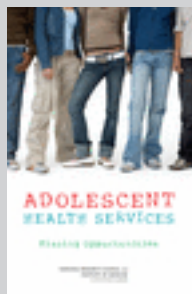


This PDF is available from The National Academies Press at http://www.nap.edu/catalog.php?record_id=12063




Adolescent Health Services: Missing Opportunities

ISBN
978-0-309-11467-7

368 pages
6 x 9
HARDBACK (2009)

Committee on Adolescent Health Care Services and Models of Care for Treatment, Prevention, and Healthy Development, National Research Council

 Add book to cart

 Find similar titles

 Share this PDF



Visit the National Academies Press online and register for...

- ✓ Instant access to free PDF downloads of titles from the
 - NATIONAL ACADEMY OF SCIENCES
 - NATIONAL ACADEMY OF ENGINEERING
 - INSTITUTE OF MEDICINE
 - NATIONAL RESEARCH COUNCIL
- ✓ 10% off print titles
- ✓ Custom notification of new releases in your field of interest
- ✓ Special offers and discounts

Distribution, posting, or copying of this PDF is strictly prohibited without written permission of the National Academies Press. Unless otherwise indicated, all materials in this PDF are copyrighted by the National Academy of Sciences. Request reprint permission for this book

Summary

Adolescence is a time of major transitions, when young people develop many of the habits, patterns of behavior, and relationships they will carry into their adult lives. Most adolescents in the United States are healthy. But many engage in risky behavior, develop unhealthful habits, or have chronic conditions that can jeopardize their immediate health and safety and contribute to poor health in future years. During adolescence, a range of health issues can be identified and addressed in ways that affect not only the functioning and opportunities of adolescents themselves, but also the quality of their adult lives. Moreover, adolescence is a critical period for developing habits and skills that create a strong foundation for healthy lifestyles and behavior over the full life span.

The health system—health services, the settings where these services are delivered, how the services are delivered and by whom—has an important role to play in promoting healthful behavior, managing health conditions, and preventing disease during adolescence. Yet health services and settings in the United States today are not designed to help young people at this critical time in their lives, and providers often are not adequately trained in adolescent issues. As is the case in many other parts of the nation’s health system, adolescents face gaps in care, fragmented services, and missed opportunities for health promotion and disease prevention.

STUDY SCOPE AND APPROACH

To address these issues, the National Research Council (NRC) and the Institute of Medicine (IOM), through the NRC/IOM Board on Chil-

dren, Youth, and Families, with funding from The Atlantic Philanthropies, formed the Committee on Adolescent Health Care Services and Models of Care for Treatment, Prevention, and Healthy Development in 2006. The 19-member committee was charged with studying adolescent health services in the United States and developing policy and research recommendations that would highlight critical health needs, promising models of health services, and components of care that could strengthen and improve health services for adolescents and contribute to healthy adolescent development. In conducting this study, the committee:

- Considered settings, systems, and policies that promote high-quality health services for adolescents, as well as barriers to the provision of such services.
- Reviewed strategies for helping adolescents—especially those at significant risk for health disorders in such areas as sexual behavior and reproductive health, substance use, mental and oral health, violence, and diet—enter and navigate the health system.
- Sought to identify approaches that link disease prevention, health promotion, and behavioral health services and show significant promise for enhancing the provision of primary care for adolescents, including those who are more vulnerable because of selected population characteristics or other circumstances.
- Considered several specific aspects of providing these services, including issues related to privacy and confidentiality, financing strategies, and provider training.

Definitions

The concept of adolescence, which emerged only at the beginning of the twentieth century, is variable and evolving. Based on its review of various definitions of adolescence and of the literature on child and adolescent behavior and development, the committee focused this report—including the data, conclusions, and recommendations presented—on those aged 10–19.¹ The report includes consideration of a number of specific groups of adolescents defined by selected population characteristics and other circumstances—such as those who are poor; members of a racial or ethnic minority; in the foster care system; homeless; in families that have recently

¹The committee recognized that there is disagreement among health care providers, researchers, and policy makers on the age bracket that demarcates the period of adolescence, but decided that on balance, focusing on ages 10–19 provides the best framework for the data analysis and evidence review in this report. Therefore, “adolescence” in this report denotes this age group, except when literature that uses a somewhat different age range is discussed.

immigrated to the United States; lesbian, gay, bisexual, or transgender; or in the juvenile justice system—and examined the relationship of these characteristics to health status and health services.

In defining health, the committee considered services provided by physicians, nurses, nurse practitioners, psychologists, social workers, dentists, and other health care providers. Health services were defined to include routine checkups; health maintenance or well care visits; school and sports physicals; psychiatric and substance abuse counseling; reproductive health services; dental care; and medical care for injury or illness, including chronic conditions. The committee also considered risky behavior and its implications for adolescent health and health services.

Study Frameworks

The committee was guided by two basic frameworks in its data collection, review of the evidence, and deliberations on various dimensions of adolescent health status and health services. The first focuses on behavioral and contextual characteristics that influence how adolescents interact with the health system, and the second on the objectives of adolescent health services. Neither framework alone is sufficient to explain significant variations in adolescent health outcomes; rather, they complement each other and, in tandem, provide a more complete picture of the features of the health system that should be improved in order to provide adolescents high-quality care and thus help to improve their health status.

Framework 1: Behavioral and Contextual Characteristics

Certain sets of behavioral and contextual characteristics, listed below, matter for adolescents in the ways they approach and interact with health care services, providers, and settings. When these characteristics are addressed in the design of health services for adolescents, these services can offer high-quality care that is particularly attuned to the needs of this age group. These characteristics helped frame the chapters of this report and, where relevant and supported by the evidence, are reflected in the committee's recommendations.

- **Development matters.** Adolescence is a period of significant and dramatic change spanning the physical, biological, social, and psychological transitions from childhood to young adulthood. This dynamic state influences both the health of young people and the health services they require (Chapter 1).
- **Timing matters.** Adolescence is a critical time for health promotion. Many health problems and much of the risky behavior that under-

lies later health problems begin during adolescence. Prevention, early intervention, and timely treatment improve health status for adolescents and prepare them for healthy adulthood; such services also decrease the incidence of many chronic diseases in adulthood (Chapter 2).

