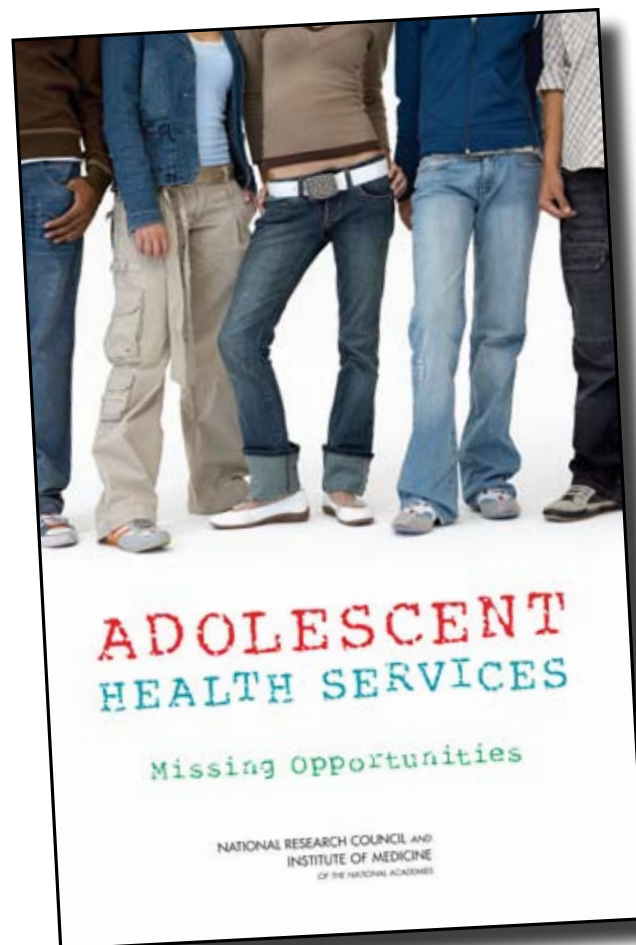


The National Research Council/
Institute of Medicine's
Adolescent Health Services:
Highlights and Considerations for
State Health Policymakers

Elizabeth Osius and Jill Rosenthal



SEPTEMBER 2009

THE NATIONAL RESEARCH COUNCIL/INSTITUTE OF MEDICINE'S *ADOLESCENT HEALTH SERVICES*:
HIGHLIGHTS AND CONSIDERATIONS FOR STATE HEALTH POLICYMAKERS

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Portland, Maine Office:
10 Free Street, 2nd Floor
Portland, ME 04101
Phone: [207] 874-6524

Washington, D.C. Office:
1233 20th Street, NW, Suite 303,
Washington, D.C. 20036
Phone: [202] 903-0101

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EXECUTIVE SUMMARY

In May 2006, the National Research Council/Institute of Medicine's (NRC/IOM's) Board on Children, Youth and Families (BCYF) convened the Committee on Adolescent Health Care Services and Models of Care for Treatment, Prevention, and Healthy Development. With funding from The Atlantic Philanthropies, the committee conducted a study of health services for adolescents ages 10-19 in the United States and issued a report, *Adolescent Health Services: Missing Opportunities*.¹ The National Academy for State Health Policy has written this paper based upon that report to highlight aspects of the publication most relevant for and applicable to state policymakers, who play an important role in improving adolescent health.

Adolescents comprise a growing percentage of the total U.S. population, with increasing racial and ethnic diversity. While traditionally adolescents have been overlooked in health care and public policy for a variety of reasons, adolescence is a critical stage of development and the health behaviors formed during this time often shape a person's health over an entire lifespan. Adolescents' health problems are primarily behavioral and environmental, which means adolescents are in particular need of services in the areas of mental health, reproductive and sexual health, oral health, and substance use treatment and prevention.

The adolescent health care system suffers from problems similar to the rest of the U.S. health care system, including a heightened focus on acute and episodic care, and fragmentation that causes specialty services to be unaffordable or inaccessible. States, in their roles as purchasers, regulators, and coordinators, have the opportunity to improve the adolescent health care system in a variety of ways to better meet the unique needs of this population.

AREAS FOR STATE ACTION TO ADDRESS ADOLESCENT HEALTH

States can use legislative authority by:

- expanding coverage to currently uninsured adolescents.
- taking advantage of a new option to provide Medicaid and CHIP coverage to lawfully residing immigrant adolescents during their first five years in the country, if they are otherwise eligible for these programs.

State can use purchasing authority by:

- Reaching out to adolescents who are already eligible for public coverage programs.
- Simplifying enrollment processes to encourage eligible adolescents to enroll in public coverage programs.
- Adopting policies to ensure that health insurance coverage programs for adolescents are accessible, appropriate, effective, and equitable.
- Enacting pay-for-performance contracting that rewards early detection of risky behaviors and emerging health conditions.
- Maximizing the use of the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program intended to ensure that Medicaid-covered children and youth receive all preventive physical and behavioral health services they need based on child and youth specific medical necessity standards.
- Developing comprehensive benefits: preventive screening and counseling at least annually; case management; reproductive health care (which includes screening, education, counseling, and treatment); assessment and treatment for mental health and substance abuse conditions; and dental services (including prevention, restoration, and treatment).

-
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- Structuring reimbursement policies in a manner that supports comprehensive preventive services (i.e. annual preventive visit for adolescents, reimbursement for risk reduction counseling, allowing preventive visit and treatment or counseling in the same day).
 - Setting out-of-pocket cost sharing at levels that do not discourage use of services.
 - Reimbursing providers at market-based rates.
 - Incorporating performance measures for comprehensive services into criteria for credentialing, pay-for-performance, and quality measurement.

States can use regulatory authority by:

- Setting and enforcing policies that ensure adolescents' rights to confidential services.
- Regulating the coverage provided in the private insurance market.
- Setting consistent standards of education and licensure for providers who will work with adolescents to ensure a competent and skilled workforce.
- Convening local professional organizations and key stakeholders to create consensus around, and incorporation of, adolescent-focused competencies into health workforce standards and systems.

States can use their role as a coordinator by:

- Helping bridge gaps among and between health and other adolescent services by promoting coordination among the many agencies involved in identification, referral, and provision of effective adolescent services.
- Adopting techniques to coordinate and link services for adolescents, including: co-location; regional planning organized by a variety of stakeholders; programs for managing referrals; electronic coordination of patient information; and establishment of adolescent call centers.

