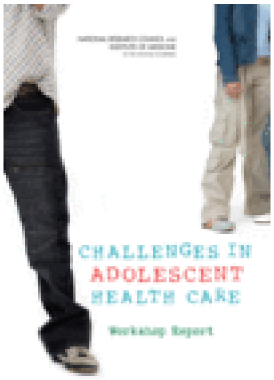

Challenges in Adolescent Heath Care: Workshop Report

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

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CHALLENGES IN ADOLESCENT HEALTH CARE

Workshop Report

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

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

NATIONAL RESEARCH COUNCIL *AND*
INSTITUTE OF MEDICINE
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Preface

The Committee on Adolescent Health Care Services and Models of Care for Treatment, Prevention, and Healthy Development was formed by the National Academies in May 2006, with funding from The Atlantic Philanthropies, to study adolescent health care services in the United States and develop policy and research recommendations that highlight critical health care needs, promising service models, and components of care that may strengthen and improve health care services for youth and contribute to healthy adolescent development. This report summarizes the presentations and discussion at two one-day workshops organized as a part of the work of this committee. These workshops were an effort to take stock of the current knowledge base on adolescent health care services, settings, and systems; to incorporate personal experiences; and to help inform the work of the committee.

In November 2006 the committee convened a community forum to elicit the views of those who use and those who provide adolescent health care, with the goal of revealing gaps in current delivery mechanisms through perspectives from people who work with vulnerable populations of adolescents, individuals who work in different settings and systems that deliver health care to adolescents, and young adults themselves. In addition, the forum invited public stakeholders to present their views. In January 2007 the committee convened a workshop to examine the research base on the organization and delivery of adolescent health care services by (1) reviewing the state of adolescent health care systems, (2) identifying quality features of an adolescent health care system, (3) reviewing the evidence base on specific service delivery models or systems of care, and (4) identifying the evidence base of health care delivery to vulnerable populations of adolescents.

Given the limitations of both time and scope, the workshops could not address all issues that are certainly critical. It is our hope, however, that this report helps illuminate important issues in adolescent health care and begins unraveling this challenging and multifaceted area of study. Individual presentations from both workshops are available at http://www.bocyf.org/.

We are grateful for the contributions of the expert presenters, speakers, and discussants who contributed to the meeting (see the appendixes for the workshop agendas and list of participants). Special appreciation also goes to the committee members who volunteered their time and intellectual efforts to shape the workshop programs and identify themes and contributors. In addition, we give special thanks to Alexandra Beatty, who prepared a comprehensive draft of the workshop report, Leslie Sim and Jennifer Gootman, who directed the planning and workshop preparation and the production of the final publication, April Higgins and Wendy Keenan, who assisted with preparation of meetings and workshop, and Matthew McDonough, who assisted with running the workshops. Although the workshop report was prepared by the committee, it does not represent findings or recommendations that can be attributed to the committee members.

This workshop report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the Report Review Committee of the National Research Council. 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 charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We thank the following individuals for their review of this report: Trina Anglin, Office of Adolescent Health, Health Resources and Services Administration, Rockville, MD; Claire D. Brindis, National Adolescent Health Information Center, Institute for Health Policy Studies, University of California, San Francisco; Denise Dougherty, Child Health and Quality Improvement, Agency for Healthcare Research and Quality, Gaithersburg, MD; Jack C. Ebeler, Ebeler Consulting, Reston, VA; Elizabeth Feldman, Pediatric/Adolescent Coordinator, UIC/Illinois Masonic Family Practice Residency, University of Illinois College of Medicine; Alan Shapiro, Community Pediatrics and South Bronx Children and Family Health Center, Montefiore Medical Group, New York, NY; and Joshua M. Sharfstein, Health Commissioner's Office, City of Baltimore, MD.

Although the reviewers listed above provided many constructive comments and suggestions, they were not asked to endorse the content of the report 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. Appointed by the National Research Council, he was 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 author(s) and the institution.

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

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1

Introduction

To view the lives of adolescents through the lens of health care is to see a paradox: while most adolescents at this stage of life are thriving, they are also experiencing their moment of greatest vulnerability in terms of susceptibility to impulsive and risky behaviors involving sex, violence, substance use, and driving. It is during adolescence that lifelong behaviors are set in such areas as diet and exercise; sexual conduct; practices related to oral health, smoking, drinking, and the use of legal and illegal substances; and peer interactions that can enhance or discourage injuries. And while much of the health care system is focused on addressing problems that derive predominantly from biological causes, the health concerns of adolescents generally involve behavioral practices. Adolescence thus is a time of tremendous opportunities, but there are daunting challenges and complexities inherent in helping young people develop practices and relationships that they can carry into their adult lives.

The most difficult issues many adolescents confront in their daily lives—from questions about sexuality and experimentation with drugs and alcohol to emotional problems, obesity, or anorexia—are or could easily turn into health problems that can persist throughout their adult lives. And the adolescents who are frequently most disconnected from routine health care services—those who lack insurance or who lack parental guidance and family support—are frequently the ones who are at greatest risk for multiple and chronic health problems.

Consequently, as this incomplete list of issues suggests, those who are responsible for delivering health care to adolescents have to resolve this paradox. They need to address the health conditions that require immediate attention while also preparing young people to adopt practices that can help improve their future health status and prevent unhealthy behaviors. They need to recruit adolescents who are difficult to reach and engage them in health care settings that often are not tailored to the sensitivities or concerns of adolescents. And as this list also suggests, health care providers need to be sensitive to the interactions between adolescents' health and their life circumstances, developing strategies that can incorporate health care in a broad array of settings—schools, neighborhoods, community centers, and social services—that interact with vulnerable adolescents and their families.

For all adolescents, health and health care can be complicated by developmental changes, questions about confidentiality, relationships with families and peers, and other factors specific to this stage of life. For especially vulnerable populations, such as adolescents who are disabled, homeless, incarcerated, in foster care, or who live in poverty, health issues can be far more complicated. The needs of adolescents vary by gender, race and ethnicity, and other factors. Many of the challenges of adolescence are not medical but reflect larger social issues, such as poverty, crime, and the prevalence of violence. Nevertheless, lack of comprehensive health coverage, severely dysfunctional families, and the lack of many supports that other adolescents may take for granted can mean disconnection from the health care system and serious deficiencies in the care these young people receive. Insufficient health care affects not just the health of individual adolescents as they are growing up, but their lifelong health status as well.

The Committee on Adolescent Health Care Services and Models of Care for Treatment, Prevention, and Healthy Development was formed by the National Academies in May 2006, with funding from The Atlantic Philanthropies, to study adolescent health care services in the United States and highlight critical health care needs, promising service models, and components of care that may strengthen and improve health care services, settings, and systems for adolescents and contribute to healthy adolescent development. Committee members brought to this task expertise in the areas of adolescent health, general pediatrics, health care services, adolescent development, school-based health services, health care finance, mental health, alcohol, tobacco, and drug use, sexual health, oral health, nursing, public policy, statistics and epidemiology, preventive medicine, program evaluation, injury research, law, and immigrant and minority adolescents.

The committee was charged with exploring the following questions:

1. What does the evidence base suggest constitutes high-quality health care and health promotion services for adolescent populations? What features do parents, community leaders, and adolescents themselves perceive to be essential components of quality health care for adolescent populations?
2. What are the strengths and limitations of different service models (such as standard care systems, special population centers, comprehensive health care centers, and others) in addressing adolescent health care needs? What lessons have been learned in efforts to promote linkages and integration among adolescent health care, health promotion, and youth development services? What service models show significant promise in offering primary care as well as prevention, treatment, and health promotion services for adolescents with special needs and for selected adolescent populations (such as those in foster care or juvenile detention)?
3. What organizational settings, finance strategies, and communication technologies promote engagement with, access to, and use of health care services by adolescents? Do important differences occur in the use and outcomes of different service models in selected adolescent populations on the basis of such characteristics as social class, urbanicity, ethnicity, gender, sexual orientation, age, special needs, or risk status?
4. What kinds of training programs for health care providers are necessary to improve the quality of health care for adolescent populations?
5. What innovative strategies have been developed to address such concerns as decision making, privacy, confidentiality, consent, and parental notification in adolescent health care settings?
6. What policies, mechanisms, and contexts promote high-quality health care services for adolescents? What barriers impede the optimal provision of adolescent health care services? What strategies help adolescents to engage with and navigate the health care system, especially those at significant risk for health disorders in such areas as sexual and reproductive health, substance use, mental health, violence, and diet?

The committee planned two public workshops to inform its members about several issues that come under this broad charge and to supplement a literature review and research analysis. The first of these was a community forum held in November 2006, designed to elicit the views of a diverse group of health care providers and young people who use and provide adolescent health care, with the goal of revealing gaps in current mechanisms for delivering health care to adolescents, with a particular focus on vulnerable groups. The second was a research workshop held in January 2007, which focused on the available evidence regarding the organization and delivery of adolescent health care. Although both sessions addressed many issues that affect the general adolescent population, each had a particular focus on the needs of special adolescent populations, such as adolescents in foster care or the juvenile justice system, adolescents from minority racial or ethnic populations, homeless or disabled adolescents, and others. See Appendix A and Appendix B for the agendas and participant lists for each session.

This report summarizes the presentations and discussion that took place at each of these events. It is intended to provide a discussion of the ideas expressed by workshop presenters and participants—not a complete review of relevant literature.

The community forum was designed to address specific questions:

1. What are the strengths of current adolescent health care services and settings?
2. What are their weaknesses?
3. Where are there opportunities to enhance and improve adolescent health care services and settings?
4. What are the threats to them?
5. What vulnerable populations are not particularly well served through current health care services and settings?
6. What lessons have been learned in efforts to promote linkages and integration among adolescent health care, health promotion, and youth development services?

The community forum allowed the committee to learn from the experiences of selected populations of vulnerable adolescents, voiced both by young people themselves and by adults who work with them. It also provided a look at the structures through which health care is provided and the perspectives of providers and funders of health care for adolescents, especially those who are in difficult circumstances. Opportunities for discussion throughout the day allowed committee members to query participants and identify themes in the presentations and discussions, and time was set aside at the end of the day for participants to present statements about issues relevant to the committee's task. A key goal for the community forum was to allow views to be aired that might not easily find a place in more traditional, academic modes of inquiry.

The second event—the research workshop—provided an opportunity to consider many of the issues raised in the community forum discussions in the context of data about vulnerable adolescent populations and the care available to them. The research workshop targeted five goals:

1. Identify current models of adolescent health care delivery.
2. Examine how measures of quality (as defined by the Institute of Medicine and adapted to adolescents) apply to adolescent health care delivery.
3. Explore the evidence base for the quality of health care and different types of health care systems and the research needs for measuring this quality now and in the future.
4. Examine the methods through which health care can and should be delivered to special populations of adolescents now and in the future.
5. Identify research needs and gaps in models, quality, and delivery of adolescent health care.

The two workshops together provided a look at the issues and the challenges from a variety of perspectives. This report provides an integrated overview of the information and ideas that were presented and discussed at both. It is organized around the themes and questions that were presented and discussed, and it is not intended as a comprehensive review of issues related to the delivery of health care to adolescents, or a comprehensive summary of available data on adolescent health issues. The committee hopes that the ideas and information presented in the report will be helpful to the variety of stakeholders with a particular interest in health care for adolescents.

2

Overview of Adolescent Health Issues

A logical starting point for a discussion of adolescent health care would be to define adolescence, but in practice the boundaries of this phase of life are not precise. Even within the Centers for Disease Control and Prevention (CDC) several definitions are in use, as Andrea MacKay (National Center for Health Statistics) pointed out to workshop participants. Students in grades 9 through 12 are covered in the National Youth Risk Behavior Survey, for example, while the Healthy People 2010 health objectives address 10- to 19-year-olds, with some attention to 20- to 24-year-olds, and the Healthy People in Every Stage of Life Program defines adolescents as 12- to 19-year-olds.[1] Other research programs related to adolescents at the National Institutes of Health and the Agency for Healthcare Research and Quality offer no definition. In the face of this confusion, Robert Blum (The Johns Hopkins University) exhorted the committee to define adolescence, and MacKay made a case for settling on ages 10, the lower bound of puberty, to 19, the age at which most adolescents embark on adult paths, such as college, employment, military service, marriage, or parenthood.

The question is more than semantic. Social and cultural changes have meant that more and younger children face challenges and health problems once very rare for them, while issues typical of adolescence may

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[1] National Youth Risk Behavior Surveillance System, available: <http://www.cdc.gov/HealthyYouth/yrbs/index.htm>; Healthy People 2010 health objectives, available: <http://www.healthypeople.gov/Document/tableofcontents.htm>; Healthy People in Every Stage of Life Program goals, available: <http://www.cdc.gov/osi/goals/people.html>.

persist into the early twenties. The average age of the onset of puberty has declined over the last century, occurring by age 10 for many children, while neuroscience has established that cognitive development is not complete until the early twenties. At the same time, as the world has become more complex, the social concept of adolescence is extending into what was once considered adulthood, and young people are assuming adult roles and responsibilities later. Such changes have challenged researchers and practitioners to sustain a coherent conceptual picture of adolescence.

To highlight the need, Blum took note of two contrasting models of care: one focused on children, and the other on adults. In a pediatric approach to medicine, the parent is the responsible agent and the focus is on nurturing the patient in a family context. In an adult-centered approach, the patient is the responsible agent; the provider offers information with which the patient makes decisions, and the focus is on the individual, not the family.[2] The treatment of adolescents does not fit either model well, and their needs change as they progress through this stage. Despite the complexity of this stage of life, the significant developmental and cognitive changes it encompasses, and the important implications of adolescent health and behavior patterns for adult health status, adolescence is the subject of less research than any other age group, Jonathan Klein (University of Rochester Medical Center) pointed out. Perhaps as a result, while some practitioners specialize in caring for adolescents, their numbers are few—less than 1 percent of primary care physicians who may see adolescents are board-certified specialists in adolescent medicine, according to data from the American Board of Medical Specialties supplied by Klein.

ADOLESCENT HEALTH STATUS

Regardless of the boundaries of adolescence, however, a variety of health issues affect this group, according to MacKay, who provided an overview of trends in adolescent health. The good news is that mortality rates for adolescents ages 15 through 19, both from injury and from all other causes, declined between 1980 and 2004, according to the CDC's National Vital Statistics System. Currently, the rate of death from all causes for this age group is approximately 65 per 100,000. Nevertheless, adolescence is a much more dangerous phase of life than childhood. Despite the improved mortality rates, three major threats to adolescents'

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[2] A third model of care is offered by family medicine, in which the family—including children, adolescents, and adults—is the focus of care for a family physician or family nurse practitioner.

health remain serious problems: death by injury, primarily by firearm or motor vehicle crash; attempts at suicide; and complications that may develop in adulthood due to overweight. Specifically:

- The National Youth Risk Behavior Survey, another CDC study, tracking suicide ideation (thoughts of suicide) and suicide attempts among students in grades 9 through 12, found that despite marked declines since 1991 in the numbers of adolescents who have "seriously considered" suicide, the rates of attempts (almost 17 percent) and attempts that cause injury (almost 2.5 percent) remained steady during that time period.
- Mortality rates for adolescents have declined in recent years, and the causes have fluctuated. Predominant risk factors include motor vehicle crashes and firearm-related injuries. Older adolescents are at higher risk than younger adolescents of mortality caused by motor vehicle crashes and firearm-related injuries. Young men are at higher risk of mortality than young women for all causes, as shown in Figure 2-1.
- The CDC's National Health and Nutrition Examination Survey, tracking rates of overweight among adolescents ages 12 to 19 since 1966, has identified a steady increase since the 1976–1980 survey, when roughly 5 percent of adolescents were overweight. According to the 2003–2004 survey, roughly 18 percent of adolescents were overweight that year, and diseases including type 2 diabetes, hypertension, and depression are associated with obesity in that age group (Daniels, 2006).

