

P r e f a c e

In 1998, the Association of Maternal and Child Health Programs (AMCHP), Policy Information and Analysis Center for Middle Childhood and Adolescence (Policy Center), and National Adolescent Health Information Center (NAHIC) initiated this collaborative project in the area of adolescent health and the State Children's Health Insurance Program (CHIP). The project grew out of the recognition of CHIP's tremendous potential to improve the health of millions of low-income adolescents and the parallel realization that, despite a proliferation of research materials and technical assistance about CHIP, relatively few efforts have been focused on using the new legislation to meet adolescents' unique needs. We hope that this document will provide readers – including policymakers, advocates, purchasers, health plans, researchers and providers – with a greater understanding of the overall health needs of adolescents, how these needs might be addressed under CHIP, and how select states are addressing this population under the new federal/state program.

This publication summarizes key findings and themes from interviews conducted in the fall of 1998 with representatives from 12 states: Alabama, California, Colorado, Connecticut, Florida, Illinois, New Mexico, New York, North Carolina, Massachusetts, Utah, and Wisconsin. Findings from the interviews

are divided into nine major sections: Benefit Package, Outreach and Enrollment, Assuring Access to Care, Confidentiality, Adolescents with Special Needs, School-Based/School-Linked Health Centers, Quality Assurance, Evaluation, and Linkages with Other Health and Social Service Programs. Following a chapter that introduces these themes and their importance relative to adolescents, each section of the Findings chapter includes an overview of key findings from interviews with 12 states, highlights of state strategies in that area, and recommendations for improving adolescent health under the CHIP program.

An important caveat: States' implementation of CHIP is rapidly evolving. At the time of the initial survey, most states were proceeding with program implementation but continuing to struggle with major issues such as conducting outreach to potentially eligible populations. As such, this publication is a work in progress. The findings represent the "state-of-the-states" in Fall 1998, however, we recognize that many states are now further along in their efforts to address the needs of adolescents under CHIP. This document is not a definitive overview of CHIP and adolescents; readers who want more information in general or in a specific area should refer to the Resources section contained in Appendix D of this document.

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Executive Summary

The State Children's Health Insurance Program (CHIP) presents an important opportunity for meeting the complex health care needs faced by low-income, uninsured adolescents, including those with special needs. Done well, it allows states to diminish financial barriers to care, thus improving adolescents' access to health care services that are developmentally appropriate, meet their health care needs, and help to ensure that these adolescents can achieve their full potential as healthy, productive adults.

While CHIP provides states with an unprecedented opportunity to expand health insurance coverage for children and adolescents, health insurance – whether public or private – does not guarantee that youth will actually receive services that can assure their overall health. In order to improve adolescent health, states must establish systems and provider networks that are available, accessible and appropriate. Given adolescents' historically low rates of insurance and service utilization, it will be especially critical for states to design and implement targeted programs that attract, enroll and serve eligible low-income adolescents, particularly those with special health care needs.

Making adolescent health a priority is timely not only because of the passage of CHIP, but also because adolescents are increasing as a percentage of the overall population for the first time in 20 years. It is estimated that the number of young people ages 10-19 will increase by 13 percent between 1995 and 2005, with even greater population growth expected in certain states, such as California, where the increase is projected to be as high as 34 percent (Brindis and Wolfe, 1997). These population projections also point

to greater numbers of young people of color, who are more likely to live in poverty, to be uninsured, and to underutilize primary and preventive health care services.

This publication represents a synthesis of interviews with state policymakers in 12 states, reviews of key research and reports, and the experience of the Association of Maternal and Child Health Programs (AMCHP), Policy Information and Analysis Center for Middle Childhood and Adolescence (Policy Center), and National Adolescent Health Information Center (NAHIC) in adolescent health financing and delivery. While the report only highlights the findings and efforts of 12 states, it represents a window to some of the nation's promising practices for adolescents under CHIP, and some of the challenges that states are facing in enrolling and serving adolescents in their CHIP programs. It is hoped that this report will illuminate the wealth and richness of states' efforts to assure adolescents are included in CHIP implementation and, building on this early experience, provide examples and recommendations for how CHIP programs might be further strengthened to best serve all adolescents, including those with special needs.

The following highlights key findings and recommendations from the study, summarized in broad themes. Readers are strongly encouraged to refer to the complete report for more detailed information regarding state findings and program efforts, examples of state innovations, and more detailed recommendations. In addition, Appendix D provides readers with a list of resources in various areas of CHIP and adolescent health.

HIGHLIGHTS OF KEY FINDINGS

States are responding to the challenge of implementing CHIP with a great deal of creativity and innovation. Particularly encouraging are efforts in the areas of outreach and enrollment, relatively comprehensive benefit packages, and collaborations between a multitude of public, private and community-based partners. Indeed, all states are conducting some form of general outreach and enrollment to adolescents, often utilizing schools and school-based health centers. A majority of states interviewed have also initiated outreach efforts to specifically target at-risk youth.

The states included in this report were covering adolescents, including those with special needs, under the basic benefit package and all were focusing efforts, in varying degrees, on some of the more critical health services needed for adolescents, including reproductive, mental health, substance abuse, and dental services. Reproductive health services, however, continue to be impacted by ongoing political debate and struggles over the perceived need for these services. As might be expected, care for youth with special health care needs under CHIP differs from state to state. Efforts to address the needs of these youth and for at-risk youth are still in the very early stages of development and in need of more comprehensive focus and attention. For example, comprehensive outreach efforts targeted to at-risk adolescents, coupled with attention to how states are actually going to serve these youth, are not fully developed.

While all states are proactively engaging schools and school-based health centers (SBHCs) in outreach and enrollment, fewer are actively engaging SBHCs in their CHIP provider networks or relationships with managed care organizations (MCOs). In fact, states do not appear to have fully leveraged the opportunities presented by CHIP to involve safety net providers, including local health departments, community health centers and SBHCs, in a comprehensive system of care for adolescents, whether through specific contract language or other mechanisms. Few states are yet assuring that adolescent-oriented providers are available and identified under their CHIP programs.

Most states are addressing access issues for all CHIP enrollees but few have identified provisions to reduce barriers to care specifically for adolescents. In particular, confidentiality protections are a key access issue and concern for many states. However, all states are beholden to state confidentiality laws, which in some cases may impede adolescents' access to care.

Finally, most states have not fully established quality assurance mechanisms and evaluation plans under CHIP for all eligible groups, let alone efforts that specifically address adolescents. Nonetheless, most states are encouraging or requiring the use of preventive service guidelines such as those developed by the Maternal and Child Health Bureau (i.e., Bright Futures), the American Academy of Pediatrics, and/or the American Medical Association (i.e., GAPS). On the other hand, few state have established mechanisms for monitoring whether or how they are being implemented.

By all indications, the 12 states interviewed for this study recognize that the unique health needs of low-income adolescents require targeted efforts and expressed intentions to further address this population. Although most states acknowledge that adolescents require special focus and efforts under CHIP, major challenges remain in addressing the unique needs of this population.

Recommendations for Assuring That CHIP Meets the Unique Needs of Adolescents

Benefit Package

- Include age-appropriate clinical preventive services in the benefit package.
- Establish age-appropriate periodicity schedules for clinical preventive health visits and update state EPSDT periodicity schedules to reflect prevailing national recommendations for annual well-adolescent exams.

- Establish a comprehensive benefit package that includes mental health, substance abuse, dental, and reproductive health services.
- Provide the same level of coverage for mental health/substance abuse services as for other forms of health care.

Outreach and Enrollment

- Develop CHIP promotional materials that are targeted to adolescents and involve adolescents in the development of such materials.
 - Locate outreach efforts and eligibility workers in areas that adolescents frequent.
 - Specifically target outreach and enrollment efforts to high-risk youth.
 - Train hotline operators to answer questions frequently posed by adolescents.
 - Simplify application and enrollment procedures.
- Educate adolescents and their families about how to access various primary, specialty and sub-specialty services (e.g., enrollment procedures, gatekeeper referrals for specialty care, grievance procedures).
 - Do not require that parents include their social security numbers on adolescents' enrollment applications.
 - Establish an adolescent "hotline" to provide information to adolescents on how to most effectively enroll for CHIP and utilize CHIP services.
 - Establish mechanisms that enable adolescents to select and access their own primary care providers (PCPs) separate from their families, and inform adolescents and family members of this option.

Access to Care

- Identify Board-eligible and/or Board-certified Adolescent Medicine Specialists to serve as primary care providers, subspecialty consultants, and referral sources for primary care gatekeepers.
 - Encourage adolescent providers who have training and skills in providing care coordination and primary care in reproductive health, mental health, and substance abuse treatment to act as primary care providers for adolescent CHIP enrollees.
 - Encourage self-designation as an adolescent provider by those who are committed to working with adolescents.
 - Clearly identify adolescent-oriented providers and services in CHIP and health plan marketing materials.
- Establish procedures to assure confidentiality for services that minors can access without parental consent, including preventive reproductive care; screening for pregnancy, HIV and sexually-transmitted infections; family planning counseling and contraception; treatment for sexually-transmitted infections; and outpatient mental health and substance abuse services.
 - Include specific requirements regarding state confidentiality laws in CHIP contracts with MCOs and providers.
 - Work with health plans to increase awareness of adolescent health confidentiality laws.
 - Educate adolescents about the confidentiality protections available to them.
 - Allow adolescents to obtain confidential services without a referral from their primary care provider.
 - Design and implement information systems that protect adolescent confidentiality.

- Monitor providers' and health plans' compliance with confidentiality protections for adolescents.

Adolescents with Special Needs

- Establish higher income eligibility ceilings for youth with special health care needs.
- Use risk adjustment methods to ensure that health plans and providers enroll and serve adolescents with special needs.
- Ensure access to a broad range of specialty services, especially mental health and substance abuse services, with reasonable or no cost-sharing.
- Ensure that provider networks established under CHIP include providers with the specialized expertise necessary to treat adolescents with special needs.
- Establish more generous benefits for adolescents with special needs, such as higher spending limits for durable medical equipment and coverage of home visiting and respite care; greater allowable numbers of occupational and physical therapy visits; and greater allowable numbers of inpatient and outpatient mental health and substance abuse services.
- Assure that case managers and care coordinators are trained and knowledgeable about transition programs for adolescents with special health care needs.
- In states where mental health services are provided as a separate program or carveout from the basic CHIP program, develop mechanisms to assure that care is coordinated between the two systems.
- Establish relationships with providers and community-based organizations that serve at-risk youth (e.g., homeless and runaway shelters).

- Build or enhance coordination and linkages between CHIP and other systems that serve adolescents with special needs, including public health, education, social services, juvenile justice, vocational rehabilitation, and adult transition programs.

- Assure that community providers (e.g., school-based health centers, family planning clinics, local health departments, and federally qualified health centers (FQHCs)) are deemed essential community providers.

- Involve at-risk adolescents and adolescents with special health care needs, as well as their families, in key areas of CHIP design and implementation, including outreach and enrollment, benefit package, and quality assurance.