The health system plays an important role in promoting healthy behavior, managing health conditions, and preventing disease in adolescents; state policymakers, through their diverse roles, have an opportunity to improve the services adolescents receive and adolescents' health over their lifetime.

INTRODUCTION

In May 2006, the National Research Council/Institute of Medicine's (NRC/IOM's) Board on Children, Youth and Families (BCYF) convened the Committee on Adolescent Health Care Services and Models of Care for Treatment, Prevention, and Healthy Development. With funding from The Atlantic Philanthropies, the 19-member committee conducted a study of health services for adolescents ages 10-19 in the United States. The report that the committee produced was published in early 2009 and offers many insights into the health of and health care system for adolescents.

The National Academy for State Health Policy, also with support from the Atlantic Philanthropies and in consultation with BCYF, has produced this paper to highlight aspects of the report for state health policymakers, who have an important role to play in improving adolescent health.

BACKGROUND

The NRC/IOM Committee on Adolescent Health Care Services and Models of Care for Treatment, Prevention, and Healthy Development was charged with studying adolescent health services and developing policy and research recommendations based on its findings. In order to produce the report, *Adolescent Health Services: Missing Opportunities*, the committee:

- considered settings, systems, and policies that promote high-quality services for adolescents, as well as barriers to the provision of such services;
- reviewed strategies for helping adolescents, including particularly vulnerable subpopulations, enter and navigate the health system;
- sought to identify approaches that link disease prevention, health promotion, and behavioral health services with a promise for enhanced provision of primary care tailored to adolescents; and,
- considered several specific aspects of providing these services, including financing strategies and provider training, among others.

A variety of sources informed the committee's work, including:

- formal meetings and public workshops;
- a community forum on adolescent health care that included perspectives from consumers and providers;
- a research workshop that highlighted the views of those familiar with current research and identified research needs and gaps;
- analysis of data and research, studies of public policies, and reviews of private-sector health funding mechanisms;
- visits to institutions focused on providing adolescent health services;
- focus groups with adolescents; and,
- an online Harris Interactive poll of a nationally representative sample of adolescents aged 10-18 about their opinions on health services.

Despite these many sources of information, the limited data and existing scientific literature on national indicators of adolescent health status presented challenges for the committee. In particular, the dearth

of information by selected population characteristics such as income, race, and other circumstances like homelessness and foster care makes longitudinal trends and comparisons of health behaviors of selected adolescent populations unattainable. In addition, the myriad settings and varied institutional structures through which adolescent health services are delivered makes a comprehensive assessment challenging to conduct.

Because the concept of “adolescence” as the transition phase to adulthood is fairly new, and because there are numerous variables that may affect its demarcation, there is disagreement among health care providers, researchers, and policymakers as to the age bracket that defines adolescence. The NRC/IOM report uses ages 10-19 as the best framework for data analysis and evidence review, although the inconsistencies in federal, state, local, and private research make defining adolescence by age complicated.

SETTING THE STAGE

ADOLESCENTS COMPRISE A GROWING PERCENTAGE OF THE TOTAL U.S. POPULATION, WITH INCREASING RACIAL AND ETHNIC DIVERSITY.

Adolescence is a critical stage of development in a young person's life, characterized by profound physical, biological, social, and emotional changes. It is a time in which identity formation begins, as individuals transition from childhood to adulthood, from dependence to independence. New attitudes, feelings, and risk-taking behavior define an individual's experience during adolescence, and potentially shape a person's behavior, health, and lifestyle over an entire lifespan.

Adolescents made up 14 percent (42 million) of the total population in the United States in 2006. According to the U.S. Census Bureau, that number is expected to increase by 28 percent through 2050, which equates to an additional 11.5 million adolescents.

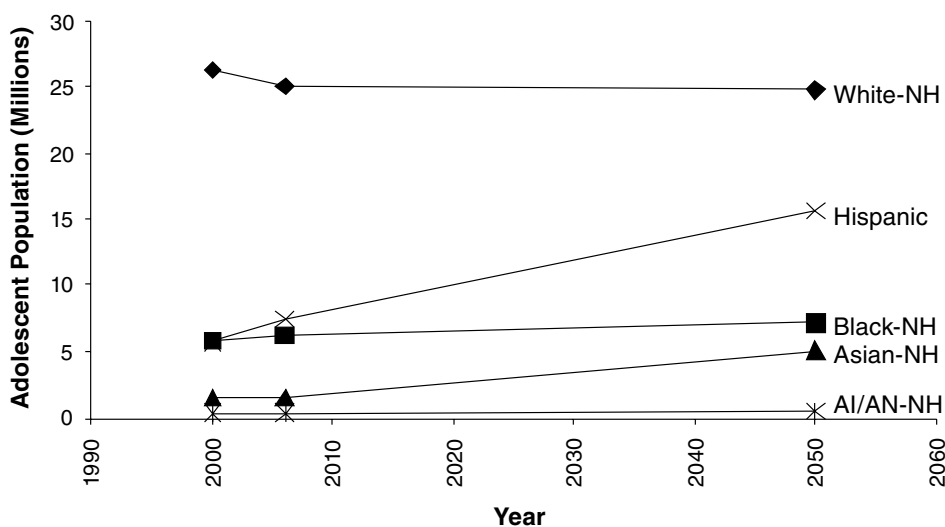
The racial and ethnic diversity of the U.S. adolescent population is also increasing. By 2050, it is estimated that more than 53 percent of adolescents ages 10-19 will

be members of racial or ethnic minority groups. Currently, Hispanic adolescents make up 18 percent of the population and white non-Hispanic adolescents make up 60 percent. By 2050, the make up is expected to be 30 percent Hispanic and 47 percent white non-Hispanic (see Figure 1).

In light of the growing diversity, the correlation between race, ethnicity, and poverty is particularly troublesome. In 2005, the U.S. Census Bureau reported that 17.6 percent of adolescents under age 18 were living in poverty. Black and Hispanic adolescents under age 18 experience poverty at a higher rate than their Asian and white non-Hispanic counterparts, which has been a stable trend since 1980. This correlation between race, ethnicity, and poverty also appears to be inextricably linked to a lack of access to quality health services and poor health status.

A variety of population variables in addition to race, ethnicity, and socioeconomic status can affect adolescents' access to health services and their development, including their social and economic environment, access to information and skills, and geographic location (for instance, in 2002, 19 percent of adolescents ages 12-17 lived in rural areas, where it can be more difficult to access health care).

