Adolescents and the State Children's Health Insurance Program (CHIP): Healthy Options for Meeting the Needs of Adolescents

Association of Maternal and Child Health Programs

Policy Information and Analysis Center for Middle Childhood and Adolescence &

National Adolescent Health Information Center at the

University of California, San Francisco





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The Policy Information and Analysis Center for Middle Childhood and Adolescence is funded through a Cooperative Agreement with the Maternal and Child Health Bureau (MCHB). It is located within the University of California, San Francisco School of Medicine, operated jointly by the Divisions of Adolescent Medicine and General Pediatrics (both of the Department of Pediatrics) and the Institute for Health Policy Studies. The overall goal of the Policy Center is to assist MCHB in identifying, developing and analyzing information to assist practitioners and policymakers at the national, state and local levels to enhance the health status of the middle childhood and adolescent populations. Its efforts focus on four major areas affecting the health status of children and adolescents: the content of primary and preventive care services; the organization, staffing and financing of clinical services; quality of care; and the development of an early warning system to monitor emerging health problems.

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NAHIC was established in 1993 with funding from the Maternal and Child Health Bureau (MCHB) to serve as a national resource for adolescent health research and information. The overall goal of NAHIC is to improve the health of adolescents by assuring the integration, synthesis, coordination and dissemination of adolescent health-related information. Its objectives are: (1) to promote collaborative relationships with MCHB, other federal and state agencies, professional and research organizations, private foundations and advocacy groups; (2) to collect, analyze and disseminate information through short- and long-term analyses of policies affecting the adolescent population; and (3) to provide technical assistance, consultation and continuing education to states, communities and providers in content areas that emphasize the needs of adolescents. Throughout these core objectives, NAHIC maintains a special emphasis on the needs of special populations who are more adversely affected by changes in the health care environment for youth and their families.

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Preface

⁷n 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

he 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 atrisk 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.

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.

- 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 Confidential Services

- 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., schoolbased 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 V MCH/ 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.



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I. Introduction and Background

THE STATE CHILDREN'S HEALTH INSURANCE PROGRAM

he 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. 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

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 pregnant 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 parttime (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.

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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.

- 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 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.

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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.

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

uring 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.

Healthy Options for Meeting the Needs of Adolescents

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.



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III. Major Issues for Adolescents Under CHIP

lthough 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:

 existing administrative and provider systems that cover the entire state;

- 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



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.

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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.

- **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, diptheria 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. Copayments 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.)

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; Weithom 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 "atrisk" 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. 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 highcost 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 highrisk 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 Finally, NCQA and AHCPR are collaborating with 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.

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, adolescentspecific 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 adolescentspecific 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 nonperformance. (See page 23 for information on current activity and developments in the field.)

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 lowincome 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 lowincome 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

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.



4

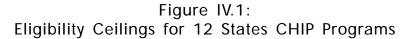
IV. Findings and Recommendations

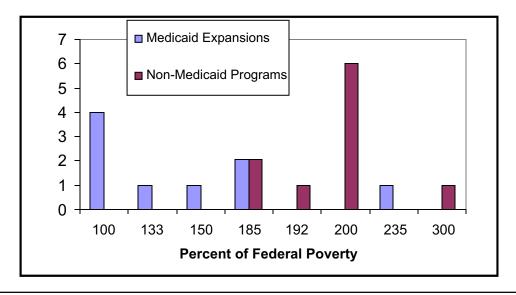
This chapter provides information from the interviews conducted with representatives from the 12 states. The first section includes general information on the states' programs/plans (e.g., program type, age and income eligibility), while the remaining sections provide findings related to the nine issue areas described in Chapter III. Included in these sections are State Innovations and Highlights specific examples of how states can structure and operate their CHIP programs to ensure their maximum impact on adolescent health. Finally, we include recommendations for each of the nine areas. These recommendations are based on information gathered during the interviews, as well as previous literature, research and advocacy in the areas of adolescent health policy, financing, service delivery and program evaluation. Although these recommendations are primarily aimed at states themselves – governors, health departments, Title V programs, and CHIP programs – many will be of interest to providers, health plans, advocates, adolescents, and their families.

PROGRAM/PLAN INFORMATION

Of the 12 states we surveyed, two (N.M. and Wis.) are implementing a Medicaid expansion; three (Colo., N.C., and Utah) chose to create or expand a non-Medicaid program; and seven (Ala., Calif., Conn., Fla., Ill., Mass., and N.Y.) are implementing a combination of the two.

All 12 states are using at least some portion of their CHIP program to provide coverage to adolescents, with every state covering adolescents up to age 18 or 19. Income guidelines are significantly more generous for non-Medicaid programs than for Medicaid expansions (see Figure IV.1). For Medicaid expansions, four states (Ala., Calif., Fla., and N.Y.) set their income eligibility ceiling at 100 percent of federal poverty; one (Ill.) established a ceiling of 133 percent; one (Mass.) uses 150 percent as its limit; two (Conn. and Wis.²⁴) use 185 percent; and New Mexico covers children and adolescents with family incomes up to 235 percent of federal poverty. Income limits





²⁴ Under BadgerCare, teens must have family incomes under 185 percent to qualify initially; however, they can maintain eligibility after enrollment with family incomes up to 200 percent of federal poverty.

New and Improved or Just Newly Funded?

Before Title XXI, several states already had innovative programs in place that subsidized insurance coverage for low-income children and adolescents. These initiatives – such as the Blue Cross/Blue Shield Caring Program for Children – were provided variously through state sponsorship, the private market, or a public/private partnership, and were typically financed through a combination of state general funds, earmarked taxes, foundation or federal grants, member contributions, and private donations. Under CHIP, states can now receive federal assistance for programs such as these, as long as they meet specified criteria contained in the Title XXI legislation. Programs in Florida, New York and Pennsylvania were explicitly cited in the legislation as providing comprehensive state-based coverage and thus qualify for CHIP funding. In addition, the Colorado CHIP program is an extension of a state initiative called The Colorado Child Health Plan (CHP), which subsidizes insurance coverage for children and adolescents in families with incomes up to 185 percent of federal poverty. The CHIP program is called Child Health Plan Plus (CHP+), and builds directly on the original CHP.

It should also be noted that many states have maintained additional programs that provide health insurance coverage to children and adolescents who do not qualify for Medicaid or CHIP. In Massachusetts, for example, the Children's Medical Security Plan (CMSP) provides preventive services on a sliding scale to all children and adolescents with family incomes above 200 percent of federal poverty, including undocumented immigrants. Although the benefit package covered under CMSP is narrow relative to Medicaid or CHIP, it is a critical component of that state's commitment to ensuring all young people have access to primary and preventive health care services. In California, two dedicated programs—California Kids and Kaiser Permanente Cares for Kids Child Health Plan—provide coverage for defined groups of uninsured children and adolescents up to age 19 through the private market. To qualify for California Kids, teens must live in families with incomes between 200 percent and 300 percent of federal poverty guidelines and not be eligible for the state's Medicaid or CHIP programs; the benefit package covers basic preventive and primary health care services, as well as emergency and preventive dental care. Eligibility criteria for Kaiser Permanente Cares for Kids are similar, but the income ceiling is 275 percent of poverty and the benefit package includes hospitalization. Both programs require a monthly contribution from families based on the family's income.

for non-Medicaid CHIP programs range from 185 percent in two states (Colo. and Ill.) to 300 percent in Connecticut. The majority of programs (Ala., Calif., Fla., Mass., N.C., and Utah) use 200 percent as their income eligibility ceiling for adolescents. Under its newly proposed Medicaid expansion, New York will cover 0-19 year-olds with family incomes up to 192

but only 100 percent for those ages 7-19 years.

percent of federal poverty. In our sample, only two states (Ala. and Calif.) retained separate income eligibility requirements for children and adolescents.²⁵ (For more detailed information on the 12 states' CHIP program/plans, please refer to Appendix C.)



²⁵ Medi-Cal, the state's Medicaid program, has expanded eligibility to 200% of federal poverty for 0-1 year-olds, while 1-5 year-olds are only covered up to 133%, and 6-18 year-olds to 100%. Healthy Families, the state's new insurance program, then covers children and adolescents up to 200%. Alabama's Medicaid expansion goes to 133% of poverty for 0-6 year-olds

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The Name Game

States have shown remarkable creativity in naming their Medicaid, Medicaid expansion, and CHIP programs. The 12 states in our study illustrate the range of possibilities.

- ALL Kids (Alabama)
- Healthy Families (California)
- Child Health Plan Plus (Colorado)
- Health Care for Uninsured Children and Youth (HUSKY) (Connecticut)
- Healthy Kids (Florida)
- KidCare (Illinois)

- MassHealth (Massachusetts)
- SALUD! (New Mexico)²⁶
- Child Health Plus (New York)
- North Carolina Health Choice for Children
- Utah Children's Health Insurance Program
- BadgerCare (Wisconsin)²

Although the states in this study were selected in part because they had made significant progress in implementing their CHIP programs, some have just begun enrolling children and adolescents. Several of the states have submitted amendments since the first interview, with New York recently adding a Medicaid expansion component to its official CHIP plan.²⁸

At the time of this writing, over 500,000 children had been enrolled in these 12 states' CHIP programs; approximately 30 percent of these were adolescents (unpublished HCFA and state data). The proportion of CHIP enrollees who are adolescent ranges from 24 percent in California to 44 percent in Illinois, and reflects multiple factors, including CHIP eligibility; previous Medicaid and other program eligibility; length of time elapsed since program inception; and state population/demographics.

Most, but not all, states we interviewed are using a managed care delivery model for at least some of their CHIP enrollees. Managed care arrangements are more common in non-rural (urban and suburban) areas, with some states using managed care systems in selected counties only. With non-Medicaid programs, managed care is more likely to be mandatory than with

Medicaid, where states are still struggling with federal waivers and related regulations. Under federal law, for example, children and adolescents with special health care needs can not be enrolled in a mandatory Medicaid managed care plan without a waiver.

BENEFIT PACKAGE

Why does a benefit package matter?

Understanding the level and type of benefits covered by various health insurance programs is one way to compare and contrast these programs. For adolescents, access to comprehensive, age-appropriate services requires both that the types of services they need are covered, and that these services are available in a sufficient number. Limits on the number of services enrollees can receive (e.g., a ceiling on outpatient mental health or substance abuse visits) may lead to adolescents being "underinsured" and unable to receive the comprehensive care they need. For adolescents eligible for CHIP, certain types of services may be more critical than others. Preventive care, reproductive health, mental health, substance abuse, and dental care all provide significant benefit to this population, but are often neglected or limited in programs designed primarily for adults or children.

²⁶ SALUD! is New Mexico's Medicaid expansion program.

²⁷ BadgerCare is Wisconsin's name for its Medicaid expansion program.

²⁸ States can amend their plans at any time, and amendments can be effective immediately, even before they are submitted **unless** the amendment restricts eligibility or benefits, in which case there are federal and state restrictions.

Results: What do states include in their CHIP benefit packages?

Although not reflected in our sample, the trend in CHIP programs nationwide leans heavily toward Medicaid expansion; however, plans have the option to submit amendments at any time and, as implementation continues, more states are choosing to add a new child health insurance program.

The ten states in our sample that include a non-Medicaid child health insurance program model their benefit packages on a variety of benchmarks. North Carolina and Utah both base their CHIP program benefits on state employee benefit plans; North Carolina supplements its Health Choice for Children program with dental, optical and hearing services, as well as Medicaid-equivalent benefits for children with special health care needs. Using the CalPERS retirement system as its benchmark, the California Healthy Families program provides mental health coverage equal to 30 days of inpatient hospitalization and 20 outpatient visits annually; plans may, with the agreement of the subscriber or "responsible adult" if appropriate, substitute for each day of inpatient hospitalization the following: two days of residential treatment, three days of day care, or four outpatient visits. And Colorado's Child Health Plan Plus builds on its Children's Basic Health Plan, with benefits based on the "standard plan" defined in Colorado's small group insurance reform law. Services are provided by HMOs willing to contract with Medicaid or through direct contracts with providers in parts of the state not covered by HMOs.

■ Only two states (Colo. and N.M.) indicated that they included specific provisions for adolescents in their benefit packages. Other respondents stated that they did not feel it was necessary to make special provisions for adolescents because the benefit package was so inclusive as to make special provisions unnecessary. For example, Utah reported that some services (such as those for reproductive health) were included in the package with the understanding that they would only be used by adolescent enrollees.