School-Based/School-Linked Health Centers

- In contracts with managed care organizations (MCOs), include requirements that MCOs include SBHCs and other adolescent safety net providers in their provider networks.
- For states that do not want to impose sub-contracting requirements on MCOs, consider "carving out" SBHC services or a subset of these services and reimbursing SBHCs for serving CHIP enrollees on a fee-for-service basis.
- For states that do not do so at present, consider supporting SBHCs through state Title V or other programs.
- States should ensure that CHIP funds are not used to subsidize services under other federal programs such as the Individuals with Disabilities Education Act (IDEA).

Assuring Quality Care

- Incorporate adolescent-specific professional guidelines for clinical preventive services such as GAPS and Bright Futures.
- Establish quality assurance measures and systems that pay specific attention to adolescents and their unique needs.
- Use data from the quality assurance process to help adolescents and their families select health plans and providers; to encourage competition and quality improvement; to shape contracts and contract decisions; and to adjust subsidies, benefits, contracts, and enrollment procedures so that CHIP programs best meet the needs of eligible adolescents.
- Establish a clearinghouse of materials for states to use in designing and implementing quality assurance activities.

Evaluation

- Build on existing measures, tools and systems to implement evaluation strategies that are feasible.
- Develop comprehensive measurement tools that emphasize health and wellness across the continuum of care using a wide range of methods, including: practice guidelines, satisfaction surveys, performance measures, internal quality improvement systems, external quality reviews, accreditation of health plans, credentialing of providers, and consumer protections.
- Involve adolescents, families, advocacy organizations, providers and other stakeholders in program evaluation.
- Conduct periodic evaluations that measure and report comparisons with baseline information and among subgroups by age, gender, race/ethnicity, household income, region, provider, and health plan.

- Track adolescents' enrollment, disenrollment and use of services within CHIP and other systems of care.
- Create partnerships between state Medicaid and public health agencies, including state Title VMCH/CSHCN programs, in order to build expertise and maximize the use of data that states are already collecting.

Linkages with Other Programs and Systems

- Develop or strengthen linkages between the state's CHIP program and other state and local health agencies and community-based health programs that serve adolescents, including Title V MCH/CSHCN, family planning, mental health, substance abuse, school-based/school-linked health centers, local health departments, and federally-qualified health centers.
- Establish linkages between state CHIP programs and non-health agencies and programs, including social services, education, and youth-serving organizations.
- Ensure that clear, uniform processes are established and/or maintained that link adolescents to needed community-based services and provide appropriate coordination and follow-up.
- Ensure that MCOs have developed linkages to public health agencies, social services, education systems, and essential community-based providers.

Although not directly addressed in much of this document, maintaining and utilizing a sufficient and comprehensive cadre of providers that are trained in adolescent health and sensitive to adolescent needs is central to the premise that CHIP can improve the health of adolescents. Even if all adolescents were covered by health insurance, states would need to continue their efforts to build and support systems that are responsive – even proactive – to adolescent needs.

Our study indicates that few states are assuring that adolescent-oriented providers are identified and available under their CHIP programs. This may be attributable, in part, to the fact that few health care providers specialize in adolescent health, and that most medical providers are inadequately trained to recognize adolescent health problems whose origins may be primarily psychosocial instead of physical.

Additionally, it is important to note that with the rapid conversion in the U.S. health care system to managed care, states and advocates for adolescents might want to focus their efforts on making managed care organizations more responsive to the needs of adolescents, and particularly the underserved adolescents now eligible for state CHIP programs. They should also work to ensure that capitation rates paid to health plans and providers are sufficient to cover the comprehensive range of services needed by adolescents, especially those with special needs. Given the generous federal match available to states for their CHIP expenditures, it is critical that policymakers and program administrators balance the desire to hold down costs with appropriate incentives for providing high-quality, accessible care to eligible adolescents.

Finally, CHIP will not resolve larger issues regarding access to care and health insurance coverage for a large number of adolescents and young adults who will not be reached by this program. The Society for Adolescent Medicine, for example, defines adolescence to include individuals ages 10-25; CHIP and other public health insurance programs, however, frequently establish eligibility ceilings at age 18 or younger. And yet, in 1996, almost 30 percent of 18-24 year-olds were not covered by any public or private health insurance (U.S. Bureau of the Census, 1998).

Indeed, those who are over 19, whose family incomes exceed state eligibility ceilings, or who face other barriers to coverage, are not well-served by CHIP; nor are the millions of adolescents with private insurance that omits or limits coverage for the services they need most. Short of enacting a universal health insurance system, covering these teens will require ongoing creativity and resources from states, territories and the federal government.

I. Introduction and Background

THE STATE CHILDREN'S HEALTH INSURANCE PROGRAM

The Balanced Budget Act of 1997 (BBA) provides approximately \$40 billion in funding over the next 10 years for the new State Children's Health Insurance Program (CHIP), established as Title XXI of the Social Security Act.¹ CHIP enables states to establish and/or expand health insurance coverage for low-income children and adolescents, including those with special health care needs. Not since the creation of the Medicaid program over 30 years ago has there been such an opportunity to expand health insurance coverage for this population.

Under Title XXI, states have the option of expanding their existing Medicaid programs, creating a separate state children's health insurance program, or developing a program which is a combination of these two approaches. They can cover uninsured children and adolescents up to age 19 with family incomes up to 200 percent of federal poverty guidelines² or higher for states which already have coverage at this level.³ By providing eligible children and adolescents with approved coverage, states can access federal matching dollars at rates that are significantly higher than their regular Medicaid matching rates, ranging from 65–84 percent based on the number of low-income uninsured children in that state⁴ (English, 1999). Under a combination program, for example, a state that currently provides Medicaid coverage for adolescents up to age

13 with family incomes up to 100 percent of federal poverty could expand this coverage to adolescents ages 14-18, while simultaneously creating a state program for children and teens with family incomes between 100 and 185 percent of poverty. That state would receive the enhanced federal match for all program expenditures resulting from the expansion and the new program.

The U.S. Department of Health and Human Services (HHS) is the federal agency responsible for approving states' CHIP plans; within HHS, the Health Care Financing Administration (HCFA) has the primary responsibility for plan review and oversight (General Accounting Office, 1999). HCFA has given states until September 30, 1999 to have their CHIP plans approved in order to access funds allotted for Federal Fiscal Year 1998.

As of May 25, 1999, 54 out of 57 states and territories had submitted CHIP plans to HCFA, 51 had been approved, and 49 state programs had been implemented (National Governors' Association, 1999). Of approved plans, 28 states proposed Medicaid expansions, 12 proposed separate state child health insurance plans, and 13 were a combination of the two (National Governors' Association, 1999). As of January 1, 1999, only seven states had plans that had been operating for a full 12 months; on average, programs had been in operation for about six months (Department of Health and Human Services, 1999). By the

¹ The Balanced Budget Act of 1997, Pub. L. No. 105-33, 111 Stat. 251 (1997), Title IV, Subtitle J, State Children's Health Insurance Program, Sections 4901-4923 (including provisions for establishing separate state children's health insurance programs, expanding Medicaid coverage, implementing presumptive Medicaid eligibility for children, continuing Medicaid eligibility for children losing SSI benefits, and creating special diabetes programs for children).

² For the 48 contiguous states in 1999, this amounts to \$33,400 for a family of 4 (Federal Register, 1999). The guidelines are higher for residents of Alaska and Hawaii.

³ Title XXI allows states to cover adolescents in families with incomes up to 200% of the federal poverty guidelines, or 50 percentage points higher than their existing eligibility ceiling if it already exceeds 150% of poverty.

⁴ For Fiscal Year 1998, federal matching rates for CHIP were 9% - 30% higher than regular Medicaid matching rates, which range from 50% - 77% in Fiscal Year 1999 (HCFA, 1999).

end of the first quarter of 1999, states had enrolled more than 1 million children and adolescents in their CHIP programs, exceeding enrollment projections for this time.⁵ It is encouraging that so many states have chosen to participate in this optional program: even given strong financial incentives, the high rate of participation and tremendous state resources expended to date are testament to states' commitment to improving children's and adolescents' access to care. Indeed, the U.S. General Accounting Office (1999) noted that, despite the short implementation period and the related challenges of establishing a stand-alone program distinct from Medicaid, the states and federal government have made considerable progress in getting CHIP up and running.

ADOLESCENT HEALTH AND ADOLESCENTS' HEALTH CARE NEEDS

2

Adolescence is a unique developmental stage, distinct from both childhood and adulthood. It is one of life's most important periods – a time of accelerated growth during which a number of physiological, cognitive, social and emotional changes occur simultaneously. Although the vast majority of adolescents are healthy by medical standards, many adolescents have serious health care needs. For example, as many as 30 percent of adolescents suffer from depression (Roberts, Lewinsohn, and Seeley, 1995; Heffron, 1998). Rates of several sexually-transmitted infections are higher among adolescents than any other age group, with 3 million adolescents contracting a sexually-transmitted infection every year (Eng and Butler, 1997). Each year, approximately 2 million young people ages 15 to 24 attempt suicide and over 4,000 take their own lives (Ventura, Anderson, Martin, and Smith, 1998). About one quarter of all new HIV infections each year occur among young people under age 22 (Centers for Disease Control and Prevention, 1998).⁶ And almost 1 million adolescent females ages 15-19 become preg-

nant every year. Other adolescent health problems include chronic medical problems such as asthma and diabetes; injuries resulting from violence or motor vehicle accidents; and complex physical and psychological conditions such as eating disorders and substance abuse (Ozer, Brindis, Millstein, Knopf, and Irwin, 1998).

In 1991, the United States Congressional Office of Technology Assessment estimated that one in five adolescents suffers from at least one serious health problem, and as many as one in four are believed to be at high risk for school failure, delinquency, early unprotected sexual intercourse, or substance abuse (U.S. Congress Office of Technology Assessment, 1991). Between 5-10 percent of adolescents have a chronic disease or disability, such as asthma, heart disease, vision impairment, or hearing loss; one half of these youth have conditions severe enough to limit their major daily activities. In addition, 20-50 percent of teens have a wide array of other, less severe medical problems such as acne, dysmenorrhea, or gynecomastia (U.S. Congress Office of Technology Assessment, 1991).

Many adolescent health problems have their origins in the risky behaviors that are frequently initiated during the teen years. In fact, the leading causes of morbidity and mortality among adolescents are directly attributable to such risky behaviors; and many of the health-damaging behaviors (including tobacco use, poor nutrition and physical inactivity) that cause adult morbidity and mortality begin in adolescence (Kann, Warren, Harris, Collins, Douglas, Collins, Williams, and Kolbe, 1998). Three out of four deaths during adolescence are caused by social morbidities: unintentional injuries, homicide and suicide (Irwin, Igra, Eyre, and Millstein, 1997). Researchers have identified six categories of risk-taking behavior which are responsible

⁵ Approximately 540,000 of these children and adolescents were enrolled in non-Medicaid state CHIP programs and 442,000 were enrolled in Medicaid-CHIP (M-CHIP) expansion programs (U.S. Department of Health and Human Services, 1999). These numbers do **not** include children and adolescents who were enrolled in traditional Medicaid programs as a result of enhanced outreach under state CHIP programs.