FIGURE 1. CHANGING RACIAL/ETHNIC COMPOSITION OF THE U.S. ADOLESCENT POPULATION, AGED 10-19, 2000-2006 AND 2006-2050 (PROJECTED)



NOTE: AI/AN = AMERICAN INDIAN/ALASKAN NATIVE; NH = NON-HISPANIC

SOURCE: US CENSUS BUREAU (2006b, 2007)

The NRC/IOM report acknowledges other circumstances that affect adolescents' health status, including immigration, homelessness, and involvement in foster care or juvenile justice systems. Adolescents in these special circumstances lack basic opportunities and supports that would typically provide for their health and well-being, making them even more vulnerable to poor health.

ADOLESCENTS' HEALTH PROBLEMS ARE PRIMARILY BEHAVIORAL AND ENVIRONMENTAL.

Overall, most adolescents are considered healthy as defined by traditional medical measures, including mortality rates, incidence of disease, and use of health services; however, adolescents' health problems are primarily behavioral and environmental in origin. For instance, motor vehicle crashes, homicide, and suicide are the leading causes of mortality among adolescents, rather than infectious or chronic diseases. Likewise, behavior that is unhealthful and risky, such as substance (including tobacco and alcohol) use and abuse, violence, and eating disorders, is the leading cause of morbidity among adolescents.

Mental health, reproductive and sexual health, oral health, and substance use are particularly problematic for adolescents and may contribute to, or be symptoms of, risky behavior.

- *Mental Health:* Mental disorders are common among adolescents (particularly in the form of anxiety and depression) and impose an immense burden on this population. According to most studies, between 10 and 20 percent of adolescents are affected annually by mental disorders; estimates for adults aged 25 and older tend to be lower. In fact, half of all cases of adult lifetime mental disorders start by age 14. According to research, rates of mental disorders are very similar across different racial and ethnic groups after controlling for income, resident status, education, and neighborhood support; however, poverty and low socioeconomic status, which are both tied to race and ethnicity, are risk factors that appear to increase the rate of mental disorders across populations. Despite a high incidence of mental disorders, there is still high unmet need for services. Analysis of 2003 data reveals that on a national basis, 36 percent of adolescents aged 12-17 who need mental health services do not receive them. The reimbursement system for mental health services traditionally focuses on the severely and persistently mentally ill, and therefore is not as capable of addressing emerging mental illness in adolescents who are functional but not healthy.
- *Reproductive and Sexual Health:* Rates of adolescent pregnancy decreased from 1990 to 2005 for adolescents aged 13-19. While all races have experienced decreasing numbers, the rate of decline for Hispanics has not matched that of other races. The rates among Hispanic and non-Hispanic black adolescents continue to be twice as high as those among non-Hispanic white adolescents. Unfortunately, while rates of pregnancy have been declining, sexually transmitted infections (STIs) continue to increase in this population and are the most commonly reported infectious diseases among adolescents. Reproductive and sexual health is a sensitive topic for both adolescents and the public at large. Many factors affect whether adolescents seek or have access to this type of service. The convenience of a clinic in terms of location, hours of operation, types of services offered, and costs affects its use by adolescents. When there is little or no cost-sharing and confidentiality is ensured, adolescents are more likely to obtain these services.
- *Oral Health:* There is a high prevalence of oral disease among adolescents and a perceived need among adolescents for improved dental care. The most common oral health problem in adolescence is dental caries; untreated dental caries occur more frequently among non-Hispanic black adolescents than among non-Hispanic white adolescents. Risk factors for poor oral health are often connected with other risky adolescent behavior, such as: poor eating patterns or eating

disorders; trauma from piercings of the tongue, lip, or cheek; use of alcohol and illicit drugs; and reckless driving or cycling. Contact with adolescents could give dentists an opportunity to detect eating disorders and risky behavior, to identify health conditions that require referral, and to engage adolescent patients in healthy behaviors; however, the dental profession and its pediatric specialty have focused little on adolescence beyond orthodontic issues.

- *Substance Use:* Substance abuse treatment and prevention is another sensitive topic, one where adolescents may not perceive a need for or seek treatment, and may not volunteer information except to professionals with whom they have a history and feel a sense of trust. Alcohol, tobacco, and marijuana use is fairly common among adolescents; there is also growing concern over adolescents' misuse of prescription medications. American Indian and Alaska Native adolescents, in comparison with other racial and ethnic groups, have the highest rates of substance abuse or dependence; Asian adolescents have the lowest rates. Substance use is associated with an increased risk for short-term mortality and morbidity, and, when there is an early onset of use, heightens the risk for substance use disorder later in life. Appropriate screening instruments and treatment guidelines are not routinely incorporated into substance use treatment programs for adolescents and a lack of professional training and certification specific to adolescent patients may deter adolescents from seeking substance abuse treatment.

TRADITIONALLY, ADOLESCENTS HAVE BEEN OVERLOOKED IN MEDICINE AND PUBLIC POLICY FOR BOTH MEDICAL AND SOCIAL REASONS.

The medical care of adolescents is not easily compartmentalized into the two current prevailing models of care. The pediatric approach to medicine relies on the parent as the responsible representative and addresses the patient within a family context. In the adult-centered approach, the patient is the responsible representative and the focus is on the individual. The needs of adolescents do not correspond with either of those models. A third model, family medicine, may offer an alternative, but there are limited numbers of family medicine practices in the United States. Adolescent care has been subsumed under various disciplines: pediatrics, psychiatry, internal medicine, and gynecology, among others, but none focus exclusively on adolescents. A lack of expertise and medical focus has hindered the development of integrated and comprehensive health systems with providers tailored to adolescents' needs.

In addition to complicated medical care, adolescents may be blamed for health conditions that arise from their risky behaviors. Negative attitudes can be even more severe for certain subpopulations of adolescents, such as those who are homeless; gay, lesbian, bisexual or transgendered; or in the juvenile justice system. The complexity of these populations and the inherently difficult issues that arise during adolescence can potentially make adolescents a less attractive population to address.

While there has been significant research on the critical nature of a young child's brain development, there is additional research that suggests that the brain is not completely developed until late adolescence. Until the brain is more fully developed, the connections between neurons affecting emotional, physical, and mental abilities are incomplete. Typical adolescent inconsistency with controlling emotions, impulses, and judgments may be attributable to this incomplete brain development and may contribute to unhealthful and risky adolescent behavior; therefore, focusing efforts on adolescent health is a necessary and valuable endeavor for policymakers and health professionals.