- **Context matters.** Social context and such factors as income, geography, and cultural norms and values can profoundly affect the health of adolescents and the health services they receive (Chapters 2 and 3).
- **Need matters.** Some segments of the adolescent population, defined by both biology and behavior, have health needs that require particular attention in health systems (Chapter 2).
- **Participation matters.** Effective health services for young people invite adolescents and their families to engage with clinicians (Chapter 4).
- **Family matters.** At the same time that adolescents are growing in their autonomy, families continue to affect adolescents' health and overall well-being and to influence what health services they use. Young people without adequate family support are particularly vulnerable to risky behavior and poor health and therefore often require additional support in health service settings (Chapter 4).
- **Community matters.** Good health services for adolescents include population-focused as well as individual and family services since the environment in which adolescents live, as well as the supports they receive in the community, are important (Chapter 4).
- **Skill matters.** Young people are best served by providers who understand the key developmental features, health issues, and overall social environment of adolescents (Chapter 5).
- **Money matters.** The availability, nature, and content of health services for adolescents are affected by such financial factors as public and private health insurance, the amount of funding invested in special programs for adolescents, and the support available for adequate training programs for providers of adolescent health services (Chapter 6).
- **Policy matters.** Policies, both public and private, can have a profound effect on adolescent health services. Carefully crafted policies are a foundation for strong systems of care that meet a wide variety of individual and community needs (Chapter 6).

Framework 2: Objectives of Health Services for Adolescents

Research from various sources and the experiences of adolescents and health care providers, health organizations, and research centers suggest the

importance of designing health services that can attract and engage adolescents, create opportunities to discuss sensitive health and behavioral issues, and offer high-quality care as well as guidance on both disease prevention and health promotion. Consistent with these findings and views, a variety of national and international organizations have defined critical elements of health systems that would improve adolescents' access to appropriate services, highlighted design elements that would improve the quality of those services, and identified ways to foster patient-provider relationships that can lead to better health for adolescents.

The World Health Organization has identified five characteristics that constitute objectives for responsive adolescent health services:

1. **Accessible.** Policies and procedures ensure that services are broadly accessible.
2. **Acceptable.** Policies and procedures consider culture and relationships and the climate of engagement.
3. **Appropriate.** Health services fulfill the needs of all young people.
4. **Effective.** Health services reflect evidence-based standards of care and professional guidelines.
5. **Equitable.** Policies and procedures do not restrict the provision of and eligibility for services.

These five objectives provided the committee with a valuable framework for assessing the use, adequacy, and quality of adolescent health services; comparing the extent to which different health services, settings, and providers meet the health needs of young people in the United States; identifying the gaps that keep services from achieving these objectives; and recommending ways to close these gaps. In general, the committee found that existing approaches to providing health services for adolescents (primary care, school-based programs, hospital-based programs, and community-based models) reflect one or more of these objectives, but none of them achieves all five.

OVERALL CONCLUSIONS

The committee's many findings presented throughout this report can be consolidated into seven overall conclusions. These conclusions serve as the basis for the committee's eleven recommendations.

Overall Conclusion 1: Most adolescents are thriving, but many engage in risky behavior, develop unhealthful habits, and experience physical and mental health conditions that can jeopardize their immediate health and contribute to poor health in adulthood.

An analysis of the 21 Critical Health Objectives for ages 10–24, a subset of the Centers for Disease Control and Prevention’s Healthy People 2010, highlights how little progress has been made in the overall health status of adolescents since the year 2000. Of the 21 objectives—which encompass a broad range of concerns, from reducing deaths, reducing suicides, and increasing mental health treatment to increasing seat belt use, reducing binge drinking, and reducing weapon carrying—the only ones that have shown improvement for adolescents since 2000 are behaviors leading to unintentional injury, pregnancy, and tobacco use. Negative trends include increased mortality due to motor vehicle crashes related to alcohol, increased obesity/overweight, and decreased physical activity.

Certain groups of adolescents have particularly high rates of comorbidity, defined as the simultaneous occurrence of two or more diseases, health conditions, or risky behaviors. These adolescents are particularly vulnerable to poor health. Moreover, specific groups of adolescents—such as those who are poor; in the foster care system; homeless; in families that have recently immigrated to the United States; lesbian, gay, bisexual, or transgender; or in the juvenile justice system—may have higher rates of chronic health problems and may engage in more risky behavior when compared with the overall adolescent population. These adolescents may have especially complex health issues that often are not addressed by the health services and settings they use. Furthermore, members of racial and ethnic minorities are becoming a larger portion of the overall U.S. adolescent population. And because minority racial or ethnic status is closely linked to poverty and a lack of access to quality health services, the number of adolescents experiencing significant disparities in access to quality health services can be expected to increase as well.

Overall Conclusion 2: Many current models of health services for adolescents exist. There is insufficient evidence to indicate that any one particular approach to health services for adolescents achieves significantly better results than others.

Evidence shows that while private office-based primary care services are available to most adolescents, those services depend significantly on fee-based reimbursement and are not always accessible, acceptable, appropriate, or effective for many adolescents, particularly those who are uninsured or underinsured. Such young people often have difficulty gaining access to mainstream primary care services; require additional support in order to connect with health care providers; and may rely extensively on such “safety-net” settings as hospital-, community- and school-based health centers for their primary care. For example, adolescents are in the age group

most likely to depend on emergency departments for routine health care. Indeed, evidence shows that for some adolescents, safety-net settings may be more accessible, acceptable, appropriate, effective, and equitable than mainstream services. This may be especially so for more vulnerable populations of uninsured or underinsured adolescents. Although an extensive literature on the quality of school-based health services for adolescents is available, few studies have examined the quality of services received in other safety-net settings.

