. Data on functioning and health potential, integral to a broader conceptualization of health, are particularly deficient. Biomarkers and environmental samples, important measures of environmental toxins, are not usually included in survey studies. Oversampling to ensure sufficient numbers of respondents in racial, ethnic, and socioeconomic subgroups is common in many but not all general population surveys, and most instruments and measures are not validated with major population subgroups.

It is unlikely that the nation will scrap its existing system of children's health measurement and design an entirely new system. However, improvements to existing measurement systems, coupled with continued rigorous research, can provide a solid foundation for analysis and action related to children's health. The committee recommends immediate action in several areas:

- Improved data collection in selected national surveys;
- Improved monitoring of the origins and development of health disparities among children and youth;
- Continued collection of local-area data and linking of those data with other data sources;
- Increased inclusion of geographic identifiers in health-related surveys and administrative data;
- Improved access to survey and record-based sources of health information by the research and planning communities; and
- Increased federal support of state and local monitoring of children's health and its influences.

Longitudinal surveys are needed to determine the relative contribution and roles played by individual and contextual characteristics in overall health. Such surveys should be a priority of federal and foundation funders. Comprehensive data collection projects also should oversample disadvantaged groups; begin to track children early in life; conduct frequent interviews and assessments with these children throughout childhood and into adulthood; measure assets as well as deficits; provide comprehensive measurement of all contexts that affect children's health; measure gene-behavior-environment and other contextual interactions; and chart health and disease trajectories and the relative contribution of various influences on health outcomes.

Data Collection in Select National Surveys

Existing data collection vehicles can be modified to provide more useful data over time (e.g., repeated cross-sectional data) and more comprehensive information. As a short-term response, this could include follow-back studies and addi-

tion of specific comparable health measures to the most comprehensive current surveys.

Recommendation 3: National surveys of health and health influences, such as the National Health Interview Survey, the National Health and Nutrition Examination Survey, the Early Childhood Longitudinal Studies, and the National Children's Study initiative, should address gaps in what is now collected and reported to reflect a more comprehensive, developmentally oriented conceptualization of children's health and its influences. Particular attention should be paid to adding data on functioning and health potential.

Monitoring of the Origins and Development of Health Disparities

Although in the committee's view policy makers should attend to the needs of all children, certain subgroups of children defined by race, ethnicity, immigration status, and socioeconomic status experience poorer health outcomes and receipt of services in ways that affect their future potential for healthy, productive adulthood. The factors leading to the development of health differences at all socioeconomic levels are poorly understood, although many have origins early in life. Better information and more conclusive evidence are needed to target interventions and to design effective policies to ameliorate these disparities. There also are differences in how various cultural and ethnic groups interpret symptoms and signs of disease that, in turn, alter their interpretation of inquiries about health and patterns of services.

Despite a large body of research on health disparities across subgroups defined by socioeconomic status, standards have not been established to characterize socioeconomic status across surveys and administrative records; the same is true for social discrimination and the effects of culture. However, ample methodological research has led to thoughtful recommendations on how surveys and administrative records could gather reliable measures of the education, household income, or occupational dimensions of socioeconomic status.

Recommendation 4: National and state surveys and records-based sources of data on children's health and its influences should gather systematic, standardized data on racial, ethnic, immigration, and socioeconomic classifications in order to measure the origins, distribution, and development of disparities in children's health and facilitate linkage and analysis across multiple datasets.

Collection and Linkage of Local-Level Data

An emerging body of evidence demonstrates a clear association between health and aspects of geographic location, such as neighborhood socioeconomic

conditions, crime and cohesion, ambient noise, traffic flow, and air quality. Efforts to monitor and understand environmental influences on children's health have been facilitated by the systematic collection of regional, neighborhood, and community-level information. Demographic and economic data about neighborhoods (e.g., census tracts), communities, cities, and states have been collected and made available to planners and researchers every 10 years as part of the decennial census. The emerging American Community Survey has been proposed as the vehicle for more frequent collection of these detailed local data. Continued collection of these data is vital. Other local and regional environmental data are also necessary for health planners and researchers to specify gradients in the impact of different influences. Improving the availability of data at the neighborhood, community, or regional level can improve the ability of a local community to target its own efforts and institute community-specific interventions. (See recommendations 8, 9, and 10 for additional recommendations affecting state efforts to monitor and improve children's health.)

Recommendation 5: Federal agencies and departments, particularly the Environmental Protection Agency and the U.S. Department of Health and Human Services, should promote the systematic collection, dissemination, and linkage of data on children's exposure to toxins, air pollution, and other environmental conditions, as well as data on policies likely to affect children's health. The Census Bureau should continue to collect and distribute local-area data and facilitate efforts to match these data to existing sources of information on children's health and its influences.