Adolescents' risky behavior or living environments not only affect their immediate health status, but also significantly impact their behaviors and health status as adults; therefore, adolescence is a crucial time for

health promotion. It is critical to identify and address a range of health conditions that affect not only adolescents' functioning, but also the quality of their adult lives. According to research conducted in 2004, half of deaths among adults are due to health-related behaviors that, for many people, have

their onset in adolescence. The significance of this issue was noted in a joint report of the World Health Organization, United Nations Population Fund, and the United Nations Children's Fund in 1995: "One of the most important commitments a country can make for future economic, social, and political progress and stability is to address the health and development needs of its adolescents."

"One of the most important commitments a country can make for future economic, social, and political progress and stability is to address the health and development needs of its adolescents."

Joint report of the World Health Organization, United Nations Population Fund, and the United Nations Children's Fund, 1995.

OVERVIEW OF CURRENT ADOLESCENT HEALTH CARE

THE WORLD HEALTH ORGANIZATION OUTLINES OBJECTIVES FOR ADOLESCENT HEALTH CARE.

Research from a variety of sources as well as the experiences of adolescents, health care providers, and health care organizations have made clear the importance of primary care services that can: attract and engage adolescents; create environments in which adolescents will discuss sensitive health and behavioral issues; and offer high-quality and tailored health services with a focus on disease prevention and health promotion. The NRC/IOM committee incorporated five objectives outlined by the World Health Organization into a framework for a system that promotes responsive adolescent health services. The health care system for adolescents should be:

- **Accessible** – Policies and procedures ensure that services are broadly accessible.
- **Acceptable** – Policies and procedures consider culture, relationships, and other environmental factors that influence how actively adolescents are engaged in their care.
- **Appropriate** – Health services fulfill the needs of all young people.
- **Effective** – Health services reflect evidence-based standards of care and professional guidelines.
- **Equitable** – Policies and procedures do not restrict the provision of and eligibility for services.

These objectives provide a basis for assessing the quality of current and future systems of health services for adolescents.

THE ADOLESCENT HEALTH CARE SYSTEM SUFFERS FROM PROBLEMS SIMILAR TO THE REST OF THE U.S. HEALTH CARE SYSTEM.

Adult and adolescent health systems share the same basic problems: lack of communication, collaboration, integration, and system-level planning among various private and public health services, settings, and providers. The problems include a heightened focus on acute and episodic care at the expense of disease prevention and health promotion. Minority groups and vulnerable sub-populations have even more trouble accessing appropriate primary and specialty care.

UNIQUE CHALLENGES AFFECT ALL ASPECTS OF THE DELIVERY OF HIGH-QUALITY SERVICES FOR ADOLESCENTS.

Insurance reimbursements are often inadequate to compensate for the time it takes to offer services that adolescents need, such as effective counseling, case management, health promotion or disease prevention services. Along with other issues, a lack of diversity of health care providers who are involved in and particularly trained for the care of adolescents often poses problems. Finally, whether or not a health care setting engages adolescents and ensures them confidentiality for their sensitive health issues also greatly affects adolescents' willingness to obtain the services.

ADOLESCENTS HAVE ONE OF THE LOWEST RATES OF PRIMARY CARE USE OF ANY AGE GROUP IN THE UNITED STATES.

Primary care programs endeavor to meet basic health needs of all adolescents, including routine checkups, immunizations, anticipatory guidance, and screening and assessment for disorders and risk factors. Primary care generally encompasses provider-based services offered in private practices as well as in safety-net programs.

- Private Office-Based Care – Adolescents with either private or public insurance commonly receive their primary medical care from private provider offices, usually from a pediatrician, family physician, general internist, or nurse practitioner. The uninsured and underinsured are often unable to access this type of care. Services in this setting are particularly vulnerable to the inadequacies mentioned above, including reimbursement and workforce issues. Services are not always suited to the particular behavioral and developmental needs of adolescents and may not create an environment that elicits questions from or engagement of adolescents.
- Safety-Net Primary Care Services – Adolescents who are uninsured or underinsured often rely on safety-net providers.
 - Community-Based Health Centers – Community-based health centers often serve adolescents that are difficult to reach or serve in mainstream primary care centers. Community-based health centers emphasize outreach, case management and social support programs, and comprehensive medical and behavioral health services. The centers are often in locations that provide easy access to and opportunities for unscheduled encounters with adolescents in need and attract staff trained in adolescent health. Unfortunately, these centers often have a low-volume patient base, are poorly reimbursed for services associated with case management, and are forced to rely on part-time health care providers as well as supplemental funds from local or state health departments.
 - Hospital-Affiliated Primary Care Services – Some hospital centers have established adolescent clinics to serve the primary care needs of adolescents. Most offer basic primary care services and emphasize reproductive health care. Notably, hospital-based settings attract adolescents who are high-users of emergency care services at public hospitals for more routine primary care.
 - School-Based Health Centers (SBHCs) – As of 2007, there were 1,709 SBHCs nationwide in 45 states, and more than 50 percent of those centers served mainly adolescents. SBHCs are a logical place to reach adolescents and serve those that lack access to other community health personnel. They also provide care from a multidisciplinary team of professionals and more than half the centers provide mental health services. SBHCs have the capacity to increase access to basic health care for low-income children and adolescents. Data suggests they are perceived as acceptable by students and families and can target underserved racial and ethnic minorities, thereby fostering equity in access to care and health outcomes for the most vulnerable populations. Funding remains an issue because of states' fiscal constraints; patient care revenues have been insufficient to support SBHCs, and additional core grants are required to sustain quality programs.

ADOLESCENTS ARE IN PARTICULAR NEED OF SPECIALTY SERVICES IN THE AREAS OF MENTAL HEALTH, REPRODUCTIVE AND SEXUAL HEALTH, ORAL HEALTH, AND SUBSTANCE USE TREATMENT AND PREVENTION.

While evidence-based therapies are available, they are not commonly integrated into routine health care practices, especially for those who depend on publicly financed programs. Many adolescents have difficulty gaining access to specialized services because of financial restrictions, shortages of skilled personnel, and a lack of appropriate or convenient settings that are suitable for their stage of development. As discussed above, adolescents would especially benefit from services in the areas of mental health, reproductive and sexual health, oral health, and substance use treatment and prevention.

STATES' ROLES IN MAXIMIZING ADOLESCENT HEALTH

In its recommendations, the NRC/IOM report provides examples of how states can use their roles and responsibilities as policymakers, purchasers, regulators, and coordinators to maximize adolescent health. Because policymaking occurs through executive and legislative mechanisms, elected officials and state agency officials make policy at various levels, and the process of law-making varies from state to state.