Evidence also shows that existing specialty services in the areas of mental health, sexual and reproductive health, oral health, and substance abuse treatment are not accessible to most adolescents, nor do they always meet the needs of many adolescents who receive care in safety-net settings. Even when such services are accessible, many adolescents may not find them acceptable because of concerns that confidentiality is not fully ensured, especially in such sensitive domains as substance use or sexual and reproductive health.

Overall Conclusion 3: Health services for adolescents currently consist of separate programs and services that are often highly fragmented, poorly coordinated, and delivered in multiple public and private settings.

The various settings, services, and providers used by adolescents often are not coordinated with each other, and the result is barriers to and gaps in care. In some areas, such as mental health services for adolescents, the system of services is in substantial disarray because of financing barriers, eligibility gaps, and both confidentiality and privacy concerns—all of which can hamper transitions across care settings. Because of this segmentation, moreover, many providers of health services are poorly equipped to foster disease prevention and health promotion for adolescents. This is especially true in the areas of mental health, oral health, and substance abuse, as well as services that address sexual behavior and reproductive health.

Overall Conclusion 4: Health services for adolescents are poorly equipped to meet the disease prevention, health promotion, and behavioral health needs of all adolescents. Instead, adolescent health services are focused mainly on the delivery of care for acute conditions, such as infections and injuries, or special care addressing specific issues, such as contraception or substance abuse.

This limited, problem-oriented approach fails to meet the broader profile, needs, and behavioral challenges that characterize adolescence.

Overall Conclusion 5: Large numbers of adolescents are uninsured or have inadequate health insurance, which can lead to a lack of access to regular primary care, as well as limited behavioral, medical, and dental care. One result of such barriers and deficits is poorer health.

More than 5 million adolescents aged 10–18 are uninsured. Uninsured rates are higher among the poor and near poor, racial and ethnic minorities, and noncitizens. As is true for all Americans, uninsured adolescents are less likely to have a regular source of primary care and use medical and dental care less often than those who have insurance. Having health insurance, however, does not ensure adolescents' access to affordable, high-quality services given current shortages of health care providers and problems associated with high out-of-pocket cost-sharing requirements, limitations in benefit packages, and low provider reimbursement levels. This is especially true in areas that involve counseling or case management of multiple health conditions, and in areas that are particularly problematic for adolescents, such as obesity, intentional and unintentional injury, mental health, dental care, and substance abuse. Furthermore, uninsured adolescents aged 10–18 who are eligible for public coverage often are not enrolled either because their parents do not know they are eligible or because complexities of the enrollment processes deter participation.

Overall Conclusion 6: Health care providers working with adolescents frequently lack the necessary skills to interact appropriately and effectively with this age group.

Whether providers report on their own perceptions of their competencies or adolescents describe the care they have received, data reveal significant gaps in the achievement of a well-equipped and appropriately trained workforce ready to meet the health needs of adolescents. At all levels of professional education, health care providers in every discipline serving adolescents should receive specific and detailed education in the nature of adolescents' health problems and have in their clinical repertoire a range of effective ways to treat and prevent disease in this age group, as well as to promote healthy behavior and lifestyles within a developmental framework. Evidence suggests this currently is not the case.

Overall Conclusion 7: The characterization of adolescents and their health status by such traditional measures as injury and illness does not adequately capture the developmental and behavioral health of adolescents of different ages and in diverse circumstances.

Developing a clear definition of adolescent health status is a critical step in delivering health services and forming health systems that can respond appropriately to the specific needs of adolescents. Moreover, the ability to understand and characterize health status within this definition is dependent on available data, particularly that related to adolescent behavior. Those concerned with the health of adolescents—health practitioners, policy makers, and families—would benefit from ready access to high-quality and more precise data that would aid in better understanding the consequences of health-influencing behaviors for the health status of adolescents.

LOOKING AHEAD: RECOMMENDATIONS

Based on the overall conclusions presented above, the committee makes eleven recommendations, directed to both public and private entities, for investing in, strengthening, and improving health services for adolescents. These recommendations embody many of the behavioral and contextual characteristics that the committee explored in its evidence review and, if acted on in a coordinated and comprehensive manner, should improve the accessibility, acceptability, appropriateness, effectiveness, and equity of health services delivered to adolescents.

Primary Health Care

Recommendation 1: Federal and state agencies, private foundations, and private insurers should support and promote the development and use of a coordinated primary health care system that strives to improve health services for all adolescents.

Carrying out this recommendation would involve federal and state agencies, private foundations, and private insurers working with local primary care providers to coordinate services between primary and specialty care services. It would also entail providing opportunities for primary care services to interact with health programs for adolescents in many safety-net settings, such as schools, hospitals, and community health centers.

Recommendation 2: As part of an enhanced primary care system for adolescents, health care providers and health organizations should focus attention on the particular needs of specific groups of adolescents who may be especially vulnerable to risky behavior or poor health because of selected population characteristics or other circumstances.

Implementing this recommendation would involve focusing explicit attention on issues of access, acceptability, appropriateness, effectiveness,

and equity of health services for an increasingly racially and ethnically diverse population of adolescents and for selected adolescent groups, such as those who are poor; in the foster care system; homeless; in families that have recently immigrated to the United States; lesbian, gay, bisexual, or transgender; or in the juvenile justice system.

Recommendation 3: Providers of adolescent primary care services and the payment systems that support them should make disease prevention, health promotion, and behavioral health—including early identification, management, and monitoring of current or emerging health conditions and risky behavior—a major component of routine health services.

For this recommendation to be realized, providers of adolescent primary care services would need to give attention to the coordination and management of the specialty services young people often need. They would coordinate screening, assessment, health management, and referrals to specialty services. They would also monitor behavior that increases risk in such areas as injury, mental health, oral health, substance use, violence, eating disorders, sexual activity, and exercise. Performance measures for these services would need to be incorporated into criteria used for credentialing, pay-for-performance incentives, and quality measurement. And perhaps most important, payment systems would need to finance such services and activities.

Public Health System

Recommendation 4: Within communities—and with the help of public agencies—health care providers, health organizations, and community agencies should develop coordinated, linked, and interdisciplinary adolescent health services.