- All 12 states surveyed indicate that they include some coverage for family planning services and preventive gynecological care in their CHIP benefit package. In states choosing Medicaid expansion, these benefits are covered automatically. However, in North Carolina, no prenatal or maternity care is included in the new state plan, as the vast majority of pregnant teens are eligible for the state's Medicaid for Pregnant Women program. In Colorado, adolescents can access reproductive health care, treatment for sexually-transmitted infections, and prenatal care without a referral from their primary care provider.
- Reproductive services for adolescents were cited by five states (Ala., Calif., Colo., N.M., and Utah) as one of the most pressing issues for adolescents under CHIP. These states expressed a desire to address the following issues: pregnancy prevention; reducing the number of low birthweight infants; increasing the availability of STI and HIV screening and treatment; and ensuring access to annual family planning exams for sexually active adolescents.
- All 12 states surveyed indicated that they had some level of mental health coverage in their benefit package, but the amount and type of services varied significantly from state to state. Connecticut offers 60 visits per year for both inpatient and outpatient substance abuse treatment under its new CHIP program. A more limited package of 20 visits for outpatient substance abuse services is offered by Alabama, California, Colorado and Florida. In states with Medicaid expansion, substance abuse treatment is covered under EPSDT for adolescent enrollees.
- Medicaid expansion programs traditionally follow federal requirements regarding mental health coverage and substance abuse. Based on the written descriptions of benefits, CHIP programs that choose Medicaid expansions can offer the widest range and most comprehensive coverage of mental health and substance abuse



treatment services. The coverage for inpatient mental health services in non-Medicaid programs ranges from 72 hours per episode in Alabama to 60 days in Connecticut, with Florida covering 15 days, California 30 days, and Colorado 45 days.²⁹ Generally, coverage for outpatient mental health services is also limited. In North Carolina, adolescents who require more than 26 visits per year (for both mental health and substance abuse) require pre-certification from the plan. In the other 11 states surveyed, the amount of coverage was generally limited to between 20 and 30 visits annually. Legislation that attempts to ensure parity of coverage between physical and mental health services for Medicare and other health insurers has been introduced, with potential ramifications for both Medicaid and CHIP.

- Five states (Ala., Calif., Colo., N.M., and Utah) indicated that mental health benefits were one of the priority concerns they would like to see addressed for adolescents under CHIP. These states identified early identification and intervention for mental health and substance abuse problems as desired outcomes for newly developed/redesigned programs.
- Eleven states included dental coverage in their CHIP plans. Only Colorado's new program does not include dental care. Although the state legislature recently authorized a separate dental program which would reach the CHIP-eligible population, funding for this program has not been allocated.
- Non-Medicaid expansion programs generally include full coverage for most preventive dental services. Five states require copayments (generally \$5) for non-preventive dental services. Connecticut requires co-payments only for crown and bridge, root canals, dentures, and extraction under the HUSKY B program.

- Two states (Ala. and Utah) indicated that dental health care is a priority concern that they would like to see better addressed in their CHIP programs. (For more information, see Appendix B.)
- Family coverage (using CHIP funding to cover all family members) is being considered by several states as a way to extend benefits to a larger segment of the uninsured population. Title XXI allows states to request a waiver, or "variance," for purchase of family coverage under a group health plan that includes coverage of targeted low-income children, if the state can prove that such purchase is cost-effective and family coverage will not substitute for other insurance coverage. Wisconsin's Phase II BadgerCare proposal to cover families under Title XXI was approved by HCFA in January 1999; two other states (Mass. and N.Y.) indicated that they were exploring this option.

State Innovations and Highlights

Florida: Prior to the passage of Title XXI, policymakers in Florida recognized the need to provide health insurance coverage for low-income children and adolescents not eligible for Medicaid. They also recognized the need to develop creative partnerships in providing this coverage. In 1992, Florida developed the Healthy Kids program, which laid the groundwork for relationships among a wide range of interested groups. Healthy Kids is based on the concept that school systems can create large groups of children and adolescents who qualify for group health insurance. Healthy Kids currently contracts with eight private managed care organizations to provide a defined benefit package to enrolled students. A longterm program goal is to have these managed care organizations open service sites at participating schools (School Health Resource Services, 1997).

Healthy Kids offers a comprehensive benefit package that includes: well-child visits, immunizations,

²⁹ This limit increases to 90 treatment days per enrollment period when pre-authorization is obtained.

SPOTLIGHT: NEW MEXICO

New Mexico's Phase I CHIP program is an expansion of coverage for children and adolescents in families with incomes between 186-235 percent of the federal poverty guidelines in the state's Medicaid managed care program.

Under its Phase II proposal to HCFA, New Mexico would establish a wraparound program administered on a fee-for-service basis by the state. The wraparound services would cover all children and adolescents from ages 0-19. Services covered by the program would include:

- ← Developmental Disabilities Services;
- ← Behavioral Health Respite Services;
- ← Home Visiting;
- ← Medical Child Care Services;
- ← Behavioral/Physical Health Risk Reduction (early identification, assessment and intervention);
- ← School-Based/School-Linked Risk Reduction (health, mental health and substance abuse prevention services and coordination); and
- ← Preventive Dental Services.

New Mexico's decision to develop this innovative approach is based on an assessment of how to best meet the needs of its children and youth. Several issues unique to this state have further influenced the state's policy decisions. For example, family incomes in the range of 186-235 percent of federal poverty guidelines are considered middle income in New Mexico, and providing publicly funded health care services to middle-income families is somewhat controversial. However, because the population eligible for this program is fairly small, the decision was made to include the wraparound services for the entire Medicaid population. In addition, the unique needs of American Indians, who comprise a substantial proportion of the state population, necessitated that traditional medicine and healers be included in the benefit package.

primary and specialty care, physician office visits, laboratory testing, inpatient care, surgical procedures, emergency services and transportation, prescriptions, vision screening and eyeglasses, hearing screening and hearing aids, physical therapy, mental health services, prenatal care and delivery, transplants, a \$1 million lifetime maximum, and no limitation on preexisting conditions. The broad coverage encompassed in the benefit package encourages low-income families to seek preventive services as well as treatment for their previously uninsured children and adolescents. Including a wide range of services in the benefit package also helps to highlight the potential of generous insurance coverage to improve health outcomes for previously uninsured children and adolescents.

Recommendations: What should states include in their benefit packages for adolescents under CHIP?

- Include age-appropriate clinical preventive services in the benefit package. As discussed earlier, preventive care is important to the long-term health of adolescents. Benefit packages which encourage the use of preventive services by limiting cost-sharing will increase the likelihood that adolescents will seek health care services earlier.
- Lestablish age-appropriate periodicity schedules for clinical preventive health visits. States should update their EPSDT periodicity schedules to reflect prevailing national recommendations for annual well-adolescent exams. Although the American Academy of Pediatrics, American Medical Association, and Maternal and Child Health Bureau all recommend annual well exams for adolescents, many states' periodicity schedules for EPSDT cover these exams only every two years. These schedules should be amended to support more frequent visits for teens enrolled in CHIP programs.



- Regardless of what type of program states implement, the available benefits should be as comprehensive as possible. Medicaid's EPSDT program is a good model for meeting the wide range of adolescent health care needs.
- Contraception, family planning, and other reproductive health care services are necessary components of a comprehensive benefit plan for adolescents. These should be included in any non-Medicaid benefit package and maintained as part of Medicaid coverage.
- Provide the same level of coverage for mental health/substance abuse services as for other forms of health care. Historically, coverage for mental health and substance abuse has been much more limited than for other types of care. Parity of coverage is critical for adolescents under CHIP.

OUTREACH AND ENROLLMENT

Why are outreach and enrollment important?

Comprehensive outreach strategies and streamlined enrollment procedures are critical to assuring that eligible adolescents are enrolled in CHIP. Outreach and enrollment efforts have been and remain a high priority for many states in the implementation phases of CHIP, as states work to identify and enroll eligible adolescents in this new program.

Results: What adolescent-specific outreach and enrollment strategies are states using?

■ As required by Title XXI, all states are conducting some form of outreach and enrollment to adolescents. All states are using schools and school-based health centers as key sites for these efforts. Seven (Ala., Colo., Mass., N.M., Ill., N.C., and Utah) of the 12 states surveyed reported targeting outreach activities to the adolescent population, although many of these efforts also target children.

- States are using a variety of creative strategies to facilitate enrollment. Strategies include: community-based outreach workers; eligibility workers "outstationed" at provider and other community sites; and computer programs that screen for eligibility at a range of community service intake points. Statewide hotlines that facilitate enrollment have been established or are planned in all 50 states and are being used to help families with issues ranging from completing the application form to answering questions about CHIP and Medicaid. In addition to helping states centralize information and client services, hotlines enable them to combine application, eligibility, and enrollment data systems (National Governors' Association, 1999).
- In states where more targeted outreach is being conducted, the most common efforts are flyers and/or brochures about CHIP targeted to adolescents. Two states (Colo. and Mass.) have developed materials specifically for adolescents. Massachusetts developed a *Teen Choices* brochure that explains the importance of preventive services for adolescents and includes information about the availability of adolescent providers in the state; the state also printed flyers and posters geared towards adolescents. In Colorado, adolescents are provided with a packet of information about CHIP which was developed specifically for them.
- Eight states (Colo., Fla., Ill., Mass., N.M., N.C., Utah, and Wis.) indicated that they had developed specific activities to target at-risk or high-risk youth. These efforts target a range of youth, including: adolescents in homeless or runaway shelters (Colo., Fla., N.C., and Wis.); youth recently released from correctional facilities (Colo.); and teens in alternative education and GED programs (Ill.) While many states have at least initiated efforts to target at-risk youth, many of

SPOTLIGHT: ALABAMA

In Escambia County, Alabama, local pediatrician Dr. Marsha Raulerson, received a \$10,000 grant from the pharmaceutical company Wyeth Lederle to conduct an outreach project that targeted adolescents. Dr. Raulerson identified seven of her adolescent patients who agreed to participate in CHIP outreach efforts to other adolescents in their county. A college student served as the director of the initiative and provided guidance for the teens. The students participated in these efforts beginning in February 1998 and continued through the summer.

The students began the outreach initiative by conducting focus groups with other adolescents in the county in order to identify local adolescents' needs and desires for health care. They also sponsored a number of receptions with local ministers and counselors in order to increase their awareness about ALL Kids and encourage them to spread the word about the program to other adolescents.

The teens distributed ALL Kids materials in numerous locations, including physicians' offices, post offices, and convenience stores throughout the county. The students also collaborated with a local hospital to obtain the names of patients under 19 years of age who were uninsured; they then attempted to reach these patients. (This information was released to the students with the understanding that the patient information would be used solely for ALL Kids outreach efforts and that their confidentiality would not be compromised.) When student athletes were at school to have their mandatory physicals prior to the school year, the teens were there to distribute information to the hundreds of student athletes about the program.

The students' efforts did not go unnoticed by community members. Local hospitals donated postage costs for mailing ALL Kids information and also donated room space to hold meetings and receptions. In addition, the Alabama Medical Association donated funds for the purchase of bright yellow tee shirts that had information printed on them about ALL Kids. The students wore these tee shirts to school to increase awareness about the program.

The outreach efforts headed by Dr. Raulerson appear to have been extremely successful. In one local hospital, the percentage of children and youth coming in without insurance dropped from 25 percent to 11 percent. The grant funds provided leverage for additional funds and support from area hospitals and other community groups. As a result, grant funds are available to support tentative plans for another outreach initiative for the summer of 1999.



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SPOTLIGHT: CALIFORNIA

In California, enrollment of Latino children and adolescents in the state's Healthy Families program lags far behind need and eligibility projections. When the federal government announced its new interpretation of the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) (see page 20), the California Primary Care Association (CPCA) launched It's Important! – a TV, radio and print ad campaign aimed at enrolling Latinos in Medicaid and Healthy Families. Seeking to spread the word that receiving public health care assistance poses no threat to immigrants fearful of deportation or delayed citizenship, the campaign – funded with a private foundation grant - will feature a toll-free telephone number with 24-hour bilingual operators to guide callers to local health services, clinic posters urging families to sign up, and TV commercials that show Latino parents bringing their children to local clinics.

these are focused on outreach and enrollment and not on service delivery or improving health outcomes for members. Many states have not yet grappled with how to actually serve these teens under their new CHIP programs. However, nearly all of the states surveyed appreciated the need to target at-risk youth.

Recommendations: What can states do to improve outreach and enrollment for adolescents under CHIP?

- Develop CHIP promotional materials that are targeted to adolescents. These materials should be developed with youth input.
- Locate outreach efforts and eligibility workers in areas that adolescents frequent. Such sites might include community centers, youth-serving organizations, schools, school-based health centers, vocational schools, and community colleges.

- Specifically target outreach and enrollment efforts to high-risk youth. Adolescents at-risk include homeless/runaway youth, adolescents living in foster care, youth who have recently been released from correctional facilities, adolescents with limited English skills, teens in alternative education or GED programs, and other special populations, including gay/lesbian/bisexual/transgender youth. For example, states could train outreach workers to work with transitional social workers in order to ensure that young people being released from youth detention centers were screened for CHIP eligibility and enrolled if eligible.
- Train hotline operators to answer questions frequently posed by adolescents. Hotline operators should be equipped to deal with questions concerning the location of convenient enrollment sites for adolescents, the availability of adolescent-oriented providers, and policies regarding confidential access to services under states' CHIP programs.
- Simplify application and enrollment procedures. Wherever possible, states should combine application forms and processes with other need-based programs such as Free/Reduced Price School Lunches. States should also combine their Medicaid and non-Medicaid application forms, coordinating the review of these forms across the programs. Finally, states should waive excessive documentation requirements not mandated by federal law.

ASSURING ACCESS TO CARE

Why is assuring access to care for adolescents under CHIP so critical?