States, in their various roles as major purchasers of health care; as regulators of health professionals, institutions, and health plans; and as policymakers, educators, analysts and conveners, have many opportunities to influence the health of adolescents. States are a major purchaser of health care for adolescents through state employee health plans, Medicaid, CHIP, and other programs for vulnerable populations (i.e. those in the foster care and juvenile justice systems); together Medicaid and CHIP covered approximately 27.1 million children, ages 0 to 19, in 2007.^{2,3} State policymakers have opportunities to expand coverage to currently uninsured adolescents and state purchasers can improve the quality of care for those who receive care through these programs. As regulators, states can ensure that the workforce and consent and confidentiality provisions of care meet adolescents' needs. They can also regulate the coverage provided in the private insurance market. As conveners, states can promote linkages and integration of services that are offered through various state health and public health programs (prevention, treatment, and health promotion services) as well as services offered through private sector providers so that adolescents receive care through coordinated systems.

The following sections describe the findings in *Adolescent Health Services: Missing Opportunities* that are particularly relevant to the state roles of purchaser, regulator, and convener. The role of states as policymakers is subsumed within these other roles. Pertinent findings of the NRC/IOM report are highlighted in bold bulleted text.

THE STATE AS INSURER AND PURCHASER: STATES CAN IMPROVE PUBLIC COVERAGE OF ADOLESCENTS AND MAXIMIZE THEIR ACCESS TO QUALITY CARE THAT IMPROVES HEALTH OUTCOMES

States have an important role to play in the adolescent health care system as purchasers through the Medicaid and the Children's Health Insurance Programs (CHIP). These programs have the capability of insuring more adolescents with tailored services and cost-sharing to make coverage meaningful and to maximize the programs' effectiveness in providing access to quality care that improves health outcomes.

Research suggests that enrollment in public coverage programs reduces unmet health care needs among adolescents.

- **The majority of medically uninsured adolescents ages 10-18 are eligible for public coverage but are not yet enrolled.**
- **Medically uninsured adolescents are less likely to have a regular source of primary care and use medical care less often compared with those who have insurance.**

More than 5 million adolescents ages 10-19 are medically uninsured. Health insurance coverage significantly influences adolescent health status. While having health insurance does not guarantee access to high-quality health services, the ability to pay for care helps adolescents, along with the rest of the population, receive timely and appropriate care. Multiple studies have found that adolescents who lack health insurance coverage have worse access to needed health services and poorer health than those who have

coverage, although challenges remain even for insured adolescents.

Covering adolescents who are already eligible for Medicaid and CHIP is one way that states can help adolescents take advantage of services offered through the health care system. Despite being eligible for public coverage, many low income adolescents, particularly those between the ages of 10 and 18, are uninsured. Overall, 65 percent of all uninsured adolescents—more than 2.8 million individuals—appear to be eligible for either Medicaid or CHIP coverage. Knowledge barriers and problems associated with Medicaid and CHIP enrollment processes appear to deter participation in public programs among these uninsured adolescents. Policies, strategies, and campaigns targeted at already eligible families and adolescents could hold promise of increasing overall coverage of adolescents. Simplifying enrollment processes, a strategy which has been successful in many states, would also help parents and adolescents begin and follow through with the application.

Adolescents who lack health insurance coverage have worse access to needed health services and poorer health than those who have coverage.

States also can consider covering a group of adolescents who previously were ineligible under the federal Medicaid and CHIP programs: legal immigrant children, adolescents, and pregnant women who have been in the country for less than five years. Until recently and at the time of the original NRC/IOM report, states were prohibited from providing federally-funded Medicaid and CHIP coverage to legal immigrants during their first five years in the country, although they could provide coverage after that. With the reauthorization of the CHIP program, signed into law by President Obama in February 2009,⁴ states now have the option to provide Medicaid and CHIP coverage to lawfully residing immigrant children and pregnant women during their first five years in the country, if otherwise eligible for these programs. Just over a third of states were providing coverage for these populations using state funding before reauthorization,⁵ but now those and all other states have the option to receive federal funding under the Children's Health Insurance Program Reauthorization Act (CHIPRA).

Adolescent care requires an emphasis on health promotion, disease prevention, and behavioral health services.

- **Having coverage does not equate to adolescents' access to affordable, high-quality services, given under-investments in disease prevention and treatment, out-of-pocket cost sharing requirements, limitations in benefit packages, and low provider reimbursement levels.**

Adolescent health services tend to focus on acute conditions or specific issues, and are poorly equipped to meet comprehensive health promotion, disease prevention, and behavioral health needs of this population, where many health problems stem from behaviors that can be addressed prior to onset of disease, illness, or injury. Shortcomings exist in the type of coverage provided to adolescents, including inadequate coverage of preventive, mental health and substance abuse treatment, dental, and reproductive and sexual health services.

As purchasers of care, states can adopt policies to ensure that health insurance coverage programs for adolescents are accessible, appropriate, effective, and equitable. Research suggests that provider reimbursement rates are insufficient for the time required to provide adolescents with the services they need. According to the NRC/IOM report, private office-based primary care services are not effective at fostering appropriate adolescent health promotion or risk reduction due to these reimbursement structures. Although surveys of clinicians indicate that most perform routine surveillance for risky behaviors, diet, and exercise, fewer than half of adolescents surveyed indicated that they had spoken with their provider about these issues.

Systematic efforts to identify and respond to unhealthy and risky adolescent behavior require screening, assessment, health management, referral, and care management of specialty services. However, standardized screening tools are used infrequently in adolescent primary care settings, and they often focus on a single risky behavior. Care management that can help avoid unnecessary or duplicative tests and coordinate services and treatments is often uncompensated by health payers. The increased willingness of payers to reimburse primary care providers for screening and assessment, and pay-for-performance contracting that rewards early detection, are likely to encourage universal screening during adolescent primary care visits.

While Medicaid and CHIP generally provide for much of these services, there is variation among state programs, particularly in CHIP. Sparse research on access and utilization for adolescents makes it difficult to understand whether or not these programs are fulfilling their potential.