To effect this recommendation, health care providers across communities would need to work together to encourage rapid and coordinated services through collocation or participation in regional planning and action groups organized by managed care plans, large group networks, health professional associations, or public health agencies. Beyond direct patient services, primary care providers and providers of mental health/substance abuse, reproductive, nutritional, and oral health services would have to establish public and private programs in a region for managing referrals; coordinating electronic patient information; and staffing adolescent call centers and regional services to communicate directly with adolescents, their families, and various providers. In addition, the particular health

needs of adolescents, especially the most vulnerable populations, would need to be addressed in the development of electronic health records. Such records offer a significant opportunity to ensure coordinated care, as well as to provide adolescent-focused patient portals, messaging and reminder services, and electronic personalized health education services to improve interventions. An overarching principle in the implementation of this recommendation is that adolescents should be asked to give explicit consent for the sharing of information about them, a point addressed in the committee's next recommendation.

Privacy and Confidentiality

Recommendation 5: Federal and state policy makers should maintain current laws, policies, and ethical guidelines that enable adolescents who are minors to give their own consent for health services and to receive those services on a confidential basis when necessary to protect their health.

To implement this recommendation, federal and state policy makers would need to examine the variations among states in the age of consent for care for adolescents and consider the impact of such variations on adolescents' access to and use of services that are essential to protecting their health (e.g., services for contraception, sexually transmitted infections/HIV, mental health, and substance use). A balance is needed between maintaining the confidentiality of information and records regarding care for which adolescent minors are allowed to give their consent, and encouraging the involvement of parents and families in the health services received by adolescents whenever possible, both supporting and respecting their role and importance in adolescents' lives and health care.

Adolescent Health Care Providers

Recommendation 6: Regulatory bodies for health professions in which an appreciable number of providers offer care to adolescents should incorporate a minimal set of competencies in adolescent health care and development into their licensing, certification, and accreditation requirements.

To implement this recommendation, regulatory bodies would need to use national meetings of specialists and educators/scholars within relevant disciplines to define competencies in adolescent health. They would also have to require professionals who serve adolescents in health care settings to complete a minimum amount of education in basic areas of adolescent

development, health issues unique to this life stage, and a life course framework that encourages providers to focus on helping their adolescent patients develop healthful habits that can be carried forward into their adult lives. Finally, agencies that fund training programs would have to adhere to the requirements of the regulatory bodies (i.e., with regard to accreditation, licensure, and certification, and to maintenance of licensure or certification where appropriate), and content on adolescent health would have to be mandatory in all relevant training programs.

Recommendation 7: Public and private funders should provide targeted financial support to expand and sustain interdisciplinary training programs in adolescent health. Such programs should strive to prepare specialists, scholars, and educators in all relevant health disciplines to work with both the general adolescent population and selected groups that require special and/or more intense services.

To effect this recommendation, public and private funders would need to ensure that professionals who serve adolescents in health care settings are trained in how to relate to adolescents and gain their trust and cooperation; how to develop strong provider–patient relationships; and how to identify early signs of risky and unhealthful behavior that may require further assessment, intervention, or referral. Also essential to the training of these professionals is knowing how to work with more vulnerable adolescents, such as those who are in the foster care system; homeless; in families that have recently immigrated to the United States; lesbian, gay, bisexual, or transgender; or in the juvenile justice system. Important as well is to increase the number of Leadership Education in Adolescent Health programs that train health professionals in adolescent medicine, psychology, nursing, social work, and nutrition, and to enhance the program by adding dentistry.

Health Insurance

Recommendation 8: Federal and state policy makers should develop strategies to ensure that all adolescents have comprehensive, continuous health insurance coverage.

Federal and state legislatures and governments should consider the following options for implementing this recommendation: require states to provide Medicaid or other forms of health insurance coverage for especially vulnerable or underserved groups of adolescents, particularly those who are in the juvenile justice and foster care systems, and support states in meeting this requirement; design and implement Medicaid and State Children’s

Health Insurance Program policies to increase enrollment and retention of eligible but uninsured adolescents; and improve incentives for private health insurers to provide such coverage (e.g., by requiring school-based coverage and allowing nongroup policies tailored to adolescents). Note that while these options would increase insurance coverage among adolescents, broader health care reform efforts would be required to ensure universal coverage. A consequence of allowing more segmentation in nongroup health insurance policies across age groups could be increased costs for older adults if younger, healthier adults are removed from the risk pool. In addition, expanding access to and election of coverage among poor adolescents would be necessary to increase the rates of insured adolescents.

Recommendation 9: Federal and state policy makers should ensure that health insurance coverage for adolescents is sufficient in amount, duration, and scope to cover the health services they require. Such coverage should be accessible, acceptable, appropriate, effective, and equitable.

Public and private health plans, including self-insured plans, should consider several options for carrying out this recommendation. First, they could see that benefit packages cover at a minimum the following key services for adolescents: preventive screening and counseling, at least on an annual basis; case management; reproductive health care that includes screening, education, counseling, and treatment; assessment and treatment of mental health conditions, such as anxiety disorders and eating disorders, and of substance abuse disorders, including those comorbid with mental health conditions; and dental services that include prevention, restoration, and treatment. Second, they could ensure coverage for mental health and substance abuse services at primary or specialty care sites that provide integrated physical and mental health care, and require Medicaid to cover mental health rehabilitation services. Third, they could make certain that providers are reimbursed at reasonable, market-based rates for the adolescent health services they provide. Finally, they could ensure that out-of-pocket cost sharing (including mental health and other health services) is set at levels that do not discourage receipt of all needed services.

Research Agenda

Recommendation 10: Federal health agencies and private foundations should prepare a research agenda for improving adolescent health services that includes assessing existing service models, as well as developing new systems for providing services that are accessible, acceptable, appropriate, effective, and equitable.