In addition to suicide attempts, death by injuries, and an epidemic of obesity, exposure to violence and victimization, untreated dental caries, and reproductive health issues were also identified by MacKay as troubling indicators of adolescent health status. Violent crime victimization rates among adolescents and young adults (ages 12–24) have generally decreased since 1995, according to the U.S. Department of Justice's National Crime Victimization Survey, but violence remains a serious concern, with approximately 2 million adolescents (ages 12–24) having reported exposure to violent crimes in 2004. From 2001 to 2004, the proportion of young adults (ages 20–24) with untreated dental caries was 50 percent higher than that of adolescents ages 10–19, according to the U.S. National Health and Nutrition Examination Survey. Overall, 23 percent of adolescents and young adults had at least one untreated dental caries or infection.

Reproductive and sexual health is another area of significant need for adolescents, who particularly need contraceptive and family planning

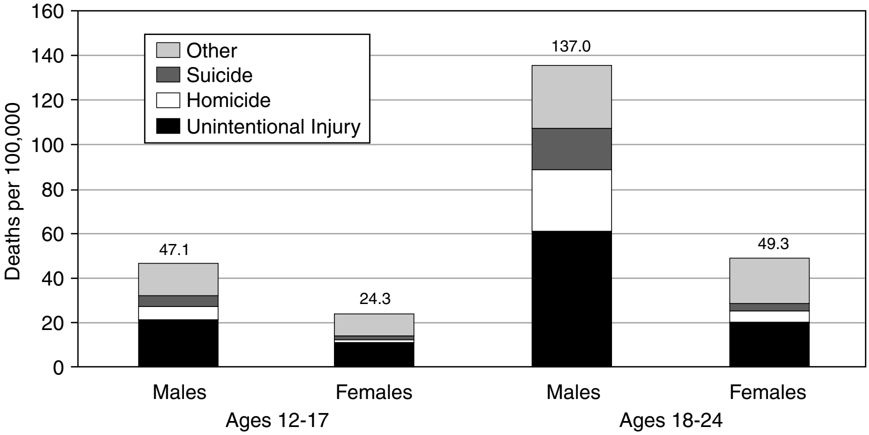

FIGURE 2-1 Mortality by cause, gender, and age group, ages 12 to 24, United States, 2003. Data from the 2003 Fatal Injury Reports of the Web-based Injury Statistics Query and Reporting System, National Center for Injury Prevention and Control.
SOURCE: Park et al. (2006). Reprinted with permission from Elsevier.

care. Although both pregnancy and birth rates for adolescents 15 to 19 have declined since 1990, there are still nearly 80 pregnancies and between 20 and 80 live births per 1,000 adolescents each year (birth rates vary by race and ethnicity as well as other factors). In 2002, over 80 percent of sexually active young women ages 15 to 19 reported use of some form of contraception at last intercourse, according to the CDC's National Survey of Family Growth. Chlamydia remains the most common bacterial cause of sexually transmitted diseases for adolescents ages 15 to 19, according to the Sexually Transmitted Diseases (STD) Surveillance collected by the National Center for Human Immunodeficiency Virus (HIV), STD, and Tuberculosis Prevention from the CDC. Young women had higher rates of chlamydia than their male counterparts. Gonorrhea and syphilis are also frequently reported. Older adolescents are at a higher risk of sexually transmitted disease than younger adolescents. Young women who become pregnant and all sexually active adolescents need medical care. The need for this type of health care affects all groups and subgroups.

From MacKay's perspective, the broad category of mental health and risk behaviors provides an important key to adolescent health that must be considered along with medically related measures of health. A significant proportion of adolescents' health problems relate to sexual activity;

use of tobacco, alcohol, and illicit drugs; driving while impaired; poor diet; mental disorders; and exposure to weapons, according to the CDC's Youth Risk Behavior Survey and the Substance Abuse and Mental Health Services Administration's National Survey on Drug Use and Health. In 2002 more than 80 percent of young women ages 18 and 19 and more than 50 percent of those ages 15 to 17 were sexually active. More than 80 percent of those young women (ages 15–19) were using birth control, but nearly 20 percent were not. Indicators for many of these behaviors have shown some improvement. For example, the rate of frequent smoking[3] dipped below 10 percent in 2005; the rate of frequent alcohol use has edged down slightly since 1991, to approximately 25 percent; and the rate of current marijuana use has also slipped down to 20 percent, after a substantial increase in the 1990s.[4] Despite these modest improvements, however, risky behaviors are still among the biggest issues in adolescents' health, and the rates are still high enough to be significant public health concerns.

A final area of concern is adolescents' access to quality health care. For a host of reasons (explored in greater detail in later sections), many adolescents have no insurance at all or insufficient health insurance, or they lack adequate information about coverage for which they may be eligible, such as Medicaid or the State Children's Health Insurance Program (SCHIP). According to the CDC's National Health Interview Survey, low-income adolescents are least likely to have health insurance—20 percent of adolescents in families below the poverty level have no insurance, compared with 8 percent of those in families at twice that level or greater. Older adolescents, ages 18 and 19, are most likely to lack coverage, while significant numbers of poor younger adolescents are covered only through public programs. Adolescents particularly tend to have dental care, routine outpatient care, mental health care, and reproductive health services that are inadequate.

Thus, as MacKay noted, many of the risks to adolescents' health are primarily caused by social and behavioral factors that require attention to preventive care, risk, environmental factors, and protective behaviors. Physically, adolescents are generally healthy and they are less prone to many illnesses than younger children are. Nevertheless, many of the behaviors that compromise adult health, such as diets and inadequate exercise that lead to cardiovascular disease and obesity; experimentation

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[3] Frequent smokers are students who smoked cigarettes on 20 or more of the past 30 days.

[4] Each of these figures is the percentage of young people in grades 9 through 12 who report having done the behavior in question frequently (or currently, for marijuana use) in the past 30 days.

with tobacco, alcohol, and drug use that can lead to addiction; and reliance on violent behaviors to address conflict and stress, are habits formed during adolescence. These behaviors and patterns have serious long-term consequences because they are linked to conditions, such as diabetes and cardiac disease, that are serious threats to individuals' health, quality of life, and life span, as well as significant public health threats.

CURRENT STATE OF CARE

With this picture of adolescent health in place, the focus of the research workshop shifted to an examination of the ways in which care is provided for this group.

Statistical Overview

Jonathan Klein presented a statistical overview of the care adolescents are currently receiving. First, the majority of adolescents (or their parents) report that they have a usual source of primary care (94 percent of young women and 91 percent of young men), although they are somewhat less likely than younger children to have had a primary care visit in the past year (Klein, 1997). However, a closer look at the nature and quality of health services for adolescents reveals some deficits. While household survey results indicate that most adolescents receive their primary care in a doctor's office or clinic, 10 percent of young women and 13 percent of young men rely on the hospital or the emergency room as their usual source of care (Klein, 1997). Over 90 percent say they have had a well-patient visit in the past two years (Klein, 1997), but only 49.2 percent have received care that followed recommended guidelines, such as those for annual well-patient visits, confidential and comprehensive health screening, and immunizations (Selden, 2006).[5]

Most guidelines for adolescent health care stress the importance of talking with adolescent patients without a parent present in the examination room. Yet just 53 percent of young women and 62 percent of young men have had the chance to speak privately with a doctor when they needed to, and 39 percent of young women and 24 percent of young men have been too embarrassed to bring up a topic about which they had questions during an appointment, according to data from Klein (1997). He showed significant discrepancies between adolescents wanting to dis-

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[5] The American Academy of Pediatrics, the American Medical Association, the American Academy of Family Physicians, the Maryland Children's Health Program, Stanford University's Center for Health Policy, Bright Futures, and the U.S. Preventive Services Task Force have all issued guidelines that concur on most but not all specifics.

cuss a range of issues—including eating disorders, drugs, contraception, abuse, and smoking—and ever having actually done so with a health care provider (Klein and Wilson, 2002).

A quarter to a third of adolescents have gone without care they needed (Klein, 1997), and approximately 19 percent reported having done so in the past year (Ford, Bearman, and Moody, 1999; Lehrer et al., 2007). Moreover, it is those who need care the most (such as low-income adolescents and those with poor health status, depression, or a history of abuse) who are most likely to fall through the cracks (Schoen et al., 1997). The key reasons adolescents give for going without care are reluctance to let their parents know why they need care, cost, and lack of insurance. Some adolescents have access to care through school-based health centers, community-based centers, and other sources (Schoen et al., 1997). The benefits of providing care through these facilities were amply demonstrated in many of the presentations discussed below, but their numbers are few. For example, fewer than 1,400 school-based centers were counted in the 2001–2002 National Assembly on School-Based Health Care Census, almost half of which serve high school students (National Assembly on School-Based Health Care, no date) (more information on school-based health centers is provided in Chapter 4).[6] Subsidized family planning services were provided in 7,682 sites in 2001; it has been estimated that 4.9 million adolescents need these services (Guttmacher Institute, 2005).

Care for adolescents falls short in some other ways, according to Charles Homer (National Initiative for Child Health Quality). The rate of medical errors (in diagnosis and treatment) is also higher for adolescents than for any other age group except (for some kinds of errors) newborns with medical conditions. Adolescents are more likely to receive inappropriate treatment with antibiotics than are younger children and more likely to incur out-of-pocket expenses. Inadequate preventive care, however, is the most important problem Homer identified. He cited state-level data indicating that only about half of the encounters with providers create the opportunity for adolescents to have private or confidential visits or to ask about any critical risk behaviors (Shenkman, Youngblade, and Nackashi, 2003). Figure 2-2 shows the percentages of adolescents who report ever having discussed critical health risk topics with a health professional.

Moreover, despite the importance of well-child visits, the percentage of children receiving them declines from 84 percent for 5- to 10-year-olds to 66 percent for 15- to 17-year-olds (Yu et al., 2002). Adolescents also lag behind younger children in the rate at which they receive recommended immunizations and dental visits. Management of chronic medical and

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[6] A recent study has found nearly 2,000 such centers (Brindis et al., 2003).

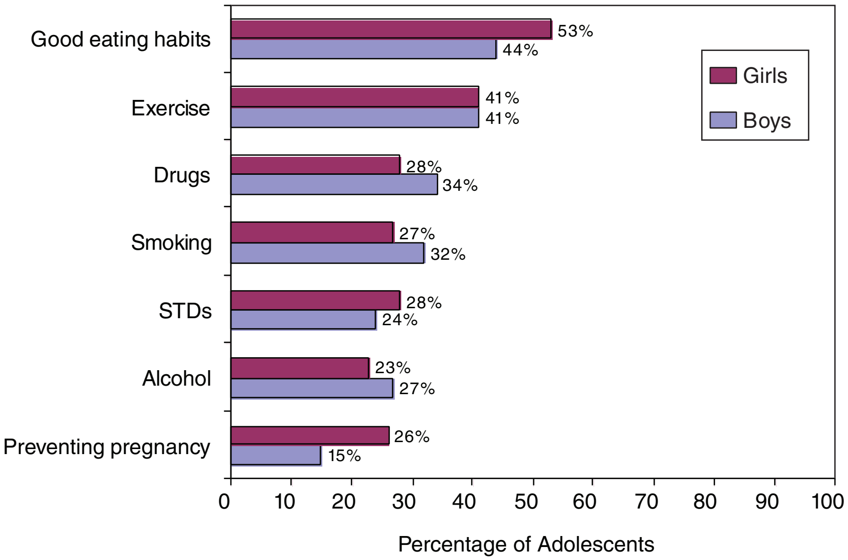

FIGURE 2-2 Summary of topics health care providers have discussed with adolescents, as reported by adolescents in grades 5 through 12. Data from the 1997 Commonwealth Fund Survey of the Health of Adolescent Girls and Boys.
SOURCE: Ackard and Neumark-Sztainer (2001). Reprinted with permission from Elsevier.

mental health conditions and the transition to adult care are also insufficient, in Homer's view. Adolescents are less likely to receive appropriate treatment to control asthma, for example, than younger children or adults (and all Medicaid recipients are less likely to than patients covered by commercial health plans). According to one study, just 20 percent of adolescents with chronic conditions have discussed with their doctors the ways their needs will change as they reach adulthood and shift to a provider who treats adults, and their plans for addressing these changing needs (Lotstein et al., 2005).

Views of Adolescents and Their Parents

When adolescents and their parents are asked about the care they receive, a similar divergence between recommended standards of care and reality is evident. The Child and Adolescent Health Measurement Initiative through the Young Adult Health Care Survey of the Oregon Health and Science University has developed standardized measures for a variety of issues related to the quality of health care for adolescents. Data presented by Christine Bethell (Oregon Health and Science University) shows, for example, that more than 40 percent of adolescents report receiving no counseling on any topics related to risky behaviors, unwanted pregnancy, or sexually transmitted diseases. Nearly 40 percent received no counseling on diet, weight, or exercise, and 41 percent received no counseling on depression, mental health, or relationships. Adolescents also say they lack opportunities for private and confidential visits with practitioners to discuss these subjects—just 25 percent in this study had a confidential visit related to risky behaviors. While the numbers are somewhat larger for other issues, only slightly over half (53 percent) reported usually or always having good communication with providers.

Even when they receive health counseling, adolescents do not always find it helpful: 83 percent of those who received counseling for birth control said it was helpful, 80 percent felt that way about HIV counseling, and the rates were 70 percent for counseling about drinking and 63 percent for smoking. The features adolescents say they look for in counseling, according to the survey, are clear explanations, shared decision making, respect, and trust.

Parents were asked a different set of questions and also reported significant dissatisfaction with the care they are able to get for their adolescents. Among parents of children and adolescents (ages 5–18), for example, fewer than half reported that their care met all the criteria for what was defined as a "medical home," which included ready access to a provider, coordination of care, and other factors linked to high-quality primary care. The percentages declined from 48 percent for children ages 4 through 7 to just 39 percent for those ages 15 to 17, and they were lowest for black and Hispanic parents.

From Bethell's perspective, care for adolescents could be improved on five critical elements of preventive care: regular visits, privacy and confidentiality, screening, counseling, and culturally sensitive partnerships with adolescents and their families.