Medicaid provides very generous coverage for services needed by adolescents through the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) mandate.⁶ It is intended to ensure that Medicaid beneficiaries receive all preventive, sexual and reproductive health, mental and oral health, and substance abuse treatment services comprehensively. Unfortunately, there is little research to describe states' use of EPSDT benefits to cover services that adolescents need, nor how managed care organizations or state utilization review staff make authorization decisions. Through Medicaid, these services should be delivered with no cost-sharing for families with incomes below 100 percent of the federal poverty level, up to 10 percent of the service cost for families with incomes up to 150 percent of the federal poverty level, and more for those with higher incomes.

Many Medicaid programs structure reimbursement policies in a manner that does not support comprehensive preventive services. Only one-third of states pay for an annual preventive visit for adolescents. About half of states reimburse for risk reduction counseling. Only seven states explicitly allow the provision of two services in the same day (i.e. preventive visit plus counseling); eighteen states explicitly deny it.

Because Medicaid is an entitlement program and CHIP is not, states that operate separate CHIP programs often provide more restrictive benefits than Medicaid. Forty states administer separate CHIP programs, 22 of which run their separate program in conjunction with a Medicaid-expansion of CHIP.⁷ Under CHIP, states operating separate benefit programs are federally required to provide preventive care and immunizations without cost sharing, but separate CHIP programs have broader discretion in the frequency and content of preventive health visits than they do under Medicaid.

Separate CHIP programs are not subject to federal requirements to cover sexual and reproductive health services. Sparse research, however, indicates that the majority of states do provide adolescents with these services without significant cost-sharing requirements. Findings from studies show that separate CHIP programs tend to cover gynecological exams, STI screenings, and commonly used prescription contraceptives.

The federal government also does not require states to cover either mental health or substance abuse treatment services under separate CHIP programs, but all states have opted to provide CHIP coverage for both inpatient and outpatient services. The extent of CHIP coverage available to adolescents in states without EPSDT-like coverage varies widely and sometimes is more restrictive for substance abuse treatment. With the signing of the CHIPRA bill in February 2009,⁸ CHIP programs are now subject to mental health parity. Under mental health parity, states are not required to cover mental health services; however, if a state chooses to provide mental health or substance abuse services through CHIP, the financial requirements and treatment limitations for those benefits must not be more restrictive than those for medical and surgical benefits.

Until recently, states were not required to cover dental services under separate CHIP programs. While all or almost all separate programs provided coverage, there was no consistent standard for dental services, and in difficult budget times the benefits were vulnerable to cuts. With the passage of CHIPRA, states are required—as of October 1, 2009—to include coverage of dental services in their programs. States meeting certain criteria also have the option to offer dental coverage as a wrap-around to children whose group health insurance or health insurance through an employer does not include dental.⁹

Historically, public policies have been designed to keep out-of-pocket cost sharing in public programs low to avoid deterring individuals and families from seeking the care they need. Under CHIP, states may not impose cost-sharing requirements for preventive services; however, generally states may impose premiums or require co-payments or coinsurance, as long as total cost sharing does not exceed five percent of a family's income. Higher cost-sharing is permitted in CHIP than in Medicaid, and the Deficit Reduction Act of 2005 permitted more cost-sharing in Medicaid. To date, no published study has examined the effects on adolescents of different co-payment schedules in public programs; however, research indicates that cost sharing—generally in the form of co-payments and deductibles—causes low-income people to delay or reduce care, leading to poor health outcomes.¹⁰

Unfortunately, having a comprehensive benefit package and low cost-sharing does not necessarily translate into access, because providers may be unwilling to offer services under certain types of insurance coverage. This is of particular concern for Medicaid programs, where provider reimbursement levels are below market rates in many service areas. Research suggests that physicians' participation in Medicaid and CHIP is higher in states that pay them more. In addition, despite the availability of mental health and substance abuse benefits for adolescents in public programs, there is an abundance of literature that documents significant access difficulties due to multiple factors, including shortages and a misdistribution of providers.

State purchasers and policymakers can address some of these challenges by ensuring that benefit packages cover critical services for adolescents and reimburse providers for these services at market-based rates. These services include: preventive screening and counseling at least annually; case management; reproductive health care (which includes screening, education, counseling, and treatment); assessment and treatment for mental health and substance abuse conditions; and dental services (including prevention, restoration, and treatment). States can ensure coverage for mental health and substance abuse services at sites that integrate physical and mental health care and cover mental health rehabilitation services through Medicaid. States can make certain that out-of-pocket cost sharing is set at levels that do not discourage use of services. The NRC/IOM report recommends that payment systems “make disease prevention, health promotion, and behavioral health, including early identification, management, and monitoring of current or emerging health conditions and risky behaviors, a major component of routine health services.” In addition to financing these activities, states can incorporate performance measures for these services into criteria for credentialing, pay-for-performance, and quality measurement.

THE STATE AS REGULATOR: STATES CAN ENSURE CONFIDENTIALITY OF SERVICES AND A TRAINED AND PREPARED WORKFORCE FOR ADOLESCENT NEEDS

As regulator, the state has the opportunity to protect adolescents' health, which it can do by both ensuring patients' rights to confidential services through state laws and regulations, and by ensuring that adolescents' providers meet certain licensure and accreditation standards.

The assurance of confidentiality encourages adolescents to obtain health care.

- **Research demonstrates that when health services are confidential, adolescents are more**

willing to seek care, in particular for their most sensitive issues, such as sexual behavior, reproductive health, and mental health.

- **In general, current state and federal policies protect the confidentiality of adolescents' health information when adolescents are able to legally consent to their care.**

Confidentiality policies for adolescents are inherently related to policies regarding consent. Every state has established in statute a right for minors to consent to their own care in an assortment of circumstances. While policies vary, each state has at least some laws that allow minors to consent on the basis of one or more categories of status (mature, emancipated, over a certain age, etc.) and one or more categories of services being sought (general health care, contraception, drug and alcohol care, etc.). This framework is the foundation for confidentiality protections in adolescent health services. Overall, many states' laws and regulations have developed over time to protect the confidentiality of adolescents' health information when adolescents are legally allowed to consent to their own care, with the exception of abortion.

While confidentiality protections often correlate with the circumstances in which minors can consent for care, this is not always the case. The degree to which confidentiality is protected at the state level varies greatly. Sometimes states are silent on the question of confidentiality, or explicitly permit (but do not require) health professionals to disclose information to parents. The decision is usually left to the health care professional's discretion based upon criteria related to the minor's health.