The geographic dimension of health patterns can be exploited only if subjects' locations (e.g., home, school, workplace addresses) have been coded with geographic identifiers and these geocoded data are made available to the planning and research communities.

Recommendation 6: Government and private agencies and academic organizations that conduct health-related surveys or compile administrative data should geocode addresses (i.e., provide geographic identifiers) in ways that facilitate linkages to census-based and other neighborhood, community, city, and state data on environmental conditions. With adequate protections to ensure the confidentiality and security of individual data, they should also make geocoded data as accessible as possible to the research and planning communities.

Access to Data by Research and Planning Communities

The importance of maintaining the confidentiality and privacy of data on specific individuals is clear. In the case of health data, specific rules govern the acquisition and use of data. Data are necessary, however, to inform and guide

public decisions and to advance public health knowledge. Administrative data *can* be integrated without identifying specific children, data security protocols *are* in place, and access to individual-level data *is* limited. Many surveys and records systems have been linked using geographic identifiers with mechanisms to both safeguard data and make them available to the research and planning communities. Yet these mechanisms are not as widely used as they could be.

Recommendation 7: Administrators of survey and records-based sources of health information should take all necessary legal, ethical, and technical steps to ensure respondent or subject confidentiality while also promoting the availability of needed data to the research and planning communities.

Federal Support for State and Local Monitoring

Technical, methodological, and measurement challenges common at the state and local levels define a role for the federal government in convening and supporting efforts to reengineer state and local health information systems. This could include providing guidance on standardized data collection; funding demonstration projects that use standardized data collection methods, aggregating data by local geographic units, and providing deidentified data on readily accessible web sites; and providing technical assistance.

Recommendation 8: The U.S. Department of Health and Human Services should formulate strategies to improve the capacity of state and local communities to monitor children's health and its influences, including funding state or local demonstration projects, standardization of data elements, and technical assistance.

State and Local Leadership and Use of Data

At the state and local levels, numerous agencies provide services to children and collect data relevant to children's health or its influences. To maximize use of these data to guide state and local decisions about interventions and policies and to inform communities about the status of children's health, it is necessary to have a single agency at the state and local levels responsible for monitoring children's health and reporting the results to policy makers and the public. This may be the state or local health department, a children's cabinet, or a senior official appointed by the governor or mayor. Most important are the mandates to relevant agencies to provide relevant data, institutionalize responsibility for coordinating data efforts, and use the data to promote and evaluate children's health.

Recommendation 9: Governors, mayors, and county executives should designate a central coordinating agency responsible for measurement and monitoring of children's health across agencies, as well as an individual responsible for reporting on progress toward integrating data on children's

health. The state coordinating agency should facilitate use of standardized data at the local level.

Although there have been increased efforts at the federal, state, and local levels to collect state- or local-level data, comprehensive state- and local-level measurement of children's health is still relatively uncommon. Substantial administrative data are collected and have been used by some states and communities to characterize children's health. Data integration—both aggregation of data from multiple sources and linkage of individual-level data across multiple sources—is an available mechanism to improve children's health in specific communities. Data standardization, provision of data at the smallest feasible geographic level, and targeted surveys to fill gaps in data, ideally drawing on standard models available at the federal level, will be needed as states develop approaches to integrating data sources.

Recommendation 10: The designated state and local coordinating agencies should advance strategies for standardizing and integrating records, including available administrative records and survey data, to maximize their potential for monitoring children's health and understanding its influences.

Promoting Research

Great strides have been made in conceptualizing the dynamic processes by which external influences interact with individuals' biology and behavior over the course of childhood. Still, additional research is needed to refine understanding of specific influences, to take advantage of new technologies for measurement, and to further advance understanding of children's health. There is a particular need for comprehensive, longitudinal surveys. The value of biomarker data is substantial, particularly as their collection and genomic testing become less invasive. More needs to be known about the relative importance of the range of influences, including the exposure of children to the large number of chemicals introduced into their environments. Valid and reliable measures are needed to assess the influence of culture and discrimination on children's health. Efforts should also be made to support application of newly developed statistical strategies using longitudinal data and to train researchers in the use of these methods. Finally, research is needed to translate potentially effective measures used primarily for research purposes into wider application for population health measurement and policy development.