Federal health agencies should consider a number of options for carry-

ing out this recommendation. First, they could identify performance standards and operational criteria that could be used to compare the strengths and limitations of different models of health service delivery in meeting the needs of all young people, as well as specific groups. In developing such standards and criteria, an effort should be made to translate the features of accessibility, acceptability, appropriateness, effectiveness, and equity into clear standards and ways to measure their achievement. Second, they could determine the effectiveness (not just the efficacy) of selected mental health, behavioral, and developmental interventions for adolescents. This research should be aimed at identifying individual, environmental, and other contextual factors that significantly affect the likelihood of establishing, operating, and sustaining effective interventions in a variety of service settings. Third, they could assess and compare the health status (defined by selected population characteristics and other circumstances) and health outcomes of young people who receive care through different service models and in different health settings, as well as of those who are difficult to reach and serve. Fourth, they could identify effective ways to reach more underserved and vulnerable adolescents with appropriate and accessible health services. Such research might also consider how to integrate the features of accessibility, acceptability, appropriateness, effectiveness, and equity into the primary care environment for all adolescents, as well as into the training of providers who interact with adolescents. Finally, they could evaluate the validity and reliability of various screening tools and counseling techniques for selected groups of adolescents.

Monitoring Progress

Recommendation 11: The Federal Interagency Forum on Child and Family Statistics should work with federal agencies and, when possible, states to organize and disseminate data on the health and health services, including developmental and behavioral health, of adolescents. These data should encompass adolescents generally, with subreports by age, selected population characteristics, and other circumstances.

To implement this recommendation, federal agencies would need to adopt consistent age brackets that cluster data by ages 10–14 and 15–19 and consistent identifiers of socioeconomic status, geographic location, gender, and race and ethnicity. Also needed are consistent identifiers of specific vulnerable adolescent populations, including those in the foster care system; those who are homeless; those who are in families that have recently immigrated to the United States; those who are lesbian, gay, bisexual, or transgender; and those in the juvenile justice system. Important as well is to track emerging disparities in access to and utilization of health services,

with attention to specific components of health care, such as screening, assessment, and referral, as well as an emphasis on racial and ethnic differences. Finally, longitudinal studies are needed on the effects of both health-promoting and health-compromising behaviors that often emerge in the second decade of life and continue into adulthood.

CLOSING THOUGHTS

While the gaps and problems in the health services used by young people discussed in this report are not unique to this age group, a compelling case can be made for improving health services and systems both to support the healthy development of adolescents and to enhance their transitions from childhood to adolescence and from adolescence to adulthood. Current interest in restructuring the way health care is delivered and financed in the United States—and defining the content of care itself more broadly—is based on a growing awareness that existing health services and systems for virtually all Americans have important and costly shortcomings. In the midst of these discussions, the distinct deficits faced by adolescents within the health system deserve particular attention. Their developmental complexities and risky behavior, together with the need to extend their care beyond the usual disease- and injury-focused services, are key considerations in any attempt to reform the nation's chaotic health care system—especially if adolescents are to benefit. Even if the larger systemic issues of access to the health system were resolved, more would likely need to be done to achieve better health for adolescents during both the adolescent years and the transition to adulthood.

ADOLESCENT HEALTH SERVICES

Missing Opportunities

Committee on Adolescent Health Care Services and Models of
Care for Treatment, Prevention, and Healthy Development

Robert S. Lawrence, Jennifer Appleton Gootman, Leslie J. Sim, *Editors*

Board on Children, Youth, and Families

NATIONAL RESEARCH COUNCIL *AND*
INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

THE NATIONAL ACADEMIES PRESS
Washington, D.C.
www.nap.edu

THE NATIONAL ACADEMIES PRESS 500 Fifth Street, N.W. Washington, DC 20001

NOTICE: The project that is the subject of this report was approved by the Governing Board of the National Research Council, whose members are drawn from the councils of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine. The members of the committee responsible for the report were chosen for their special competences and with regard for appropriate balance.

This study was supported by Award No. 14356 between the National Academy of Sciences and The Atlantic Philanthropies (USA), Inc. 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

Adolescent health services : missing opportunities / Committee on Adolescent Health Care Services and Models of Care for Treatment, Prevention, and Healthy Development, Board on Children, Youth, and Families ; Robert S. Lawrence, Jennifer Appleton Gootman, Leslie J. Sim, editors.

p. ; cm.

Includes bibliographical references and index.

ISBN 978-0-309-11467-7 (hardback)

1. Teenagers—Medical care—United States. I. Lawrence, Robert S., 1938- II. Gootman, Jennifer Appleton. III. Sim, Leslie J. IV. National Research Council (U.S.). Committee on Adolescent Health Care Services and Models of Care for Treatment, Prevention, and Healthy Development.

[DNLM: 1. Adolescent Health Services—United States. 2. Adolescent Development—United States. 3. Delivery of Health Care, Integrated—United States. 4. Health Status—United States. 5. Needs Assessment—United States. 6. Quality of Health Care—United States. WA 330 A239 2009]

RJ102.A375 2009

362.19600835—dc22

2008042174

Additional copies of this report are available from the 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>.

Copyright 2009 by the National Academy of Sciences. All rights reserved.

Printed in the United States of America

Cover photo © Getty Images.

Suggested citation: National Research Council and Institute of Medicine. (2009). *Adolescent Health Services: Missing Opportunities*. Committee on Adolescent Health Care Services and Models of Care for Treatment, Prevention, and Healthy Development, R.S. Lawrence, J. Appleton Gootman, and L.J. Sim, *Editors*. Board on Children, Youth, and Families. Division of Behavioral and Social Sciences and Education. Washington, DC: The National Academies Press.

THE NATIONAL ACADEMIES

Advisers to the Nation on Science, Engineering, and Medicine

The **National Academy of Sciences** is a private, nonprofit, self-perpetuating society of distinguished scholars engaged in scientific and engineering research, dedicated to the furtherance of science and technology and to their use for the general welfare. Upon the authority of the charter granted to it by the Congress in 1863, the Academy has a mandate that requires it to advise the federal government on scientific and technical matters. Dr. Ralph J. Cicerone is president of the National Academy of Sciences.