Because adolescence marks the transition from childhood to adulthood, a time during which minors are aging out of the initial parent-child relationship, adolescents' rights to confidentiality are not inherent the way adults' are considered to be. It can be challenging for both policymakers and providers to define when information should be strictly between the patient and provider and when it is more appropriate to share with the adolescent's parent or primary caregiver. However, it is well-documented that the assurance of confidentiality encourages adolescents to divulge more information to providers and increases their willingness to obtain health care, particularly for sensitive issues.

Various health care professional organizations acknowledge the fundamental role played by parents in caring for adolescents while at the same time supporting the role of and benefits from confidentiality in the delivery of health care. The Society for Adolescent Medicine (SAM)¹¹ notes the import of confidentiality in its position paper, which states that "confidentiality protection is an essential component of health care for adolescents because it is consistent with their development of maturity and autonomy," and, "laws that allow minors to give their own consent for all or some types of health care and that protect the confidentiality of adolescents' health care information are fundamentally necessary."

"Laws that allow minors to give their own consent for all or some types of health care and that protect the confidentiality of adolescents' health care information are fundamentally necessary."

The Society for Adolescent Medicine

Protections of confidentiality in adolescent health services derive from a variety of federal and state laws. At the federal level, Medicaid and the Title X clinics funded under the Public Health Service Act, which offer minors confidential family planning services, are often the target of controversy. Other public programs, such as CHIP, have laws that defer to and vary from state to state, or, like the Maternal and Child Health Block Grant, are less explicit in their requirements for confidentiality protection for adolescents.

The potential to compromise confidentiality for adolescents has increased with the uptake of certain disclosure of information practices. Private insurance, Medicare, Medicaid, and managed care organizations require records to be shared (to set, maintain, and enforce standards), which increases the potential for a breach in confidentiality. This is a concern particularly with the development of electronic medical records. Private and public insurance administrative and billing practices may violate confidentiality protections. According to one study, explanation of benefits (EOB) policies vary among commercial and public insurers, as well as by state, payer, and program. These EOB statements, which contain information such as the patient's name and services provided, may be mailed home to the adolescent or directed to the parent or head of household. States can ensure that their managed care plans for public insurance programs, as well as private insurance payers' practices, are not in conflict with state confidentiality laws.

States have a stake in ensuring that their policies respect adolescents' confidentiality and that the policies are upheld by providers and payers so that adolescents do not forego needed health services and risk the financial and health costs of preventable illnesses and disabilities.

Too few health care providers feel prepared to work with adolescents in ways that are appropriate for their care.

- **The professional adolescent health care workforce is multidisciplinary; however, existing adolescent health care training across disciplines does not adequately address the specific needs of adolescents.**
- **Specific adolescent health content and competencies are not consistently or sufficiently included in the licensing, certification, and accreditation of programs for health care providers in the various disciplines that are likely to be serving adolescents.**

A critical component of improving adolescent health is having a workforce that is competent and prepared to address the complex needs of this age group. To appropriately work with adolescents, providers of all disciplines need to be accustomed to adolescent health problems, as well as feel comfortable with a range of strategies for risk assessment, disease prevention, care coordination, treatment, and health promotion. Data reveal that too few health care providers feel prepared to work in this way with adolescents. The care of adolescents is distributed among many types of providers, both primary and specialty, but not enough of these providers choose, or are required, to become trained specifically to serve adolescents.

Since 1994, when the first certification exam in adolescent medicine was administered, only approximately 700 pediatricians and internal and family medicine physicians have been certified in adolescent medicine. According to the American Board of Pediatrics, the American Board of Family Medicine, and the American Board of Internal Medicine, from 2004 to 2005 the number of fellows in adolescent medicine (pediatric, family medicine, and internal medicine) actually decreased by 10 percent. In 2005, only 1.4 percent of first-time candidates applying for the general pediatrics examination who indicated an interest in one of the subspecialty areas cited adolescent medicine. Of the 16 subspecialties areas offered by the American Board of Pediatrics, adolescent medicine ranked fifteenth.

The lack of provider interest in the subspecialty of adolescent medicine is concerning. Of equal concern is that the inclusion of adolescent health content and competencies in the licensing, certification, and accreditation of programs for health care providers that may serve adolescents is minimal, inconsistent, and insufficient. Additionally, the programs for these health care providers vary significantly by discipline, state, and governing regulatory body or accreditation council or board. For example, a registered nurse candidate is permitted to take the licensure exam after either completing a 2-year associate's or a 4-year baccalaureate degree. There is also variation in requirements, according to one study, in the two very

distinct training models (formal curricular training versus an apprentice model) for U.S. providers of drug and alcohol use counseling and mental health counseling. In addition, certification requirements for these providers vary from state to state. Furthermore, in current dental education accreditation standards there is no adolescent-specific content, not even in the subspecialty of pediatric dentistry where adolescents are included in the definition of children.

Consistent licensure and certification standards for providers who work with adolescents would help to ensure a more competent and skilled workforce. Depending on the specific regulatory body in each state that governs licensing, certification, and accreditation, the state may want to convene local professional organizations and key stakeholders to create consensus around and incorporation of adolescent-focused competencies into the health workforce standards and systems.

THE STATE AS COORDINATOR: STATES CAN PROMOTE LINKAGES BETWEEN HEALTH SERVICES FOR ADOLESCENTS

States can help bridge gaps and reduce duplications in adolescent health services by 1) promoting coordination among the various public agencies involved in identification, referral, and provision of health services for adolescents and 2) helping link these services with private primary health care. State agencies, including those for mental health, Medicaid, education, and public health (the latter including Maternal and Child Health, oral and reproductive health, injury prevention, nutrition and physical activity, and substance abuse programs), can assist in coordination and linkage of services.

Adolescent health services could be improved by linking separate, fragmented, and poorly coordinated programs.

- **Improving health systems for adolescents will require attention to coordinating behavioral, reproductive, mental health, and dental services in practice and community settings.**
- **Incorporating health promotion, disease prevention, and youth development throughout the health system and within the community is an important part of advancing adolescent health.**

Currently adolescent health services consist of separate, fragmented, and poorly coordinated programs that are delivered in a variety of public and private settings. Because adolescent health issues are often social in nature, they can be addressed through various systems: health, school, family, and community. Many health services take a problem-oriented approach and focus on care for specific conditions or issues, failing to meet the broader needs and behavioral challenges for adolescents. Public health interventions and case management can play a critical role in promoting adolescent health.

The NRC/IOM report recommends that “federal and state agencies, private foundations, and private insurers support and promote the development and use of a coordinated primary health care system that strives to improve health services for adolescents.” This system would coordinate services between primary and specialty care and interaction among primary care services and programs for adolescents in safety-net settings, including schools, hospitals, and community centers.