⁶ Given the long latency period between HIV infection and symptoms of AIDS, and given low rates of HIV testing among adolescents, researchers speculate that these data significantly understate the real threat and prevalence of HIV/AIDS in America's adolescents.

for 70 percent of adolescent mortality and morbidity: drug and alcohol abuse, unsafe sexual activity, violence, injury-related behavior, tobacco use, inadequate physical activity, and poor dietary habits (National Academy of Sciences, 1998). Between 25-30 percent of adolescents are considered at high risk based on the reported prevalence of high-risk behaviors such as drinking and driving or drinking to abuse (Downs and Klein, 1995).

In addition, certain subgroups of adolescents face special, heightened health risks. For example, adolescents with chronic physical or mental health conditions; who live in foster or group homes; who are homeless or have run away from home; who are undocumented, migrant or newly immigrated to the United States; whose English language skills are limited; who are gay, lesbian, bisexual or transgender; who are incarcerated or involved in the juvenile justice system; and who are pregnant or parenting are all vulnerable groups. These teens are more likely to have acute and complex health care needs (Irwin, Brindis, Holt, and Langlykke, 1994).

Many of the health problems described above occur disproportionately among the CHIP target population. In fact, low-income adolescents have been shown to have higher rates of morbidity, mortality and health risk behaviors in almost every category studied. These risks also tend to be higher among adolescents of color (Newacheck, Hughes, and Cisternas, 1995).

The above information highlights the critical need and value for providing adolescents, particularly those eligible for CHIP, with comprehensive, accessible health care services. Prevention and primary care services are particularly critical for this population given that the most serious, costly and widespread adolescent health problems – unintended pregnancy, sexually-transmitted infections, motor vehicle injuries, unintended injury, and substance use – are potentially preventable (English, Kappahn, Perkins, and Wibbelsman, 1998). Through education, screening, anticipatory guidance, counseling, early intervention and treatment, preventive care can help to establish health habits in

adolescents that last a lifetime (Ozer, et al., 1998). In addition, research shows that resources allocated toward preventive services for adolescents can have significant economic benefits. For example, immunizations, chlamydia screening, teen pregnancy prevention programs and tobacco prevention/cessation have all been demonstrated to be cost-effective (Centers for Disease Control and Prevention, 1999).

ADOLESCENTS' ACCESS TO CARE

Health Insurance

Health insurance is an important means by which adolescents gain access to health care services. Uninsured teens use fewer health services, have longer intervals between receiving health care services, return for fewer follow-up appointments, and have a greater likelihood of seeking care in an emergency room (Newacheck, Hughes, and Cisternas, 1995; Lieu, Newacheck, and McManus, 1993). They are less likely to have their health problems treated and less likely to receive medical care from a physician when necessary.

In 1995, 14.1 percent of adolescents ages 10-18 (4.2 million teens) were not covered by any form of public or private health insurance (Newacheck, Brindis, Cart, Marchi, and Irwin, 1999). In other words, one in every seven adolescents was uninsured. For low-income and non-white adolescents, this proportion is even higher: adolescents with family incomes below the federal poverty guidelines are three times more likely to be uninsured as those from families with incomes above federal poverty; African-American teens are 40 percent more likely than white adolescents to be uninsured; and Hispanic adolescents are three times more likely than their white peers to be without health insurance (Newacheck, et al., 1999). In fact, nearly one in three Hispanic adolescents was uninsured in 1995; this proportion may have grown following the introduction of anti-immigration policies in recent years.⁷ These ethnic differentials persist even when controlling for family income, employment and family composition.

⁷ See page 20 for information about the 1996 Personal Responsibility and Work Opportunity Reconciliation Act.

In the past several years, the number and proportion of adolescents covered by private, employer-based health insurance has declined (Newacheck et al., 1999). As a result of increasing health insurance costs, more employers are requesting higher employee contributions for dependent coverage, while other employers are eliminating dependent coverage entirely. The incomes of many families have been too high for their adolescent children to qualify for Medicaid eligibility, but too low to purchase private health insurance. In fact, nearly 60 percent of uninsured adolescents live in families in which at least one parent is employed full-time year-round, with another 20 percent in families with a parent who is employed part-time (Klein, Slap, and Elster, 1992). In other words, the majority of uninsured adolescents live in “working poor” or near-poor families, further emphasizing the importance of programs such as CHIP that are linked neither to welfare receipt nor to employer-based coverage. These families are among those targeted by CHIP.

The Role of Medicaid

Since 1965, the federal/state Medicaid program has represented an important source of insurance coverage for poor and near-poor adolescents. Due to the passage of the Omnibus Budget Reconciliation Acts (OBRA) of 1986 and 1989, greater numbers of adolescents are currently eligible for Medicaid. OBRA legislation mandated that states gradually phase older adolescents with higher family incomes into their Medicaid programs, with all adolescents under age 19 living in families with incomes less than 100 percent of federal poverty required to be covered by the year 2002.⁸

Title XXI encourages states to accelerate the Medicaid phase-in and to cover all poor adolescents up to age 19 immediately by allowing them to claim the enhanced federal match for extending this coverage. Prior to CHIP, approximately half of states had not included 14-18 year-olds with family incomes below 100 percent of federal poverty in their Medicaid programs.

Since CHIP, almost all of these states have accelerated the phase-in, with 23 states covering adolescents with family income levels equal to or higher than 200 percent of federal poverty, either through Medicaid or a separate state program (English, 1999).

Barriers to Access

Historically, adolescents have used the fewest primary care services of all age groups in the United States (U.S. Congress Office of Technology Assessment, 1991). In a recent study of the 1994 National Ambulatory Medical Care Survey, all groups of adolescents studied were underrepresented in office-based physician visits relative to their proportion of the population (Ziv, Boulet, and Slap, 1999). Although health insurance helps to facilitate utilization, even teens who do have health insurance coverage may not use needed services that are available to them. Some additional barriers to adolescents’ receiving necessary care include:

- **Transportation/inconvenient hours:** Most teens have to rely on walking, their parents, and/or public transportation to reach health care providers, yet physicians and community health clinics have traditionally not scheduled their locations or hours of service around adolescents’ needs. Long waits to obtain an appointment and/or long waiting times at the provider site may deter adolescents even more than they do adults, especially when the health need is not perceived as urgent.
- **Cost:** Even very low co-payments for visits may discourage teens and their families from initiating preventive or primary care visits. Families with low incomes may also struggle with premiums and deductibles demanded by employers, state-sponsored/subsidized programs, and/or private insurance policies.
- **Fragmentation:** The traditional health care system has been characterized as “seriously inadequate in dealing with the health of adolescents” (National Academy of Sciences, 1998). The com-

⁸ Federal law currently requires Medicaid coverage for all children under age 6 whose family income is less than or equal to 133 percent of federal poverty; of those between 6 and 15 years of age, only those with incomes \leq 100 percent need to be covered.

plexity of this system, as well as the rapid changes underway, are difficult for even the most sophisticated adult consumers to navigate. Most teens are far less experienced with recognizing and anticipating their own needs, accessing health care services, navigating their way through complex sets of categorical programs and eligibility requirements, and/or advocating for their needs. For adolescents just beginning to access health services independently, the system may be an overwhelming experience that deters or delays appropriate care. Providing physical and mental health services in different distinct locations may further reduce utilization of preventive services.

- **Concerns about confidentiality:** Most states have laws requiring that an adolescent's parent or legal guardian provide consent for the teen to receive health care services. Such laws and policies may stand in the way of adolescents receiving care when consent is unavailable or teens are worried that their parents will learn about "sensitive" medical or behavioral information. The wide variation in state laws pertaining to parental consent and confidentiality complicates these issues for health professionals, adolescents, and parents. The resulting confusion, coupled with fears of disclosure, diagnosis and treatment, may cause adolescents to delay or avoid needed care (Society for Adolescent Medicine, 1992). Although most physicians support providing confidential care for adolescents, many are uncomfortable with family negotiations that may surround independent care and decision-making (Society for Adolescent Medicine, 1992).
- **Lack of provider participation:** Historically, this has been more of a factor for adolescents covered by Medicaid, for which reimbursement rates were significantly lower than private insurance, and for which delays in receiving payment acted as a strong disincentive for providers to accept Medicaid patients. Under managed care, this often translates into low capitation rates that may not adequately reflect the comprehensive health care needs of Medicaid/CHIP beneficiaries.
- **Shortage of providers trained in adolescent health:** Few clinicians specialize in adolescent health, and most medical staff are inadequately trained to recognize health problems whose symptoms may be primarily psychosocial instead of physical. Although most adolescent medicine specialists are trained as pediatricians, only 21 percent of office visits by patients 15-17 years old are to pediatricians (Ziv, Boulet, and Slap, 1999). Regardless of specialty, relatively few health professionals are comfortable with providing care for many of the preventable health problems of adolescents (Blum and Bearinger, 1990).
- **Cultural barriers:** Analysis of the 1994 National Ambulatory Medical Care Survey reveals that black and Hispanic adolescents are underrepresented in physician office visits relative to their white peers, and that these differences in utilization persist after controlling for health insurance and socioeconomic factors (Ziv, Boulet, and Slap, 1999). This finding suggests a mismatch between health care providers, teen clients, and their families. Although increasingly diverse, the current provider workforce does not reflect the growing ethnic and cultural diversity of America's adolescents. According to the U.S. Congress Office of Technology Assessment (1991), the disproportionately high incidence of some health problems, historical inequity and discrimination, and a dearth of information about how racial and ethnic minority youth experience adolescence make it especially difficult for minority adolescents to receive appropriate services.
- **Limited insurance coverage:** Some private insurance policies do not cover preventive services for adolescents, or cover fewer than the number of preventive visits that most professional groups recommend. Adolescents who are "underinsured" have health insurance policies that do not include or sharply limit visits for preventive care, mental health services, substance abuse treatment, dental health, or other needed care.

DEVELOPING SYSTEMS OF CARE THAT RESPOND TO ADOLESCENTS' NEEDS

A number of criteria can be used to evaluate how well adolescents' health care needs are being met in new or existing health care systems. These parameters may be useful in helping a state design and implement a CHIP program that is more responsive to the unique needs of adolescents. For example, the Society for Adolescent Medicine (SAM) has compiled a list of criteria with which to evaluate access to quality care for adolescents (Klein et al, 1992). These dimensions reflect the specialized needs of adolescents which are important to consider in understanding how well youth are being served. They include:

- **Availability:** Age-appropriate services and trained health care providers must be present in every community.
- **Visibility:** Health services for adolescents must be clearly recognizable, convenient, and should not require extensive or complex planning by adolescents or their parents.
- **Quality:** Health professionals treating youth should demonstrate a basic level of competence with adolescents who, in turn, should feel satisfied with the care they receive.
- **Confidentiality:** Adolescents should be encouraged to involve their families in health decisions, but confidentiality must be assured.
- **Affordability:** Public and private insurance programs must provide adolescents with both preventive and other additional services to decrease morbidity and mortality and to promote positive health behaviors.
- **Flexibility:** Providers, services and delivery sites must consider the cultural, ethnic and social diversity among adolescents.
- **Coordination:** Service providers must ensure that comprehensive services are available to adolescents.

■ **Focus on acute, medical care:** Traditionally, the U.S. health care system has emphasized the treatment of physical problems rather than health promotion and disease prevention; mental health services have also been limited. Both providers and insurers are accustomed to this emphasis, despite the fact that adolescents often benefit more from preventive and primary care services that integrate their physical and psychosocial needs.