Disparities in Health Status and Care

Indications of disparities in access to health status and quality of care among population subgroups were evident in almost every discussion. Anne Beal (The Commonwealth Fund) presented some of the data on this issue and also described some of the limitations to the available data. Her troubling finding is that minorities are at a disadvantage in most of the indicators she presented. Black and American Indian young men have the highest death rates—at 173 and 145 per 100,000 males ages 15 to 24, respectively. The rate for Hispanic males is 114 and that for whites is 107 (Center for Applied Research and Technical Assistance, no date). Hispanic adolescents are more likely than those of any other group to lack health insurance—28 percent of them are uninsured compared with 12 percent of black and 8 percent of white adolescents (Newacheck et al., 2004). Hispanic young women also have the highest birth rates among adolescents, at 82 per 1,000 females ages 15 to 19, compared with 64 for blacks and 27 for whites (Martin et al., 2005). Blacks are the most likely to contract acquired immune deficiency syndrome (AIDS), with 3.4 per 100,000 adolescents ages 13 to 17 reported in 2003, compared with 0.7 for Hispanics and 0.1 for whites (Agency for Healthcare Research and Quality, 2005).

While this evidence is compelling, Beal explained that measures of disparities in health care rely on quality measures that frequently are not adequate to characterize important differences. Methods for collecting data about the race and ethnicity of patients vary significantly, for example. Admitting clerks or providers may either ask the patient or record their own observations, or the patient may reply to a question on a form—and this inconsistency could significantly skew results. Moreover, while quality measures are in place for the care of children, relatively few are exclusive to adolescents, so the results of child health quality measures make it difficult or impossible to disentangle the relevance for a specific group—by distinguishing among the treatment of infants, children, and adolescents.

A related problem is that data about nonmedical issues, such as behavior and social contexts, and questions about access to health care are collected in separate ways and by separate groups. As a result, integrating data about these two sets of issues can be difficult, yet they are intimately linked in terms of their influence on adolescents' health status and care. The relationship between clinical outcomes and nonmedical and access issues is clearly an important factor in disparities in care and outcomes, but making these connections is very difficult using current data collection structures.

Denise Dougherty (Agency for Healthcare Research and Quality) addressed another set of questions about the quality of care available to different adolescent populations. She reviewed the available research on the effectiveness, quality, and costs of health care provided in community- and school-based centers, whose patients are overwhelmingly members of vulnerable groups. Dougherty found the research base limited and described a number of issues for future researchers to consider. Looking just at work that addressed programs that both delivered traditional health care (rather than categorical services, such as STD screening or family planning, exclusively) and served adolescents, she found relatively few studies. Moreover, those studies varied in their use of terms, methodological rigor, and the populations, settings, and topics studied.

From this evidence, Dougherty concluded that school-based health centers appear to meet a need for services, although the evidence was less clear for neighborhood centers; that health outcomes were mostly favorable to the extent that data were available; and that the overall quality of centers could best be described as mixed.[7] However, limitations of this body of research did not support any meaningful comparisons with other means of delivering care to vulnerable populations. She highlighted the importance of research that would

- address the issues for which adolescents are most likely to need care;
- address adolescents' experiences and satisfaction with the care they receive in these settings;
- identify the effects of the programs on individuals, communities, schools, etc.;
- consider cost-effectiveness; and
- evaluate different models for serving vulnerable groups.

Distinct Needs of Adolescents

Robert Blum presented another perspective on caring for adolescents. Building on the point that social and behavioral issues are the causes for the majority of adolescents' health problems, he noted that these issues are often least well addressed by those providing care to young people. Adolescents need care that bridges the space between pediatrics and adult internal medicine and that addresses the nonmedical factors that affect their health.[8] Adolescents, especially those with chronic or ongoing health problems, are not likely to receive guidance about making the transition to adult care and are not receiving care that adequately addresses behavioral issues. He acknowledged that although the benefits of this kind of guidance have received little research attention, they have been empirically demonstrated for certain health categories, such as STDs, HIV, and family planning care (Ozer et al., 2005). Moreover, broader benefits for more comprehensive care are likely to include promoting psychosocial and family well-being, addressing medical concerns, and teaching self-advocacy skills.

Richard Catalano (University of Washington) also addressed the social and behavioral factors that influence adolescent health, but focused on

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[7] Much of the data on community health centers dates from the 1960s and 1970s, and it is not known how many such centers currently offer adolescent health care programs. One recent study is Klein et al. (2001).

[8] Family practitioners, who were consulted in 31.5 percent of primary care visits for patients ages 10-21, are in a good position to bridge this gap (S. Schuppert, personal communication).

mechanisms for affecting adolescents' health outcomes other than visits to physicians' offices and health centers. Catalano described the risk factors for adolescent behavior problems (see Box 2-1).

He also described key individual protective factors (high intelligence, resilient temperament, and competencies and skills) as well as social protective factors (prosocial opportunities, reinforcement for prosocial involvement, bonding (such as with a caring parent or other adult), and healthy beliefs and clear standards for behavior set by parents or guardians. Catalano traced the association of both risk and protective factors with a variety of the behaviors and circumstances that have a significant impact on health for good or ill: alcohol or illicit drug use, mental and

BOX 2-1
Risk Factors for Adolescent Behavior Problems

Community Risk Factors
- Availability of drugs
- Availability of firearms
- Community laws and norms favorable toward drug use, firearms, and crime
- Media portrayals of violence
- Transitions and mobility
- Low neighborhood attachment and community disorganization
- Extreme economic deprivation

Family Risk Factors
- Family history of problem behavior
- Family management problems
- Family conflict
- Favorable parental attitudes toward and involvement in the problem behavior

School Risk Factors
- Academic failure beginning in late elementary school
- Lack of commitment to school

Individual/Peer Risk Factors
- Early and persistent antisocial behavior
- Rebelliousness
- Friends who engage in the problem behavior
- Early initiation of the problem behavior
- Constitutional factors

SOURCE: Presentation by Richard Catalano, January 22, 2007.

social problems, degree of academic success, and involvement with violence. He has concluded that although both risk and protective factors are linked to diverse health and behavior problems in ways that are predictable and consistent across population groups, contextual factors influence their effects on the health and behavior problems of adolescents. That is, risk factors are not evenly distributed within geographic areas, and the profile of risk, protection, and outcomes for the adolescents of a particular neighborhood should determine the strategies and interventions that are available to the adolescents who live there.

Catalano noted a number of widely used strategies that have not been demonstrated to be effective in preventing certain risk behaviors. These include peer counseling, mediation, and positive peer culture; nonpromotion to succeeding grades; after-school activities with limited supervision and programming; drug information, fear arousal, and moral appeal; the Drug Abuse Resistance Education program or DARE; gun buyback programs; firearm training; mandatory gun ownership; shifting peer group norms of gangs; and neighborhood watch.

He contrasted these interventions with others that have shown effectiveness in prevention of certain risky behaviors. The latter include

- Prenatal and infancy programs
- Early childhood education
- Parent training
- After-school recreation
- Mentoring with contingent reinforcement
- Adolescent employment with education
- Organizational change in schools
- Classroom organization, management, and instructional strategies
- School behavior management strategies
- Classroom curricula designed to promote social competence
- Community and school policies

In addition to programs and interventions for adolescents, several programs that make use of strategies that have been evaluated and have demonstrated effectiveness for parent training include

- Guiding Good Choices® (Spoth, Redmond, and Shin, 1998)
- Adolescent Transitions Program (Andrews, Soberman, and Dishion, 1995; Dishion and Andrews, 1995)
- Staying Connected with Your Teen® (Haggerty et al., 2006)
- Creating Lasting Connections (Johnson et al., 1996)
- Strengthening Families Program 10–14 (Spoth, Redmond, and Shin, 1998)

Catalano expressed concern that programs that either do not work or have not been evaluated are in wider use than those that have been shown to be effective. He also pointed out the challenges of using prevention strategies carefully, the most significant of which is to match the strategy to the specific risks that need to be addressed. Not only do the risk and protective factors in the community need to be accurately assessed, he explained, but the community's resources and its readiness to take an active part in a strategy to protect its youth must also be considered. Moreover, even successful interventions do not bear fruit overnight—measurable results in the form of behavioral changes may not be evident for two to five years, and significant improvements in population health measures would lag well behind those changes.

LOOKING SYSTEMWIDE

Claire Brindis (University of California, San Francisco) challenged workshop participants to consider what a truly effective system of care for adolescents might look like, given what is known about their health profile, the ways they use care, and the unique attributes of this developmental stage. In making the argument that a far greater investment in adolescent health is needed, she pointed to four key points about health care for adolescents:

1. Preventable risky behaviors have a big impact on the health of adolescents.
2. There are significant gender and racial differences in adolescent health problems and risk factors and in the care needed by special populations.
3. There are four major developmental stages within the age span—early (10–14), middle (15–17), and late (18–19) adolescence, and early adulthood (20–24)—each of which presents distinct issues.
4. The transitions from middle childhood to adolescence and from adolescence to adulthood merit special attention from the health care system.

The cost to individuals, families, and communities of inadequate and inappropriate care may be difficult to measure, but without a doubt the economic cost is high. Considering only the direct and long-term social costs associated with six of the most common health issues adolescents experience (pregnancy, sexually transmitted diseases, motor vehicle injuries, alcohol and drug problems, other unintentional injuries, and mental health problems), at least $700 billion is spent annually in the United States on preventable adolescent problems (Hedberg, Bracken, and Stashwick, 1999).

Brindis argued that an improved approach to preventing these health problems should begin with understanding the way risky behaviors are clustered and shaping programs and policies for each. She identified four broad categories of adolescents whose needs are distinct: demographic subgroups; legally defined groups, such as incarcerated adolescents and adolescents in foster care; adolescents with chronic physical or emotional conditions; and adolescents in other circumstances that magnify their need, such as those who are pregnant or parenting or those who are homeless. The need is growing. Demographic groups that are generally less well served by the health care system are growing as the U.S. population becomes increasingly diverse. At the same time, the U.S. health care system is in a state of growing crisis, as rising prices and other factors put coverage out of reach for increasing numbers of families. Low-income adolescents already report poorer health status, less continuity of care, and more challenges in obtaining care than other groups.

While the circumstances and challenges facing these broad categories of adolescents vary, several factors hold true across the groups. When social and behavioral patterns are causing health problems, they are likely to cause multiple problems. Current medical practice tends to focus on individual health problems and to assign them to different practitioners, but a variety of issues may be interrelated and have a common etiology. A segmented approach may fit the needs of providers' skills but lack the capacity to address the needs of adolescents with multiple health problems. An approach to care that takes into account the effects of the contexts in which adolescents live is likely, Brindis argued, to be more effective than the current approach to prevention, which tends to focus on isolated problems in individuals and families, one at a time.

Moreover, the positive youth development model, through which resiliency and protective factors are fostered, is likely to be more effective at promoting healthy development in adolescents than a deficit model focused on the challenges and problems common in this phase of life. Brindis offered a list of protective factors similar to the one offered by Catalano, including caring relationships, high expectations, and opportunities to participate and contribute, as well as traits that make adolescents resilient, including social competence, problem-solving skills, autonomy and a positive sense of self, and a sense of purpose and anticipation of a positive future.

Brindis sees training for providers who treat adolescents as the best way to create a broad-based prevention strategy for adolescent care that builds on protective factors and targets risk factors. Currently, she pointed out, just 25 of the 213 accredited pediatric residency training programs in the United States have fellowship programs in adolescent medicine that are approved by the Accreditation Council for Graduate Medical Education, and of those 25, only 7 include interdisciplinary training.[9] Both physicians in training who expect to treat adolescents and nurses in practices that serve adolescents have been surveyed and report that they feel inadequately prepared to address the needs of this group of patients.

Both the Society for Adolescent Medicine and the American Academy of Pediatrics have both offered lists of key elements of high-quality care for this age group that include reproductive and mental health coverage, consent and confidentiality, trained and experienced providers, and coordination of care. Brindis closed her remarks with her view of the essential elements of a health care system that serves adolescents well:

- Adolescents have access to a comprehensive system that provides necessary specialty care and coordination of care.
- The system is adequately financed.
- Adolescents have the skills to negotiate the system.
- Preventable problems are prevented.
- Chronic conditions are effectively managed and the transition to adult care is ensured.

David Grossman (Group Health Permanente) took another tack in considering the question of what adolescent care ought to look like. He argued that distinctions between managed care and other systems for delivering care are less useful than distinctions among systems that are or are not well organized to provide coordinated care. From his perspective, there is extensive variation among managed care plans, in terms of how well they coordinate care and provide access to specialty care, as well as other important indicators of quality. Thus, he prefers to focus on the necessary characteristics of care models that provide integrated care, rather than on the ways in which they are internally structured or financed.

Two models illustrate Grossman's conceptual approach. The medical home model, originally developed as a way to ensure coordination in care for pediatric patients, focuses on collaboration with families to facilitate access to both primary and specialized care and develop continuous relationships with a personal physician (Sia et al., 2004). An overlapping concept is the chronic care model, which focuses on proactive, planned care that makes use of information technology to improve coordination between primary and specialty care and helps patients manage their own

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[9] It should be noted that the three primary care disciplines—pediatrics, family medicine, and internal medicine—do mandate the inclusion of adolescent health as part of basic residency training, although only pediatrics mandates in-depth coverage or clinical experiences. Obstetrics and gynecology also include coverage of treating adolescents in their residency requirements. Other organizations, such as the Society of Teachers of Family Medicine, also have interest groups devoted to adolescent issues.

care. Both models draw on community resources as well as health care systems to create productive relationships between informed patients and proactive providers that yield improved outcomes.

Some research indicates that these models can improve continuity of care, patient satisfaction, access to care and outcomes, and other characteristics (see for example Hung et al., 2007). Grossman suggested that these models are likely to be very well suited to caring for adolescents, but he observed that research is needed to explore such questions as their effects on costs and outcomes for adolescents, the optimal design for an adolescent care model, and the best approaches for engaging adolescents in taking responsibility for their own health.

HEALTH INSURANCE

Finally, almost every presenter in both workshops raised issues related to health insurance and other coverage. Abigail English (Center for Adolescent Health and the Law) summarized the issues in the context of the needs of vulnerable adolescents. In 2005, 47 million people in the United States, or 16 percent of the population, were uninsured, and the numbers are increasing (DeNavas-Walt, Proctor, and Lee, 2006). Moreover, the percentage of those covered who obtain their insurance through an employer declined, while the percentage who rely on publicly funded coverage increased. If stretches of less than a year without insurance were counted, the numbers would be even larger. Older adolescents (15–18) are more likely to be uninsured than younger ones (10–14) (Newacheck et al., 2004), and 30.6 percent of young adults (18–24) were uninsured in 2005 (DeNavas-Walt, Proctor, and Lee, 2006). The uninsured of all ages are disproportionately Hispanic and black, and 40 percent of uninsured adolescents have a family income less than 200 percent of the federal poverty level (Newacheck et al., 2004).