Techniques to coordinate and link services include: co-location and regional planning organized by a variety of stakeholders; programs for managing referrals; coordinating electronic patient information; and establishing adolescent call centers. Electronic health records, which provide a critical opportunity to coordinate care, and electronic personalized health education services, need to be designed to meet the needs of adolescents.

The NRC/IOM report calls for coordinated, linked, and interdisciplinary adolescent health services to be established within communities with the help of public agencies. In many cases, primary care providers are not familiar with community resources that can be used for referrals to address behaviors. Primary care providers cite a lack of referral sources as a major barrier to identifying and meeting mental health needs of adolescents and their families. Managed care “carve outs”—separate insurance plans for specialty oral health, mental health, and substance abuse benefits—provide enrollees with a limited panel of professionals who may not have expertise working with adolescents or using evidence-based interventions. Primary care providers may not have access to the list of professionals on the insurance plan’s panel; families must obtain these services directly. Directories of community providers or family support networks can assist in linking adolescents to community referral sources.

Mechanisms such as specific referral practices, referral management, and specialty consultation can improve links between primary care and specialty services (behavioral, nutritional, oral, sexual, and reproductive health services) and would improve the accessibility, acceptability, and appropriateness of health services for adolescents.

NEW OPPORTUNITIES

The NRC/IOM report presents recommendations to strengthen and improve health services for adolescents. Several recent developments will position states to act on these recommendations:

- The Children’s Health Insurance Program Reauthorization Act of 2009 (CHIPRA), enacted in February 2009, increased funding for the CHIP program over a four and a half year period. CHIPRA provides funding to cover an additional 4.1 million otherwise uninsured children, 83 percent of whom were already eligible before reauthorization.¹² The law gives states incentives and tools to cover low-income children, with a particular focus on already eligible but unenrolled children, and includes funding for outreach. CHIPRA also reduces barriers for states to provide subsidies for the purchase of employer-sponsored insurance and contains several provisions around improving child health quality. As mentioned in this report, CHIPRA also allows states to cover otherwise eligible legal immigrant children; mandates dental benefits for CHIP beneficiaries; and establishes mental health parity.
- There are multiple resources through the American Recovery and Reinvestment Act (ARRA) of 2009 for states to address missing opportunities to improve adolescent health.
 - Prevention and wellness funds will be available to “carry out evidence-based clinical and community-based prevention and wellness strategies and public health workforce development...”.
 - The act provides financial opportunities to improve health information technology in ways that could improve services and care coordination for adolescents.
 - ARRA includes \$87 billion for a temporary increase in the federal matching percentage for Medicaid from October 1, 2008 through December 31, 2010, which is designed to help states during a time in which there will be increased demands on their Medicaid programs for all populations, including adolescents.
 - Community health centers (CHCs) are receiving significant funds from ARRA to be invested in capital, infrastructure, HIT, and operations to enhance the availability of primary care for the under- and uninsured of all ages. In 2007, CHCs served approximately 2.5 million adolescents ages 10-19; these patients made up 16 percent of the total CHC patient population.¹³

CONCLUSION

The NRC/IOM committee envisions improved systems for adolescent health services that: incorporate evidence-based and standardized screening tools and management of referral processes in primary care settings; facilitate linkages between primary and specialty care providers; and expand connections between primary care providers and community agencies that provide health promotion, disease prevention, behavioral health, and youth developmental services provided by health professionals with appropriate training in adolescent medicine.

States, in their various roles, including as major insurers and purchasers of health care; regulators of health professionals, institutions, and health plans; and coordinators, have many opportunities to improve system performance for, and influence the health of, adolescents.

As the NRC/IOM report asserts, “Policy matters. Policies, both public and private, can have a profound effect on adolescent health services. Carefully crafted policies are a foundation for strong systems of care that meet a wide variety of individuals and community needs.”

ENDNOTES

- 1 National Research Council and Institute of Medicine. (2009). *Adolescent Health Services: Missing Opportunities*. Committee on Adolescent Health Care Services and Models of Care for Treatment, Prevention, and Healthy Development, R.S. Lawrence, J. Appleton Gootman, and L.J. Sim, *Editors*. Board on Children, Youth, and Families. Division of Behavioral and Social Sciences and Education. Washington, DC: The National Academies.
- 2 U.S. Census Bureau, Current Population Survey, 2008 Annual Social and Economic Supplement, Table HI08: Health Insurance Coverage Status and Type of Coverage by Selected Characteristics for Children Under 18: 2007. Retrieved online 27 April 2009. http://www.census.gov/hhes/www/macro/032008/health/h08_000.htm
- 3 National Conference of State Legislatures, *Adolescent Health: A Snapshot for State Legislatures* (Denver, CO: NCSL, 2009).
- 4 Children's Health Insurance Program Reauthorization Act of 2009, Pub. L. no.111-003, 123 Stat 8 (2009). Print.
- 5 Center for Children and Families, *The Children's Health Insurance Program Reauthorization Act of 2009: Overview and Summary* (Washington, DC: Center for Children and Families, Georgetown University Health Policy Institute, February 2009).
- 6 The Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit is the package of benefits for children and adolescents enrolled in Medicaid. Under EPSDT requirements, states must provide comprehensive health and developmental assessments, as well as vision, dental, and hearing services, to children and youth up to age 21. EPSDT focuses on prevention-oriented services for the early identification of disabling conditions, but also covers the diagnostic and treatment services necessary for acute and chronic physical and mental health conditions.
- 7 NASHP staff tracking efforts.
- 8 Children's Health Insurance Program Reauthorization Act of 2009, Pub. L. no.111-003, 123 Stat 8 (2009). Print.
- 9 Ibid
- 10 Kaiser Family Foundation, *Health Coverage for Low-Income Americans: An Evidence-Based Approach to Public Policy* (Washington, DC: KFF, January 2008).
- 11 The Society for Adolescent Medicine (SAM) is a multi-disciplinary organization of health professionals who advance the health and well-being of adolescents through education, research, clinical services, and advocacy activities.
- 12 Center for Children and Families *The Children's Health Insurance Program Reauthorization Act of 2009: Overview and Summary* (Washington, DC: Center for Children and Families, Georgetown University Health Policy Institute, February 2009).
- 13 Authors' calculations from U.S. Department of Health and Human Services, Health Resources and Services Administration, Bureau of Primary Health Care. "The Health Center Program: 2007 National Aggregate UDS Data."