Eligibility levels that states establish for their CHIP programs are critical to assuring access to care for adolescents; access to care for adolescents; access to care for adolescents is influenced by a variety of factors beyond health insurance itself. Early reports are encouraging, indicating that states are taking advantage of the opportunities presented by CHIP to increase eligibility levels for adolescents. According to a recent report by the National Governors' Association (NGA), states have greatly increased eligibility levels for certain subgroups of children and adolescents compared with eligibility levels from 1997. The median eligibility level for children ages six and older was 100 percent of poverty in 1997, compared with 185 percent of poverty for the same group in 1998 (National Governors' Association, 1999).

Results: What are states doing to assure access to care for adolescents under CHIP?

- Few states identified provisions to reduce barriers to care specifically for adolescents. Most of the states interviewed for this study address access issues for all CHIP enrollees children and adolescents within the state's CHIP program. Most are using managed care organizations to deliver services under CHIP, and respondents indicated that barriers to access would be addressed by the managed care organizations with which the state contracted. Few respondents, however, were knowledgeable about specific provisions included in their states' MCO contracts which might mitigate barriers to access for adolescents.
- A major concern for states is ensuring that adolescents enrolled in CHIP establish a medical home. In Alabama, for example, the state works with health plan contractors to identify young people who do not visit a primary care provider within the first 60 days of their enrollment. The health plans' contractors review claims data

- to identify possible patterns and monitor ER data, in conjunction with the health plans, to ensure that adolescents' use of emergency services is appropriate.
- Eight states (Ala., Fla., Ill., Mass., N.Y., N.M., N.C., and Wis.) indicated that they had implemented specific provisions to reduce financial barriers to care for adolescents under CHIP. Strategies to reduce cost-sharing include: limiting co-payments and/or premiums to families with incomes over 150 percent of federal poverty guidelines (Ala., N.C., and Wis.); maintaining a single premium (\$15/month) regardless of family size (Fla.); eliminating all co-payments (N.Y.); and establishing low average co-payments (\$5/visit) (N.M.). In New Mexico, services provided at Indian Health Service facilities, urban Indian providers, and Tribal 639 clinics are exempt from cost-sharing.
- Nine states (Ala., Calif., Colo., Fla., Ill., Mass., N.M., N.Y., and Wis.) permit adolescent specialists to function as primary care providers (PCPs) according to the state's CHIP plan. In these states, adolescents and their families were most frequently made aware of this option through a list of adolescent specialists in the provider roster and other materials provided by MCOs.
- Most of the states surveyed indicated that they do not specifically identify adolescentoriented providers.
- Some states are facilitating adolescents' independent access to providers. Massachusetts has a provision that enables adolescents to select their own primary care provider independent of their parent or guardian. In Colorado, adolescents are not required to obtain a primary care provider referral for reproductive and mental health services.



■ Some states are trying to ensure that eligible immigrants are able to access their CHIP programs. In New Mexico, for example, a parent's social security number is not required on the Medicaid/CHIP application, thus eliminating this barrier for eligible adolescents with non-citizen parents.

Recommendations: What can states do to improve access to CHIP for adolescents?

- Identify Board-eligible and/or Board-certified Adolescent Medicine Specialists to serve as PCPs, subspecialty consultants, and referral sources for primary care gatekeepers.
- Encourage adolescent providers who have training and skills in providing primary care and care coordination to act as primary care providers for adolescent CHIP enrollees. Those with skills in providing primary reproductive health, mental health, and substance abuse treatment will be valuable as adolescent PCPs.
- 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.
- Educate adolescents and their families about how to access various primary, specialty and subspecialty 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. Such requirements only act as a barrier to immigrant families with fears of deportation. In fact, federal law states that the citizenship status of parents may not be taken into account when determining a child or adolescent's eligibility status.

- 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. Teens should have the option of selecting a general practitioner as their PCP. States and health plans also need to inform adolescents and family members of this option and of the roles and focus areas of various providers' practices.

CONFIDENTIALITY

Why is confidentiality important for adolescents?

As states develop and implement their CHIP programs, they have the opportunity to ensure that confidentiality protections already in place for adolescents are comprehensively utilized by the health plans and providers with which they contract. They also have the option to include language in their CHIP contracts that delineates how confidentiality for adolescents must be addressed. The ways in which states address these issues may be an important indicator of how likely adolescents will be to seek care under their states' CHIP programs.

Results: What are states doing to address confidentiality issues?

Five states (Calif., Colo., Conn., Fla., and Mass.) cited confidentiality concerns as a priority issue for adolescents under their CHIP programs. Respondents from these states described wanting to respect the privacy of adolescents, their ability to access confidential services, and the need to address limits on confidentiality as a potential barrier to access for specialty services such as mental health or family planning.

SPOTLIGHT: CALIFORNIA

The goal of California's *Medi-Cal Minor Consent Program* is to ensure that adolescents can access certain types of health care services without parental consent. The program allows youth ages 12 and older the opportunity to apply for Medi-Cal coverage for specified "sensitive services" without parental consent and specifically prohibits providers or eligibility workers from notifying parents about this coverage or the provision of related services under the program. Minor consent services include: outpatient mental health treatment/counseling, outpatient substance abuse treatment, pregnancy testing and pregnancy-related care, family planning services, and sexual assault services. Under the provisions of this program, adolescents age 12 and up can apply for individual Medi-Cal coverage based on their own assets; in other words, their families' financial status is not used in calculating eligibility. In addition, verification procedures are much less stringent than those used to determine eligibility for full-scope Medi-Cal. Being able to apply for insurance that covers these sensitive services and that is based on their own resources provides adolescents with a valuable opportunity to receive needed services for which there might otherwise be multiple barriers.

One disadvantage of this program is that eligibility for the *Minor Consent Program* must be re-determined by an eligibility worker on a monthly basis.³⁰ This requirement creates a significant barrier for adolescents, who may not remember or be willing to come in for a monthly face-to-face meeting with the Medi-Cal Eligibility Worker. In an attempt to reduce this barrier, the Alameda County Health Care Services Agency (Alameda County is just east of San Francisco, and includes the cities of Oakland and Berkeley) has requested a waiver in regulatory procedures to allow 12-month continuous eligibility for all minor consent services in Alameda County. If granted, this waiver would significantly improve adolescents' access to minor consent services and, as a result, it is expected that youth will better utilize these much-needed services and demonstrate improved health outcomes.

- Most states did not develop specific confidentiality provisions for adolescents under their CHIP programs. States have the flexibility to establish mechanisms that protect adolescent confidentiality within the confines of state law: for example, they can require that managed care plans under CHIP not send Explanations of Benefits to the homes of adolescent enrollees. Most respondents, however, stated that their CHIP programs had not developed such mechanisms.
- Only certain categories of adolescents such as those who are emancipated, pregnant, parenting, or married can apply for CHIP coverage independent of their parents. In Illinois only, minors can apply for CHIP programs on their own; however, they must declare their parents' income if they live at home.



³⁰ This requirement is waived for adolescents receiving outpatient mental health services. Providers who certify that a young person will benefit from outpatient mental health care without parental consent or involvement specify the estimated length of treatment, and eligibility is customarily extended for that length of time.

- All 12 states responded that adolescents can consent for some services confidentially. The types of services included were: family planning; pregnancy testing and prenatal care; testing and treatment for sexually-transmitted infections; and some outpatient mental health and substance abuse services. For example, New York state law allows minors to receive services related to emergency health care; family planning; STI testing and treatment; certain mental health, alcohol and substance abuse services; and HIV testing (but not treatment) without parental consent. In a recent referendum, Colorado voters passed legislation which requires parental consent for adolescents to receive abortion services, although pending legal processes have prevented this legislation from being implemented.
- Many states are relying on managed care organizations to address adolescents' confidentiality concerns. Health plans in the commercial market may be less aware of the need for adolescent-sensitive policies; however, contracts with MCOs can address these concerns. For example, Wisconsin has written specific language into its contracts to address confidentiality of medical records; under the MassHealth program in Massachusetts, neither managed care plans nor the PCC plan send an Explanation of Benefits (EOB) to adolescents' homes following service delivery.

Recommendations: What can states do to ensure that adolescents have access to confidential services?

Specific measures can be taken to ensure that adolescents' confidentiality concerns are addressed under new CHIP programs. Most of these measures can be explicitly written into contracts; however, their implementation will take place largely at the service delivery level. For example, providers who care for adolescents should clearly understand the scope of confidentiality protections and their limits in their respective states. Adolescent "safety net" providers may be more familiar with confidentiality laws – another reason to

include these providers in CHIP provider networks. Because confidentiality laws change over time, however, a system of continuing education and consultation for providers and health plans may need to be established (English and Knopf, 1999).

- Establish procedures to assure confidentiality for services that minors can access without parental consent. These services should include, at a minimum: preventive reproductive care, including screening for pregnancy, HIV and sexually-transmitted infections; family planning counseling and contraceptive options; treatment for sexually-transmitted infections; and outpatient mental health and substance abuse services. In all cases, providers should encourage adolescents to speak to a parent or other adult about their health care needs if they feel safe doing so.
- Include specific requirements related to state confidentiality laws in CHIP contracts with MCOs and providers. Since state programs must follow state law regarding adolescent confidentiality, explicitly re-stating those laws in contracts with providers and managed care organizations would help to increase awareness of the laws, and help assure that these laws are fully adhered to by MCOs and providers.
- Work with health plans to increase awareness of adolescent health confidentiality laws. Systems for training and continuing education should include those programs and staff involved in caring for adolescents under states' CHIP programs.
- **Educate adolescents about the confidential- ity protections available to them.** In order to be informed consumers of health care, it is crucial that adolescents themselves be informed about the circumstances under which they may consent to their own care and other confidentiality protections available to them. This may take place through information delivered by providers or through a wider education campaign conducted by the state and its partners. Providers should also have written policies about the conditions

under which issues discussed with an adolescent client can be revealed to a parent (e.g., suicidal ideation or threats of violence). Policies should also be in place that urge adolescents to share with their parents or guardians information about their health and health care. Such policies should not only be written, but reviewed frequently at staff meetings and with new employees.

- Allow adolescents to obtain confidential services without a referral from their primary care provider. Teens who continue to see a family pediatrician as their PCP may be reluctant to initiate discussions about sensitive topics such as sexuality, contraception or substance use. To ensure that other providers are willing to deliver these services, states might want to reimburse them for this type of care on a fee-for-service basis.
- Design and implement information systems that protect adolescent confidentiality. For example, systems for storing, accessing and transferring medical records should ensure that confidential information is maintained in strict accordance with legal protections. Some providers use separate charts or sections in the chart for information concerning confidential services over which minors can control disclosure. Other providers maintain simple or elaborate "dummy systems" for coding sensitive information such as HIV test results.
- Monitor providers' and health plans' compliance with confidentiality protections for adolescent enrollees. Health plans and providers can be assessed for how well they follow adolescent confidentiality provisions under their CHIP contracts. Adolescents themselves can also be surveyed about this using new tools being developed by the Foundation for Accountability (see page 23).

ADOLESCENTS WITH SPECIAL NEEDS

Why is it important for states to address adolescents with special needs under their CHIP programs?

How states will serve adolescents with special health care needs and at-risk adolescents under CHIP programs is still unclear. One report written early in states' implementation of CHIP indicates that, for the most part, states had not structured their CHIP programs with particular attention to youth with special health care needs; however, a number of states were pursuing innovative strategies in this area (Fox, 1998).

Because at-risk adolescents often receive health care services in non-traditional settings, it is important for states to consider ways to include these and other health and social service systems in their CHIP program design. Linkages to the public health, social service and juvenile justice systems are critical. Assuring that school-based health centers and other community providers such as local health departments and federally qualified health centers (FQHCs) are deemed essential community providers under state CHIP programs is also instrumental in ensuring that these youth receive high-quality, comprehensive, continuous and coordinated care.

Results: How are states addressing adolescents with special needs under CHIP?

■ All 12 states indicated that adolescents were covered under the benefit package designed for children with special health care needs. Few states, however, indicated that there were any special provisions for these adolescents either in the state's benefit package or in their outreach and enrollment efforts. (Appendix C contains detailed information about the 12 states' programs for children and adolescents with special health care needs.)

- Eligibility and care for youth with special health care needs under CHIP differs from state to state. For example, in Florida, adolescents with special health care needs who are eligible for CHIP are served through a special managed care plan; those with mental health problems are served through a separate behavioral health plan. In California, youth with special health care needs receive primary care from the Healthy Families Program (the state's new child health insurance program) and specialty services from the Title V children's services program – a special carveout from the state's CHIP plan. In Colorado and North Carolina, these adolescents receive "wraparound" specialty services for services above and beyond those covered by the state CHIP plan through a special needs component administered by the state Title V CSHCN program. In Connecticut, youth with special health care needs receive services under two separate state plans (HUSKY Plus Physical and HUSKY Plus Behavioral). And in Massachusetts, adolescents who meet the citeria for disability under the federal Supplemental Security Income (SSI) definition are eligible for Medicaid coverage regardless of their family income.
- States' efforts to address the needs of at-risk youth under CHIP are still in the very early stages of development. The predominant efforts were those targeting at-risk youth through outreach and enrollment activities.
- These settings include: youth may be identified. These settings include: youth-serving organizations (N.M.), juvenile justice systems (Colo.), youth recently released from corrections facilities (Colo.), migrant programs (Utah), homeless and runaway shelters (Colo., Fla., N.C., and Wis.), native tribal communities (Colo., N.C., and Wis.), GED and alternative education sites (Ill.), and "at-risk school districts" (Mass. and Utah). In New Mexico, social workers and other staff in the Children's Medical Services program within the state Department of Health have been trained and certified as Presumptive Eligibility/Medicaid

SPOTLIGHT: FLORIDA

In Florida, eligible adolescents with special health needs receive services through the Children's Medical Services (CMS) Network. The CMS Network is operated by Florida's Children's Medical Services — the state's Title V program for children with special health care needs. Under CHIP, the CMS program has developed and operates integrated delivery systems that form a statewide system of care. CMS provides children and youth with special health care needs with a family-centered, comprehensive, and coordinated system of care that links community-based health care with multidisciplinary, regional, and tertiary pediatric care.