The **National Academy of Engineering** was established in 1964, under the charter of the National Academy of Sciences, as a parallel organization of outstanding engineers. It is autonomous in its administration and in the selection of its members, sharing with the National Academy of Sciences the responsibility for advising the federal government. The National Academy of Engineering also sponsors engineering programs aimed at meeting national needs, encourages education and research, and recognizes the superior achievements of engineers. Dr. Charles M. Vest is president of the National Academy of Engineering.

The **Institute of Medicine** was established in 1970 by the National Academy of Sciences to secure the services of eminent members of appropriate professions in the examination of policy matters pertaining to the health of the public. The Institute acts under the responsibility given to the National Academy of Sciences by its congressional charter to be an adviser to the federal government and, upon its own initiative, to identify issues of medical care, research, and education. Dr. Harvey V. Fineberg is president of the Institute of Medicine.

The **National Research Council** was organized by the National Academy of Sciences in 1916 to associate the broad community of science and technology with the Academy's purposes of furthering knowledge and advising the federal government. Functioning in accordance with general policies determined by the Academy, the Council has become the principal operating agency of both the National Academy of Sciences and the National Academy of Engineering in providing services to the government, the public, and the scientific and engineering communities. The Council is administered jointly by both Academies and the Institute of Medicine. Dr. Ralph J. Cicerone and Dr. Charles M. Vest are chair and vice chair, respectively, of the National Research Council.

www.national-academies.org

COMMITTEE ON ADOLESCENT HEALTH CARE SERVICES AND
MODELS OF CARE FOR TREATMENT, PREVENTION, AND
HEALTHY DEVELOPMENT

- ROBERT S. LAWRENCE (*Chair*), Bloomberg School of Public Health,
The Johns Hopkins University
- LINDA H. BEARINGER, School of Nursing, School of Medicine,
University of Minnesota
- SHAY BILCHIK, Public Policy Institute, Georgetown University
- SARAH S. BROWN, National Campaign to Prevent Teen and Unplanned
Pregnancy, Washington, DC
- LAURIE CHASSIN, Department of Psychology, Arizona State University,
Tempe
- GORDON DeFRIESE,¹ University of North Carolina at Chapel Hill
- NANCY DUBLER, Montefiore Medical Center, Yeshiva University, New
York
- BURTON L. EDELSTEIN, College of Dental Medicine, Mailman School
of Public Health, Columbia University
- HARRIETTE FOX, Incenter Strategies, Washington, DC
- CHARLES E. IRWIN, JR., School of Medicine, University of California,
San Francisco
- KELLY KELLEHER, College of Medicine, College of Public Health,
Nationwide Children's Hospital, The Ohio State University
- GENEVIEVE KENNEY, Urban Institute, Washington, DC
- JULIA GRAHAM LEAR, School of Public Health and Health Services,
George Washington University
- EDUARDO OCHOA, JR., College of Medicine, College of Public Health,
University of Arkansas for Medical Sciences
- FREDERICK P. RIVARA, School of Medicine, School of Public Health,
University of Washington, Seattle
- VINOD K. SAHNEY, Blue Cross Blue Shield of Massachusetts, Boston
- MARK A. SCHUSTER, Children's Hospital Boston, Harvard
Medical School, Harvard University
- LONNIE SHERROD, Society for Research in Child Development, Ann
Arbor, MI
- MATTHEW STAGNER, Chapin Hall Center for Children, University of
Chicago
- LESLIE R. WALKER, Department of Pediatrics, University of
Washington, Seattle Children's Hospital

¹Member until February 2007.

THOMAS G. DeWITT (liaison from the Board on Children, Youth, and Families), Cincinnati Children's Hospital Medical Center, University of Cincinnati

JENNIFER APPLETON GOOTMAN, *Study Director*

LESLIE J. SIM, *Program Officer*

REINE Y. HOMAWOOD, *Senior Program Assistant* (from August 2007)

WENDY KEENAN, *Program Associate*

APRIL HIGGINS, *Senior Program Assistant* (until July 2007)

BOARD ON CHILDREN, YOUTH, AND FAMILIES

- BERNARD GUYER (*Chair*), Bloomberg School of Public Health, The Johns Hopkins University
- BARBARA L. WOLFE (*Vice Chair*), Department of Economics and Population Health Sciences, University of Wisconsin
- WILLIAM R. BEARDSLEE, Department of Psychiatry, Children's Hospital, Boston
- JANE D. BROWN, School of Journalism and Mass Communication, University of North Carolina at Chapel Hill
- LINDA MARIE BURTON, Sociology Department, Duke University
- P. LINDSAY CHASE-LANSDALE, Institute for Policy Research, Northwestern University
- CHRISTINE C. FERGUSON, School of Public Health and Health Services, George Washington University
- WILLIAM T. GREENOUGH, Department of Psychology, University of Illinois
- RUBY HEARN, Robert Wood Johnson Foundation (*emeritus*), Princeton, NJ
- MICHELE D. KIPKE, Saban Research Institute, USC Childrens Hospital Los Angeles
- BETSY LOZOFF, Center for Human Growth and Development, University of Michigan
- SUSAN G. MILLSTEIN, Division of Adolescent Medicine, University of California, San Francisco
- CHARLES A. NELSON, Laboratory of Cognitive Neuroscience, Children's Hospital, Boston
- PATRICIA O'CAMPO, Centre for Research on Inner City Health, St. Michael's Hospital, Toronto, Canada
- FREDERICK P. RIVARA, Schools of Medicine and Public Health, University of Washington, and Children's Hospital and Regional Medical Center, Seattle
- LAURENCE D. STEINBERG, Department of Psychology, Temple University
- JOHN R. WEISZ, Judge Baker Children's Center and Harvard Medical School
- MICHAEL ZUBKOFF, Development of Community and Family Medicine, Dartmouth Medical School
- ROSEMARY CHALK, *Board Director*
- WENDY KEENAN, *Program Associate*