There are several reasons why older adolescents and young adults are particularly likely to be without coverage. In most states, Medicaid and SCHIP coverage ends at age 19, and employer-based coverage of dependents usually covers dependents over age 18 years only if they are full-time students. The cost of individual policies is often out of reach for this age group. Vulnerable groups, such as homeless and incarcerated adolescents, adolescents in foster care, and immigrant adolescents, are especially likely to lack coverage, even when they are eligible, because they tend to lack supports, are frequently unemployed, and do not have an ongoing connection to responsible adults.

Brindis cited data indicating specific weaknesses in insurance coverage. One analysis of private health insurance in 48 states found coverage of rehabilitation and mental or behavioral health care, including treatment for substance abuse, was inadequate (Fox, McManus, and Reichman, 2003), while another study found that less than 10 percent of adolescents who abuse or depend on substances had received treatment (Substance Abuse and Mental Health Services Administration, 2006). Blum also addressed this point, noting that the current system for financing health care specifically precludes coverage for much of the care that is most needed. Insurance companies cannot shoulder this burden alone, Blum argued; a public-sector commitment is needed to take on an issue of this magnitude. English described options that have been proposed, such as MediKids,[10] which would have expanded publicly funded coverage to age 23, as well as local initiatives that are filling some gaps. In her view, workable policy options exist, but advocacy, supported by research to document both the need for and the potential value of proposed solutions, is necessary to bolster the political will needed to put them to work.

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[10] MediKids is part of Florida's KidCare, the state's children's health insurance program for uninsured children under age 19. It is made up of four parts: MediKids, Healthy Kids, the Children's Medical Services Network for children with special health care needs, and Medicaid for children.

3

Needs of the Most Vulnerable Adolescents

While the committee is concerned with the needs of all adolescents and with broad policy questions about the delivery of care, the two workshops examined the challenges in care for the most vulnerable groups. Developmental and social needs affect the delivery of health care for any adolescent, and they are of special importance for the care of the most vulnerable adolescents. The workshop presenters highlighted gaps in care for vulnerable adolescents that are of a different order from those that affect young people who are less vulnerable or disadvantaged. Adolescents whose life circumstances are seriously disadvantaged may go years without seeing a doctor, may have serious and multiple untreated physical or mental illnesses, or may live without necessary vaccinations, preventive reproductive, dental, and other care, for example. Moreover, they often need support that bridges the divide between health and social services, if they live in a severely dysfunctional family, are homeless or physically neglected, or for a variety of other reasons.

In planning the community forum, which focused on the experiences of the most vulnerable groups, the committee members faced a dilemma. While they were eager to hear from a variety of adolescents about their experiences, there was time available to hear from only a handful of individuals. Asking any individual to speak on behalf of large numbers of others facing similar circumstances is problematic, and the very young people who are most affected by difficult circumstances—as well as younger adolescents who already may have the least voice in their own care—may be the least likely to be willing to speak at a public community forum hosted by the National Academies. At the same time, hearing the accounts of adolescents who have themselves experienced the kinds of disadvantage that seriously compromise health care, though anecdotal, was essential to the committee's goals.

Fortunately, the committee was able to identify several young people, as well as some adults who work directly with disadvantaged adolescents, who provided thoughtful and compelling descriptions of what they have experienced and observed. Their observations provided insights into complex issues that the committee could pursue.

Matthew Morton, who at the age of 22 is the vice chair of the National Council on Youth Policy of the National Network for Youth, described for the audience the most pressing issues he sees facing three groups of adolescents: those in foster care, those in the juvenile justice system, and those who have run away from home or are homeless. His views on the needs of these young people have been shaped by his own childhood, during which he was orphaned and cared for, as he explained, "in a home marked by alcoholism, cocaine addiction, neglect, and occasional police visits." Shawn Denise Semelsberger, who spent many years in foster care and serves on the board of directors of a crisis intervention center, followed up on Morton's presentation with her observations about issues that affect adolescents in foster care. Paul Fogle, a college senior who is also a member of the board of the National Youth Leadership Network and has lived with a disability all his life, reflected on particular challenges in providing care for adolescents with disabilities.[1]

In addition, three adults with many years of experience working with vulnerable people offered their perspectives on providing health care to adolescents who live in the U.S.-Mexico border areas (Salvador Balcorta), unattached or homeless adolescents (Alan Shapiro), and low-income adolescents (Coleen DeFlorimonte). The information provided by these presenters was supplemented by the findings discussed by researchers Abigail English, Robert Garofalo, Kimberly Hoagwood, and Constance Weisner at the research workshop.

ADOLESCENTS IN FOSTER CARE

In 2005 there were nearly 227,000 adolescents (age 12 and older) residing in foster care (U.S. Department of Health and Human Services,

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[1] Tricialouise Gurley, a young adult who was invited to present on the health care experiences of gay and lesbian youth, was unexpectedly unable to attend the community forum.

2006).[2] Morton explained that the health status of these young people is frequently compromised by such problems as mental disorders, chronic medical conditions that are not properly managed, substance abuse, risky sexual behavior, abuse, and malnutrition (English, Stinnett, and Dunn-Georgiou, 2006). Abigail English described their health care needs, which include comprehensive health assessments, dental care, family planning and prenatal care, mental health services, treatment for substance use and abuse, and oversight of the coordination of the care they receive.

While adolescents in foster care families are generally eligible for Medicaid, they nevertheless often receive inadequate preventive care, oral and mental health services, and treatment for substance abuse.[3] Moreover, as adolescents age out of foster care, they often find themselves with no health coverage at all, even though states do have the option of extending Medicaid coverage for them during the period of transition from care to self-sufficient adulthood. The federal Administration for Children and Families has estimated that more than 65,000 adolescents age 16 and older left foster care in 2005, only about 25,000 of whom were ready for complete emancipation (Administration for Children and Families, 2005).

Shawn Denise Semelsberger provided a firsthand account of how difficult it can be for young people to navigate the system of health care services. Now 21 years old and an advocate for adolescents in foster care, Semelsberger has been in foster care herself and has only recently been responsible for negotiating her health care and Medicaid coverage entirely on her own. Her account of a frustrating and confusing process of supplying documentation, filling out forms, resubmitting an application that had been lost by administrators, and interacting with an array of individuals who often gave her conflicting information about her eligibility demonstrated the challenges adolescents can face as they make the transition out of foster care. She pointed out that the obstacles to obtaining coverage and care to which they are entitled could overwhelm many adolescents. Many more face gaps in coverage because they earn slightly more than the cutoff for Medicaid eligibility but are not covered by employers and cannot afford the alternatives available through community colleges or other sources.

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[2] Abigail English presented slightly different figures: approximately 500,000 minors, of whom more than 250,000 are adolescents ages 11 to 18.

[3] Variations in Medicaid coverage and eligibility were mentioned frequently during both the community forum and the research workshop. States determine their own cutoffs for Medicaid eligibility in reference to the federally determined poverty level. That is, each state determines the percentage of the poverty level that will be eligible for Medicaid coverage and significant variation occurs among state eligibility criteria as a result. Medicaid provides coverage of defined treatments for defined conditions and applies other restrictions on coverage.

ADOLESCENTS IN THE JUVENILE JUSTICE SYSTEM

In 2003, 2.2 million adolescents under age 18 were arrested, and in that year 97,000 were held in juvenile residential facilities, according to figures supplied by Morton (Office of Juvenile Justice and Delinquency Prevention, 2006). English supplemented this description, noting that that minorities and low-income adolescents are overrepresented in this group. These adolescents have the same range of health needs as any other group—as well as a high rate of problems with mental health and substance abuse—but two factors limit their access to care. First, the care they receive through the juvenile justice system is often inadequate. Morton cited as one example a finding that the 5,000 adolescents who pass through the juvenile justice system in New York City annually are cared for by one full-time doctor and a staff of mostly part-time physician assistants and nurses (von Zeilbauer, 2005).

Second, states have the option to suspend adolescent's health coverage under Medicaid when they enter the juvenile justice system because they do not receive federal financial assistance for adolescents in these circumstances. Where Medicaid coverage has been terminated, it can be very difficult for young people to reactivate their coverage once they leave the juvenile justice system. Moreover, Morton explained, many juvenile justice systems do little to help adolescents reactivate their coverage or make other connections with the social services that can help them address their health and emotional problems once they leave the system.

RUNAWAY AND HOMELESS ADOLESCENTS

Perhaps the group of adolescents most disconnected from services and support consists of those who run away from home or are homeless for other reasons, as explained by both Morton and Alan Shapiro, a physician who works in a Community Pediatric Program run by the Children's Hospital at Montefiore in the Bronx borough of New York City. According to the Centers for Disease Control and Prevention (CDC), some 1.6 million adolescents run away or become homeless every year in the United States (Robertson and Toro, 1999), and 68 percent of this group are young people ages 15 to 17. Counting these adolescents is difficult, as English noted, in part because the definitions of both adolescent and homelessness are not precise, and also because these populations are often in transition. And the primary sources for counts of homeless adolescents are providers of services, so homeless adolescents who do not receive services are not included. Morton also noted that the absence of more recent counts of this population is indicative of the extent to which this group is overlooked.

Programs exist around the country to provide emergency shelter as well as social and medical services for these adolescents. However, they are not sufficient to locate and serve the numbers of adolescents who need them. These young people may lack health insurance and a stable home (and thus medical records and parental permission for treatment), and they often lack access to any health care at all, despite their particular vulnerability to health problems associated with life on the street, such as substance abuse and sexually transmitted diseases. The health of homeless adolescents with chronic medical conditions, such as diabetes or positive HIV status, is at particular risk because it is very difficult for them to take critical medications regularly.

As one report on homeless adolescents has shown, these adolescents often must choose from "a short list of survival strategies," such as gang membership, drug sales, or paid sex, which have serious health consequences (New York City Association of Homeless and Street-Involved Youth Organizations, 2005). Their health is often further compromised by inadequate sleep, poor nutrition, and exposure to the elements.

Shapiro illustrated these points with a snapshot of five patients—all homeless—whom he had recently treated: a young woman who was diabetic; a 19-year-old who is addicted to cocaine, has been diagnosed with bipolar disease, and engages in "survival sex"; an HIV-positive gay young man; an 18-year-old mother who brought her infant in for a checkup; and a young woman who had recently emigrated from Central America who had been abused and is battling alcoholism and depression. While shockingly sad, these cases are typical of those who seek care from the center at which Shapiro works—and, he suggested, countless others around the country.

Shapiro presented a diagram to illustrate his view of both the most common reasons why adolescents end up homeless or "throwaway" and the factors that place them at increased risk (see Figure 3-1). He distinguishes intrinsic problems—the most significant of which is the family—from extrinsic causes. Not only are these adolescents mostly from impoverished families, but they are also extremely likely to have been physically, sexually, or emotionally abused. Parental neglect or rejection—because of intolerance of homosexuality or teen pregnancy or just because of family dysfunction—is a frequent factor. The foster care and juvenile justice systems are extrinsic factors, in that young people who are in trouble often encounter even worse problems with the systems that are intended to help them.

Given the combinations of problems these adolescents face, they are frequently drawn to such programs as the one Shapiro described, viewing them as a kind of home. He noted that many young people tend to return regularly even when they have no medical needs because "we are their parents, we are their relatives." His broader point was that almost any health problem and clinical outcome one might examine looks worse for

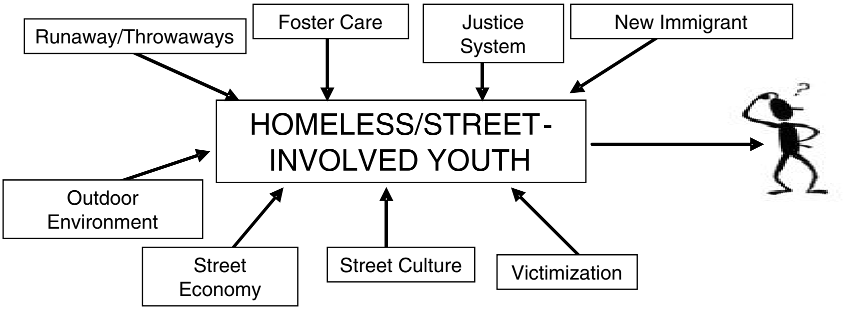

FIGURE 3-1 Factors contributing to and fostering homelessness and street involvement in youth.
SOURCE: From presentation by Alan Shapiro at A National Community Forum on Adolescent Health Care, Nov. 6, 2006.

homeless adolescents than for others. Preventing homelessness would be the best way to improve health outcomes for these adolescents, regardless of any other factor.

Short of eliminating homelessness, Shapiro had a number of specific recommendations for improving care to this population:

- Insurance eligibility should be expanded to cover 21- to 24-year-olds. Enrollment should be easier—the required procedures should reflect the realities of homeless life.
- Mental health and substance abuse services for adolescents should be significantly expanded.
- Interagency task forces should provide oversight and coordination—so that components of the system, such as justice system discharge programs, supported independent living, and aftercare safety nets, can work together to meet adolescents' needs.

LOW-INCOME ADOLESCENTS

Poverty, a factor that can exacerbate other problems that adolescents may face, is also a challenging circumstance on its own that often limits access to high-quality health care. Coleen DeFlorimonte, a pediatric nurse practitioner with the Woodson Adolescent Wellness Center in Washington, DC, described the needs she sees in a group whose primary shared characteristic is poverty. Run jointly by the District of Columbia Department of Health, the Maternal and Family Health Administration, and the DC public school system, the Woodson program provides comprehensive

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health care, dental care, pregnancy prevention, and health education to adolescents. Housed in a public high school, the program depends for its success on a close relationship with the school's administrators.

The population at Woodson Senior High School is disadvantaged: 65 percent are eligible for free or reduced price lunch. Tests scores are low, and the dropout rate is high. Nearly 500 students (out of 561 who are eligible) visited the clinic one or more times in the past year for health problems, and another 244 visits involved mental health problems. Among the most common services requested at the clinic are required vaccinations, sports physicals, treatment for sexually transmitted diseases, HIV counseling, contraceptive management, laboratory testing for such diseases as sickle cell anemia, and dental services. The clinic finds itself not only providing basic primary care services but also addressing problems, particularly violence, which are especially prevalent in large urban areas.

DeFlorimonte identified two principal challenges in the care available to these young people. First, the programs themselves often struggle financially. As Shapiro also noted, they bring in almost no revenue and are dependent on external funding from a combination of sources, although they face the same costs—for laboratory tests and medications, for example—that other kinds of medical facilities do. There are not enough such programs, and existing ones often have insufficient staff and resources for all the needs they see in the communities they serve. Second, the staff in many programs struggle to forge relationships with some of the adolescents most in need of their services. DeFlorimonte would like to see young people more involved in planning and running these programs so that they can more easily reach this challenged population. This may be particularly important because, in her experience, it is very difficult to engage the parents of adolescents in their children's medical care.

ADOLESCENTS WITH DISABILITIES

A group that faces many of the challenges related to health care already described, as well as some additional ones, is adolescents with disabilities, including learning disabilities, speech and language impairments, and a host of other physical and mental impairments. Paul Fogle offered some perspective on their needs. His involvement with the National Youth Leadership Network—a group that works to develop leadership skills in adolescents with disabilities—as well as his comments at the community forum were shaped by his own experiences growing up with a congenital neurological malformation that has required ongoing medical attention.