Through CMS, the state is making efforts to specifically serve adolescents with special needs enrolled in CHIP. CMS currently operates four clinics that focus on the delivery of services for adolescents with special needs: University of Miami; University of Southern Florida; University of Florida; and the CMS local office in West Palm Beach. Physicians at these clinics are internists or pediatricians who specialize in adolescent health. They are trained to be sensitive to the needs of adolescents, and are well-equipped to deal with sensitive issues such as diet, nutrition and sexuality. These physicians work as members of a team that may include social workers, dietitians and other providers with specialized training and experience with adolescent populations. Some of the clinics also sponsor special adolescent and young adult group programs and seminars that are organized and administered by medical residents. These programs provide support for adolescents with self-image and transition issues.

Case managers for adolescents with special needs refer adolescents to these clinics. Once an adolescent is seen at the clinic, the physician can serve as his or her primary care provider (PCP), ideally through the transition into adulthood. Each CMS adolescent has a transition plan as part of his/her family support plan. When appropriate, clients are referred to various community-based agencies such as the Vocational Rehabilitation School to Work Program, Centers for Independent Living, and Developmental Services.

On-Site Application Assistance (PE/MOSAA) providers, allowing them to enroll into Medicaid and CHIP the eligible children and adolescents with special health care needs with whom they work. Although, several states are addressing at-risk youth in their outreach and enrollment efforts, few have yet addressed how these adolescents will be served once they are enrolled.

State Innovations and Highlights

■ Connecticut. Connecticut's HUSKY Plan includes a "HUSKY Plus" component that provides two supplemental benefit packages to provide services to children and adolescents with intensive physical and/or behavioral health needs. Special physical needs are addressed through the state's Title V centers and the state contracts with the Yale Child Study Center to provide special services related to behavioral health needs.

Recommendations: What can states do to address adolescents with special needs in their CHIP programs?

- Establish higher income eligibility ceilings for youth with special health care needs. As described earlier, states can provide more generous CHIP coverage for adolescents with special health care needs, or enroll youth with higher family incomes in their Medicaid programs.
- Use risk adjustment methods to ensure that health plans and providers enroll and serve adolescents with special needs. If providers and managed care organizations are not compensated for the additional costs of serving populations with special needs, they will tend to avoid enrolling or providing care to these populations. Methods to adjust risk include enhanced capitation rates; incentive payments; and other provisions that spread the risk of high-risk populations among providers and health plans equitably. As states become increasingly sophisticated purchasers of care, they can help to support the development, testing and implementation of more advanced risk adjustment methods.

SPOTLIGHT: COLORADO

In Colorado, Rocky Mountain Youth MNC, Inc., a local nonprofit health organization based in Denver, is conducting outreach efforts to enroll at-risk youth to the Child Health Plan Plus (CHP+) program, Colorado's non-Medicaid CHIP program. The organization conducts outreach to runaway and homeless youth who live at Urban Peak, a Denver-based shelter.

Urban Peak is a daytime drop-in center and emergency overnight shelter for homeless and runaway youth. It provides a safe haven from the streets, in addition to counseling, food, clothing, housing assistance, job referrals, education assistance, medical care, legal aid, HIV testing and counseling, street outreach, recreation, and other services.

Providers from Rocky Mountain Youth began delivering services to youth at Urban Peak in the early 1990s. Rocky Mountain Youth had identified Urban Peak as a site where adolescents did not understand how to be consumers of health care; many of them were using the emergency room as their source of primary care. Since that time, an on-site clinic has been developed at Urban Peak and youth are now able to receive health services at the shelter as well as at the main Rocky Mountain Youth clinic.

When CHP+ was implemented, Rocky Mountain Youth began efforts to enroll Urban Peak youth into the program. At the start of the CHIP program, Urban Peak youth were referred to the main Rocky Mountain Youth clinic to enroll; however, there were numerous barriers to this process. Soon thereafter, Rocky Mountain Youth committed to sending an outreach worker to Urban Peak for a few hours once a week. The outreach worker helps Urban Peak youth with applying for and enrolling in CHP+.

In Spring 1999, Rocky Mountain Youth began tracking numbers of youth enrolled in CHP+ based on this partnership. Although preliminary reports suggest that the partnership has been successful, it is still too early to determine the success of the outreach program.



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- Ensure access to a broad range of specialty services, especially mental health and substance abuse services, with reasonable or no cost-sharing. Other important specialty services include case management, respite care and nutritional services.
- Ensure that provider networks established under CHIP include providers with the specialized expertise necessary to serve adolescents with special needs.
- Establish more generous benefits for adolescents with special health care needs. Expanded benefit packages could include 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. As they approach adult-hood, these teens may need assistance in making the transition from pediatric to adult health care systems. Such assistance has become a primary focus of states' Title V CSHCN programs, and CHIP programs should take advantage of this special emphasis.
- 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 atrisk youth (e.g., homeless and runaway shelters).
- **Build or enhance coordination and linkages**between CHIP and other systems that serve
 adolescents with special needs. These systems
 include public health, education, mental health,
 social services, juvenile justice, vocational rehabilitation, and transition programs for adolescents
 with special needs (programs that assist adolescents who may need assistance making the transition from pediatrics to adult health care).
- 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. These "safety net" providers have traditionally served low-income adolescents, who may be familiar and comfortable with them. This comfort will help to encourage utilization of cost-effective primary care and preventive services.
- 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. Input from these stakeholders is critical to assuring a responsive, effective program that meets the needs of adolescents with special needs.

SCHOOL-BASED/SCHOOL-LINKED HEALTH CENTERS

Why are school-based/school-linked health centers (SBHCs) important for CHIP?

SBHCs are a valuable resource in states' arsenals for reaching and serving adolescents under their CHIP programs. Every state interviewed for this brief had at least some school-based health centers and was utilizing these centers in some capacity. And yet, it appears that many states are underutilizing SBHCs in their CHIP strategies.

Results: What are states doing about SBHCs under CHIP?

All 12 of the states interviewed were home to some SBHCs, ranging from three in Utah to 158 in New York. All of the respondents also noted that they were including schools and SBHCs in their CHIP outreach and enrollment efforts. On the other hand, there were significant discrepancies in the extent to which states were using or planning to use SBHCs as delivery sites for services under their CHIP programs and/or including SBHCs as essential community providers (ECPs) in these programs.

With respect to SBHCs, states seem to be following similar strategies under CHIP as they did with Medicaid managed care. Although this "mirroring" approach may allow for consistency and ease of implementation, it often neglects the important role that SBHCs could play in new, more flexible programs. States that merely encourage managed care organizations to collaborate or contract with SBHCs may find that health plans are reluctant to do so. Barriers to MCOs' contracting with SBHCs include lack of knowledge about the role of SBHCs and the scope of services they provide; a belief that the existing provider network is adequate; unwillingness to invest the administrative and contracting resources in a small, "niche" provider; concerns about the quality of care provided at SBHCs; and/or strict requirements that SBHCs can not always meet (e.g., 24-hour, year-round medical coverage).

There are many possible explanations for this phenomenon. Given the very rapid progression from legislation to planning to implementation, many states have not had time to consider, debate and include language that specifically addresses SBHCs beyond a very basic level. Others may be hesitant to promote the use of SBHCs given that there have been controversies regarding their delivery of reproductive health care services and because parents are not on-site when their children receive services. Still others may be unsure of ways to use contracting language or other tools to promote the inclusion of SBHCs. Finally, it is clear that some of the individuals and agencies charged with planning and implementing state CHIP programs are not familiar with SBHCs or their role in delivering health care services.

- All 12 states are proactively engaging schools and SBHCs in outreach and enrollment efforts for their CHIP programs (see Outreach and Enrollment). For example, a television station in Illinois aired a segment on SBHCs, their function, and how parents can get an application package for KidCare - the state's Medicaid lookalike plan – at their local school-based health center. SBHC staff are also given presentations on KidCare by CHIP staff. In Massachusetts, family planning providers who conduct outreach for CHIP are working closely with SBHCs and the state Department of Public Health to identify and enroll eligible youth. In New Mexico, school and SBHC staff have been trained and certified as Presumptive Eligibility/Medicaid On-Site Application Assistance providers, and thus can enroll adolescents directly into Medicaid and CHIP.
- Few states are actively assuring SBHC participation in their CHIP networks. Six of the states interviewed indicated that SBHCs could be included in CHIP plans' provider networks, either as primary care or adjunct providers, at the health plans' discretion. Many states have followed a similar path with their Medicaid managed care programs deferring to the health plans with respect to their provider networks and allowing, or



perhaps encouraging, but not requiring, that SBHCs be represented or included. In Illinois, MCOs are required to contract with SBHCs only to share and coordinate information on common clients; no payment/reimbursement relationship is explicitly mandated. Similar provisions are in place in Alabama and California.

- Some states are encouraging CHIP plans to contract with SBHCs. In Massachusetts, for example, health plans are "strongly encouraged" to establish contracts with SBHCs and to set quality assurance and improvement goals jointly with the state in the area of school-based health. The state has developed quality standards for SBHCs, which SBHCs must meet in order to be reimbursed by MassHealth for services delivered. MCOs can make their own reimbursement arrangements with SBHCs, but have been informed that they have to comply with the state's quality standards.
- Only five states (Colo., Conn., Ill., N.C., and Wis.) are including SBHCs as essential community providers (ECPs).
- Only two states are requiring that managed care plans under CHIP contract with school-based health centers. On January 1, 1999, New York joined Connecticut in its requirement that managed care insurers under Medicaid and its new child health insurance program, Child Health Plus, contract with SBHCs. The goal of this requirement is to promote a seamless system of coverage for enrolled members. Managed care plans contracting with Connecticut under HUSKY A are required to contract with SBHCs as ECPs.
- Reimbursement practices for SBHCs appear to vary by state, type of plan (Medicaid expansion vs. new child health insurance program), managed care vs. fee-for-service arrangement, health plan/insurer, county/locality, and provider/service type. The primary types of reimbursement described for SBHCs were fee-for-service and capitation, with some variation in each category. Although this was far

from an exhaustive survey of states, in general, it appears that SBHCs that are contracted as primary care providers are paid on a per-member per-month (capitated) basis, while SBHCs that act as supplemental or adjunct providers receive primarily fee-for-service payments. Contracts that cover only specified services, such as immunizations, EPSDT, or case management, are also more likely to be fee-for-service than those that include the entire continuum of primary and specialty outpatient care.

- Some states are "carving out" school-based health care from the CHIP benefit package and capitation rate paid to health plans, allowing SBHCs to bill the state directly on a fee-for-service basis. In Illinois, for example, certified SBHCs can acquire a special status that allows them to bill directly for their services. This arrangement is similar to the one many states use under Medicaid managed care.
- Four states (Ala., Colo., Mass., and N.M.) indicated that they would like to explore and potentially expand the role of SBHCs in their CHIP programs. For example, school-based and school-linked services will be included in New Mexico's Phase II wraparound program. Active involvement in CHIP by staff from the state's Office of School Health increases the likelihood that the role of SBHCs will be expanded. Representatives from Colorado indicated that they would like to address HMOs' reimbursement of SBHCs and inclusion in their provider networks.

State Innovations and Highlights

Colorado. In Colorado, collaboration between managed care plans and school-based health centers has a long history. Under Medicaid managed care and CHP+, SBHCs are essential community providers, with which health plans must make a "good faith effort" to contract; prospects for contracting are therefore more contingent on good relationship-building than on legislative requirements. Colorado's health department was actively involved in designing CHIP legislation – including the benefit package and enrollment strategies – and in the process, the department educated other agency staff about the role that SBHCs could play within CHIP. Under the state's Child Health Plan, the child health insurance plan that preceded CHIP, year-round SBHCs serving as full-service Primary Care Providers (PCPs) were eligible to receive the same capitation rate as other network PCPs.

For years, Kaiser Permanente – one of the largest HMOs in the state – has been working in partnership with local SBHCs and has established its own child health insurance program known as *School Connections*. Assuming a role as one of Colorado's CHIP plans, Kaiser is contracting with SBHCs that are capable of providing services, coordination and data. In return, SBHCs will receive a portion of the capitation rate for primary care and mental health services.

- New York. Of all states, New York State has the largest number of SBHCs and provides the highest level of state funding to SBHCs (Guiden, 1998). In addition to its historical financial commitment to the centers, New York has also worked hard to integrate school-based health with managed care delivery systems. Under Medicaid managed care and now CHIP, state officials have issued guidelines for contracts between managed care organizations and SBHCs, requiring that contracts be in place by March 21, 2000.
- Connecticut. Connecticut is implementing both a Medicaid expansion program and a new child health insurance product. The two programs are known as HUSKY Part A and Part B, respectively. Managed care plans contracting with the state under HUSKY A are required to contract with SBHCs as essential care providers. Although there is no equivalent mandate for HUSKY B, there is a clear policy expectation that this too will occur with time.