■ **Provider attitudes:** Perhaps more than adults, adolescents are sensitive to the attitudes of the individuals to whom they turn for advice and care (Klerman, 1999). The age difference between adolescent and provider, the more limited ability of adolescents to seek alternative providers, and general feelings of insecurity and conflict about dependency make adolescents more sensitive to provider expressions of indifference or disapproval.

THE ROLE OF STATE TITLE V PROGRAMS UNDER CHIP

State Title V maternal and child health (MCH) and children with special health care needs (CSHCN) programs⁹ are critical partners in states' efforts to serve adolescents under CHIP. These agencies have a long history of serving the needs of adolescents, particularly through programs such as teen pregnancy prevention, school health, and school-based health centers. In addition, many pregnant and parenting teens receive prenatal and support services through Title V funding dedicated to preventive health services for women and infants.

State Title V programs have resources and expertise in developing and administering programs and service delivery systems that meet the unique needs of all women, children and adolescents, including those with special health needs, and have particular experience in meeting the needs of low-income populations who are underserved by existing health systems. In 1999, over \$580 million in federal funds were allocated to state Title V programs. States matched these funds (three state dollars for every four federal dollars) and in many cases provided additional state funds above the match requirement. By law, state Title V programs are required to spend 30 percent of funds on preventive and primary care for children and youth (ages 0 to 21) and 30 percent on services for CSHCN. Through grants, contracts, and/or reimbursement to public and private providers, state Title V programs support the availability and accessibility of community health and family support services for uninsured and underinsured families. In 1996, Title V programs served nearly 19 million women, children and adolescents (Association of Maternal and Child Health Programs, 1999).

State Title V programs offer multiple areas of expertise to CHIP planning and implementation, including:

- conducting outreach and enrollment for low-income adolescents and their families;
- developing public health prevention programs and services targeted to adolescents, including those at risk for poor health;
- developing programs and services for children and adolescents with special health care needs;
- providing services or connecting adolescents to other programs that may not be part of states' benefit packages;
- developing monitoring and quality assurance systems to measure whether adolescents are receiving services and whether these services are impacting their overall health status;
- providing data on the health status of youth; and
- designing service delivery systems with a focus on coordination and integration of various public and private systems (Hess, 1997).

A few state Title V programs, working with state Medicaid agencies and other partners, have the lead responsibility for the administration and implementation of state CHIP programs. In states where Title V programs are not the lead agency, they are often key partners in the development and implementation of CHIP programs.

⁹ Authorized under Title V of the Social Security Act, the Maternal and Child Health (MCH) Services Block grant focuses broadly on the health of women, infants, children and youth, including those with special health care needs. In 1981, Title V's categorical programs were consolidated under block grant legislation, and states were given increased discretion in their use of federal funds. Amendments in 1989 included important changes which improved state accountability while maintaining program flexibility. The term "state Title V programs" is used throughout this document to refer to the state Title V MCH Services Block Grant.

OPPORTUNITIES PRESENTED BY CHIP

The State Children's Health Insurance Program represents an important opportunity for meeting the complex health care needs faced by low-income, uninsured adolescents in the United States. Done well, it allows states to diminish financial barriers to care, thus improving adolescents' access to health care services that are developmentally appropriate, meet their health care needs, and help to ensure that these adolescents can achieve their full potential as healthy, productive adults. While states may be facing many of the same problems their Medicaid programs faced (e.g., the stigma of public benefits, complex enrollment procedures), the flexibility of CHIP offers those states a clear opportunity to improve, for example, enrollment efforts and screening levels for eligible adolescents.

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While CHIP provides states with an unprecedented opportunity to expand health insurance coverage for children and adolescents, health insurance – whether public or private – does not guarantee that young people will actually receive health care services that can assure their overall health. In order to improve adolescent health, states must establish systems and provider networks that are available, accessible and appropriate. Given adolescents' historically low rates of insurance and service utilization, it will be especially critical for states to attract, enroll and serve eligible low-income adolescents, particularly those with special health care needs.

Making adolescent health a priority is timely not only because of the passage of CHIP, but also because adolescents are increasing as a percentage of the overall population for the first time in 20 years. It is estimated that the number of young people ages 10-19 will increase by 13 percent between 1995 and 2005, with even greater population growth expected in cer-

tain states, such as California, where the increase is projected to be as high as 34 percent (Brindis and Wolfe, 1997). These population projections also point to greater numbers of young people of color who are more likely to live in poverty, to be uninsured, and to underutilize primary and preventive health care services. Nationally, the number of Latino youth age 10-19 will increase by 44 percent between 1995 and 2005; the African-American youth population is expected to increase by 17 percent; and adolescents of "other ethnicity" (Asian/Pacific Islander, Native American) are expected to grow by 39 percent (Brindis and Wolfe, 1997).

The remainder of this document is devoted to critical issues for adolescents under CHIP; ensuring that the federal/state CHIP program is successful in meeting its stated goals; and ways in which some states are addressing these critical issues.

II. Methodology

During the fall of 1998, staff from AMCHP, the Policy Center and NAHIC developed an eight-page survey designed to elicit information regarding states' CHIP plans and programs for adolescents. The survey was based on the three organizations' experience in adolescent health financing, organization and delivery, as well as the parameters of the new legislation. The final survey reflected a focus on key areas of interest, including confidentiality, access to care, and quality assurance.

States were selected based on a number of factors, including: a history of innovative programs in adolescent health; whether their CHIP plan had been approved by HCFA; and preliminary information about the creativity of the state program/plan. A preliminary list was generated and then adjusted to ensure broad geographic and demographic representation, as well as a balance between Medicaid expansion, new state programs, and combination plans. One state that was initially selected was replaced because it was at too early a stage in its CHIP implementation. The final 12 states selected for the project were: Alabama, California, Colorado, Connecticut, Florida, Illinois, New Mexico, New York, North Carolina, Massachusetts, Utah and Wisconsin.

The survey was mailed to each state's Title V director, adolescent health coordinator¹⁰, CHIP coordinator, and/or other individuals who had been identified as working on CHIP planning and implementation. Because our goal was to obtain the most comprehensive

and accurate information available, we added and/or substituted interview respondents as appropriate. A complete list of those interviewed is provided in Appendix A.

After the selected respondents had a chance to review the survey instrument, project staff scheduled telephone interviews with respondents individually or in groups of up to five persons. Phone interviews followed the format of the written survey, but with supplemental probes added where appropriate to further elicit relevant information.

Although staff relied primarily on information obtained through the interviews, this document also reflects information gathered from other sources, including published literature, conference presentations, states' formal CHIP plans/amendments, and other documentation submitted by states. Where information could not be obtained from interview respondents, staff used supporting data sources or contacted additional state representatives.

The recommendations in this document were developed based on the survey findings and experiences of state respondents. They were also based on existing research, literature, and the experience of AMCHP, the Policy Center and NAHIC in adolescent health services financing and delivery. NAHIC's work, most notably *Assuring the Health of Adolescents in Managed Care*, and several AMCHP documents, including *Partnerships for Healthier Families: Principles*

¹⁰ State adolescent health coordinators (SAHCs) are individuals within a given state or territory that are responsible for planning, implementing and evaluating policies and programs that impact the health and well-being of adolescents. Currently, 54 states and territories support at least a part-time SAHC, with many of these positions funded in whole or in part through the Title V Maternal and Child Health Block Grant. The extent to which SAHCs are involved in CHIP planning and implementation in their states varies significantly; the representation of SAHCs in this study reflects that variation. For more information on state adolescent health coordinators, please refer to Appendix D.

for Assuring the Health of Women, Infants, Children and Youth Under Managed Care Arrangements and Focusing on Results: How State Title V and Children's Health Insurance Programs Can Work Together for Healthier Children, helped to provide the framework and foundation for this project, the key areas of study, and the survey design.

Finally, the document was reviewed by a number of internal and external experts, including interview respondents; staff from the Maternal and Child Health Bureau's Office of Adolescent Health; and representatives from multiple national organizations, including the National Governors' Association; Center for Adolescent Health and the Law; Family Voices; and National Assembly on School-Based Health Care. All relevant feedback was incorporated into the final document.

III. Major Issues for Adolescents Under CHIP

Although a multitude of issues were raised by the interviews, and by the group's previous work in adolescent health, many of these issues fell into nine consistent "domains": Benefit Package, Outreach and Enrollment, Assuring Access to Care, Confidentiality, Adolescents with Special Needs, School-Based/School-Linked Health Centers, Quality Assurance, Evaluation, and Linkages with Other Health and Social Service Programs. This chapter identifies the nine areas; why they are important for adolescents in general; and how they might be addressed by states and their partners under CHIP. Although we have made every effort to address the issues separately here, it should be obvious to readers that interrelationships between them are more common than distinctions. For example, adolescents with special needs are treated as an "issue area" distinct from others, and yet, for these adolescents, the CHIP benefit package, outreach efforts, and linkages with other systems of care are clearly critical. In addition, Appendix B contains a table which indicates the issues that interview respondents identified as their top three priorities for adolescents under CHIP.

Benefit Package

States that elect to provide CHIP coverage through Medicaid expansion are required to cover a standard set of benefits that includes physician visits, hospitalization, prescriptions, immunizations, and preventive care. In addition, state Medicaid programs must cover services specified under the Early and Periodic Screen-

ing, Diagnostic and Treatment (EPSDT) program (see page 12). EPSDT includes many of the services adolescents need, including anticipatory guidance, case management, family planning services, mental health care, substance abuse treatment, and rehabilitative services. With EPSDT, Medicaid is highly comprehensive, covering all medically necessary services for children and adolescents.

States that elect to provide coverage through a non-Medicaid plan under Title XXI have significantly more leeway in their benefit package design. A few states have opted to provide the full Medicaid benefit package, but without the entitlement¹¹ feature; these plans are known as Medicaid "look-alike" plans. According to Title XXI, other states must provide a benefit package that is the same or actuarially equivalent¹² to the coverage provided to enrollees under one of the three following "benchmark" plans: the standard Blue Cross/Blue Shield Preferred Provider option offered under the Federal Employees Health Benefits Program; a health benefits plan that is offered and available to state employees in that state; or the HMO with the largest commercial enrollment in that state. These are only minimum requirements; in fact, the definition of child health assistance that states may provide with the new funds includes a very lengthy and comprehensive list of benefits. Services covered under a separate child health insurance program may be provided in a broad range of settings and by a broad range of providers.

¹¹ Under an entitlement program, any individual who meets the defined eligibility criteria is "entitled" to receive the benefits of that program; Medicaid is an entitlement program because states **must** cover all persons deemed eligible and receive federal matching funds to do so. Under a non-Medicaid CHIP program, states can "cap" the number of enrollees they accept based on costs or other factors; thus, eligible children and adolescents are not legally "entitled" to this program. Because federal matching for states' non-Medicaid programs is capped, some states may perceive a non-entitlement program as a fiscally safer alternative to expanding Medicaid.