Recommendation 11: The U.S. Department of Health and Human Services and the Environmental Protection Agency should prioritize research and training on emerging methods for characterizing children's health and understanding influences on it, including research on:

- **creation of improved measures of functioning and health potential;**
- **the relative importance of and interactions among the range of influences;**
- **biopsychosocial pathways of development;**
- **assessment of children's exposures to environmental toxins and other environmental health hazards;**
- **reasons and remedies for health disparities;**
- **longitudinal methods that can identify causal relationships between developmental and functional levels and the health status of children;**
- **development of profiles and integrative measures of children's health;**
and
- **construction of trajectories for each domain of children's health.**

In sum, health extends beyond traditional notions of disease and disability and is influenced by myriad factors external to the individual. Conceptualizations of health have generally not considered development as part of health. The committee has proposed both a definition of health and a framework that portrays these interactions. New measures need to be developed that capture the multidimensional nature of children's health.

Although numerous data collection efforts capture data on children's health and health influences, none has kept pace with the evolving understanding of health, and none provides a complete understanding of the interactions between and across influences. Comprehensive, longitudinal surveys are essential to filling critical gaps in data collection. More immediate, short-term approaches could include modifications to existing surveys and better use of extensive administrative data at the state and local levels. Regardless, efforts to improve collection of data need to be supported by additional research that will address key gaps in knowledge (such as limited understanding of disparities in health) and advancing children's health research by embracing new methodologies (such as use of biomarkers and improved health measures).

Finally, federal, state, and local governments need to establish a shared vision to focus on children, the nation's most valuable resource. It is time to develop comprehensive ways of assessing the health of children that will foster the nation's ability to nurture and develop its children with all their inherent richness and potential.

CHILDREN'S HEALTH, THE NATION'S WEALTH

ASSESSING AND IMPROVING CHILD HEALTH

Committee on Evaluation of Children's Health

Board on Children, Youth, and Families
Division of Behavioral and Social Sciences and Education

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Washington, D.C.
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This study was supported by contract number 282-99-0045, task order number 6 between the National Academy of Sciences and the Department of Health and Human Services. Supplementary funding for a report synthesis and dissemination of the report and report synthesis was supported by contract number N-01-OD-4-2139, task order number 125. Any opinions, findings, conclusions, or recommendations expressed in this publication are those of the author(s) and do not necessarily reflect the views of the organizations or agencies that provided support for the project.

Library of Congress Cataloging-in-Publication Data

Children's health, the nation's wealth : assessing and improving child health / Committee on Evaluation of Children's Health, Board on Children, Youth, and Families, Division of Behavioral and Social Sciences and Education.

p. ; cm.

Includes bibliographical references and index.

ISBN 0-309-09118-7 (hardcover)

1. Children—Health and hygiene—United States. 2. Child health services—United States.

[DNLM: 1. Public Health—Child—United States. 2. Child Welfare—United States. 3. Data Collection—methods—United States. 4. Health Policy—Child—United States. 5. Research Design—United States. WA 320 C5379 2004] I. National Research Council (U.S.). Committee on Evaluation of Children's Health.

RJ102.C4895 2004

362.198'92'000973—dc22

2004016741

Additional copies of this report are available from National Academies Press, 500 Fifth Street, N.W., Lockbox 285, Washington, DC 20055; (800) 624-6242 or (202) 334-3313 (in the Washington metropolitan area); Internet, <http://www.nap.edu>.

Printed in the United States of America.

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Suggested citation: National Research Council and Institute of Medicine. (2004). *Children's Health, the Nation's Wealth: Assessing and Improving Child Health*. Committee on Evaluation of Children's Health. Board on Children, Youth, and Families, Division of Behavioral and Social Sciences and Education. Washington, DC: The National Academies Press.

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Acknowledgments

This report is the work of the Committee on Evaluation of Children's Health, a project of the National Research Council (NRC) and the Institute of Medicine. The expertise and hard work of the committee was advanced by the help of our sponsor, able consultants and staff, and the input of outside experts. The funding for this project was provided by the Office of Disease Prevention and Health Promotion of the U.S. Department of Health and Human Services. Woodie Kessel served as project officer and provided valuable insights and guidance in framing the project. The National Institute of Child Health and Human Development provided supplementary funding to print and disseminate the report and a report brief summarizing the report's findings.

The committee's early meetings included presentations by experts in a range of disciplines as well as representatives from other federal government offices: Duane Alexander, National Institute of Child Health and Human Development; Brett Brown, Child Trends; Merry Bullock, American Psychological Association; John Cohrsen, Public Health Policy Advisory Board; Jose Cordero, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention; Michael Donnelly, Integrated Health Information Systems, Centers for Disease Control and Prevention; Lauren Fasig, Society for Research in Child Development; Lynn Goldman, Children's Environmental Health Network; Wayne Holden, OCR Macro; Eric Kodish, Rainbow Center for Pediatric Ethics; Kristin A. Moore, Child Trends; Tom Sinks, National Center for Environmental Health, Centers for Disease Control and Prevention; Sandra Tirey, American Chemistry Council; Peter van Dyck, Maternal and Child Health Bureau, Health Resources and Services Administration; Rachael Wallace, Children's National

Medical Center; and Randolph Wykoff, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services.