Massachusetts. Most SBHCs in Massachusetts are licensed as primary care providers through community health centers or local hospitals. The Department of Public Health establishes contracts with SBHCs to provide adolescent health services. These contracts require that the centers provide 24-hour coverage and an on-site adolescent specialist, and that they participate in the state's quality improvement program.

Although SBHCs are licensed as PCPs, they can also act as satellite sites under both Medicaid and CHIP. The state is working to improve the ability of the MassHealth Primary Care Clinician (PCC) Plan to coordinate with SBHCs by facilitating meetings between PCCs and SBHC staff.

North Carolina. After months of debate, the North Carolina legislature eventually determined that SBHCs are eligible to be reimbursed by Health Choice, the state's new child health insurance program. The ability of advocates to overturn the initial decision is testament to the powerful alliance that has been forged in this state between schools, families and health care providers in serving children and adolescents "where they are."

Recommendations: How can states include school-based/school-linked health centers in their CHIP plans and programs?

In contracts with managed care organizations (MCOs), states should include requirements that MCOs include SBHCs and other adolescent safety net providers in their provider networks. This is especially true in underserved areas, where services such as reproductive health and mental health/substance abuse services may not be widely available. SBHCs are more likely to play a role in CHIP when there is a strong state agency that requires or encourages the contracting process and an effective state SBHC association that can educate both its members and health



plans about how the two can complement one another. Connecticut and Colorado fit the above model because they have sophisticated SBHC networks and substantial managed care penetration, as well as strong health departments that can educate health plans, the state Medicaid agency and SBHCs about how to include SBHCs in provider networks and CHIP programs.

- For states that do not want to impose subcontracting 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 Title V or other state programs. These resources can be used to expand or maintain services, create additional programs that address critical health issues, and to help ensure and document the quality of care provided at the centers.
- States should ensure that CHIP funds are not used to subsidize services supported by other federal programs such as the Individuals with Disabilities Education Act.

QUALITY ASSURANCE

Why is quality assurance an important component in CHIP programs?

Two distinct but related activities, quality assurance (QA) and program evaluation, help to ensure: (1) that programs are implemented as planned; (2) that target populations are identified and enrolled; (3) that enrolled members utilize covered services appropriately; and (4) that the services delivered are comprehensive, effective and clinically appropriate. These activities, and the way they are designed and implemented, are especially important for adolescents given their historic underutilization of services and unique developmental needs. Information from QA and pro-

gram evaluation efforts can also be used to modify and improve health insurance programs throughout and beyond CHIP implementation. Finally, evaluation results and quality measures permit comparisons among health plans that can inform consumer choices, state purchasing decisions, and allow plans to identify deficiencies and implement improvements over time.

Results: What are states doing in the area of quality assurance?

At the time of the interviews, few states were highly advanced in their planning or implementation of quality assurance for adolescents under CHIP. On the other hand, there is reason for hope – several states are planning more ambitious adolescent-focused initiatives, and almost all respondents acknowledged the need for such targeted systems. Specific findings include the following:

- Most states relied on service providers and advocates to speak for adolescents in their planning processes. Unlike children, who are often too early in their cognitive development to understand abstract concepts related to health care, adolescents are an important source of information regarding barriers to access and other factors in designing a health insurance program. And yet, this population was almost entirely overlooked in the mandatory public input process that states underwent prior to submitting their CHIP plans to HCFA. To represent adolescent concerns, states requested input from adolescent providers, advocates and parents. Some states, including Colorado and Utah, have maintained this voice in an ongoing advisory capacity.
- Most states are taking advantage of established measures for quality assurance within health plans. California and Connecticut are using HEDIS, for example, and California may use the new Adolescent Health Survey being developed by FACCT when it becomes available.

Table IV.1:

States' Use of Preventive Services Guidelines for Adolescents under CHIP

State	Require	Encourage	Neither require nor encourage	Guidelines/Notes
Alabama	X			American Academy of Pediatrics (AAP)
California	X			AAP; Advisory Committee on Immunization Practices (ACIP) schedule
Colorado		X		Providers receive additional \$30 for using Guidelines for Adolescent Preventive Services (GAPS) or similar questionnaire
Connecticut			Χ	
Florida		X		AAP
Illinois		X		GAPS
New Mexico			X	GAPS is included in proposed Phase IIA amendment
Massachusetts	X			AAP
New York:				
- Periodicity for well- child visits	X			AAP
- Content of care		X		GAPS and Bright Futures
North Carolina			X	Trying to implement GAPS for Medicaid
Utah:				
- Medicaid	X			Bright Futures
- Child Health	X			ACIP
Insurance				
Wisconsin		X		Bright Futures/GAPS
TOTAL STATES: 31	6	5	3	

Other states are developing their own practice guidelines for CHIP. For example, officials in New York are developing a special screening tool for adolescents which incorporates GAPS and Bright Futures guidelines. The Massachusetts EPSDT schedule was developed in conjunction with the state chapter of the American Academy of Pediatrics. Health officials in that state are conducting a broad-based campaign to encourage parents, providers and purchasers to follow the EPSDT visit schedule, which requires one health visit per year for adolescents and emphasizes

anticipatory guidance. The state Title V program in Wisconsin has taken a leadership role in disseminating and facilitating training for Bright Futures, and publishing a strong recommendation that adolescent health care delivery should follow Bright Futures and/or GAPS. In Alabama, the use of preventive services guidelines for adolescent members will be one performance measure used to rank providers and health plans under the ALL Kids program. Finally, Colorado's CHIP program reimburses providers an additional \$30 for each GAPS type visit they provide to adolescents.



³¹ Two states (New York and Utah) are included twice because they support two different policies within their CHIP programs.

- Many states are building on QA systems established under Medicaid. For example, the North Carolina Medicaid agency is responsible for QA under the state's new child health insurance program, and is working with the state Title V agency to develop a new QA system for this program.
- Most states are encouraging or requiring the use of preventive service guidelines. Five states (Ala., Calif., Mass., N.Y., and Utah) are requiring that health plans and/or providers use preventive service guidelines with their adolescent patients; five (Colo., Fla., Ill., N.Y., and Wis.) are encouraging their use; and only three states (Conn., N.M., and N.C.) have not specifically addressed preventive service guidelines under their CHIP programs. The most frequently cited guidelines were Guidelines for Adolescent Preventive Services (GAPS) and American Academy of Pediatrics (5 each), followed by Bright Futures (3) and the Advisory Committee on Immunization Practices (ACIP) (2).
- Several states identified the development, use and promotion of guidelines as a priority issue for future years. In Florida, for example, respondents stated that they would like to promote the use of GAPS within Healthy Kids. New Mexico hopes to establish standards of care for adolescents based on GAPS, and North Carolina is trying to implement GAPS for its Medicaid population.
- Most states are relying on managed care plans to assure quality for adolescents within their CHIP programs. In Illinois, for example, enrollment in managed care under CHIP is voluntary; therefore, the rate of members disenrolling from various health plans will serve as an indicator of quality. Wisconsin respondents state that MCOs are responsible for identifying members who under- or over-utilize services and for conducting outreach to these members.

- Very few states are using contract terms as a mechanism for quality assurance. Specifying standards for providers and/or health plans in contracts, together with sanctions for non-compliance, is one way states can ensure quality in their CHIP programs. Only respondents from Massachusetts and Illinois in our sample, however, were using contract terms in this way. Massachusetts specifies contractual standards of care, and Illinois includes AAP guidelines in managed care contracts. Wisconsin's Division of Health Care Financing conducts on-site audit reviews of quality indicators specified in its contracts, but has not yet implemented penalties for non-compliance.
- Many states are planning to incorporate adolescent satisfaction measures in the future.

 Massachusetts is pilot testing a survey to assess adolescents' satisfaction with their CHIP providers and/or health plans. This survey was developed based on the Consumer Assessment of Health Plans (CAHPS). California is researching various tools in an effort to design a new instrument focused on adolescents. Alabama plans to survey members directly regarding access to care and, with the health plans, interview program dropouts to determine their reasons for leaving ALL Kids.
- Although the fact that states are beginning to view adolescents as discriminating consumers is commendable, adolescent satisfaction measures may fail to illuminate underlying access and outcome issues, especially in an underserved population.³² In addition, adolescents, even more than adults, may base their assessments of quality on factors such as provider communication skills which, while important aspects of quality, may not be directly related to clinical quality of care. Finally, adolescents often lack benchmarks with which to compare their health care experiences.

³² Studies have revealed that member satisfaction in privately insured populations is highly correlated with access to care, but that lower-income persons and Medicaid recipients do not exhibit such a clear correlation (Ladenheim, 1999; Love, 1999). This suggests that the adolescents targeted for CHIP may not be as sensitive to access barriers when ranking health plans and providers.

SPOTLIGHT: MASSACHUSETTS

Health officials in Massachusetts have operated according to principles of quality assurance and continuous quality improvement (CQI) for years. The state Medicaid agency applies a "quality-focused management approach" to managing its health plans and providers, using data from various sources as the basis for contracting decisions and making this information available to consumers on an annual basis. The state's underlying philosophy is that regulation and legislation are limited in their ability to improve quality, and that enhanced quality requires using information as a tool in the role of purchaser.

Health plans that contract with the state must participate in the state's quality improvement program. Each year, the Division of Medical Assistance (DMA) works with plans to establish performance standards, QA goals and quality improvement projects. Together they identify specific areas for improvement both statewide and by plan based on data reported from previous years and comparisons to national benchmarks. This year, three out of six plans have chosen to work on improving well-child care; two of the three plans are focusing specifically on adolescents. The state has updated its EPSDT schedule to include annual visits for teens and expects 85 percent of adolescent members to receive annual visits.

In addition, the agency issues a health plan performance report every year that includes information on member satisfaction and outcome measures; this report is intended to help members select plans and help plans improve their performance. One outcome measure is adolescent-specific: the percent of members aged 12-18 who had one or more well visits within the past two years. *In 1997, 73 percent of 12-18 year-olds enrolled in MassHealth*³³ had had a well-child visit in the past two years. *This compares very favorably to the 32 percent national average for this age group enrolled in private, non-Medicaid HMOs* (Matthews, 1999). Other indicators include access to care (e.g., how easy it is to get an appointment when sick) and cultural competence of providers. Measures are rotated on an annual basis, so the adolescent measure is not included every year.

Massachusetts takes its role as an expert purchaser for the Medicaid and CHIP populations very seriously. In recent years, a contract with a major health plan was not renewed because the plan could not meet the state's timeframe for enhanced MCO contract standards for mental health/substance abuse services.

The state has also assembled a Child and Adolescent Advisory Group, composed of representatives from the Department of Public Health, DMA, providers, and child/adolescent advocates. This group is actively engaged in quality improvement activities and is currently working to improve the ability of primary care providers to deliver anticipatory guidance to children and adolescents. They will also be sending various adolescent risk assessment tools to providers to help them screen patients and requesting that they document these efforts.



³³ MassHealth refers to the programs administered by the Division of Medical Assistance.

SPOTLIGHT: CALIFORNIA

California's new child health insurance program, Healthy Families, has established a Quality Improvement Work Group (QIWG) to help ensure that the services designed, offered and provided to eligible children and adolescents are appropriate, accessible and high-quality. Funding for the QIWG has been provided primarily by the California HealthCare Foundation; this funding helps to support meetings, travel costs for participants, and the services of a consultant who specializes in health care quality assurance/improvement. Participants include physicians, psychologists and dentists; representatives from private and county-based health plans; local health departments; and advocates. The group also hopes to add a consumer representative (i.e., adolescent and/or parent).

Since August 1998, the QIWG has been developing recommendations on implementing a Quality Accountability Framework for Healthy Families. These recommendations address four key areas: dental quality, HEDIS reporting, consumer satisfaction, and health status assessment. They have also been asked by the Managed Risk Medical Insurance Board (MRMIB), the agency that administers Healthy Families, to consider how cultural and linguistic variables might be incorporated into quality monitoring efforts for Healthy Families. The QIWG has established four subcommittees to address these issues, one of which is focused on adolescent measures. In recognition of the inadequacy of the current HEDIS measures for adolescents, the latter group has been charged with developing adolescent health-related measures, a survey, and/or a focused chart review instrument.

The group has established a framework for purchasing higher quality care for Healthy Families members (children and adolescents); this framework attempts to create clinical quality accountability among both providers and health plans. Detailed measures have been proposed by the consultant for review by the work group. Standards include health plan accreditation by the National Committee for Quality Assurance or the Joint Commission on Accreditation of Healthcare Organizations; use of specified preventive service guidelines; application of a standardized health survey for enrollees; and systematic integration with schools and other community institutions. The group hopes to create incentives for various levels of performance (e.g., to measure provider compliance with evidence-based guidelines for well-child visits and specific conditions). One guiding principle is that quality should be measured across the continuum of care (i.e., monitoring will include those who are very healthy, those who are very ill, and everyone in between).