From Fogle's perspective, two critical concerns face adolescents with disabilities. First, these young people need support in learning to take responsibility for their own care and decisions about their care at early ages, to prepare them to take over this responsibility to the extent that they can when they reach adulthood. Making this happen entails both education, to help adolescents fully understand the nature of their disabilities and the challenges they are likely to face, and opportunities for guided decision making as they get older. Fogle observed that many doctors he has seen addressed themselves solely to his parents, as if he were not present.

Second, adolescents with disabilities often face very significant problems with continuity of health coverage, especially as they reach the ages of 18 or 21 and are no longer eligible for coverage under their parents' policies or other coverage available to minors. Many young people end up institutionalized, he observed, even though they could live independently with the right supports, because the coverage they have is not sufficiently flexible to encompass alternative arrangements. Finally, transportation can be a significant obstacle for those with disabilities, and families may not be in a position to provide all that is needed. For adolescents who want to be as independent as possible and are otherwise able to do so, this obstacle exacerbates difficulties they have in coordinating care from multiple providers.

ADOLESCENTS WITH MENTAL ILLNESS

Mental health and substance use disorders are prevalent among adolescents in the United States, as Kimberly Hoagwood (Columbia University) explained. Looking just at the prevalence rates of several of the most common mental disorders in school-age children and adolescents demonstrates how many young people are affected: depression/bipolar disorder, 7.8 percent; anxiety, 8.0 percent; disruptive disorders, 5.6 percent, attention deficit hyperactivity disorder, 5.0 percent; substance use disorders, 7.7 percent, and autism/pervasive developmental disorder, 0.5 percent (Office of the Surgeon General, 1999). A significant body of research has explored the efficacy of various treatments for these and other common mental disorders of adolescence. Meta-analyses of the effects of psychosocial treatments, hundreds of clinical trials on the safety and efficacy of psychotropic medications for adolescents, and other work offer some clear guidelines for the treatment of adolescents (selected examples of meta-analyses are Burns and Hoagwood, 2002; Burns, Hoagwood, and Mrazek, 1999; U.S. Public Health Service, 1999; Weisz, 2004).

Despite this research, adolescents with these conditions are not, by and large, receiving the care they need. Hoagwood described a system in which standards for effective care have been developed almost completely in isolation from models for delivering care. The result of this situation is that effective treatments for most disorders are not supported by the structures through which mental health care is delivered. For example, nonspecialty sectors, including schools, primary care, child welfare, and juvenile justice, are the default system for adolescents with mental health needs, but they are not set up to identify and meet these needs.

Adolescents tend to receive their health care in multiple and nonspecialist settings, with little coordination among providers, Hoagwood explained. Young people and their families must patch together services available to them from various sources. Factors such as distrust for professionals, concerns about losing custody, and the experience of blame for serious problems may discourage families from taking advantage of services that are available. Psychotherapeutic treatments (communication sessions between a patient and a trained therapist) that have been found to be effective at improving outcomes in research settings have proved far less effective when offered in routine clinical settings (Weisz et al., 1995). While information about evidence-based treatments is often disseminated rapidly among practitioners, the process is not systematic. Some states have focused on ensuring that adolescents receive the mental health care that has been demonstrated to be most effective—Hoagwood cited 12 states that have worked to implement this goal.[4] In others, the care may be haphazard. Given that situation, she observed that recent efforts in schools, primary care settings, home-based services, and family-based services may offer the most promise for implementing research-based practice with adolescents. Studying models and adopting strategies for delivering specific therapies in particular settings to certain populations of adolescents may help make treatments more effective in a clinical setting. Such policies as incentives that promote the monitoring of outcomes for patients and wider dissemination of new treatments (some of which involves proprietary material) could also be effective in the implementation of evidence-based practices in clinical settings.

ADOLESCENTS WITH SUBSTANCE USE DISORDERS

Adolescents with substance use disorders face multiple challenges in getting the care they need. Most insurance plans lack coverage for substance use disorders. Even in the minority of cases in which mental health coverage is otherwise adequate, substance use disorders are often not covered. Moreover, as Constance Weisner (University of California, San Francisco) explained, adolescents tend not to seek treatment of these disorders until they become severe and more difficult to treat than if the patient had been evaluated at an earlier stage.

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[4] She listed California, Colorado, Connecticut, Maryland, Massachusetts, Michigan, New Hampshire, New York, Ohio, Oklahoma, Oregon, and Washington.

Substance use disorders have a big impact on long-term health for adolescents. Young people in alcohol and drug treatment have significantly higher prevalence of a variety of medical conditions, including asthma, injuries, sleep disorders, pain conditions (e.g., headaches, arthritis, back and neck pain), and sexually transmitted diseases. They also have higher rates of other mental health problems, such as depression, anxiety disorder, eating disorders, and conduct disorders. They are more likely than other adolescents to engage in high-risk behaviors, such as injecting drugs and sharing needles, and unprotected and other risky sexual behavior.

Many factors may prevent adolescents with substance use problems from being identified, diagnosed, or treated. Fear of stigma and embarrassment may prevent them and their parents from seeking care, and they may not be certain where they should go for care. Diagnosis can also be subjective. Practitioners, however, miss opportunities to screen and identify adolescents with these problems, Weisner pointed out. One study of adolescents who ultimately were treated for chemical dependence found that 90 percent of them had a primary care visit in the 24 months prior to entering treatment without recognition of the disorder, and over half of the young people had a visit within the previous 3 months. Half had a visit with a psychiatrist within the 24-month period, and a third had one within 3 months prior to beginning their treatment. Smaller but still significant numbers made emergency room visits—all of these were missed opportunities to address a significant health problem (Sterling et al., 2004).

Although screening for risky behaviors in primary care settings is recommended by the American Medical Association, the American Academy of Pediatrics, and the Institute of Medicine (see for example, the description of one such tool in Box 3-1, the CRAFFT screening test for adolescent substance abuse), Weisner reported that relatively few providers do so. Among the reasons they give for not screening their patients are time constraints, concerns about confidentiality, lack of awareness of resources for patients, and lack of awareness of effective treatments (see Box 3-1).

Once problems are identified, a range of treatments is available, which have been the subject of a significant body of research. While many research questions remain—about the comparative effectiveness of different programs, for example—Weisner made clear that practitioners have many evidence-based options (selected research: Dasinger, Shane, and Martinovich, 2004; Deas and Thomas, 2001; Liddle and Dakof, 1995; Liddle et al., 2004; Waldron and Kaminer, 2004; Winters, 1999). Key elements of effective treatment that have emerged from this research include assessment and monitoring; a comprehensive, integrated approach; family involvement; developmental appropriateness; and continuing care.

BOX 3-1
CRAFFT: A Brief Screening Test for Adolescent Substance Abuse

C Have you ever ridden in a CAR driven by someone (including yourself) who was "high" or had been using alcohol or drugs?
R Do you ever use alcohol or drugs to RELAX, feel better about yourself, or fit in?
A Do you ever use alcohol or drugs while you are by yourself, ALONE?
F Do your family or FRIENDS ever tell you that you should cut down on your drinking or drug use?
F Do you ever FORGET things you did while using alcohol or drugs?
T Have you gotten into TROUBLE while you were using alcohol or drugs?

SOURCE: Knight et al. (2002).

This last point is especially important, in Weisner's view, because while many programs are effective in the short term, these disorders are likely to recur and patients need long-term monitoring and follow-up for chronic conditions.

Weisner suggested modeling a system that effectively addresses substance use problems as one in which clinicians:

- make use of effective links among primary care, specialty care, and community agencies to offer all available resources to patients;
- use illness self-management practices;
- screen for all comorbid conditions;
- routinely ask patients and families for permission to share clinical information with other providers; and
- make use of evidence-based care and coordination.

She further recommended that health plans cover screening and care for these disorders and support the coordination of information and care, perhaps using electronic record-keeping.

LESBIAN, GAY, BISEXUAL, TRANSGENDER, OR QUESTIONING ADOLESCENTS

One group that is often overlooked in the design of health care services is the estimated three to eight percent of the adolescent population who are lesbian, gay, bisexual, transgender, or questioning their sexual orientation, or LGBTQ, as Robert Garofalo (Children's Memorial Hospital) explained. While these adolescents are found in all communities and types of medical practices, they are not a homogeneous group and only limited research is available on their health status and health care needs. What is available is a significant body of data on risk behaviors, especially among urban young men, related to HIV infection and AIDS. However, because few groups of clinicians have a special interest in adolescents, and perhaps also because of stigma sometimes associated with these issues, very few data have been collected about young women or about transgender, bisexual, and questioning adolescents.[5]

LGBTQ adolescents have a disproportionate risk of health problems related to risk behaviors, including suicide attempts, drug use, and high-risk sexual behaviors, as well as a high rate of nonmedical problems, such as school truancy and dropout that can contribute to high-risk choices (Garofalo, et al., 1998). They also are more likely to engage in multiple risk behaviors than are other adolescents. Their care is complicated both by a lack of training for practitioners and by the discomfort they may have with revealing their sexual identity, particularly in the presence of their parents. Garofalo advocated an approach to their care that focuses less on their risk factors or their feelings about disclosing their sexual identity and more on the strengths they are likely to have, such as pride, self-determination, and resilience.

He described the Broadway Youth Center in Chicago, a program opened in 2004 by the Howard Brown Health Center, which serves LGBTQ adults, to focus on the needs of LGBTQ and homeless adolescents. The center serves between 4,000 and 5,000 adolescents per year and offers comprehensive services, including housing assistance; case management; medical care and counseling; food, showers, and laundry; general education development and job training; and mentorship. The program has successfully engaged many adolescents, and Garofalo expressed the hope that the stigma experienced by these young people will decrease and that training for practitioners around these issues will improve so that these adolescents can get the care they need in any health care setting. Significant work remains to be done—Garofalo cited a 1998 study of pediatricians in the Washington, DC, area, showing that these practitioners had many misconceptions about LGBTQ adolescents and had reservations about raising the issue (East and El Rayess, 1998). A total of 68 percent

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[5] One group of note in this context is the Gay and Lesbian Medical Association, a group of health care providers who are gay or lesbian that serves as a focus of expertise for the provision of health care to LGBTQ patients. Another is the Society for Adolescent Medicine's special interest group for members interested in the care of LGBTQ youth.

reported that they did not raise questions about sexual orientation in taking medical histories. A big step forward, Garofalo added, would be the inclusion of questions about sexual identity in large-scale surveys, as well as other research on adolescents in this group.

ADOLESCENTS WHO LIVE IN U.S.-MEXICO BORDER COMMUNITIES

Salvador Balcorta, a social worker and chief executive of the Centro de Salud Familiar La Fe, Inc., in El Paso, Texas, described the health care issues facing a group of adolescents in border communities, whose needs are not very familiar to many Americans. This group is much larger than many people may realize. The 6.7 million residents of border county areas make up 2.2 percent of the nation's population. Of these residents, 1.8 million, or 27 percent, are under 18, which means that if the border region is compared with U.S. states, it ranks among those with the highest percentages of total population who are children and adolescents (Annie E. Casey Foundation, 2005).[6]

Balcorta spoke passionately as he sketched a portrait of life for the adolescents who live on the border, a group that includes not only Mexican Americans and immigrants from other Central American countries, but also legal and illegal residents. These adolescents are even less likely to complete high school than Hispanic students nationwide, for example, although Hispanics are already less likely to graduate than any other group (Annie E. Casey Foundation, 2005). Extreme poverty in the region, as well as an active drug trade, mean high rates of substance use for adolescents in border areas, and the influence of gangs is difficult for them to avoid.

These adolescents have a high rate of incarceration or residential placement, and 60 percent of those incarcerated come from low-income families. In addition, among those incarcerated at the Texas Youth Commission, 34 percent say they are members of a gang, 46 percent have a high need for drug treatment, 41 percent have severe mental health problems, and 36 percent have been abused or neglected (Texas Youth Commission, 2007).

There is also a high rate of adolescent pregnancy among the general border population. Texas has the highest rate of any state (15 versus 12 percent nationally), and the rate among border residents is even higher, 17 percent (Annie E. Casey Foundation, 2005). Border adolescents also tend to face this problem at very young ages—Balcorta has recently worked

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[6] The populations of several states are 27 or 28 percent children or adolescents. Only Utah, at 30 percent, surpasses the border region.

with six girls who became pregnant the year they turned 12. There is also a high rate of suicide and other mental health problems, of obesity, and of HIV/AIDS among adolescents.

Despite these problems, border residents have inadequate health coverage. Balcorta explained that Texas, the home of the majority of border residents, has the highest rate of uninsured residents of any U.S. state (25.2 percent compared with 15.4 percent nationally), and that rate is even higher in the border counties (varying from 29 to 35 percent) (Angel et al., 2007). Texas also ranks very low among the states in the percentage of its low-income residents who are covered by Medicaid, and recent policy changes for the State Children's Health Insurance Program (SCHIP) have made those benefits more difficult to obtain, resulting in a significant decrease in enrollment among border residents, particularly those with the lowest incomes (Angel, Bennett, and El Paso Diabetes Association, 2007; Center for Public Policy Priorities, 2006).

In addition, the border region ranks low among the states in numbers of health professionals per capita and in other health care resources. Adolescents living in this region face an inadequate supply of pediatricians, health care and social assistance facilities, hospital beds, emergency rooms, diagnostic labs, and other resources that are taken for granted in other settings. Indeed, Balcorta observed, the residents of the areas along the U.S.-Mexico border live in third world conditions. The deficits in health care for these adolescents begin with basic services that even very vulnerable groups in other parts of the country may take for granted.

OBSERVATIONS

Morton believes that many programs that serve disadvantaged adolescents fail to capitalize on the strengths that even highly stressed young people have. He argued that programs that serve vulnerable adolescents would do well to adopt the positive youth development approach, in which the focus is not the problems often associated with adolescence, but an intentional and strategic focus on the resilience and positive potential that most young people have. This approach is discussed more extensively in the National Research Council and Institute of Medicine (2002) report *Community Programs to Promote Youth Development*. Frequently, decisions are made for them and little attempt is made to engage them or encourage them to take responsibility for their own health and well-being.

A related point that Morton made is that health care and other supports look very fragmented from the adolescent's vantage point. A problem in one area of life—mental, dental, or physical health, housing, or family relationships, for example—can impair any or all other aspects of daily living. However, the programs that offer support typically address one area only and seldom can encompass the needs of an entire family. Services that are both coordinated and comprehensive could be far more effective in the long run. Moreover, Morton argued, if supports were better coordinated, adolescents could more easily navigate the system for themselves and feel empowered to take charge of their own health and health care.

Other participants echoed these points. Most shared the concern that programs do too little to encourage and support adolescents in taking charge of their own health care, regardless of the populations they serve. Most also made note of the critical importance of coordination among available services.