The committee commissioned papers that provided information incorporated into this report from Eric Kodish and Rachael Wallace, Emory University; Howard Frumkin, Emory University; and Elizabeth Vandewater, University of Texas. We wish to thank Brett Brown for providing the framework and core information on data sources included in Appendix A and Greg Stevens of the Center for Healthier Children, Families and Communities, University of California at Los Angeles (UCLA), for preparing the analysis of major national surveys included as Appendix B.

In addition, several experts helped prepare background or related materials that were incorporated into this report, and we wish to acknowledge their advice and assistance: Lee Pachter, St. Francis Hospital and Medical Center; Deborah Klein Walker, Abt Associates (formerly Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health); and Ellen Wartella, College of Communication, University of Texas, Austin.

Matthew Zerden, a research associate at the UCLA Center for Healthier Children, Families and Communities, provided valuable assistance in confirming references. Camelia Arsene and Jennifer Roberts, National Academies interns, helped manage and identify references and provided valuable research assistance.

This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the NRC's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process.

We wish to thank the following individuals for their review of this report: Beverly Bauman, Department of Emergency Medicine and Department of Pediatrics, Oregon Health and Sciences University; Janet Currie, Department of Economics, UCLA; Allen J. Dietrich, Community and Family Medicine, Dartmouth Medical School; Andrew S. Doniger, Monroe County Health Department, Rochester, NY; Lynn R. Goldman, Occupational and Environmental Health, Johns Hopkins Bloomberg School of Public Health; Tamara Halle, Early Childhood Development, Child Trends, Washington, DC; Marie C. McCormick, Department of Society, Human Development and Health, Harvard School of Public Health; Susan Redline, Pediatrics, Medicine, and Epidemiology and Biostatistics, Case Western Reserve University and Rainbow Babies and Children's Hospital, Cleveland, OH; Lynn Singer, Provost's Office and Department of Pediatrics and Psychiatry, Case Western Reserve University and Rainbow Babies and Children's Hospital, Cleveland, OH; Richard D. Todd, Child and Adolescent Psychiatry, Washington University School of Medicine; and Deborah Klein Walker, Abt As-

sociates (formerly Center for Health Information, Statistics, Research and Evaluation, Massachusetts Department of Public Health).

Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by Aletha C. Huston, Human Development and Family Science, The University of Texas at Austin, and John C. Bailar, III, Department of Health Studies (emeritus), University of Chicago. Appointed by the NRC, they were responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

The committee appreciates the support provided by members of the Board on Children, Youth, and Families under the leadership of Michael I. Cohen. We are grateful for the leadership and support of Michael Feuer, executive director of the NRC's Division of Behavioral and Social Sciences and Education; Jane Ross, director of the Center for Economic, Governance, and International Studies; Rosemary Chalk, director of the Board on Children, Youth, and Families and her predecessor, Susan Cummins; and Susanne Stoiber, executive officer of the Institute of Medicine.

Finally, the committee benefited from the support and assistance of several members of the National Academies staff. Bill Selepack (until April 2002 and between October 2002 and April 2003) and Anthony Mann (between April and October 2002 and since April 2003) managed all administrative aspects of the project. The research needs of the project were greatly aided by the able assistance of William McLeod of the Institute of Medicine library. Final preparation of the report, including incorporating edits, helping to respond to review comments, and finalizing references, was handled with grace, competence, and patience by Elizabeth Townsend and Neesha Desai. We are indebted to Christine McShane who provided superb editorial guidance, Yvonne Wise, who helped prepare the report for publication, and Kirsten Sampson Snyder, who guided the report through the review and release process.

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Contents

Executive Summary	1
1 Introduction	13
2 Children's Health: A New Conceptual Framework	28
3 Influences on Children's Health	45
4 Measuring Children's Health	91
5 Measuring Influences on Children's Health	116
6 Developing State and Local Data Systems	164
7 Conclusions and Recommendations	192
References	211
Appendixes	
A Datasets for Measuring Children's Health and Influences on Children's Health	253
B Gaps Analysis of Measures of Children's Health and Influences on Children's Health in Select National Surveys	262
C Selected Indicators from National Children's Data Syntheses	288
D Glossary	302
E Acronyms	305
F Biographical Sketches of Committee Members and Staff	308
Index	315