Reviewers

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 National Research Council'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: Nancy Birkhimer, Teen and Young Adults Health Program, Maine Department of Human Services, Augusta, ME; Claire D. Brindis, National Adolescent Health Information Center, Institute for Health Policy Studies, University of California, San Francisco; Angela Diaz, Adolescent Health Center, Mount Sinai School of Medicine, New York, NY; Denise Dougherty, Child Health and Quality Improvement, Agency for Healthcare Research and Quality, Gaithersburg, MD; Daniel Eisenberg, Health Management and Policy, School of Public Health, University of Michigan; Elizabeth Feldman, Pediatric/Adolescent Coordinator, UIC/Illinois Masonic Family Practice Residency, University of Illinois College of Medicine; Brandon Hayes-Lattin, Adolescent and Young Adult Oncology Program, Oregon Health and Science University Cancer Institute, Portland; Jonathan Klein, Departments of Pediatrics and Community and Preventive Medicine, University of Rochester; Vaughn I. Rickert, Clinical Population and Family Health, Mailman School of Public Health, Columbia University; and Alan Shapiro, Community Pediatrics

and South Bronx Children and Family Health Center, Montefiore Medical Group, New York, NY.

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 Robert Graham, Department of Family Medicine, University of Cincinnati College of Medicine, and Nancy E. Adler, Center for Health and Community, University of California, San Francisco. Appointed by the National Research Council, 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.

Preface

Under the best of circumstances, providing appropriate and comprehensive health services to adolescents poses many challenges. In the early years of adolescence, young people struggle with what Erik Erikson has described as the life stage of Identity versus Role Confusion, with many questions about who they are and where they fit in. As they move into young adulthood, the life stage of Intimacy versus Isolation raises questions of what to do with their lives and with whom, and where and how to settle down and take on adult responsibilities. Most adolescents are healthy, with a low incidence of acute illness and low prevalence of chronic conditions. Some adolescents, however, engage in unhealthful habits and risky behavior that expose them to the harmful effects of, for example, unsafe sex and experimentation with drugs, tobacco, and alcohol. Many high school students drink heavily or “binge” drink regularly. Others succumb to violent acts directed at others or themselves. Unintentional injuries are the leading cause of death among adolescents, dominated by those due to motor vehicle crashes. Between 10 and 20 percent of adolescents have mental health problems, and overweight and obesity place an increasing number of adolescents at risk for type 2 diabetes and other health problems. Rising rates of asthma interfere with normal activities and school attendance and diminish the quality of life.

Adolescence is a period when patterns of health-promoting or health-damaging behaviors are established that will have a substantial influence on health status during adulthood, affecting rates of acute and chronic disease and life expectancy. Identification and treatment of the acute effects of

health-damaging behaviors provides an opportunity to counsel and educate adolescents about the lifelong benefits of establishing a healthy lifestyle.

The current system of health services in the United States is ill suited to providing the appropriate mix of clinical and preventive services to adolescents, especially those in certain circumstances, such as those who are part of the child welfare or juvenile justice system. Even adolescents with strong family and social supports and adequate financial resources are faced with a bewildering array of separate and poorly coordinated health programs and services delivered in multiple public and private settings. This arrangement may be sufficient for the majority of adolescents who are healthy, but it is woefully inadequate to meet the acute and chronic needs of vulnerable youths, especially those suffering from mental and behavioral disorders. Still less adequate is the system's ability to mount an effective screening program to support interventions focused on risk assessment, health promotion, and fostering of positive youth development. The current health services workforce includes few adolescent health generalists, specialists, educators, and scholars, and standards for accreditation of training programs for health providers for adolescents and for licensure and certification are inadequate.

To address these issues and develop recommendations for improving health care services for adolescents, The Atlantic Philanthropies provided funding to the National Research Council/Institute of Medicine (NRC/IOM) Board on Children, Youth, and Families. Through the board, the NRC and IOM formed the Committee on Adolescent Health Care Services and Models of Care for Treatment, Prevention, and Healthy Development in 2006. This report, *Adolescent Health Services: Missing Opportunities*, is the product of a multidisciplinary collaboration among committee members, NRC/IOM staff, and consultants.

The committee held five meetings and two workshops—one for research and health care service experts, and one for community and youth leaders. Committee members and staff conducted five site visits to learn firsthand about creative approaches to providing health services to adolescents, especially underserved groups. We engaged in vigorous discussion of the best approaches to improve adolescent health services, clarifying our underlying assumptions and reconciling different perspectives and priorities. It is our hope that the findings and recommendations presented in this report will help policy makers, service providers and their professional societies, and funders and government agencies shift the current patchwork quilt of health services for adolescents from a series of individual services into a coherent system of care.

The committee could not have done its work without the outstanding guidance and support provided by NRC/IOM staff Jennifer Gootman, study director, and Leslie Sim, program officer. Wendy Keenan and Reine

Homawoo provided highly skilled logistical support. Rosemary Chalk's guidance and counsel were invaluable throughout our deliberations. Finally, the young people and health professionals who participated in our workshops and those who shared their stories during our site visits deserve special thanks. Their experience in coping with the current system of care and their aspirations for something better fueled the committee's resolve to make a difference.

Robert S. Lawrence, *Chair*
Committee on Adolescent Health Care Services and Models
of Care for Treatment, Prevention, and Healthy Development

Acknowledgments

Beyond the hard work of the committee and National Research Council/Institute of Medicine (NRC/IOM) project staff, this report reflects contributions from numerous other individuals and groups.

The committee greatly benefited from the opportunity for discussion with those who made presentations at and attended the committee's workshops and meetings, including Dr. Kristin Adams, Salvador Balcorta, Dr. Anne Beal, Dr. Christina Bethell, Dr. Robert Blum, Rhonda Braxton, Dr. Claire Brindis, Dr. Richard Catalano, Coleen DeFlorimonte, Dr. Denise Dougherty, Dr. Abigail English, Dianne Ewashko, Paul Fogle, Dr. Robert Garofalo, Dr. David Grossman, Dr. Kimberly Hoagwood, Dr. Charles Homer, Linda Juszczak, Dr. Jonathan Klein, Andrea MacKay, Matthew Morton, Dr. Kathaleen Perkins, Shawn Semelsberger, Dr. Alan Shapiro, Dr. Josh Sharfstein, Dr. Warner Slack, Dr. Connie Weisner, and Dr. Charles Wibbelsman.