Morton also identified some concrete needs for mental health services, substance abuse treatment, and oral health care, some of which often are not covered by government-funded health plans. Moreover, adolescents who have little support and guidance from responsible adults tend to lack awareness of the need for and availability of these kinds of services. He summarized the principal holes in health care as follows:

- Lack of health coverage—many adolescents live in uninsured families. Even young people who are eligible for Medicaid and SCHIP programs may have difficulty because they are transient, cannot follow up with appointments, or cannot obtain and manage complicated forms. They may be unaware of resources available to them and have inadequate documentation, or other paperwork. Young adults ages 18 to approximately 24 may be the most likely to lack coverage and services because they fall between the options available for children and those for adults.
- Lack of services in rural areas—many vulnerable adolescents live in rural areas, and fewer programs are available to serve them in less populated areas.
- Poor coordination—adolescents may need support from a variety of sources and are generally ill equipped to inform themselves about resources that are available in their communities. Moreover, coordination of care among providers requires navigation skills that adolescent patients may not have. While the recently passed Tom Osborne Federal Youth Coordination Act (P.L. 109-365, 2006) has drawn attention to the significant problems with coordination of services, particularly for young people in the juvenile justice system, the issue is far from resolved.
- Lack of cultural sensitivity—a variety of factors may make adolescents at risk uncomfortable and even push them away from services they need. Programs that usually serve families and younger pediatric patients may alienate adolescents from

less stable situations, while those that serve adults and adolescents may seem unsafe or uncomfortable. The needs of lesbian, gay, and transgender adolescents are not always recognized or addressed.

- Lack of parental consent—many states require the consent of a parent or guardian before health care services can be provided, but unaccompanied adolescents may not have anyone to provide that consent.
- Lack of stability—adolescents who lack a stable home, especially those in foster care, may have difficulty taking medication consistently, receiving follow-up or reminder calls or letters from providers, or making and keeping appointments for preventive or follow-up care.
- Lack of specialty care—while primary care can be available even to those who lack health insurance, access to specialized services—including mental health and substance abuse treatment, dental care, and other important kinds of care—is even more difficult. For example, while approximately 60 percent of children in out-of-home care have moderate to severe mental health problems, only one-third of them are receiving the care they need (Child Welfare League of America, 2006).

Discussion of these presentations provided some elaboration on several key points. With regard to challenges in mental health care, participants noted that adolescents who lack family supports may be less equipped to recognize a problem, to see it as a priority, or to understand the possibilities that exist for treatment and support. Participants identified the transition from adolescent care to adult care as a great stress for adolescents ages 19 to 21, especially for those who lose coverage under Medicaid. Continuous care for all kinds of services would be affected, for example, mental and dental services. Moreover, the stigma that is often associated with mental health problems can discourage adolescents from acknowledging and addressing a problem. With regard to dental health, participants noted a lack of utilization and lack of adolescent-friendly consistent services. By the same token, young people with disabilities may have difficulty accepting that they have a disability and embracing help that is available.

The young people who spoke all agreed that finding ways to reach and educate vulnerable adolescents, one by one, could make existing services far more effective. Relationships with caring adults who reach out to an individual adolescent may be the most promising way to provide that kind of guidance. Participants reflected on ways to build adolescent-centered interactions into the system, perhaps using training to help those who work with vulnerable young people recognize, seek, and take advantage of unexpected opportunities to reach, educate, and support them. Adults who have the best opportunity to reach adolescents could have significant impact if they are aware of both the circumstances that are likely to affect adolescent health and available resources that may be outside their area of specialty. As DeFlorimonte noted, every positive interaction with an adolescent is a success story that paves the way for him or her to feel comfortable seeking help when the need arises.

Moreover, if care provided in different contexts could be better coordinated, so that providers had more insight into the histories of their patients or clients, they would be in a better position to recognize and address the full extent of their patients' pressing needs. However, participants noted that hierarchies within and among the professions can work against coordination among programs and even against collaboration among colleagues. Both nurses and social workers, for example, may have relevant educational credentials and experience, yet informal protocol may inhibit a nurse or social worker from making recommendations to a physician or documenting key points. Because no single discipline has made health care for adolescents a central focus, and because coordinating and collaborating strategies are seldom incorporated into training or institutionalized in other ways, programs tend to struggle on their own with the resulting vacuum.

Shapiro pointed out that his mobile unit is well equipped to address this issue because the staff can deliver care precisely at the sites where adolescents are getting other services, such as food, shelter, or needle exchange. His ideal program would be a mobile team that includes social service, mental health, and medical personnel, all working together every day. Yet the needs are so broad that a mobile team that could truly address them all would be cumbersome. Legal and educational counseling, as well as nutrition counseling for obesity, are part of the picture as well, so interagency cooperation is critical.

At the same time, Balcorta and others stressed that funding is tight for attempting comprehensive service such as this, and that programs and communities cannot afford to be completely dependent on federal funding—they have to find ways to magnify the benefits of federal resources with local support.

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Making the System Work

Despite the many challenges of providing quality health care to vulnerable adolescents, many organizations have found ways to address their needs in diverse settings. The committee invited a variety of providers to share their perspectives on gaps in care and strategies for bridging them as a way of illuminating these issues and pointing to areas in which more evidence would be valuable.

PROVIDING CARE TO ADOLESCENT GIRLS AND YOUNG WOMEN[1]

Offering the perspective of a nongovernmental entity, Kristin Adams of Girls, Inc., spoke about the ways in which this national group serves a population of largely low-income, minority females. Girls, Inc., is an umbrella for more than 100 member organizations, each of which is its own nonprofit entity, serving communities throughout the United States and Canada. The group's mission is to inspire and empower all adolescent girls to "understand, value, and assert their rights." The organization reports that it served 800,000 girls in 2004 through its programs, website, and publications (available: http://www.girlsinc.org/ic/page.php?id=7, accessed July 22, 2007).

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[1] Male adolescents also have a distinct set of health care needs that are equally deserving of attention. Girls, Inc., was viewed by the committee as an important group to include in the workshop because of its approach to meeting the needs of vulnerable adolescents.

Adams enumerated some of the key health issues that affect the girls they serve: pregnancy prevention, sexually transmitted diseases, and reproductive health care; abuse, neglect, and violence; and substance use and abuse. Issues related to body image—anorexia and bulimia—and stress, affecting girls as young as eight or nine, are also of particular concern for clinicians who work with adolescent girls and young women.

Looking at the system for providing care through the lens of adolescent girls and young women's needs, familiar issues arise. Lack of insurance or inability to afford available insurance or care; language barriers; transportation; and parental support all affect the young people served by Girls, Inc. Confidentiality can also be a particular concern for adolescent girls and young women when they need reproductive health care. For all these reasons, health education is a prime concern for the organization, although it does not provide health services. Adams noted that neither health education nor physical education is included in the requirements of the No Child Left Behind legislation, and as a result both are being significantly cut back in many jurisdictions. Girls, Inc., has begun advocating for the inclusion of these programs when the legislation is reauthorized and also focuses on programs that provide these opportunities outside school.

The role of parents is a key issue. Adams noted that often parents of vulnerable adolescents lack information about health and health care. Those who are not experienced at advocating for themselves or their children have not been able to teach their children to advocate for themselves. To address this problem, Girls, Inc., has developed the concept of the health bridge for adolescent girls and young women—a means of both linking them to the health services they need and teaching them to advocate for themselves. On a very practical level, Girls, Inc., staff work with adolescents as they practice looking through the telephone book to find a practitioner, calling for an appointment, and visiting a clinic before becoming a patient to assess the environment and establish a comfort level.

At the same time, Girls, Inc., works at the community level to educate providers about the perspectives adolescents bring and to identify ways they can do more to reach adolescents and provide them with what they need. Girls, Inc., has organized adolescent forums to spread their messages among adolescent girls and young women, parents, and community leaders, as well as parent-daughter workshops to provide education about health issues, health fairs, and other activities designed to reach as many people as possible.

PROVIDING CARE TO RURAL ADOLESCENTS

Several distinct challenges face providers who work with adolescents in rural areas, as Kathaleen Perkins, a physician from West Virginia University, explained. While rural adolescents experience many of the same problems as young people in other settings—such as poverty; high rates of teen pregnancy, substance abuse, and violence; and mental health problems—their situation poses some unique challenges, as well as some twists on the problems already described. These challenges also complicate the efforts of the caregivers who work with rural adolescents.

For example, with regard to teen pregnancy, Perkins noted that in the Appalachian region, as elsewhere, rates are declining, but that pregnancy rates are increasing among the youngest adolescents. With regard to drug use, she noted that crystal methamphetamine has become a very significant problem, in many cases affecting entire families. This situation is exacerbated by an increasing problem with criminals who travel from urban areas to West Virginia, where legal restrictions are minimal, and purchase guns with drugs.

West Virginia is also one of three states with the highest rates of obesity; two-thirds of its population has a body mass index over 30, and 50 percent of fifth graders are overweight, according to a recent study (Neal et al., 2001). It is not uncommon for Perkins to see adolescents weighing between 300 and 600 pounds in her own practice. The state, as well as all 55 counties, has tackled this problem with a variety of interventions at both the school and family levels, from employee and school fitness programs to meal planning programs to individual counseling.

Another tough challenge is that of access—long distances and dispersed populations are a practical obstacle to improving access to crucial services for every adolescent. Rural health centers, funded jointly by the state and the federal government, provide a significant portion of care for West Virginia adolescents. Collectively and working in partnership with communities, they see 13,000 medical patients of all ages each month and an additional 4,720 dental patients. School-based health services are another important resource for adolescents, although not all schools offer them.

Finding and retaining adequate staff to serve this large geographical area has been a big problem for the state. Educating, recruiting, training, and retaining caregivers to serve the rural areas of the state have become priorities for policy makers. Perkins identified key strategies to address the problem, including the use of rural rotations for medical students as well as clinicians, integration of curriculum in training programs, and close relationships between universities and care providers. Technology has also provided some valuable tools for bridging these gaps in care—telemedicine (Mountaineer Doctor Telemedicine) has allowed providers to gain access to university lectures on neurology and adolescent medicine, for example, while video conferencing facilitates consultations with specialists (currently this technology is used for psychiatry).

PROVIDING CARE TO URBAN ADOLESCENTS

The director of the adolescent health center and counseling services at The Door, a multiservice youth development agency in New York City, Rhonda Braxton, turned the focus to the challenges of providing adolescent care in an urban setting. The Door provides comprehensive care, including health care, dental, counseling, education, and legal and career development services, free of charge, to adolescents between ages 12 and 21. It also has a laboratory and medical dispensary on site so it can provide medications and birth control and provide test results mostly free of charge.

The needs of the more than 4,000 clients seen at The Door in a year are great. Predominantly female and black or Hispanic, they seek the services that vulnerable adolescents need in many settings—such as primary and reproductive health care, HIV counseling and testing, dental services, and mental health services. These adolescents have low income and often have trouble affording and navigating the health care system. Like many adolescents, they may have issues related to parental consent (required in New York state for general physical and dental care but not for reproductive care), may be misinformed about health issues, and may be anxious or embarrassed when they seek treatment.

From the perspective of providers at The Door, the major challenges are maintaining full funding, ensuring continuity of care, obtaining required parental consent, and gaining patient compliance with recommended treatments and follow-up care. Because adolescents' priorities are different from those of the adults who work with them, patience and effort are required to get them to take crucial steps for their own well-being.

The key to success at The Door, Braxton explained, is its internal capacity to coordinate services. A practitioner can literally walk a patient down the hall for mental health counseling, for example, or introduce him or her to a counselor who can help the patient apply for Medicaid family planning benefits. Moreover, The Door has developed relationships with community partners so that if it is unable to meet an HIV-positive patient's complex medical needs, for example, it can oversee the transfer of care for that patient to another facility. The Door also has a school- and community-based outreach program through which it provides health education to some 10,000 students every year, as well as more than 500 parents.

Several practical strategies have been important to success. Open access appointment scheduling, which allows adolescents to be seen within 48 hours of making a request, has reduced their no-show rate from 50 to 20 percent. Peer education programs include young people who work with adolescents who come into the center, as well as young adults who offer education in schools and community organizations. Finally, the staff has made cultural sensitivity a priority, so that adolescents will feel welcome there regardless of sexual orientation or other issues, and they have also worked to protect the adolescent's privacy. A fish symbol is displayed prominently at the center so that cards bearing just the symbol can be sent to young people at home as a discreet signal to get in touch with the center.

PROVIDING CARE THROUGH SCHOOL-BASED HEALTH CENTERS

Reaching adolescents through schools is a logical way to circumvent some of the obstacles that impede their care. In 2005 in the United States there were 1,725 school-based health centers—partnerships among schools and community health organizations that provide medical and some mental and dental health services to school-age children and adolescents in the schools—according to Linda Juszczak (National Assembly on School-Based Health Care). Those centers, 80 percent of which serve adolescents, provided approximately 1.7 million students with physical examinations, immunizations, lab testing, medications, dental care, and health education, among other services.

And 71 percent of the centers also provided mental health services. They may target issues that are common for adolescents by providing counseling for pregnancy prevention, testing for pregnancy and sexually transmitted diseases, substance abuse counseling, and nutrition and weight loss counseling.

Juszczak drew on several sources of current data, as well as her own experience, to describe some of the benefits and challenges to delivering care through the schools.[2] The school location makes it much easier to reach some of the adolescents who are least accessible to providers, such

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[2] Juszczak mentioned the 2004 to 2005 National Assembly on School-Based Health Care Census, which provides information on the demographic characteristics of students using the centers, staffing and services, and quality indicators and evaluation efforts, a 2006 survey of state agencies, which provides information on funding, data collection efforts; and Medicaid and State Children's Health Insurance Program policies; and professional literature from original research and articles in peer reviewed journals and evaluation reports to states, foundations, and others. It also includes policy statements and endorsements from professional organizations such as the Society for Adolescent Medicine, the American Medical Association, and the National Association for Pediatric Nurse Practitioners.

as young men, the uninsured, and those who are reluctant or embarrassed to seek care. In particular, adolescents are more likely to seek mental health care in a school-based center than elsewhere. Both parents and students have reported strong support for these centers. Moreover, when center-based care is available, adolescents make less use of urgent and emergency care, which can reduce costs to Medicaid (Adams and Johnson, 2000; Kaplan et al., 1998, 1999; Key, Washington, and Hulsey, 2002; Webber et al., 2003). At the same time, the incidence of risk behaviors among students served by a school-based center decreases, and health-promoting behaviors increase. This is best documented when school-based health centers put interventions in place with the goal of changing specific behaviors. Risk behaviors related to adolescent sexual activity, pregnancy, and contraceptive use have received the most attention and centers have demonstrated that they can, for example, increase contraceptive use and compliance among adolescents with appropriate interventions. Other selected examples of school-based health centers successfully targeting risk behaviors among adolescents include substance use, including tobacco use, school attendance truancy, and discipline problems.