Although the QIWG is recommending the use of existing instruments where available, they are planning to modify others in order to ensure their relevance. For example, they are recommending that MRMIB require contracting health plans to report the five categories of HEDIS 3.0 measures relevant to children and adolescents one through 19 years old, but that MRMIB replace the adolescent immunization measure included in HEDIS 3.0 with a new measure that addresses counseling services for risk behaviors such as pregnancy, STIs and substance abuse that should occur during an office visit. They are also recommending that Healthy Families automatically incorporate the adolescent satisfaction survey being developed by FACCT and NCQA when it becomes available. It is expected that this survey will be used for members ages 13 through 19 years to complement the use of CAHPS for parents of children one through 12. As with CAHPS, the survey will need to be translated into Healthy Families' 11 threshold languages. In addition, the work group hopes to add questions on behavioral health and assistive services, such as transportation and language interpretation.

Final recommendations from the group will be submitted to MRMIB. They will be available for public comment, after which MRMIB will make decisions about how to proceed. In November 1999, the Board will consider changes to its current contracts based on the QIWG recommendations.

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■ Quality assurance is a "work in progress."
From Colorado to North Carolina, respondents noted that quality assurance was a priority to be addressed at a later date. Mechanisms to ensure quality, including ones that focus on adolescents, were simply not in place at the time of the interviews.

State Innovations and Highlights

New York: Health plans that contract with the state through CHIP are required to submit Quality Assurance Reporting Requirements (QARR) on an annual basis. This system captures some adolescent-specific themes and monitors several health indicators relevant to adolescents. In addition, the state is exploring the possibility of conducting focused reviews to assess compliance with elements identified in GAPS.

Recommendations: What should states do to ensure that eligible adolescents are enrolled in CHIP and receive high-quality health care services?

- Incorporate adolescent-specific professional guidelines for preventive services such as GAPS and Bright Futures. Mechanisms to accomplish this include legislation, regulations, and contracts with health plans/providers.
- Establish QA measures and systems that pay specific attention to adolescents and their unique needs. In developing new measures, states might want to identify a few sentinel issues specific to their adolescent Medicaid and CHIP populations (e.g., injuries, substance abuse, chlamydia, depression) and gather baseline data for the target population.
- Assure collaboration between Title V, CHIP and Medicaid agencies. State Title V agencies in particular have valuable experience with data surveillance systems and MCH performance measures.

- be prepared to use this information 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 their 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. This clearinghouse could include the standardized resources described above, as well as specific tools used in various states to assure quality in CHIP programs for adolescents.

EVALUATION

Results: How are states planning to evaluate their CHIP programs for adolescents?

Not surprisingly, it appears that states have paid more attention to program design and start-up than to ongoing needs for program evaluation. Even less attention has been paid to mechanisms which specifically ensure that eligible adolescents are enrolled, served, retained, and receive quality services that meet their multiple needs. On the other hand, there are some encouraging findings from several states.

partnering with other agencies to help support their evaluation activities. In California, for example, the Packard Foundation is expected to contribute funding and in-kind resources, while faculty at the University of Alabama at Birmingham will help to conduct the ALL Kids evaluation. North Carolina is working with Sheps Center at University of North Carolina (UNC)-Chapel Hill for the overall evaluation of NC Health Choice for Children, and with UNC-Charlotte to conduct an extensive consumer survey for the program. In New Mexico, a major amendment to the original CHIP plan, together with an extensive evaluation



plan (see *Spotlight*), was developed by a statewide collaborative group including interagency staff, providers, parents, volunteers, advocates, and school staff.

- Few states have developed detailed evaluation plans that include adolescent-specific measures. In many cases, decisions and plans were made quickly, with little opportunity to weigh competing alternatives. Where an existing infrastructure was in place, states often used this, even if it had been designed exclusively or primarily for younger children. And where strong evaluation elements are included, they often fail to address adolescents as a unique population with different needs than younger children or adults.
- Many states are planning more sophisticated evaluation efforts after their programs are operational. For example, Alabama will convene an advisory group, together with university experts, to design and implement its CHIP evaluation. As a component of this process, they will compare the enrollment distribution from the first several months of the program with their target demographic profile to ensure that eligible adolescents are accessing and being retained in the program.
- Most states are planning to evaluate their programs at a much more detailed level than HCFA requires. For example, states are planning to report enrollment and encounter data in one-year age intervals rather than the wider 4-6 year groupings requested by HCFA.

State Innovations and Highlights

with public health agencies to conduct surveillance and community health assessment. The health data authority, a separate office within the Department of Health, collects data for assessment and evaluation purposes. This is expected to be a strong partnership with the ability to provide detailed information on various age groups, including adolescents eligible for the state's CHIP program.

California: The Managed Risk Medical Insurance Board is working with partners, including universities and private foundations, to design and implement a comprehensive evaluation that will include a strong adolescent focus.

SPOTLIGHT: NEW MEXICO

An extensive evaluation plan has been developed for this state's CHIP program. The plan includes outcome measures for adolescents in the areas of risk factor reduction; decreased education-related problems (suspensions, expulsions, course failures, disciplinary action); early and continuous prenatal care; reduced out-of-home placements; oral disease prevention; and others. Adolescent client and provider satisfaction surveys will also be utilized. Findings from this evaluation will be very useful to other states and to the field in general as researchers and policymakers attempt to measure the impact of health insurance coverage and access to care on broad social, behavioral and educational indicators.

Recommendations: How should states structure their program evaluations to focus on adolescents?

- Build evaluation efforts on existing measures, tools and systems. In the past several years, as state agencies have increasingly enrolled their Medicaid populations in managed care systems, these agencies have become sophisticated purchasers of health care services for low-income populations, devising complex contracts that specify service delivery, access and other expectations. Rather than reinventing the wheel, states that create new child health insurance programs under CHIP should leverage and build on this valuable experience.
- Implement evaluation strategies that are feasible. When constructing evaluation plans for adolescents under CHIP, states should consider whether baseline data (or reasonable proxies) are available from existing sources or can be created for the targeted medical, behavioral, epidemiological, enrollment and service delivery goals. The

challenge for states is to design simple but effective measures that can be easily tabulated and efficiently used to indicate strengths and weaknesses in their CHIP programs.

- Develop comprehensive measurement tools that emphasize health and wellness across the continuum of care. A wide range of methods should be used, including practice guidelines, satisfaction surveys, performance measures, internal quality improvement systems, external quality reviews, accreditation of plans, credentialing of providers, and consumer protections. Through the use of complementary data collection strategies, a more thorough evaluation profile will emerge, providing planners with the information they need to more effectively target various populations and program objectives.
- Involve adolescents, families, advocacy organizations, providers and other stakeholders in program evaluation. Input from these individuals and groups can help to ensure that the evaluation design is authentic and responsive to the needs of various constituents.
- Conduct periodic evaluations. These should 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. States need to track when and where adolescents enter health care systems so that critical opportunities for improving enrollee health are identified and optimally utilized.
- Create partnerships. Working alliances between state Medicaid and public health agencies, including state Title V MCH/CSHCN programs, will help CHIP programs build expertise and maximize the use of data that states are already collecting.

LINKAGES WITH OTHER HEALTH AND SOCIAL SERVICE PROGRAMS

Why are linkages with other programs important for adolescents under CHIP?

Because the range and number of federal, state and community programs addressing adolescent needs are vast and complex, coordination is essential to reduce costly fragmentation and duplication. States are required by federal law to coordinate Title XIX (Medicaid) and Title V (MCH/CSHCN Block Grant Services); Title XXI requires states to evaluate CHIP coordination with both of these programs. Coordination with other key federal, state and local programs such as schools, employers, family planning agencies, mental health and substance abuse centers, and special education programs is also important. Most state Title V programs and health agencies already have linkages with many of these programs and can facilitate further coordination. However, CHIP provides additional opportunities to enhance and formalize such relationships.

Results: How are states linking CHIP to important health, social and education systems?

All 12 states surveyed are working with local schools and school districts to provide information about CHIP to families. States are engaging in multiple partnerships and creating linkages with other services and programs in a variety of ways. Most notable at this stage of CHIP implementation are the linkages states have developed with other agencies and systems for outreach and enrollment. In Illinois, as in several other states, much of the outreach effort is being conducted in partnership with local school systems. In Fall 1998, Illinois sent CHIP information home with every student's report card. Similarly, eligibility for Florida's Healthy Kids program is coordinated with its school lunch program: students who qualify for subsidized lunches automatically qualify for Healthy Kids.

SPOTLIGHT: NORTH CAROLINA

In North Carolina, local outreach coalitions are playing a primary role in conducting outreach for CHIP to eligible children and families. These local coalitions are comprised of county health and social services agencies, community groups, and other grassroots organizations. The state is providing a great deal of support to these coalitions through print and electronic materials and media, toll-free hotlines, and technical assistance offered through monthly coalition letters, regional consultants and workshops/meetings. The state has also been able to provide a small amount of funding to local coalitions to support their efforts.

The state requested that county health departments and departments of social services convene initial meetings between various organizations and community groups in their respective counties. Based on these meetings, outreach coalitions were formed in each county. Due to the wide range of resources and needs across the state's counties, the types of groups included in each coalition vary. Coalitions include, but are not limited to:

- Community and migrant health centers
- Health care providers
- Public schools
- Child care/Head Start programs
- Family support networks for children with special health care needs
- Media groups
- Churches
- Local businesses
- Chamber's of Commerce
- Housing authority
- Non-profit organizations
- Smart Start³⁴
- Consumer groups

Local coalitions have targeted their initial CHIP outreach efforts to schools, child care providers, health providers, and the former Caring Program³⁵ and Medicaid recipients. In order to reach all those who are eligible for CHIP, groups that represent a wide spectrum of the community are being encouraged to participate in the coalitions' outreach efforts.

Although the coalitions' efforts vary, many of these groups indicate that one of the most successful outreach strategies is sending CHIP information to homes with school report cards and with children in child care. Other efforts include informing local media about the program, including information in utility mailings, posting information on Cable TV Community Bulletin Boards, and distributing CHIP materials door-to-door and in post office boxes.

The coalitions' outreach efforts appear to have been quite successful. Since the implementation of the CHIP program in October 1998, over 50 percent of the population estimated to be eligible for CHIP has enrolled in the program. The state is currently planning several evaluation efforts to determine the effectiveness of the coalitions' outreach efforts.

³⁴ Smart Start is a public-private initiative whose programs provide children under age six with access to high-quality and affordable childcare, health care and other family services.

³⁵ The Caring Program was a 501(c)(3) sponsored insurance program, primarily sponsored by Blue Cross/Blue Shield, which raised funds to purchase ambulatory health insurance for children. When *Health Choice* was implemented, the Caring Program terminated its coverage in favor of the more comprehensive coverage provided through *Health Choice*.

- Most states have established linkages between their Medicaid agencies and Title V programs. Current activities resulting from these linkages include conducting outreach and enrollment to eligible populations, and establishing service delivery systems under CHIP for children and adolescents with special health care needs. For example, the CHIP program in California requires that children and adolescents with special health care needs be referred to the state Title V agency for specialized medical services. In Colorado, the Medicaid contract requires that referrals be made in both directions between Medicaid and the Title V Health Care Program for Children with Special Needs. Other linkages were created prior to the passage of Title XXI and have provided states with an important foundation for further collaborative efforts.
- All 12 states indicated that their CHIP plans specify some type of ongoing collaboration between the state's CHIP program and state and local public health agencies. This collaboration varied and in many cases was planned for the future. Several states intend to collaborate or continue to collaborate on outreach and enrollment efforts; several will collaborate on planning and related policy development; and many plan to collaborate around community assessment and surveillance.

State Innovations and Highlights

■ New York: The Child Health Plus program makes a special effort to coordinate with the state's Medicaid managed care program. The intent is to have children and adolescents move between programs with relative ease and also maintain relationships with their primary care providers. New York uses a joint application process for Medicaid, Child Health Plus and WIC to help solidify this connection.

Recommendations: What can states do to build or strengthen linkages with other programs and systems?

- program and other community-based programs that serve adolescents, including school-based/school-linked health centers, local health departments, federally-qualified health centers, and other youth-serving organizations such as Boys and Girls Clubs and recreation centers. Through active integration and collaboration, the various systems that serve low-income youth can attempt to achieve a seamless system of care that meets adolescents' multiple needs.
- Create linkages between state CHIP programs and other state agencies and programs. Linkages should be established with Title V programs, social services, family planning, mental health, substance abuse, and education agencies.
- Ensure that clear, uniform processes are established and/or maintained which link adolescents to needed community-based services. Mechanisms should also be in place to provide appropriate coordination and follow-up.
- Ensure that managed care organizations (MCOs) have developed linkages to public health agencies, social services, education systems, and essential community-based providers. In states where services for adolescents are delivered through managed care arrangements, this can be achieved through the use of specific contract language that specifies the relationships MCOs are expected to maintain.

V. Discussion and Implications

he State Children's Health Insurance Program offers tremendous promise in efforts to improve the health of America's adolescents. The legislation that created Title XXI of the Social Security Act was enacted with bipartisan support from the U.S. Congress. Since then, virtually every state, district and territory has invested resources in programs to provide health insurance coverage to adolescents at incomes up to and above federal poverty guidelines.