¹² To be actuarially equivalent, the total value of the CHIP benefit package must be at least equivalent to one of the benchmark packages. The package must include, at a minimum, inpatient and outpatient hospital services; physicians' surgical and medical services; laboratory and x-ray services; and well-child care, including age-appropriate immunizations. Additional services, such as prescription drugs, mental health services, and vision or hearing services, must be included only if such services are covered in the benchmark package; if they are, the actuarial value of these benefits under the CHIP plan must be at least 75 percent of their actuarial value in the benchmark package.

EPSDT

Federal law establishes a minimum benefit package that must be available to all children and adolescents who are eligible for Medicaid. This federally mandated Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program includes periodic comprehensive physical and mental health assessments that must be provided in accordance with a schedule developed by states in consultation with professional child health organizations. Under Medicaid EPSDT, states are required to provide a comprehensive range of early detection and prevention services that includes health assessment, screening and support services; comprehensive acute and chronic care; medical, dental, vision, hearing and well-child check-ups; immunizations; lab tests; and health education. Finally, EPSDT requires states to provide children and adolescents with services that are “medically necessary” in order to treat physical and/or mental conditions identified during EPSDT screenings. Medically necessary services include physical, speech and occupational therapies, as well as assistive devices such as wheelchairs and orthotic equipment.

Although EPSDT is widely hailed as the “gold standard” for child and adolescent benefit packages, there have been widespread problems with states’ implementation of the program. For example, few states have established periodicity schedules that require annual screening for teens, despite virtual consensus in the professional community that annual exams are appropriate (English et al., 1998). In addition, states have struggled to reach all eligible beneficiaries with EPSDT services, with reported rates of delivery that fall well below federal goals. In contrast to HCFA’s goal of 80 percent participation in EPSDT for adolescents, the national participation rate for 15-20 year-olds in 1996 was only 51 percent (Olson, Perkins, and Pate, 1998). Only 11 percent of Medicaid beneficiaries in this age group received vision screens, 6 percent received hearing screens, and 18 percent received dental screening services (Olson, Perkins, and Pate, 1998). Low screening rates reflect many of the same barriers that prevent teens from receiving services throughout the country. Despite these problems, however, most adolescent health professionals support EPSDT as an important program with high potential.

While specific benefit packages vary from state to state, generally a non-Medicaid CHIP package will include routine care services, such as physician services, prescription drugs, laboratory services, and radiological services with no stated limits, while offering mental health, substance abuse, ancillary therapies, and other specialized services on a more limited basis (Fox, McManus, Graham, and Almeida, 1998). According to English (1999), virtually all states offer more than the minimum benefit package required by Title XXI.

In general, advantages to implementing a Medicaid expansion program under CHIP include:

- a comprehensive benefit package that can meet the needs of all adolescents, including those with special health care needs;
 - enhanced purchasing power with managed care plans and providers;
 - reduced confusion due to different rules, administration and services (e.g., different children in the same family being eligible for different programs); and
 - less financial risk to the state.¹³
- existing administrative and provider systems that cover the entire state;

¹³ If a state exceeds its federal CHIP allotment, all remaining expenditures for a separate state program must be paid entirely through state funds, whereas any costs incurred under a state’s Medicaid expansion would be eligible for federal matching at that state’s regular Medicaid matching rate.

On the other hand, non-Medicaid programs offer states certain advantages in serving their adolescent populations, including:

- greater flexibility to target specific groups and/or areas of the state;¹⁴
- the ability to control costs better by crafting a more limited benefit package;
- the ability to cover more children and adolescents by offering a less costly benefit package;
- potentially less “welfare stigma”;
- the ability to modify programs more easily because there are fewer federal requirements; and
- the fact that CHIP does not create a new entitlement, allowing states to scale back eligibility and/or benefits when budgets are tight.

Combination programs allow states to tailor these two sets of incentives based on their unique demographics, needs, insurance markets, and managed care/delivery systems.

Although Medicaid has received its share of criticism, advocates have expressed more concern with states’ non-Medicaid CHIP programs. They observe that the benchmark plans available to states under Title XXI are not likely to be ideal for child or adolescent members. With the exception of Medicaid, none of these plans was developed with a pediatric population – let alone a low-income, previously uninsured population with a potentially high level of unmet need – in mind. The risk is that the services low-income adolescents often need, including mental health/substance abuse, reproductive health, dental services, and preventive care, will not be covered to an adequate degree under states’ new or expanded CHIP programs. For example, if a state’s CHIP program does not specify

that health plans must cover contraception and family planning, these services may not be available to teens enrolled in CHIP. The following information highlights adolescents’ needs in these four areas of health care services.

- **Mental Health and Substance Abuse.** Recent studies indicate that the rate of depression among adolescents may be as high as 30 percent (Roberts, Lewinsohn, and Seeley, 1995; Heffron, 1998); epidemiological studies indicate that many teens suffer from more than one mental health problem (Weist, Ginsberg, and Shafer, 1999). It is estimated that between 10 and 20 percent of adolescents attempt suicide each year and that one quarter of high school students have suicidal thoughts. In fact, suicide is the third leading cause of death for adolescents (Kann, Warren, Harris, Collins, Douglas, Collins, Williams, and Kolbe, 1996; Kann, Warren, Harris, Collins, Douglas, Collins, Williams, and Kolbe, 1998). In addition, approximately 13 percent of young people ages 9-17 are considered seriously emotionally disturbed: they have severe emotional or behavioral difficulties that significantly interfere with their ability to function socially, academically, and/or emotionally (Heffron, 1998).

Finally, substance use among teens is high and appears to be growing in at least some subgroups (Johnston, O’Malley, and Bachman, 1998). Although not all substance use requires treatment, a significant number of low-income adolescents require intensive assistance to help them with addiction to alcohol and/or illicit drugs. In short, access to a continuum of preventive through emergency inpatient and outpatient mental health services is critical to the health and well-being of many young people.

¹⁴ Non-Medicaid CHIP programs are not required to be statewide.

14 ■ **Reproductive Health.** Data from the 1997 Youth Risk Behavior Survey (YRBS) indicate that 49 percent of high school students report ever being sexually active (Kann et al, 1998), however, only 44 percent of sexually active teenage males consistently use condoms (Sonenstein, Stewart, Duberstein, Lindberg, Pernas, and Williams, 1998). An estimated 3 million adolescents contract a sexually-transmitted infection each year (Eng and Butler, 1997), and about one quarter of all new HIV infections each year occur among young people under age 22 (Centers for Disease Control and Prevention, 1998). Nearly 1 million teens become pregnant each year (National Campaign to Prevent Teen Pregnancy, 1997). Coverage of contraception, family planning and other reproductive health care services for adolescents under CHIP is crucial in assuring that young people who are sexually active can act responsibly.¹⁵ For pregnant and parenting teens, access to comprehensive perinatal care and ongoing health education and support services are also critical.

■ **Dental Coverage.** Dental services are an important area of need for many adolescents. A national survey indicates that by age 17, the average adolescent will have eight cavities; 60 percent of adolescents are reported to have gingivitis and bleeding in more than one tooth (Permanente Medical Group, Inc., 1996). Federal officials note that dental caries are much more common than childhood asthma, and that poor oral health can lead to rare heart damage, pain, malnutrition, and sleeplessness. They are also responsible for 52 million missed school hours every year (Goldberg, 1999). For low-income, uninsured adolescents, these needs may be even greater. Data from the National Health and Nutrition Examination Survey III indicate that the amount of tooth decay is inversely related to income level (Edelstein, 1998); moreover, uninsured children are 2.5 times less likely to obtain dental care than insured children (Monheit and Cunningham, 1992).

These data reflect the finding that dental services, particularly preventive ones, may not be readily available to low-income and/or uninsured adolescents. Clearly, then, dental coverage is an important element for states to include in their non-Medicaid CHIP programs for adolescents. States are encouraged, but not mandated, to provide dental services in their CHIP programs, and coverage varies based on the benefit package states implement. States that want to provide the most comprehensive dental coverage available should consider following the Medicaid EPSDT model.

■ **Preventive Services.** As described in Chapter I, a wide range of prevention services can help to ensure that adolescents are physically and emotionally healthy. Preventive services recommended for adolescents by all of the major clinical preventive services guidelines include screening for depression, sexually-transmitted infections, suicide risk, tuberculosis and substance use; counseling for diet, exercise, injury prevention, substance use and violence prevention; and immunizations for measles, mumps, rubella, tetanus, diphtheria and Hepatitis B (American Medical Association, 1992; Green, 1994; Stein, 1997; U.S. Preventive Services Task Force, 1996; and U.S. Public Health Service, 1998). Unfortunately, private insurance policies often do not cover as wide a range of preventive services as does Medicaid.

¹⁵ Like Medicaid, Title XXI contains severe restrictions related to abortion.

Outreach and Enrollment

Well-intentioned programs with comprehensive benefit packages and minimal cost-sharing requirements will fail to achieve their most fundamental goal – to decrease the number of children and adolescents without health insurance – if they do not identify and enroll eligible youth. Historically, it has been more challenging to enroll adolescents in public health insurance programs than it has been to enroll younger children (Selden, Banthin, and Cohen, 1998). Therefore, it will be especially important for state CHIP programs to make additional efforts to reach out to eligible adolescents.

Under Title XXI, states must describe how they will enroll eligible children into CHIP. They can use up to 10 percent of their total program expenditures for outreach and enrollment, administration, the direct purchase of health services, and other child health assistance. Unfortunately, this level of expenditure may be limiting to states' efforts; therefore, many states are using private funding, such as the Robert Wood Johnson Foundation's Covering Kids Initiative, to support or enhance their strategies. Successful programs will need to use these funds creatively to develop engaging and compelling information campaigns to attract significant numbers of youth and their families.

States can improve adolescent CHIP enrollment by streamlining enrollment procedures and coordinating them with the eligibility and enrollment procedures for related programs (e.g., Free and Reduced Lunch Program; Women, Infants and Children Supplemental Nutrition Program (WIC)). Title XXI also provides states increased flexibility regarding presumptive eligibility and continuous eligibility for Medicaid. Under Title XXI, states can immediately and temporarily en-

roll children and adolescents under 19 in Medicaid if they appear to qualify based on their age and family income levels. This process is known as *presumptive eligibility*. While states have experience with presumptive eligibility for pregnant women, implementing this approach for adolescents may require different strategies, particularly in selecting sites where eligible adolescents can be identified. The legislation also specifies that WIC, child care and Head Start programs, in addition to Medicaid providers, can qualify eligible clients presumptively for Medicaid. In addition to presumptive eligibility, states can implement *continuous eligibility* provisions – guaranteeing Medicaid coverage for up to 12 months regardless of changes in family income or family structure.

States also have flexibility in determining eligibility that can help to further streamline application and enrollment processes. These include simplifying CHIP applications and the process for completing and submitting these applications; limiting or eliminating some of the documentation required to determine eligibility; and allowing families to self-declare assets (HCFA letter, 9/10/98). As of May 25, 1999, 22 of the 25 states that were implementing separate child health insurance initiatives had developed joint applications for their Medicaid and non-Medicaid programs (National Governors' Association, 1999). Moreover, most states have created mechanisms for families to submit CHIP applications by mail and make applications available at multiple sites (Office of the Inspector General, 1999). On the other hand, the U.S. Office of Inspector General reports that joint Medicaid/CHIP applications are typically longer than CHIP-only applications and found that, for the 19 states' CHIP applications it analyzed, questions and vocabulary were complex and difficult for families with limited education to comprehend.