A number of challenges remain, however. Perhaps most serious are the limitations to access. First, most centers are available only to students enrolled in the school in which they are located, so students who have dropped out or are homeless or otherwise transient (and thus among the most vulnerable) may not be able to receive care. A high proportion of students simply move to another school every year, which also may interrupt their ongoing care and relationships with caregivers. Second, varying state and local laws may restrict adolescent's access to reproductive health care, while parental consent requirements pose additional limitations in many jurisdictions. Funds are chronically limited, and mental services in particular are not sufficient to meet demand.

Insurance issues also pose problems. School-based centers may identify problems that require follow-up care but are not in a position to ensure that uninsured adolescents who require care are referred to another provider. Although the available data indicate that care provided through school-based centers complements, rather than duplicates, services available elsewhere, adolescents who do have insurance may still need to see a primary care physician in their health plan to obtain necessary referrals.

School-based centers have been operating for more than 25 years, and the funding available for them has grown, particularly over the past decade. Although more diverse sources of funding have been identified, Juszczak noted that funds from the settlement of tobacco lawsuits, which have been a significant revenue source in a number of states, will begin to decline soon. At the same time, maternal and child health block grant monies have been diminished in recent years, and these combined losses could have a profound impact on small, school-based centers.

Moreover, she noted, a significant portion of the care provided in school-based settings that is eligible for Medicaid coverage is uncompensated since the care is not provided by the recognized primary care physician, providers in school-based health centers cannot be the primary care physician and the state does not have policies in place which allow school-based health centers to be reimbursed outside of this relationship. Finally, an important component of the service that school-based centers provide (as do other kinds of programs that serve adolescents) goes beyond the kind of medical care that could be covered by insurance, even if more of their clients were covered. Counseling and health education are important and save money by preventing a variety of problems, but they are not generally reimbursable costs. Juszczak closed with the observation that these circumstances all clearly point to a need for new funding sources to keep these centers in place and expand their reach.

PROVIDING CARE THROUGH A MANAGED CARE ORGANIZATION

Managed care providers do not often care for the most vulnerable adolescents, yet they still face some of the same issues, as Charles Wibbelsman, a physician with Kaiser Permanente in San Francisco, explained. Perhaps the greatest challenge is that of confidentiality. Adolescents seeking contraception or care for other issues that they do not want to share with their parents may not want to risk having their parents receive a bill or other notification of services rendered through a family plan. In Wibbelsman's experience, young people will often forgo the care available through a family's health plan and go to Planned Parenthood or another kind of center to avoid this risk.

Wibbelsman pointed out that many varieties of managed care are available and Kaiser's approach has sought to maximize preventive medicine in serving adolescents. Kaiser is a group model health maintenance organization (HMO)[3] in which care is prepaid (by the employer or subscriber), so itemized bills are not required, although copayments may be required at the time of service. Kaiser is thus able to offer comprehensive care for adolescents, including contraception and care for sexually transmitted diseases, on a confidential basis. As the organization has grown, they have opened a growing number of adolescent centers throughout Northern California. A primary goal of the centers is to offer comprehensive evaluations, including risk assessment, to all their patients—rather than treating only the condition that instigated the visit.

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[3] A group model health maintenance organization contracts with a single multispecialty physician group to provide all physician services to the HMO members. It is the group that employs the physicians.

Moreover, the organization has been very flexible in responding to the recommendations of practitioners regarding ways to better serve their adolescent patients. For example, they found that by offering emergency contraception on site at the clinic, rather than writing a prescription that would need to be filled at a pharmacy or referring the patient to another site, they could better serve adolescents and also save money.

Kaiser is a unique HMO, in part because it has focused so much attention on creative ways to deliver health education. Their strategies include an educational theatre program that works with school-based centers, as well as a variety of guides for adolescents and parents to help them understand both health issues and alternative care options. Few other HMOs have made comparable efforts to serve the needs of adolescents.

PROVIDING CARE THROUGH PUBLIC PROGRAMS

One element of the system was mentioned perhaps more than any other throughout the day: government programs and funding that support care for adolescents. Dianne Ewashko (New York State Office of Children and Family Services) offered the state perspective, while Josh Sharfstein, a physician and commissioner of health (Baltimore City Health Department) offered a local government perspective.

Ewashko began with the point that the needs of adolescents are more complex than those of any other age group. The percentage of this group with mental health issues is three to four times higher than that of other age groups, and the same holds true for substance abuse issues. Other risky behaviors are also prevalent with this group, and adolescents also display a variety of developmental needs. Moreover, many adolescents present themselves with multiple needs at once, coming to centers with urgent needs for major dental work, asthma, and a sexually transmitted disease, for example. Approximately 70 percent of the young women who enter the juvenile justice system, Ewashko explained, test positive for a sexually transmitted disease, while 76 percent of the male and female population entering that system have a history of substance abuse. Moreover, when addressing the problems of vulnerable adolescents, providers need to include children as young as 9 or 10 years old, who routinely enter the system because they are already using and selling controlled substances, for example.

New York state has additional challenges because so many vulnerable adolescents go to New York City. The state has made it a priority to offer care to every child, and, as Ewashko mentioned, they have worked on fostering collaboration and coordination among different elements of the system to better serve so-called cross-system children, who need more than one kind of service or support. Training and technical assistance for staff at each agency with responsibility for adolescents has helped them better understand what services are covered by Medicaid.

Because of low reimbursement rates, many practitioners do not accept Medicaid patients; dentists and psychiatrists are two kinds of specialists the adolescent population badly needs that are in short supply in the state. However, New York City's Medicaid managed care approach establishes a consistent primary care doctor for each enrollee and provides Medicaid recipients with a list of participating specialist providers and facilities. From Ewashko's perspective, perhaps the biggest challenge is to find ways to serve not just the child but the entire family. Because the most vulnerable adolescents have such complex needs, it is critical that providers address not just health issues, such as substance abuse or the consequences of risky sexual behavior, but underlying causes as well. There may be a need for legal services for the foster or biological family, a need for other kinds of support so that the caregiver can succeed in his or her role, or a need to set up a system to make sure the child takes prescribed medication regularly. Like most of the presenters, Ewashko stressed the critical importance of coordination throughout the system.

Sharfstein echoed that point, noting that coordination across agencies and levels of government is very difficult. Although much of the conversation about caring for adolescents refers to a "system," the term does not adequately describe what actually exists. A child seeking care has little understanding of the boundaries between organizations, regulations, and policies that affect what is available where, or even, perhaps, of the relationships among his or her assortment of problems. Individual agencies tend to focus on the adolescents they see and on planning their own budgets and priorities and are not generally in a position to consider the system as a whole or to take action on their own to improve quality and efficiency. Policy makers at the local, state, or federal level may want to focus on ensuring care for the whole population of adolescents, but they typically are assigned responsibility for one element, such as medical care or foster care.

From Sharfstein's perspective, the world's greatest health care program cannot effectively address the complex needs of a child who is dealing with a dysfunctional family, school, and neighborhood.

The problems that Sharfstein sees in Baltimore are the same ones that other speakers enumerated: depression, sexual risk taking, teen pregnancy, substance abuse, dropping out of school, violence, and the like. The city has a variety of health centers and centers for adolescents and for the community at large, academic health centers, and school-based centers. They have after-school initiatives, some run by the Health Department, which include services that target adolescents at particular risk for mental illness, school failure and delinquency, and those in out-of-home foster care placement. One effective strategy has been to develop teams that can visit adolescents who are at risk and individually link them to an agency or program that can help with the immediate problem. After a year of operation, the program has seen a one-third decline in arrests and rearrests among young people who were enrolled.

The principal challenge Sharfstein cited, apart from lack of insurance coverage, was lack of capacity. Baltimore has not been able to put in place interventions there is reason to believe can be very successful, such as screening for sexually transmitted diseases among middle school students, or to cover all the adolescents who could be helped by others, such as the Operation Safe Kids violence prevention program. Sharfstein reiterated the lack of reimbursement for mental health services as a critical deficit. For example, he described multisystemic therapy, an intervention recommended by the Surgeon General, in which a team addresses the mental health problems of serious juvenile offenders comprehensively by providing therapy to build the skills of the parents as well as the child, intervening at the school if necessary, and so on. While this intervention has demonstrated significant benefits and has become a reimbursable expense in other states, Baltimore is able to offer this intervention to a tiny fraction of the roughly 2,000 adolescents he believes would qualify for it. Sharfstein believes that without this kind of therapy, adolescents who might benefit from it end up costing the city and the state far more when they require detention, out-of-home foster care, and other programs.

Sharfstein had three ideas for improving adolescent care. First, the federal government should develop clear incentives for states to follow best practices as soon as evidence becomes clear. Second, the state governments should both hold agencies accountable for outcomes and provide leadership from the top to facilitate interagency collaboration. Third, local governments should take the lead in identifying innovative ways to link community resources.

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Issues to Address

Flaws in the U.S. health system are particularly apparent when the needs of adolescents are considered. This group's needs are distinct, extremely complex, and include—for many—insufficient health coverage, lack of financial resources, lack of understanding of the systems through which health care is available, lack of confidential services, and inadequate transportation. There are relatively few specialists who focus on adolescents' needs, compared with those of other age groups. In addition, most health care providers who encounter adolescents lack the knowledge and skills needed to address their developmental needs and the distinct issues that influence their health, safety, and well-being. Just as adolescents can find it awkward to be neither children nor adults, the health care system does not easily adapt itself to their changing needs as they mature.

Workshop discussions identified a set of issues that can affect any adolescent: a need for confidentiality and privacy despite continued dependence on parents or guardians; mental health issues that are unlikely to be recognized without screening; the convergence of health issues and other life problems and the stresses of adolescent development; and exposure to substance abuse or other health risk behaviors to which adolescents are particularly prone. Insurance plans generally provide only limited coverage for dental and mental health or substance use disorders, and older adolescents and young adults may have serious difficulty obtaining or maintaining coverage even if they are not in difficult life circumstances.

On top of these issues, many adolescents in the United States face far more serious challenges. Specific kinds of vulnerability bring somewhat different health challenges that frequently overlap. In general, vulnerable adolescents are at risk from substance abuse, risky sexual behavior, family dysfunction and abuse, and violence. Many programs exist to help and support them, and considerable ingenuity has gone into planning and adapting these programs. Government at all levels plays a critical role, as do a host of other institutions and private funders. Schools can be important partners in building community health resources. Expertise from a wide range of disciplines is incorporated into the care that is available, and countless individuals in every community are working hard to make the most of the resources they have to offer this vulnerable group.

But all this is not enough. Just as the discussion revealed that the needs are generally consistent across communities, the workshop speakers consistently also revealed significant gaps in the care that adolescents are receiving. In short, while these workshops were not exhaustive examinations of the issues, together they strongly suggest that both the system through which care is delivered and ways of reaching individual adolescents are insufficient to meet the need. The committee will return to these issues, but the areas of agreement evident at the workshops will be a valuable foundation for its work.

SYSTEM CHALLENGES

Gaps in the health care system serving adolescents were mentioned repeatedly at both the community forum and the research workshop. They are straightforward and generated no controversy:

- Too many adolescents have either no health insurance coverage or inadequate health insurance coverage.
- The programs, both volunteer-run and publicly sponsored, that attempt to serve adolescents have insufficient funding to adequately serve all those who need them.
- The public and private programs that exist provide fragmented coverage that is disconnected and poorly coordinated. Excellent programs are available—although not in every place where they are needed—but the burden is often on adolescents and their families to identify the problem that needs treatment, identify a place where they can get help, get themselves there, and figure out how it might be paid for. Moreover, providers must often treat adolescents without access to medical histories or opportunities to collaborate with professionals from other relevant disciplines who can address other elements of their patient's situation.

- Many prevention strategies and treatments that are supported by compelling research are not available to the adolescents who need them most. The most critical omissions include treatments for mental health and substance use disorders, utilization of dental health services, and strategies that can target the early behavioral patterns likely to lead to future health problems.

GAINING ADOLESCENTS' TRUST

Another set of challenges mentioned by many presenters relates to the relationships between health care providers and adolescents. Consent and confidentiality are critical, and both legal requirements and practices vary among states. Adolescents may be particularly reluctant to let their parents know that they are seeking reproductive health care or mental health care or make them aware of problems they are facing, yet the provider may be required to inform parents in certain situations, be restricted to seeing the patient for only a few visits before obtaining parental permission, or worry about itemized billing being sent to the parents. Yet adolescents may not ever seek care for sensitive problems if they believe their parents will be notified (Lehrer et al., 2007).

Practitioners also sometimes face dilemmas related to the health or other status of parents, which presents a different set of questions. For example, a child who is asked if he or she ever drives with anyone who has been drinking may respond "yes, my Dad," or the practitioner may become aware that the parent has a drug or mental health problem or engages in violent behavior. In such cases, the practitioner's responsibilities may be complex, while his or her options for addressing the parent's problems are limited.

Questions about confidentiality are not the only ones that can compromise adolescents' willingness to seek care. Many participants talked about adolescents' reluctance to seek help for mental health problems because of embarrassment, fear of stigma, or lack of understanding, in addition to the fears they may have about disclosing sensitive information to their parents. Thus, one participant suggested that making primary care universally available may not be enough—the typical clinician's office may just not be a place adolescents will go on their own to seek certain kinds of care. Systems in which every kind of care is available under one roof, in a place that is easily accessible to adolescents, may have better capacity to overcome that particular barrier, which can affect almost any adolescent.

Trust is also key on an individual level. Adolescents need adults who are not only equipped professionally to diagnose and treat their problems, but also are able to establish a connection that promotes trust. The most vulnerable adolescents frequently lack consistent relationships with caring adults and are most in need of connectedness. Many participants talked about strategies for reaching adolescents and proving to them that if they seek and accept care, they will be safe. However, given the diversity of adults who work with these young people—from pediatricians and psychiatrists to teachers, social workers, and truant officers—much more could be done to make these strategies integral to adolescent care.

QUESTIONS FOR FURTHER EXPLORATION

Several important issues arose during the two workshops that deserve further explanation.

Research on the effectiveness of both selected treatment interventions and different systems of providing care. Participants noted that some persuasive research findings that are available are not being applied widely, for example, in mental health and substance use disorder treatment. In other areas, additional research is urgently needed, for example, to provide best practices for providing services to vulnerable populations of adolescents, such as adolescents who are lesbian, gay, bisexual, transgender, or questioning their sexual orientation; low-income adolescents; adolescents in foster care and the juvenile justice system; and runaway and homeless adolescents. Government officials, in particular, need criteria with which to assess the value of alternative approaches as they allocate funds and consider ways to structure the programs they oversee. Researchers have identified key challenges to providing high-quality care for this age group, and practitioners and others have provided models for ensuring continuity of care and addressing many of the other challenges. The workshops also explored strategies that government could pursue. Analyses of the effectiveness of these policies and models of delivering health care to adolescents are desperately needed.

A broader view of the adolescent period is needed. The adolescent period is characterized by transitions: leaving childhood, entering adulthood, and all that transpires during the 8 to 10 years between these two developmental stages. Not only are the needs of younger adolescents ages 10 to 13 very different from those in middle adolescence (ages 14–17) and young adults (ages 18–21), but also adolescence itself is a concept with imprecise boundaries. Scaffolding is the term used to describe the ways in which adults can provide a supporting structure to guide adolescents through these transitions; it is a strategy that could be much more widely used—and one that merits additional study.