As this report highlights, 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. These findings are particularly notable as many states were in the early stages of implementation at the time of this study and therefore had not yet had significant time to more fully develop their efforts. Clearly, more programmatic changes will continue to emerge as states submit amendments to HCFA and refine their existing programs. By all indications, most states recognize that the unique health needs of low-income adolescents require targeted efforts and expressed intentions to further address this population.

While the states interviewed for this publication represent a broad geographic and demographic distribution, there were no significant differences in CHIP implementation across states that might be explained by geography or demographics. Furthermore, while these states were selected for being more advanced in CHIP implementation and/or adolescent health services, overall this did not seem to result in any one state or region being further along in its efforts to address the health needs of adolescents under CHIP.

While most states recognize that adolescents require special focus and efforts under CHIP, major challenges remain in addressing the needs of this unique population. For example, in spite of the experience that state Title V programs, state adolescent health coordina-

tors and others can bring to the table, these individuals and groups have not been consistently involved in CHIP planning and implementation. Future efforts to target adolescents under CHIP could benefit from the expertise of these programs and groups.

Many of the states we interviewed had at least begun to simplify their application processes and to utilize eligibility workers outstationed at provider and other community sites. While a few states have broadened their outreach efforts beyond education agencies to include other sites such as homeless and runaway shelters – places where at-risk youth might be found – more comprehensive and targeted outreach efforts that involve adolescents, that consider where and how adolescents access and utilize services, and that address the needs of at-risk adolescents, are needed to ensure that the adolescents who need services the most are enrolled in their states' CHIP programs.

Respondents expressed their states' intentions to address mental health and substance abuse coverage under the CHIP benefit package and to expand these services through amendments, if necessary. Unfortunately, reproductive health services, while a covered benefit in most states in this sample, still appear to be impacted by ongoing political debate and struggles over the perceived need for these services.

Except for a few isolated efforts, little comprehensive attention has yet been placed on adolescents with special health care needs in most states' planning and implementation efforts; even less seems to have been done for at-risk adolescents. Policymakers may consider adolescents with special health care needs to be a population that has already been addressed under the state's Title V program for children with special health care needs. Further work to identify adolescent-oriented specialty providers, target outreach efforts to these populations, assure continuity of coverage, and create connections to other critical social services are urgently needed. Few states, moreover, have established a means by which to ensure continuous eligibility for at-risk adolescents who may be mov-



ing in and out of various living, health and social service systems.

There is a need to build on existing data and surveillance systems in state health agencies, many of which are already collecting child and adolescent health-related information that can contribute to a greater understanding of CHIP's overall impact. Title V performance measures, which all states are required to collect and annually submit to HRSA, could prove useful in states' evaluation efforts. Unfortunately, states have little funding through CHIP to devote to evaluation and monitoring activities – activities which are often costly and time-consuming – due to statutory limits on spending for administrative functions. Because states can not expend more than 10 percent of their total federal and state CHIP allotment on outreach, enrollment, evaluation, and other administrative activities, these efforts are likely to suffer. Similar data issues are being addressed by multiple entities, including states themselves, HCFA, HRSA, and others. However, leadership, support and collaboration at the federal level, particularly from HCFA and HRSA, will continue to be needed.

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 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. Providers' reluctance to ask their adolescent clients questions about certain topics further reduces their ability to respond to the unique needs of these clients. In the absence of

more specially trained clinicians, continuing education and training of traditional health care providers becomes even more essential.

Safety net providers – including local health departments, community health centers, and school-based health centers – have historically served as key health care delivery sites for low-income adolescents and their families. In general, states do not appear to have fully leveraged the opportunities presented by CHIP to involve safety net providers in a comprehensive system of care for their adolescent enrollees.

Experts disagree about whether managed care arrangements primarily benefit or primarily harm adolescents. Certainly, the core principles that managed care has traditionally embraced – including prevention, wellness, population-based planning, and health promotion – are principles that, if operationalized, stand to serve adolescents well. On the other hand, some studies suggest that managed care plans impose restrictions on care that threaten teens' access to needed services, and that these barriers are even greater for those with special needs.

Despite significant legal and regulatory tinkering, managed care is likely to remain a permanent fixture in the U.S. health care delivery system. Given this reality, states and advocates for adolescents might want to focus their efforts on making managed care organizations more responsive to the needs of adolescents, 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. As competition and competitive pressures rise, reimbursement levels tend to fall, creating an incentive for MCOs and providers to withhold services or enroll and serve only low-risk clients. 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.



The Big Picture

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 cutoffs 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).

CHIP also does little to improve access for those whose family incomes exceed eligibility cutoffs. It is estimated that 41 percent of uninsured children and adolescents live in families with incomes greater than 200 percent of federal poverty guidelines and therefore will not qualify for CHIP coverage in most states (Klerman, 1999). Although some of these teens may be able to afford necessary medical services, others are likely to forego the preventive care that could help them to establish healthy behaviors and reduce the impact of undetected conditions.

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. For example, states should endorse, sponsor or otherwise support public or private initiatives that provide health insurance coverage for adolescents with family incomes too high to qualify for Medicaid or CHIP programs. They should ensure that eligibility for public programs is consistent across age groups so that younger children in families will not be eligible for programs for which their adolescent siblings are not. Finally, states might want to experiment with other approaches, such as subsidizing employers for providing dependent coverage, providing tax credits to families that purchase health insurance for their children, or creating scaled-back state-run programs that cover all child and adolescent residents.

The State Children's Health Insurance Program provides states with an unprecedented opportunity to extend and expand health insurance coverage for low-income, uninsured adolescents. To maximize the potential of Title XXI in reaching and serving adolescents, the gaps and challenges outlined in this report will need to be addressed. No single state or entity possesses all the answers as to how CHIP can best meet the health needs of low-income adolescents. But as this report illustrates, several existing state efforts can prove useful to other state policymakers, health plans, providers, and advocates.

Each state has its own unique set of issues and circumstances which must be considered as CHIP is further implemented. However, our interviews suggest that states would benefit from more formal opportunities to share information, strategies and peerto-peer technical assistance. In addition to ongoing federal leadership and support from national organizations such as the National Governors' Association, National Conference for State Legislatures, Association of State and Territorial Health Officials, AMCHP, Policy Center and NAHIC, a national clearinghouse focused on best practices in serving adolescents under CHIP would be extremely effective. Finally, continued inter- and intra-agency collaboration will be crucial to the ultimate success of this exciting new program.



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Appendix A

Names and Titles of Interview Respondents

State Contacts and Interview Dates

Gayle Lees Sandlin Phyllis Gilchrist

Director, CHIP Director, Women's Health Branch and Alabama Department of Health State Adolescent Health Coordinator Interview date: 10/26/98 Department of Public Health

Bureau of Family Health Services

Interview date: 11/30/98

California

Bob Bates Leslie Cummings

Adolescent Health Coordinator

Department of Health Services

Maternal and Child Health Branch

Associate Director for Health Policy

Department of Health Services

Interview date: 12/2/98

Interview date: 10/30/98

Colorado

Barbara Ritchen Merril Stern

Director, Child, Adolescent & School Health
Department of Public Health & Environment
Family & Community Health Services Division

Director, Family and Community Health Services
Department of Public Health & Environment
Family & Community Health Services Division

Interview date: 11/10/98 Interview date: 11/10/98

Connecticut

Jadwiga Goclowski Lynn Noyes

Title V and CSHCN Director, Family Health
Connecticut Department of Public Health Services

Supervisor, School & Primary Health Unit
Department of Public Health

Interview date: 11/9/98

Bureau of Community Health
Interview date: 11/9/98

Florida

Donna Barber Sylvia Byrd

Former Director Executive Community Health Nursing Director Division of Family Health Services Family Health Services/School Health Program

Department of Health, Family Health Interview date: 12/10/98

Interview date: 12/10/98

Massachusetts

Louise Bannister Deborah Klein Walker Assistant Director, PCC Plan Assistant Commissioner

Division of Medical Assistance Bureau of Family and Community Health

Interview date: 12/14/98 MA Department of Public Health

Interview date: 12/4/98

New Mexico

Kathleen Valdez Patsy Nelson

Chief School Heath Director

Medicaid Planning Program Operations Bureau Office of School Health Medical Assistance Interview date: 12/1/98

Interview date: 12/4/98

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New York

Taimy Carnahan

Director, Adolescent And School Health Unit

Interview date: 12/2/98

George Diferdinando

Director, Division of Family and Local Health

NY State Department of Health

Interview date: 12/2/98

Lorraine McCann

Adolescent Health Coordinator

Department of Health

Bureau of Child & Adolescent Health

Interview date: 12/2/98

Susan Moore

Director, Bureau of Health Economics

Department of Health Interview date: 12/2/98

North Carolina

Carolyn Sexton, RN, BSN, MPH

Division of Public Health Interview date: 11/13/98

Utah

Linda Abel

Immunization Program

Interview date: 11/9/98

Kathleen Glasheen Bureau Director

Community & Family Health Services Maternal and Child Health Bureau

Interview date: 11/9/98

Dawn Higley

Community & Family Health Services

Maternal and Child Health Bureau Interview date: 11/9/98

Chad Westover CHIP Program

Utah Department of Health Interview date: 11/9/98

Wisconsin

Millie Jones

Section Chief

WI Division of Health

Interview date: 12/16/98

Sharon Lidberg

Adolescent Health Program Consultant

Division of Public Health Interview date: 12/16/98

Katherine McCabe

Bureau of Managed Health Care Programs

Interview date: 12/16/98

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Appendix B

Respondents' Priority Issues for Adolescents

The following table depicts interview responses to the open-ended question:

What are three specific adolescent health issues you would most like to see addressed in your state's CHIP program?

То	pic/Details	# Respondents who Cited	States	
1.	Mental Health Benefits:	7	AL (2), CA, CO,	
	• Behavioral health/early identification services		NM (2), UT	
	 Early intervention mental health services – EPSDT does not adequately capture mental health problems 			
	 Adequacy of mental health coverage 			
	◆ Sexual abuse			
2.	Reproductive Services:	7	AL (3), IL, NC,	
	• Family planning		NM, UT	
	Pregnancy prevention			
	 Low birthweight babies 			
	 Pregnant adolescents 			
	◆ STDs and HIV			
	 Annual exams for family planning for sexually active adolescents 			
3.	Preventive Health Services:	6	AL, CA, FL, MA, NC, UT	
	• Periodic health exams			
	 How to make them desirable and attainable, how to utilize them 			
	◆ Immunizations			
	◆ Using GAPS more			
	 Improving the delivery of anticipatory guidance by physicians 			
	 GAPS/adolescent package being approved in Medicaid 			
4.	Access and Utilization:	6	CT, FL (2), MA	
	 Addressing barriers for adolescents to access and utilization of specialty services (including empowerment/confidentiality) 		(2), WI	
	◆ Transportation			
	• Access to private visits by physicians			
	 Assuring primary and preventive care is accessible to teens 			



То	pic/Details	# Respondents who Cited	States	
5.	School-Based/School-Linked Services:	5	CO, FL, MA, NC,	
	◆ Providing services in schools		NM	
	◆ SBHCs being included as essential providers			
	 Managed care reimbursing SBHCs and including SBHCs in provider network 			
	 Continuing link with SBHCs to increase the rate of visits by adolescents 			
6.	Substance Use/Abuse:	5	AL, CA (2), CO,	
	◆ Coverage and benefits		NM	
7.	Confidentiality:	5	CA, CO, CT, FL,	
	 Respecting the privacy of adolescents and their ability to access confidential services 		MA	
	◆ Addressing confidentiality as a barrier to access and utilization of specialty services			
8.	Outreach and Enrollment:	4	CA, CO, CT, UT	
	◆ Self-enrollment for adolescents who have dysfunctional families who will not follow through with the application			
	Outreach to special populations			
9.	Expanding Eligibility:	3	MA (2), WI	
	 Medicaid coverage for all children 			
	◆ Coverage for 18-21 year-olds			
	◆ Expanded coverage for children with special health care needs; carveout for CSHCN so that they can come in at higher income level (e.g., 200% of federal poverty or the child can be regarded outside the family unit			
10.	Tobacco Use	2	CT, NM	
11.	Dental Health	2	AL, UT	
12.	Special Populations:	2	CT, WI	
	♦ Adolescents with special health care needs			
	◆ Out-of-school youth/at-risk kids			
13.	Service Delivery:	2	CO, WI	
	◆ Provider training			
	 Specialized clinics for teens that are culturally appropriate 			

Topic/Details	# Respondents who Cited	States
14. Quality Assurance:	2	CO, WI
 Assuring that specific needs for teens are actually provided through solid follow-up 		
15. Injury Prevention	1	CA
16. Vision Care	1	AL
17. Others:		
 Asthma-related hospitalizations 	1	UT
 Making sure youth know their rights as consumers 	1	WI
TOTAL RESPONSES	62	