Delinking Welfare and Health Care

Prior to the passage of the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) in 1996, all families who received AFDC were automatically eligible for Medicaid. Under the new law, families covered by Temporary Assistance for Needy Families (TANF), the time-limited financial support program that replaced AFDC, are still eligible for Medicaid, but they must enroll independently. Welfare experts fear that families will not enroll until there is a medical emergency, and that opportunities to provide eligible children and adolescents with primary and preventive care services will be missed.

Resources for Outreach and Enrollment

- **Covering Kids: A National Health Access Initiative for Low-Income, Uninsured Children.** This program, sponsored by the Robert Wood Johnson Foundation (RWJF), is designed to help states and local communities increase the number of eligible children and adolescents who are enrolled in health insurance programs. Working through broad state-local coalitions, this three-year initiative will facilitate efforts to design and conduct outreach programs that identify and enroll eligible children into Medicaid, CHIP and other programs; simplify enrollment processes; and coordinate existing coverage for low-income children and adolescents.

Covering Kids is intended to complement new and ongoing federal, state, and private-sector activities to expand coverage to children and adolescents, and to involve private sector organizations (e.g., churches, businesses, health plans, providers) and traditional child advocacy organizations in an effort to ensure better health outcomes for children and teens.

Initially, Covering Kids was planning to award grants ranging from \$500,000 to \$1 million to no more than 15 state-community coalitions over a three-year period. Coalition memberships must include child advocates, providers, health plans, private coverage programs, state representatives, and two to three local community coalition members. Because intense interest created by the passage of CHIP led to an overwhelming response – 45 states submitted proposals to join the program – RWJF expanded its commitment to \$47 million to enable funding of any state recommended by the National Advisory Committee. In order to be recommended, states must submit proposals that meet the program’s criteria and have a successful site visit. All 50 states and the District of Columbia are eligible for Covering Kids under the new terms.

- **Welfare Reform.** The 1996 legislation that created welfare reform also contained provisions for states to access a significant amount of funding which they can use to conduct outreach and enrollment for children and adolescents eligible for Medicaid and CHIP. This legislation established a \$500 million Medicaid fund to help states ensure that children and parents losing welfare were made aware of their continued eligibility for Medicaid. These funds, which are allotted to states, provide an enhanced federal matching rate – up to 90 percent for certain outreach activities – for outreach and administrative costs related to this narrow group of Medicaid-eligible people. States are just beginning to take advantage of these funds for their Medicaid and CHIP initiatives (Health Care Financing Administration, 1999).
- **Insure Kids Now.** In February 1999, a national hotline was launched to expand access to information about health insurance coverage available through CHIP and Medicaid for families with uninsured children and adolescents. The toll-free hotline (**1-877-KIDS-NOW**) connects callers to information about the health insurance program(s) in their state of residence. Parents can request applications to be mailed to them, receive help completing the application, check on the status of a submitted application, and get answers to general questions about CHIP and Medicaid. Many states provide this information in several languages and operate during extended hours to ensure access for working families. A variety of creative approaches are being implemented to increase awareness of the hotlines and to increase calls from potentially eligible clients. For example, Alabama sent out 850,000 application packets to public school children which generated an increased volume of calls and enrollees. The National Governors’ Association (NGA) developed the hotline and is working with the Clinton Administration, as well as several public and private sector partners, to promote it. In addition, the U.S. Department of Health and Human Services has sponsored a radio publicity campaign to increase awareness. More information can be found at <http://www.insurekidsnow.gov>.

Given their extensive experience in this area, many state Title V programs are serving as the lead agency in conducting outreach and enrollment efforts under CHIP. Indeed, the Title V Maternal and Child Health Services Block Grant statute requires states to conduct outreach activities that enhance Medicaid enrollment and improve access to preventive and primary health services for women, infants, children and adolescents, including those with special health care needs.¹⁶

Unfortunately, outreach and enrollment efforts are likely to be complicated by recent changes in other social service programs, most notably welfare reform. In 1996, the federal Welfare Reform Bill separated eligibility for Temporary Assistance to Needy Families (TANF - the program that replaced Aid to Families with Dependent Children (AFDC)) from eligibility for Medicaid, eliminating an important opportunity to enroll young people and families in both programs simultaneously. As a result, advocates warn that both Medicaid and CHIP will need to increase their efforts to reach eligible youth.

Assuring Access to Care

The need to assure access to care is not unique to CHIP; many of the issues that health care professionals have struggled with for decades remain as states plan and implement their CHIP programs. Strategies for reducing barriers to access for adolescents include: relaxing age and financial eligibility requirements; limiting financial barriers such as co-payments and insurance premiums; reducing geographic barriers to care in rural and other underserved areas; assuring appropriate numbers and qualifications of primary care and specialty providers; ensuring that providers, staff and services are age-appropriate; and addressing cultural and linguistic barriers.

According to Title XXI, no cost-sharing, including deductibles or co-payments, may be imposed for preventive services, specifically well-child care and immunizations (English, 1999). States also have flexibility in calculating family income: for example, they can disregard certain expenses, such as medical expenses for children with special health care needs in determining program eligibility.

Approximately half of CHIP plans submitted to HCFA in September 1998 included some cost-sharing provisions, whether through premiums, co-payments, and/or enrollment fees (National Academy of State Health Policy, 1998). It is important that cost-sharing requirements under CHIP do not create a barrier to adolescents' access to care. One study by the Urban Institute (1997) found that when premiums were one percent of income, over half (57 percent) of the uninsured would participate in a publicly subsidized insurance program; premium increases above this level resulted in a significant reduction in participation. Co-payments pose additional barriers for families of children and adolescents with chronic conditions because they tend to require a higher volume of services. In those few circumstances where adolescents are able to access coverage and services based on their own assets (see *Confidentiality*), cost-sharing should be kept to a minimum.

Rural and frontier communities face numerous barriers in delivering health care services to adolescent CHIP enrollees. It is more difficult for these communities to develop and maintain a basic infrastructure for delivering health care; recruit and retain health care providers; maintain adequate emergency medical services; overcome barriers to telemedicine; and structure managed care arrangements to meet their populations' health needs (National Governors' Association, 1998).

¹⁶ Under Title V of the Social Security Act, the state Title V program (1) "will provide for a toll-free telephone number (and other appropriate methods) for the use of parents to access information about health care providers and practitioners..." and (2) "provide, directly and through their providers and institutional contractors, for services to identify pregnant women and infants who are eligible for medical assistance."

In addition, families living in urban communities may face additional barriers to access – such as fears about personal safety due to higher rates of community violence, limited public transportation, and a shortage of trained providers – that require unique solutions. Whether bound by geographic or other barriers, CHIP implementation in rural or other underserved communities is complicated by a limited number of providers with expertise in adolescent health; a limited number of multicultural and multilingual service providers; and hours of service that are not conducive to working families. Assuring that there are sufficient numbers of quality primary care and specialty providers willing and able to serve the influx of adolescents enrolled in CHIP is an issue many states are just beginning to address. Fortunately, states can obtain a waiver to use additional funds (beyond the 10 percent set-aside) to purchase services directly through community providers in cases where it is cost-effective (e.g., in rural areas or inner-city neighborhoods that lack other service providers.)

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Confidentiality

During adolescence, young people begin to seek increased autonomy and to take more responsibility for their own health and well-being. Even in the best family circumstances, adolescents may be hesitant to discuss some health concerns with their parents. The ability to access some types of health care independently may encourage teens to seek services they might not otherwise receive if care were only available with parental consent. It may also increase adolescents' sense of competence and self-efficacy.

There are two primary issues concerning confidentiality and adolescent health care. The first is the opportunity for adolescents to consent confidentially for certain types of services without parental involvement. This right is often reserved for certain categories of adolescents, such as emancipated or pregnant teens, and may be restricted to certain types of “sensitive” services. The second is the right of adolescents to have information from confidential medical records made available to others (e.g., parents, other providers) only with their explicit written consent.

Data indicate that young people are capable of giving informed consent between 12 and 15 years of age and, depending upon the circumstances, generally arrive at the same health care decisions as adults (McCabe, 1996; Weithorn and Campbell, 1982). Studies also demonstrate that adolescents have health concerns they do not want their parents to know about, and that some would forgo health care if they thought their parents might find out (Cheng, Savageau, Sattler, and DeWitt, 1993). Because of these concerns, some adolescents delay seeking help for a variety of sensitive problems such as sexually-transmitted infections, physical or sexual abuse, pregnancy, substance abuse, and mental health concerns. As a result, many youth face these problems with misinformation, lack of adult guidance, and fear of recrimination. They risk worsening their health problems, and increasing the physiological, psychological, and financial costs (English and Knopf, 1999).

To encourage early detection and treatment of sensitive health problems, most states have legal provisions allowing adolescents to receive some types of confidential health care in specific circumstances. Although most states' CHIP programs will follow these laws and policies, Title XXI appears to allow states the flexibility to address adolescent confidentiality in different and creative ways.

Adolescents with Special Needs

Children and adolescents with special health care needs are defined as “those who have or are at increased risk for a chronic, physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson, Arango, Fox, Lauver, McManus, Newacheck, Perrin, Shonkoff, and Strickland, 1998). According to the 1988 National Health Interview Survey on Child Health, as many as 8.6 million (31.5 percent) of adolescents ages 10-17 years old had one or more chronic conditions; 16 percent of these – 1.4 million adolescents with chronic conditions – experienced long-term limitations in their activities as a result of their conditions (Blum, Garell, Hodgman, and Slap, 1993). Ser-

vices provided to youth with special health care needs account for an estimated 25-50 percent of all child health expenditures (King, 1999). In addition to the primary and preventive services that all adolescents need, youth with special health care needs require access to a range of services that consider their overall growth and development, including pediatric specialty and tertiary care; family support services (e.g., respite care); nutritional counseling; special education; and related habilitative/rehabilitative services. The challenge for families of adolescents with special health care needs lies in accessing an often fragmented system of care, where specialty services are not coordinated with primary care, and coverage for services is not comprehensive (Brown, 1999). Because these families often confront unique barriers to obtaining and maintaining adequate health insurance and access to care, it is critical that states' CHIP programs include elements and features that are specifically designed to address common issues for adolescents with special health care needs.

The above estimate does not include adolescents who are at increased risk for a variety of adverse health outcomes. This population is impossible to quantify, given the absence of an accepted definition of "at-risk" or standardized method for measuring it. Generally, groups considered to be at-risk include: pregnant and parenting teens; undocumented and migrant adolescents; gay, lesbian and transgender youth; and homeless and runaway teens.

Young people who are living apart from their families, including homeless and runaway youth, adolescents in foster care, and incarcerated youth, experience a higher incidence of certain health problems and may also experience severe barriers to access because of logistic complexities and separation from families who

can facilitate their care (English, 1998). For example, adolescents living in foster homes have both an increased need for health care services, as a result of their high rates of physical, developmental and mental health problems, and documented limitations in their access to necessary care (English, 1999).