Parents and families are critical. The influence of parents and families was mentioned many times, although it was not the focus at either of the workshops. While it stands to reason that improving a family's interactions, its approach to medical issues, and other factors may be the best way to improve the health status of a adolescent patient, strategies to achieve this goal are not well articulated. Many programs certainly acknowledge the issue and look for ways to address the broader needs an adolescent may have, whether with family members, the criminal justice system, or school, but resources and strategies for doing so are scarce.[1]

Recent developments in the study of neurological and cognitive development are likely to be very useful both to the overall understanding of adolescents and to the development of effective strategies and programs for members of this age group. As researchers and practitioners seek to improve their understanding of adolescence in important areas, such as decision making, risk assessment, and a connectedness, it will be important for them to monitor this blossoming field. However, research centers lack institutional and funding supports for collaboration among specialists in each of the fields for which adolescence is a concern.

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[1] A useful resource in this regard is A. Rae Simpson's *Raising Teens: A Synthesis of Research and a Foundation for Action* (2001). See http://hrweb.mit.edu/worklife/rpteens.html.

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Appendix A

Community Forum Agenda and Participants

AGENDA

A National Community Forum on Adolescent Health Care
November 6, 2006
Keck Center of The National Academies
Washington, DC

Forum Goal:

Identify the organizational and contextual factors that should enhance the delivery of adolescent health care services.

Engage in presentations and discussion around the following questions:

1. What are the *strengths* of current adolescent health care services and settings?
2. What are the *weaknesses* in current adolescent health care services and settings?
3. Where are the *opportunities* to enhance and improve adolescent health care services and settings?
4. What are the *threats* to adolescent health care services and settings?
5. What vulnerable populations are not particularly well served through the current health care services and settings?

PROGRAM

Welcome, Introduction, and Overview

Moderator: *Robert Lawrence, MD*, Committee Chair

Background and Overview of Forum

Shay Bilchik, JD, Committee Member

SESSION 1: VULNERABLE POPULATIONS PERSPECTIVE

Moderator: *Eduardo Ochoa*, *MD*, Committee Member

Session 1 Goals:

1. What is the size/make-up of this adolescent population?
2. What is the state of access and use of health care services for this adolescent population? What key changes have occurred over time?
3. What are the gaps in services for this adolescent population? How can these gaps be filled? What special training issues require attention for health care providers?
4. What outcomes should be measured to monitor access and use of health care for this adolescent population?
5. What are the promising initiatives for the access and use of health care services?

PANEL 1

Health Care Experiences in Foster Care
Matthew Morton, Stetson University, Florida
Health Care Experiences of Uninsured Youth
Shawn Semelsberger, Traverse City, Michigan
Health Care Experiences of Youth with Disabilities
Paul Fogle, Middletown, Pennsylvania

Discussion of Panel 1

PANEL 2

Health Care of Youth with Border Health Issues
Salvador Balcorta, Centro de Salud Familiar La Fe Inc., El Paso
Health Care of Unattached/Homeless Youth
Alan Shapiro, MD, South Bronx Children and Family Health Center

Health Care of Low-Income Youth
Coleen DeFlorimonte, MSN, CPNP, Woodson High School Adolescent Wellness Center, Washington, DC

Discussion of Panel 2

SESSION 2: SYSTEMS PERSPECTIVE

Moderator: *Sarah Brown,* Committee Member

Session 2 Goals:

1. What are the particular health needs of the populations served by the setting? What health care services are routinely covered in their programs? What are areas of significant challenge or gaps?
2. How consistent or intermittent is insurance coverage for adolescents and what are the associated problems?
3. What arrangements would help strengthen the services provided or address the gaps that now occur? Do significant opportunities exist to create public/private partnerships that could enhance the capacity?
4. How does the system seek to coordinate its services? Who manages the referral systems and how are case management services financed? Identify significant policy, organizational, financial, legal, and training issues (gaps, promising initiatives, barriers) with health care services to adolescents and the coordination of care with other providers.

PANEL 1

Nongovernmental Settings
Kristin Adams, PhD, Girls Inc.
Rural Settings
Kathaleen Perkins, MD, West Virginia University
Urban Settings
Rhonda Braxton, The Door, New York
Schools
Linda Juszczak, DNS, National Assembly on School-Based Health Care

Discussion of Panel 1

PANEL 2

Managed Care Provider
  Charles Wibbelsman, MD, Kaiser Permanente, San Francisco
Publicly Financed Institutions (juvenile justice/foster care)
  Dianne Ewashko, New York State Office of Children and Family Services
Local Government
  Josh Sharfstein, MD, Baltimore City Health Department, Maryland

Discussion of Panel 2

PUBLIC FORUM

Moderator: *Shay Bilchik, JD,* Committee Member

CLOSING

PARTICIPANTS

Kristin Adams, Girls Incorporated National Resource Center
Trina Anglin, Office of Adolescent Health, Maternal and Child Health Bureau, Health Resources and Services Administration
Kelita Bak, Camp Fire USA
Salvador Balcorta, Centro de Salud Familiar Le Fe Inc.
Brenda Barron, National Assembly on School-Based Health Care
Linda H. Bearinger,* School of Nursing, University of Minnesota
Shay Bilchik,* Center for Juvenile Justice Reform and Systems Integration, Georgetown University
Rhonda Braxton, The Door
Sarah Brown,* The National Campaign to Prevent Teen Pregnancy
Rosemary Chalk, Board on Children, Youth, and Families
Laurie Chassin,* Department of Psychology, Arizona State University
Sharron Corle, Association of Maternal and Child Health Programs
Coleen DeFlorimonte, Woodson High School Adolescent Wellness Center, Washington, DC
Gordon H. DeFriese, The University of North Carolina at Chapel Hill
Debra Delgado, The Atlantic Philanthropies
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Elise Desjardins, Grantmakers in Health
Thomas DeWitt, Cincinnati Children's Hospital Medical Center
Nancy Dubler,* Montefiore Medical Center
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Dianne Ewashko, Division of Strategic Planning and Policy Development, New York Office of Children and Family Services
Kathleen Ferrier, Girl Scouts of the USA
Paul Fogle, Middletown, PA
Harriette Fox,* Maternal and Child Health Policy Research Center
Michele Gains, University of California, Los Angeles, Martin Luther King/Charles R. Drew Medical Center
V.J. Gibbins, Camp Cedar
Pauline Ginsberg, Utica College
Mark Goldstein, Division of Adolescent Medicine, Massachusetts General Hospital, Harvard Medical School
Kathi Grasso, U.S. Department of Justice
LaVerne Green, School-Based Health Programs, Health Resources and Services Administration

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Karen Hendricks, Department of Federal Affairs, American Academy of Pediatrics
Catherine Hess, National Academy for State Health Policy
Elizabeth Hoffman, Subcommittee on Education and Early Childhood Development, Senator Chris Dodd, Ranking Member
Charles Irwin, Jr.,* School of Medicine, University of California, San Francisco
Kayla Jackson, National Network for Youth
Jennifer Joseph, National Association of County & City Health Officials
Linda Juszczak, National Assembly on School-Based Health Care
Kelly Kelleher,* Columbus Children's Research Institute, The Ohio State University
Genevieve Kenney,* Urban Institute, Washington, DC
Eva Klane, American Bar Association Center Children and the Law
Kathryn Kushner, National Institute for Health Care Management Foundation
Robert S. Lawrence,* Bloomberg School of Public Health, The Johns Hopkins University
Julia Graham Lear,* School of Public Health and Health Services, Department of Prevention and Community Health, The George Washington University
Jonathan Lever, YMCA Activate America
Susan Lin, Columbia University
Keith Loud, Northeast Ohio Universities' College of Medicine, Adolescent Health Services, Akron Children's Hospital
Jennifer Maehr, Maryland Department of Juvenile Services
Arik Marcell, Departments of Pediatrics and Population, Family & Reproductive Health, The Johns Hopkins University School of Medicine, Bloomberg School of Public Health
Stephen Mautner, National Academies Press
John McInerney, National Academy for State Health Policy
Hugh McIntosh, Consultant
Elaine McLaughlin, Food and Nutrition Service/USDA, National 4H Headquarters, Families, 4-H and Nutrition, Cooperative, State Research, Education and Extension Service
Matthew Morton, Stetson University
Eduardo Ochoa, Jr.,* Section of General Pediatrics, Arkansas Children's Hospital

Pat Paluzzi, Healthy Teen Network
Kathaleen Perkins, West Virginia University
Janis Richter, Partnership for Youth Transition
Frederick P. Rivara,* Department of Pediatrics, University of Washington, Seattle
C. Anita Robinson, The Catholic University of America
Jennifer Rogers, American College of Preventive Medicine
Vinod K. Sahney,* Blue Cross and Blue Shield of Massachusetts
Laura Schiebelhut, Child Welfare League of America
Sarah Schulman, Maternal and Child Health Bureau, U.S. Department of Health and Human Services
Mark A. Schuster,* RAND and University of California, Los Angeles
Shawn Semeslberger, Foster Club, Traverse City, MI
Alan Shapiro, Montefiore Medical Group, South Bronx Children and Family Health Center
Josh Sharfstein, Baltimore City Health Department
Matthew Stagner,* Chapin Hall Center for Children, The University of Chicago
Donald Stechschulte Jr., Bucknell University
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Charles Wibbelsman, Kaiser Permanente
Nicole Yohalem, Forum for Youth Investment, Cady-Lee House

Appendix B

Research Workshop Agenda and Participants

AGENDA

Research Workshop on Adolescent Health Care Services and Systems
January 22, 2007
Keck Center of The National Academies
Washington, DC

Workshop Goal:

Engage in presentations and discussion on examining the research base on the organization and delivery of adolescent health care services in the following areas:

1. Identify current models of adolescent health care delivery.
2. Examine how measures of quality (as defined by the Institute of Medicine and adapted to adolescents) apply to adolescent health care delivery.
3. Explore the evidence base for the quality of health care and different types of health care systems and the research needs for measuring this quality now and in the future.
4. Examine the methods in which health care can and should be delivered to special populations of adolescents now and in the future.
5. Identify research needs and gaps on models, quality, and delivery of adolescent health care.

PROGRAM

Welcome, Introduction, and Overview

Moderator: *Robert Lawrence, MD,* Committee Chair

Background and Overview of the Workshop
F*rederick Rivara, MD, MPH,* Committee Member

PANEL 1 Overview of Adolescent Health Care and Adolescent Health Care Systems

Moderator: *Burton Edelstein, DDS, MPH,* Committee Member

Adolescent Population: Health Status, Utilization of Health Care Services, and Indicators of Need
Andrea MacKay, MSPH, National Center for Health Statistics

Adolescent Population: Connection of Needs of Services to Health Care Systems
Claire Brindis, Dr PH, MPH, University of California, San Francisco

The Adolescent Health Care Systems
Jonathan Klein, MD, MPH, University of Rochester Medical Center

Structure of and Settings for Adolescent Health Care Services: Comparison with Pediatric and Adult Health Care
Robert Blum, MPH, PhD, Johns Hopkins Bloomberg School of Public Health

Prevention in Adolescent Health Care: Needs, Opportunities, and Long-Term Impact
Richard Catalano, PhD, School of Social Work, University of Washington

Discussion of Panel 1

PANEL 2 Quality in the Delivery of Adolescent Health Care: Safety, Timeliness, Efficiency, Clinical Effectiveness, Equity, and Patient-Centeredness

Moderator: *Mark Schuster, MD, PhD,* Committee Member

Safety, Timeliness, Efficiency, and Clinical Effectiveness
Charles Homer, MD, MPH, National Initiative for Child Health Quality

Patient-Centeredness
Christina Bethell, PhD, MPH, MBA, Child and Adolescent Health Measurement Initiative and Oregon Health and Science University

Equity
Anne Beal, MD, MPH, The Commonwealth Fund

Discussion of Panel 2

PANEL 3 Evidence-Base for Service Delivery Models or Systems of Care

Moderator: *Genevieve Kenney, PhD,* Committee Member

Models or Systems of Care in the Public and Private Sector
David Grossman, MD, MPH, Group Health Permanente

Community Models or Systems of Care
Denise Dougherty, PhD, Agency for Healthcare Research and Quality

Health Care Using New Technologies
Warner Slack, MD, Beth Israel Deaconess Medical Center in Boston

Discussion of Panel 3

PANEL 4 Assessing Effective Health Care Systems for Special Adolescent Populations

Moderator: *Laurie Chassin, PhD,* Committee Member

Youth with Substance Use Disorders
Connie Weisner, DrPH, University of California, San Francisco

Youth with Mental Illness
Kimberly Hoagwood, PhD, Columbia University

Incarcerated, Foster Care, and Homeless/Runaway Youth
Abigail English, JD, Center for Adolescent Health and the Law, Chapel Hill

Lesbian, Gay, Bisexual, and Transgender Youth
Robert Garofalo, MD, MPH, Children's Memorial Hospital, Chicago

Discussion of Panel 4

CLOSING

PARTICIPANTS

Trina Anglin, Office of Adolescent Health, Maternal and Child Health Bureau, Health Resources and Services Administration
Chrisa Arcan, University of Minnesota
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Kelly Betha, Maria Fareri Children's Hospital, West Chester Medical Center
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Robert Blum, The Johns Hopkins Bloomberg School of Public Health
Wendy Braund, American College of Preventive Medicine
Claire Brindis, University of California, San Francisco
Debra Brinson, School-Community Health Alliance of Michigan
Sarah Brown,* The National Campaign to Prevent Teen Pregnancy
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Rosemary Chalk, Board on Children, Youth, and Families
Laurie Chassin,* Department of Psychology, Arizona State University
Anita Chandra, RAND Corporation
Lynn Choromanski, University of Minnesota
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Carol Ford, University of North Carolina at Chapel Hill
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Bethany Hardy, Institute of Medicine Office of Reports and Communications
Scott Harpin, University of Minnesota
Karen Hendricks, American Academies of Pediatrics
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Eduardo Ochoa, Jr.,* Section of General Pediatrics, Arkansas Children's Hospital
Valerie Ovholt, Oakwood Teen Health Center, Wayne County, Michigan

Pat Paluzzi, Health Teen Network
Kathaleen Perkins, West Virginia University
Nalini Ravindranath, The Forum for Youth Investment
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BOARD ON CHILDREN, YOUTH, AND FAMILIES

The Board on Children, Youth, and Families (BCYF) serves as the focal point for independent and authoritative analysis of child and family issues relevant to policy decisions. The Board brings a multidisciplinary and evidence-based perspective to bear on the development of policies and programs for children, youth, and families, drawing upon the collective knowledge and analytic tools of the behavioral, health, and social sciences. The Board also fosters the recognition that children, adolescents, and families constitute unique populations whose important differences are often not addressed in public policy and program development discussions or the organization and financing of health and human services. More information about the Board on Children, Youth, and Families is available at www.bocyf.org.