This study was sponsored by The Atlantic Philanthropies. We wish to thank Jackie Williams Kaye, Gara LaMarche, Charles Roussel, Mini Sanyal, Stuart Schear, and of course Debra Delgado for their support and guidance. Paula Elbirt's early advice on the development of this project is greatly appreciated.

We appreciate the extensive contributions of Dr. Robert Blum, Tumaini Coker, Abigail English, Dr. Gerry Fairbrother, Carolyn Garcia, Jose Lascal, Stephanie Limb, Andrea McKay, Daniel Moller, Joseph Schuchter, and Katherine Suellentrop, whom we commissioned to provide technical reviews of various portions of the report. Their insight and expertise added to the quality of the evidence presented. Additionally, Rona Briere and Alisa

Decatur provided superb editorial assistance in preparing the final report. The work of Eric Slade and his colleagues at Eric Slade Productions in preparing the video/DVD on adolescent health services enhanced opportunities to disseminate this report more broadly.

The committee was grateful for the opportunity to conduct five site visits during which committee members and NRC/IOM staff toured facilities and spoke with a variety of staff members and patients to learn about the successes and challenges in delivering adolescent health services to thousands of young people.

Thanks are extended to the staff at the Howard Brown Health Center and Broadway Youth Center, including Tony Alvarado-Rivera, Daniel Alvarez, Lara Brooks, Vea Cleary, Dr. Michael Cook, Michelle Emerick, Dr. Robert Garafalo, Amy Herrick, Joseph Hollendonner, Kristin Keglovitz, Jerry Lassa, Letty Martinez, Michael McFadden, Nicole Perez, Wendell Ward, Ebonii Warren, and Linda Wesp, as well as program partners Barb Bolson from The Night Ministry and David Myers from the Teen Living Program.

Thanks are due as well to the staff at Denver Health, including Lisa Abrams, Carolyn Carter, Audrey Gill, Dr. Paritosh Kaul, Abigail Mann, Dr. Paul Melinkovich, Trisha Mestas, Adrienne Pederson, and Nancy Riordan, as well as the other staff from Sandos Westside Community Clinic who took the time to meet with us.

We also thank the staff at the State of Louisiana Office of Youth Development and the Jetson Center for Youth, including Ms. Brezina, Dr. Richard Dalton, Ms. Erwin, Dr. Ronald Feinstein, Simon Gonsoulin, Dr. Stewart Gordon, Dr. Rhonda Kendrick, Dr. Seth Kunen, Ms. Lewis, Dr. Macdonald, Philippe Magloire, Dr. Menou, Gene Perkins, and Chef Ron Sonnier and his youth staff in the culinary arts program, as well as the other staff who spent time with us.

We appreciate the contributions of the staff at the Adolescent and Sports Medicine Center and the Eating Disorders Clinic at Arkansas Children's Hospital, including Dr. Bill Bandy, Marian Casey, Dr. Elton Cleveland, Kim Cossey, Brian Cox, Dr. Yancey Craft, Jennie Freyman, Dr. Brian Hardin, Skip Hoggard, Dr. Andrew Martin, Dr. J. Darrell Nesmith, Dr. Tracie Pasold, Dr. Maria Portilla, Cynthia Pumphrey, Dr. Wendy Ward-Begnoche, Dr. Jennifer Woods, and the other staff who met with us, as well as the Central High School football coaches.

Thanks are also due to the staff at the Mt. Sinai Adolescent Health Center in New York City, including Dr. Celia Blumenthal, Kelly Celony, Rachel Cymrot, Dr. Angela Diaz, Dr. Paula Elbirt, Dr. Alison Eliscu, Zayaini Lavergne-Freedman, Arlette Louden, Dr. Anne Nucci-Sack, Ken Peake, Rich Porter, and Jimmy Rao.

ACKNOWLEDGMENTS

xvii

Others at the NRC/IOM—Athena Abdulah, Chantel Fuqua, Stephen Mautner, Matthew McDonough, Matthew Von Hendy, and Dianne Wolman—provided support in various ways to this project. As well, we are indebted to Kirsten Sampson Snyder, DBASSE reports officer, who patiently worked with us through several revisions of this report and DBASSE production editor, Yvonne Wise, who managed the production process through final publication.

Robert S. Lawrence, *Chair*
Committee on Adolescent Health Care Services and Models
of Care for Treatment, Prevention, and Healthy Development

Contents

Summary	1
1 Setting the Stage	17
2 Adolescent Health Status	52
3 Current Adolescent Health Services, Settings, and Providers	135
4 Improving Systems of Adolescent Health Services	194
5 Preparing a Workforce to Meet the Health Needs of Adolescents	240
6 Health Insurance Coverage and Access to Adolescent Health Services	265
7 Overall Conclusions and Recommendations	293
Appendixes	
A Acronyms	311
B Harris Interactive Omnibus Survey Questions	314
C Biographical Sketches of Committee Members and Staff	317
Index	329

Tribute to Debra Delgado

This report is dedicated to Debra Delgado, who served as program executive for The Atlantic Philanthropies on this project until she passed away on December 2, 2007, at the age of 50. Debra was a long-time advocate for children, youth, and families, adding tremendous value over her lifetime to the work of The Atlantic Philanthropies, The Annie E. Casey Foundation, The Robert Wood Johnson Foundation's Program Office for School-Based Health Care, the Title X Family Planning Program for the District of Columbia, Planned Parenthood of Metropolitan Washington, the Los Angeles Free Clinic, and the Watts Health Foundation. Debra influenced many individuals and communities through her advocacy and support for America's most vulnerable children, youth, and families.

Debra was a strong and dedicated advocate; a leader; a gentle and loving spirit; a problem solver; a patient mentor; uncommonly wise; wonderfully fun and compassionate; vibrant, kind, honest, insightful, gracious, elegant, and joyful. Her friends and colleagues miss her tremendously.

The committee's focus and its deliberations were guided by Debra's insights. This report is dedicated to her memory.