The size of the homeless population has been estimated to be approximately 300,000 young people each year (Institute for Health Policy Studies, 1995).¹⁷ A 1995 study by the Research Triangle Institute estimated that 2.8 million youth in the United States reported a runaway experience during the prior year (Green, Ringwalt, and Kelly, 1995). Although most runaways return home, 25 percent become chronic "street kids," often as a way of coping with dysfunctional families. Many of these teens have been abused or neglected, and many use drugs or engage in prostitution in order to survive. They are at higher risk for suicide than their peers, and at least one half of runaways suffer severe long-term social and medical problems that persist into adulthood (Society for Adolescent Medicine, 1992). Finally, the 300,000 adolescents confined in juvenile justice facilities each year are at especially high risk for many health problems. Many of these teens have health problems when first incarcerated and do not receive adequate care during their confinements (Bilchik, 1999; Butts, Snyder, Finnegan, Aughenbaugh, and Poole, 1996).

Under Title XXI, states may not restrict program eligibility based on disability, and eligibility standards may not discriminate on the basis of diagnosis or deny eligibility because of a preexisting condition.¹⁸ On the other hand, states do have the flexibility to target children and adolescents with special health care needs (CSHCN) within their CHIP programs. This flexibility in the law is important, because most existing state

¹⁷ Estimating the number of runaway and homeless youth is extraordinarily difficult for multiple reasons, including the lack of a common definition of what constitutes runaway behavior, failure to report teen absences, and the transient nature of this population (National Network for Youth, 1998).

¹⁸ State plans may not permit exclusions for treating preexisting conditions, *unless the state contracts with an existing group plan that has such exclusions*. (In that case, the plan may apply the exclusion to the newly enrolled children under CHIP, but must meet other federal law requirements related to covering preexisting conditions under the federal Health Insurance Portability and Accountability Act of 1996 (King, 1999)).

Immigration and Adolescents Under CHIP

The 1996 Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) included provisions to restrict some legal immigrants' access to public programs of various kinds. This law created a concern among some providers and policymakers that immigrants' enrollment in and use of health and social services for which they might still be eligible – including Medicaid, WIC, prenatal care, Head Start and Food Stamps – would decline as a result of this legislation.

CHIP administrators have reported that some families have been reluctant to apply for CHIP as a result of their immigration status (Office of Inspector General, 1999). Individuals involved in the CHIP application process state that fear of being detected makes illegal aliens reluctant to complete an application even for their children who meet citizenship requirements. Legal immigrants may also be reluctant to apply for CHIP, fearing that use of a public benefit will adversely affect their application for permanent residence or citizenship (Office of Inspector General, 1999).

On May 25, 1999, however, the Immigration and Naturalization Service (INS) and Department of Justice (DOJ) released guidelines clarifying that receipt of non-cash health benefits such as Medicaid and CHIP can not be used as criteria to declare a person a “public charge” and therefore make them subject to certain sanctions. These guidelines state that immigrants who receive non-cash assistance programs such as Medicaid, CHIP, WIC, immunizations and prenatal care will not be subject to deportation or “public charge” status that would negatively impact their chance for citizenship (Health Resources and Services Administration, 1999). Although this guidance does not change underlying eligibility for programs such as Medicaid and CHIP, it may help to encourage immigrants to apply for health insurance coverage for their children. In addition, the U.S. Department of Health and Human Services has officially indicated that states may not deny benefits to otherwise qualified legal alien children under Title XXI CHIP programs. Both qualified and unqualified immigrant children may be served using the 10 percent of funds that states can use for outreach, administration, and purchase/provision of direct services.

For Hispanic/Latino children and adolescents particularly, whose enrollment rates in CHIP have been low, this interpretation helps to support state efforts to conduct more targeted outreach efforts to these populations. In California, for example, Hispanic children and adolescents are estimated to comprise 62 percent of those eligible for the new Healthy Families program (Finberg, 1998); however, they represent only 51 percent of enrollees (Healthy Families, 1999). Although nine of ten eligible Latino children are U.S. citizens, 40 percent of them have a parent who is an immigrant (Finberg, 1998). Given sufficient education and outreach efforts (see *State Spotlight* on page 35), enrollment of eligible Latino adolescents can be expected to rise.

insurance programs target relatively healthy children and rely on Medicaid to cover those who have high-cost medical needs (King, 1999). They do not cover many of the services needed by children with intense medical needs; instead, states tend to shift those children to their Medicaid programs precisely because of its generous benefit package and federal matching funds. In fact, one recent study reveals that the majority of non-Medicaid CHIP programs impose amount, duration or scope of restrictions on the most services important to children and adolescents with special needs (Fox, Graham, McManus, and Chen, 1999). Although state Title V programs may be able to provide supplemental services for adolescents who need additional benefits not covered under a non-Medicaid CHIP program, advocates suggest that providing comprehensive coverage to these adolescents through CHIP is a preferable strategy.

Thus, provisions in Title XXI allow states to design a separate state program for most children and adolescents at a given income level, but provide Medicaid coverage to CSHCN at the same income level (Grumet, 1998). In other words, a state could receive enhanced federal matching for extending Medicaid to adolescents with special health care needs whose family income would not otherwise qualify them for Medicaid coverage. States can create less restrictive income categories for children and adolescents with special health care needs, providing them with program eligibility at higher income levels than other youth of the same age. They can also disregard some types of income for the families of CSHCN (e.g., uninsured medical expenses for supplies, equipment, assistive devices, ancillary therapies, and expenses related to home modifications).

School-Based/School-Linked Health Centers

Over the past several decades, school-based health centers (SBHCs) and school-linked health centers (SLHCs) have emerged as important sites for delivering comprehensive primary and preventive health care services to children and adolescents.¹⁹

SBHCs provide a comprehensive range of physical and mental health services to students at locations that are accessible and familiar. Multidisciplinary teams of physicians, nurses, nurse practitioners, health educators, social workers and psychologists ensure that care is continuous, age-appropriate, culturally sensitive, and coordinated both within the center and with outside agencies and providers. SBHCs have traditionally provided high-quality care, with a focus on prevention, early intervention, and primary care services. Respect for confidentiality within the confines of state law is also a high priority. For all these reasons, SBHCs are supported by a wide range of professional organizations, including the American Academy of Pediatrics, Society for Adolescent Medicine, American Medical Association, American Nurses Association, and Association of Maternal and Child Health Programs.

Although SBHCs are only one model for delivering care to adolescents under CHIP, this unique safety net provider can play an important role in helping states to assure that their CHIP goals are fulfilled. The following are some reasons that SBHCs can help states and health plans reach and serve their target population. School-based/school-linked health centers:

- reduce barriers to access;
- promote quality of care;
- contribute to patient/member satisfaction;
- reduce the stigma teens sometimes associate with other health care providers;
- help to ensure access to preventive primary care and mental health services; and
- often maintain strong links to other community-based providers and systems, including state Title V programs.²⁰

¹⁹ For the purposes of this brief, the term “school-based health center” will be used to include both school-based and school-linked health centers. The two provide a similar range of services; the major difference is that SBHCs are located physically **on** a school campus, while SLHCs are located **near** one or more schools.

²⁰ The Title V Maternal and Child Health Block Grant is a major source of funding for SBHCs, providing \$9.27 million in 1998 (Making the Grade, 1998).

Moreover, although the evidence is mixed, and not always able to be replicated, some SBHCs have reported success in improving contraceptive use, decreasing pregnancy and substance use rates, preventive school dropout, improving school attendance, decreasing emergency room use, and increasing utilization of mental health and substance abuse services (Society for Adolescent Medicine, 1992; Kaplan, Guernsey, and Hanrahan, 1998). In short, SBHCs can reduce the impact of many of the barriers that adolescents enrolled in CHIP programs might otherwise face, thus helping states and health plans reach and serve their target populations.

Quality Assurance

In recent years, the U.S. health care system has taken an increasing interest in measurements and systems that attempt to monitor the quality of care provided to various populations. Despite concerted efforts by researchers, health care purchasers, providers and policymakers, the movement to define, measure and assure health care quality continues to pose a significant challenge. Given the relatively limited experience in this area, consensus about how to operationalize constructs of quality has been difficult to achieve. Available tools and systems are still in their early stages of development. Even more absent are valid, accepted and affordable quality assurance (QA) tools that focus on children and, more specifically, adolescents. Thus, while the use of performance and outcome measures as a means to evaluate quality in an adult population has been widely studied, the knowledge base is much more limited for adolescents. Most progress in this area focuses on immunizations, specific diseases (such as asthma), and/or health outcomes in neonates and infants.

Commonly cited elements of quality for adolescents include: access to care, clinical effectiveness, integration of services (e.g., coordination and continuity of care), cultural competence, and comprehensiveness of services. Potential data sources include satisfaction surveys, utilization and encounter data, medical record reviews, grievance/complaint data, disenrollment rates, and independent external reviews.

Quality assurance efforts can target health care providers (most often physicians), health plans (more common under managed care arrangements), and/or other aspects of the CHIP program. Quality assurance activities directed toward providers are often based on professionally established standards of care. For years, guidelines regarding the treatment of patients with specific medical conditions have been available; more recently, a number of guidelines have proliferated that focus on the delivery of clinical preventive services for children and adolescents. Sources for these guidelines include professional organizations (American Medical Association and American Academy of Pediatrics) and federal agencies (U.S. Public Health Service, Maternal and Child Health Bureau, and U.S. Preventive Services Task Force). Although the major guidelines differ somewhat in their recommendations for adolescents, all converge in certain areas, particularly regarding the provision of immunizations, anticipatory guidance for health risks, and screening for high-risk behaviors and common health and mental health conditions.

Medicaid's Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program includes recommendations for periodic screening based on guidelines from the American Academy of Pediatrics (AAP), but allows states to establish their own periodicity schedules in consultation with other provider groups concerned with child health.²¹ For states that implement non-Medicaid CHIP programs, no such guidelines exist.

Practice standards and guidelines are clearly not a panacea. Despite federal law requiring states to demonstrate that 80 percent of eligible children and adolescents are appropriately screened under the EPSDT program, rates for vision, hearing and dental screening among eligible adolescents remained well below 30 percent from 1994-1996 (Olson, Perkins, and Pate, 1998). Making the translation from available clinical standards to assuring access and utilization of care for adolescents will clearly remain a significant challenge for states under CHIP. In spite of these challenges, requirements that providers adhere to one or

²¹ In the past, HCFA has explicitly recommended that AAP guidelines be followed.

Quality Assurance Tools

Quality measurement and documentation tools have been developed by several organizations, including the Health Care Financing Administration (HCFA), National Committee for Quality Assurance (NCQA), Foundation for Accountability (FACCT) and Agency for Health Care Policy Research (AHCPR). These measures and tools attempt to help consumers and purchasers evaluate and compare health plans. For example, NCQA has created the Health Plan Employer Data and Information Set (HEDIS), a set of standard measures designed to help purchasers and consumers compare the performance of managed care plans. AHCPR created the Consumer Assessment of Health Plans (CAHPS), which includes patient/family satisfaction queries on pediatric health access and preventive care. And HCFA has implemented the Quality Improvement System for Managed Care (QISMC) to assure that managed care organizations contracting with Medicaid protect and improve the health and satisfaction of enrolled beneficiaries. Under QISMC, a uniform set of quality standards is used by HCFA and state Medicaid agencies in initial and ongoing determinations that an organization is eligible to enter into a Medicaid contract. Under this system, organizations must demonstrate that they operate an internal program of quality assessment and performance improvement that achieves demonstrable improvements in enrollee health, functional status and/or satisfaction across a broad spectrum of care. They must collect and report data reflecting performance on standardized measures of health outcomes and enrollee satisfaction, and meet minimum performance levels on the measures established by HCFA or the state Medicaid agency. Some states are using QISMC as the basis for quality assurance under their CHIP programs.

In HEDIS 3.0, the most current version available, only 13 indicators are child-specific and only two relate specifically to adolescents: a preventive services visit within the past 12 months and adolescent immunization status.²² Although HEDIS has been revised several times to address Medicaid populations and to include measures on adolescent health counseling, the majority of measures focus on long-term, chronic illness rather than primary care and prevention. While new measures being considered may help to alleviate this problem, no accurate national benchmark data exists. For its part, CAHPS only obtains responses from parents of children ages one through 12, and thus fails to capture information on the majority of adolescents or to include their experiences and opinions.

Finally, NCQA and AHCPR are collaborating with FACCT to develop a standardized tool for measuring the quality of care provided to children and adolescents. This tool, known as the Child and Adolescent Health Measurement Initiative (CAHMI), will include an adolescent-specific survey targeted to 14-18 year-olds and is therefore an important potential tool for states to monitor and evaluate their CHIP programs. Through CAHMI, FACCT has developed an adolescent health survey (AHS) that draws performance and satisfaction data from survey-based measures with adolescents. The survey captures the following information regarding adolescents' health care visits: the provision of preventive counseling for depression, smoking, alcohol and sexual activity; risk screening in such areas as diet, physical activity, bike helmet use, peers, school performance, and weapon-carrying; whether the visit was private and confidential; the adolescent's experience of the provider and the visit, including the usefulness of any preventive counseling and provider respect/communication; and adolescent risk behavior, including seat belt use, depression, tobacco use, drinking, and sexual activity. Recently, the AHS was field tested in six Medicaid and commercial managed care organizations (MCOs) across the United States. With the results of these field trials, adolescent-specific performance measures will be developed that capture recommendations from a number of national bodies – including the American Academy of Pediatrics, Healthy People 2000, and the American Medical Association – about the measures described above (The Foundation for Accountability, 1999).

According to studies, most states are using or planning to use established measurement standards, with many relying on HEDIS or some variation to create report cards on MCOs. The advantage of this widespread approach is that it permits comparisons of quality and access within and across CHIP programs, health plans, populations, states, and time. The disadvantage is that these pre-packaged tools contain very few adolescent-specific measures and focus more on utilization of care than health outcomes. Although additional materials specific to CHIP should be available in the future, states may want to modify existing measures, while simultaneously participating in the development of new ones. Given the limitations of any one tool to capture the complexity of the health care delivery system, it will be important for states to use several complementary measures.

²² Two additional measures are in the HEDIS testing set to be implemented in future years: physician counseling regarding alcohol use and chlamydia screening for young women 15-25 years of age.

more set of practice guidelines can help states to establish and achieve a professionally acceptable level and quality of care for their CHIP enrollees.

Because so many states are utilizing managed care systems to expand their child health insurance programs, much of the focus of quality assurance activities has been, and will continue to be, on health plans. Fortunately, a great deal of innovation is occurring in this area. Unfortunately, few states have developed a comprehensive approach to data collection and reporting for Medicaid managed care plans; fewer still have done so for adolescents under their CHIP programs. An additional challenge to crafting clear performance measures for health plans is developing contract specifications that are tied to reporting requirements and that provide effective sanctions for non-performance. (See page 23 for information on current activity and developments in the field.)

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CHIP legislation directs states receiving funds under Title XXI to set strategic objectives and performance measures, describe their assessment, and report to the Secretary of Health and Human Services on these performance goals and measures. The state plan must describe how performance measures will be assessed through objective review of program and clinical data. For each strategic objective, the state must specify at least one performance goal. The state's performance measures must be measured through "objective, independently verifiable means" and compared against performance goals (English, 1999). For states expanding Medicaid eligibility under CHIP, quality assurance (QA) activities will likely build on current systems. States that create or expand non-Medicaid insurance programs may closely coordinate their new programs with Medicaid or model these programs based on their Medicaid experience. Surveillance and data systems such as the ones described on page 23 can play a critical role in monitoring adolescent access and utilization patterns and health status over time, holding managed care plans directly accountable for the quality of services they provide to adolescent enrollees.

States face several additional challenges in creating and implementing QA systems for adolescents under CHIP. These include: problems with collecting data and tracking members through multiple and fragmented systems of care; limitations of standard MCO data; methodological problems such as double counting enrollees; and limited comparability of data across states. Finally, states should be cautious not to anticipate dramatic outcomes from their CHIP programs, given the multiple systems and factors that are involved in low-income adolescents' health status. Given the relatively embryonic stage of our knowledge base in these areas, it will be important to implement systems of accountability that enable states and their partners to correct problems identified and make necessary modifications in the existing systems of care. Through an iterative process, service providers and CHIP administrators can continue to improve their programs over time.

Evaluation

States must include in their CHIP programs an evaluation component that assesses progress in reducing the number of uninsured low-income children and assuring their access to quality health care services. By March 2000, states must submit an overall evaluation report to HCFA with CHIP enrollment counts and expenditures by age, poverty level and service delivery categories. Their evaluation must assess a number of additional items, including the effectiveness of the state plan in increasing the number of children with health coverage; the effectiveness of other private and public programs; state activities to coordinate the plan with other public and private programs; trends in the state that affect the provision of health care to children; plans for improving the availability of health insurance and health care for children; and recommendations for improving the program. In requesting this information, HCFA hopes both to determine states' compliance with the new law and to compare the effectiveness of various state programs and program types.

Evaluation Tools for States

Multiple resources are available to help states in their evaluation efforts. For example, the American Academy of Pediatrics (AAP) has developed a tool to help states assess the implementation and impact of their CHIP plans on three closely linked dimensions of quality assessment in health care: access, process and outcomes. The tool provides 30 indicators, many of which address adolescents eligible for Title XXI. According to the AAP, special measures are needed to ensure that adolescents who are eligible for Title XXI are well served by the program. Its four adolescent-specific indicators address immunizations, counseling for sexually-transmitted infections, risky behaviors, and attempted suicide. The tool also recommends data sources and model instruments for states to use in designing and implementing their CHIP evaluations.

In addition, since 1998, state Title V programs have been required to measure and report on 18 national and seven to 10 state-negotiated MCH performance measures. Although these measures are typically population-based, focusing on broad groups of women, infants and children, they may provide some guidance to states in designing their CHIP evaluations, particularly given that these data must be collected and reported on an annual basis, and that low-income adolescents are a major target population for Title V program efforts.

The standardized CHIP reporting forms issued by HCFA list wide age breakdowns that may not be sufficient for assessing whether various groups of adolescents have been enrolled and/or served.²³ Because HCFA's requirements are minimal, more comprehensive program evaluation by states can serve multiple purposes. For example, data from evaluation efforts can be used to help guide states' program modifications and improvements, helping to ensure that their CHIP programs are responsive to the needs of low-income adolescents and effective in meeting these needs. Given the extreme flexibility that states have had in designing their CHIP programs, it will be important to determine whether specific program decisions have had the desired effect(s) on specific target populations. Unless there is consistent reporting of reliable data within and across states, it will be difficult to evaluate the program's overall impact.

Unfortunately, state officials face significant problems in attempting to design and implement rigorous evaluations for adolescents under their CHIP programs. Challenges include: limited availability of data; a shortage of valid, accurate, and useful measures that are adolescent-specific; sample sizes too small to permit reliable estimates; and publicizing data that cast a nega-

tive light on their, or their partners', performance. However, without mechanisms for evaluation in place—even ones that are incremental in nature—program managers and policymakers will have little information to guide their decision-making regarding continuation and/or revisions of the program.

Another concern both within and across states is the absence of reliable data and information systems to evaluate CHIP and related programs. Even the single measure required by HCFA for CHIP evaluation—the number of uninsured children and adolescents—is controversial, with multiple agencies issuing multiple estimates, each with its own set of methodological challenges. This “data drought” is seen as a major constraint and is being addressed by multiple entities, including states themselves and the Health Resources and Services Administration (HRSA). Moreover, as states continue to simplify their application forms in order to attract the maximum number of eligible enrollees, they lose data that could be valuable for evaluation purposes. Indeed, the U.S. Department of Health and Human Services (1999) reports that states have had difficulty submitting the required information to HCFA due to: incompatibility of data systems; Y2K priorities; and inability to break out CHIP and Medic-

²³ The required age breakdowns are <1 year, 1-5 years, 6-12, 13-18, and 19-20. The American Medical Association and Maternal and Child Health Bureau, on the other hand, define the following developmental stages of adolescence: early (10-14 years old); middle (15-17 years); and late (18-21).

aid data by age, income and service delivery categories. HCFA has sent a letter to states emphasizing the importance of timely reporting and will work with states to collect this information. Other efforts by HCFA and national organizations aim to provide further guidance and assistance to states.

One final concern relates to the statutory limit on spending for administrative functions under CHIP. States can not spend more than 10 percent of their total federal and state CHIP expenditures on outreach, enrollment, evaluation and administrative activities, including the direct purchase of health care services. Given the premium placed on outreach and enrollment efforts, program evaluation is likely to suffer from highly limited resources.

Linkages with Other Health and Social Service Programs

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How a state's CHIP program is integrated with other services and programs for adolescents and their families will be a key factor in its ability to improve the health of eligible youth. Adolescents' physical and mental health, educational and social development are all interrelated, and their needs are often closely tied to those of their families. A wide range of federal, state and community programs are in place to address these various needs. In order to ensure that services are not duplicated, and that teens are able to access an integrated, comprehensive, continuous system of care, coordination between programs is critical.

Adolescents' use of health care services is only one factor influencing their health. Other health, social service and education programs and systems, particularly for at-risk youth and youth with special health

care needs, play an important role in assuring that adolescents grow to be healthy adults. Many of these agencies, organizations and programs have critical expertise and systems designed to meet the unique needs of adolescents and have been serving adolescents now eligible for CHIP for years. They have gained familiarity, competence and confidence with this population, as well as the trust of both adolescents and their families. Health, mental health, social service, education, and other agencies all have unique roles to play in assuring a comprehensive system of care for adolescents. Programs such as Title V, WIC, Head Start, family planning, HIV prevention, and school and community health centers can provide opportunities for coordinating overall care, increasing access to services, and conducting outreach and enrollment to potentially eligible adolescents. State Title V programs, because of their fundamental mission to improve the health and well-being of all adolescents, are an especially critical partner in the development and implementation of CHIP.

Federal requirements in the Title V, Medicaid and CHIP statutes provide further incentives and opportunities for establishing coordination among these and other programs serving children and adolescents at the state level. States are required to coordinate Title XIX (Medicaid) and Title V programs; under Title XXI, states are also required to evaluate CHIP's coordination with both of these and other programs.