Appendix (

Summary of CHIP Programs/Plans for Surveyed States

	Medicaid: 0-6, up to 133% FPL			
The state is planning an amendment to create a wraparound program called ALL Kids Plus.	7-19, up to 100% FPL Separate: 0-6, 134-200% FPL 7-19, 101-200% FPL	VTT Kids	Combination plan	smsdslA
CHIP families are referred to California Children's Services (CCS), the Title V program for CSHCN.	Medicaid: 0-1, up to 200% FPL 1-5, up to 133% FPL 6-18, up to 100% FPL Separate: 1-5, 133-200% FPL 18, 100-200% FPL	morgor4 esilimo4 yhtasH	Combination plan	California
CHIP families are referred to Health Care Program, the Title V program for CSHCN.	J4H %281 ot qu ,81-0	(CHP+) Child Health Plan Plus	Separate state plan	Colorado
Husky Plus is a wraparound program designed for CSHCN. CHIP families are served through current Title V programs.	Medicaid: 14-18, up to 185% FPL Separate: 0-19, 185-300% FPL	иојА ХүѕпН	Combination plan	Connecticut
CSHCN are served through Children's Medical Services (CMS), the Title V program for CSHCN.	Medicaid: 15-19, up to 100% FPL Separate: 0-19, up to 200% FPL	Florida Healthy Kids	Combination plan	Florida
CSHCN are served under the Medicaid program or with Medicaid look-alike benefits.	Medicaid: 0-19, up to 133% FPL (Pregnant women and infants up to 200% FPL) Separate: 0-19, 133-185% FPL	KidCare	Combination plan	sioniIII

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Provisions for Children with Special Health Case Needs (CSHCN)	Age and Income Eligibility	Изте оf Ргодгат	Type of Program	State
CSHCN are enrolled in the Medicaid fee-for-service program and become part of the state's 1115 demonstration waiver program.	Medicaid: 1-19, up to 150% FPL Separate: 0-19, 150-200% FPL	hiln9HгглМ	Combination plan	Massachusetts
CSHCN are served under the Medicaid program.	Medicaid: 0-19, 186-235% FPL	ZV F\(\Omega\)Di	Medicaid expansion	oəixəM wəN
CSHCN are served under the regular additional benefits will be added to the CHIP program to augment services for CHIP program to augment services for the company of the co	Medicaid: 15-18, up to 100% FPL Separate: 0-19, up to 192% FPL	Child Health Plus (CHPlus)	Combination plan	Ием Уогк
CSHCM receive services through the NC Title V program.	J47 %002 of qu, e1-0	NC Health Choice for Children	Separate state plan	North Carolina
The state requires that CSHCM have access to appropriate pediatric specialists, even if the specialists are not included within the network of the managed care plan.		Utah Children's Health Insurance Program (UT (HIP)	Separate state plan	dвзU
CSHCN are served under the Medicaid program.	고역국 %≥81 or qu ,91-1	Вад <i>8е</i> нСаre	Medicaid expansion	Wisconsin

Sources:

Governor's Association: Washington, DC. 1998 State Children's Health Insurance Program: Annual Report. (1999) National Conference of State Legislatures: Denver, CO. National

(1999) Association of Maternal and Child Health Programs: Washington, DC. Brown, Treeby. The Impact of the State Child Health Insurance Program (CHIP) on Title V Children with Special Health Care Needs Programs.

Children's Health Insurance Program: Eligibility Levels Under CHIP (April 15, 1999) National Conference of State Legislatures: Denver, CO.

Health Care Financing Administration: Baltimore, MD.

MGA Supplement: State Children's Health Insurance Program 1998 Annual Report. (May 25, 1999) Center for Best Practices, National Governor's

Association: Washington, DC.

State CHIP plans and interviews with state officials.

Appendix D

RESOURCES ON CHIP AND ADOLESCENTS

This resource section provides background information on many of the available publications, newsletters, journal articles, websites and other resources on CHIP and adolescents. The first subsection, entitled "organizational resources" highlights groups that have extensive CHIP resources and linkages available on the Internet. The resources are divided into the following areas:

- General
- Benefit packages
- Outreach and enrollment
- Adolescents with special health care needs (CSHCN) and at-risk youth
- School-based health centers
- Confidentiality
- Access
- Quality assurance and evaluation
- Linkages

ORGANIZATIONAL RESOURCES

Health Care Financing Administration (HCFA): HCFA's website on the Children's Health Insurance Program (CHIP) provides materials of interest to various audiences regarding CHIP. The website contains the following information:

- CHIP state plan submissions
- Outreach
- Title XXI legislation
- Reserved CHIP allotments
- CHIP-related White House and Administration Information

HCFA's website on CHIP is located at: http://www.hcfa.gov/init/children.htm.

Maternal and Child Health Policy Research Center: The Children's Health Insurance Project of the MCH Policy Research Center conducts research and analysis on children's health insurance status and trends, issues and options under CHIP, employer attitudes and policies about dependent health insurance coverage, and the scope of private health insurance benefits for children. A series of analytic issue briefs and fact sheets about CHIP are available on the website. For more information, visit http://www.mchpolicy.org.

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National Academy for State Health Policy (NASHP): Funded by the David and Lucile Packard Foundation, NASHP's CHIP Implementation Center is designed to assist states in the planning, implementation, and refinement of their Children's Health Insurance Programs. The website includes the Academy's issue briefs on CHIP implementation and *CHIP Chat*, an interactive forum for the exchange of ideas and questions on CHIP programs. The CHIP Implementation Center is located at: http://www.nashp.org/progs/prog0001.htm.

National Conference of State Legislatures (NCSL): In an effort to provide information on state actions involving CHIP, this website contains several resources on general CHIP issues, as well as more detailed information on implementation topics such as outreach plans and specialized coverage. Some of the areas of information available on the website are listed below.

- Cost-Sharing
- Crowd-Out
- Eligibility Levels
- Enrollments
- Oral Health

For more information, visit: http://www.ncsl.org/programs/health/chiphome.htm.

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In addition, the NCSL maintains the Health Policy Tracking Service (HPTS), which is available to legislators and legislative staff on the HPTS website at http://www.hpts.org. HPTS publishes issue briefs on CHIP which are updated monthly. The site also provides state activity updates. For more information, contact Patrick Johnson at 202-624-7781 or e-mail patrick.johnson@ncsl.org.

National Governors' Association (NGA): The Health Policy Studies Division of the NGA's Center for Best Practices conducts numerous activities and services for governors and their staff to support and assist state efforts to implement Title XXI. The website provides links to numerous CHIP reports and resources, including the following:

- *Issue Briefs* and *StateLines*
- policy positions
- testimony and correspondence
- SCHIP Tools
- Related links to other resources

For more information, visit: http://www.nga.org/CBP/Activities/SCHIP.asp or call 202-624-5300.

Healthy Options for Meeting the Needs of Adolescents

GENERAL

Assuring the Health of Adolescents in Managed Care. 1998: UCSF/National Adolescent Health Information Center. NAHIC developed this quality checklist to aid in evaluating and planning health care services for adolescents in managed care settings. A managed care organization can use this checklist, which presents key components of health care for adolescents, to review current practices and to develop procedures designed to better meet the needs of adolescents. For more information, contact David Knopf at NAHIC at 415-502-4856.

Brindis, C., Irwin, C., Ozer, E., Handley, M., Knopf, D., and S. Millstein. *Improving Adolescent Health: An Analysis and Synthesis of Policy Recommendations*. 1997: UCSF/National Adolescent Health Information Center. This analysis identifies consensus areas where policy recommendations in adolescent health have been made. It also delineates critical barriers to implementation, identifies areas that have been omitted or have only emerged more recently and highlights strategies that may aid in developing programs that reflect policy priorities. For more information, contact NAHIC at 415-502-4856.

Children's Health Insurance Program: State Implementation Approaches are Evolving. May 1999: United States General Accounting Office. This GAO publication reports on the first year of CHIP implementation and focuses on the efforts of 15 states. In particular, it examines: SCHIP design choices, pursuit of statutory options, development of innovative outreach strategies, and strategies to avoid the "crowd out" of both private insurance and Medicaid coverage by CHIP. The report notes that states have made considerable progress in implementing CHIP, but emphasizes that design approaches will change as states finalize their plans. For a copy of the report, visit http://www.gao.gov.

CHIP Resources for Advocates. 1999: Families USA. This resource is a 500-page notebook that contains useful resources and information to help state advocates work on implementation of CHIP. There are sections on the following topics: The Basics, State Data, Getting It Right, Medicaid or Not, Benefits, Cost Sharing, Outreach and Coordination, Crowd Out, Quality and Access, Managed Care, Children with Special Needs, Special Populations and Key Contacts. In addition to materials prepared by FUSA, materials from numerous other organizations are included. For ordering information, visit http://www.familiesusa.org or call Rachel Klein at 202-628-3030.

Focusing On Results: How State Title V and Children's Health Insurance Programs Can Work Together for Healthier Children. September 1997: Association of Maternal and Child Health Programs. This issue brief discusses child health considerations in six areas: overall design; planning and administration; benefits and other services; service delivery systems; eligibility, outreach and enrollment; linkages with other programs; and monitoring and evaluation. This brief also highlights roles that state Title V programs can play in planning and implementing new federal provisions to reach their goal of healthier children. Call 202-775-0436 or visit http://www.amchpl.org for more information.

Health Insurance for Children: State and Private Programs Create New Strategies to Insure Children. January 1996: General Accounting Office. This report provides in-depth background on policy issues regarding children's health issues and profiles six innovative programs in five states (Ala., Fla., Minn., N.Y. and Pa.). This report is available on the Internet at http://www.gao.gov (report #96-35) or call 202-512-6000.

Kann, L., Warren, C., Harris, W., Collins, J., Douglas, K., Collins, B., Williams, B., and L. Kolbe. *Youth Risk and Behavior Surveillance-United States, 1997.* 1998: Surveillance and Evaluation Research Branch, Division of Adolescent and School Health, Centers for Disease Control and Prevention. The YRBS monitors six categories of priority health-risk behaviors among youth and young adults. The report summarizes results from the national YRBS survey, 33 state surveys, three territorial surveys, and 17 local surveys conducted among high school students from February through May 1997. Data from this survey is being used by health and education officials to improve national, state, and local policies and programs to reduce risks associated with the leading causes of morbidity and mortality. For further information, visit http://www.cdc.gov/nccdphp/dash/yrbs/ov.htm.

Ozer, E., Brindis, C., Millstein, S., Knopf, D., and C. Irwin. *America's Adolescents: Are They Healthy?* 1998: UCSF/National Adolescent Health Information Center. This monograph provides an overview of the health of adolescents, including: demographic trends, health care utilization, mortality during adolescence, and risky behavior during adolescence. This information highlights the needs of adolescents, programs and policies that focus on adolescent health promotion and disease prevention, as well as the health care delivery system. For more information, contact NAHIC at 415-502-4856.

Riley T. and C. Pernice. *How are States Implementing CHIP?* 1998: National Academy for State Health Policy. This publication updates NASHP's earlier *How Will States Implement the Children's Health Insurance Plans?* Based on the 47 state plans submitted to HCFA by late September 1998, the report identifies trends among the states and provides detailed summaries of each state's plan. New to this edition are policy briefs on Cost Sharing, Crowd Out, Evaluation, Employer Based Coverage, and Outreach. Call 207-874-6524 or visit http://www.nashp.org to order.

The State Adolescent Health Coordinators Network (SAHCN): SAHCN is the organization for the State Adolescent Health Coordinators, 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. SAHCN's mission is to provide leadership and advocacy for comprehensive adolescent health and youth development within state and national agencies; to advocate for the improvement of adolescent health, safety, and welfare; and to provide information and consultation to other organizations and agencies regarding adolescent health. For more information, contact Chair, Steve Conley at 804-371-4098 or e-mail sconley@vdh.state.va.us or contact Trina Anglin at MCHB at 301-443-4291 or e-mail tanglin@hrsa.gov.

State-Subsidized Insurance Programs for Low-Income People. November 1996: Alpha Center. This report reviews the evolution of state programs that have subsidized health insurance coverage over the last decade. It reviews current state programs and discusses challenges these programs may face in the future. For a copy call 202-296-1818.

VanLandeghem, K., Sonosky, C.A., and J. Kagan. *Maternal and Child Health Principles in Practice: An Analysis of Select Provisions in Medicaid Managed Care Contracts*. 1998: Association of Maternal and Child Health Programs. This report was developed with the recognition that as Medicaid populations increasingly are being served under managed care arrangements, state agencies, including state Title V programs, must become highly sophisticated purchasers of care. This report examines state Medicaid contracts. For more information, contact the AMCHP office at 202-775-0436.



Why Title V Maternal and Child Health Programs are Key to the Success of State Child Health Initiatives. June 1997: Association of Maternal and Child Health Programs. This fact sheet describe the unique expertise of Title V programs that should be tapped in the implementation of CHIP programs. Contact the AMCHP office at 202-775-0436 for a copy of this fact sheet.

BENEFIT PACKAGES

Edelstein, B. *Oral Health Services in the Child Health Insurance Program (CHIP)*. 1998: Children's Dental Health Project. This document promotes the need to include dental services in State Child Health Insurance Program (CHIP) plans. This fact sheet provides information on who and what benefits are covered under the program, state options and responsibilities, the intent of Congress regarding dental coverage, and the importance of providing dental benefits to CHIP children. A listing of submitted proposals from State CHIP plans is included. For more information, e-mail Burton_Edelstein@hms.harvard.edu.

Fox, H., McManus, M. Graham, R., and R. Almeida. *Plan and Benefit Options Under the State Children's Health Insurance Program*. 1998: Maternal and Child Health Policy Research Center. The purpose of this issue brief is to assist states in evaluating the various plan and benefit packages that could be offered. A brief overview of the five types of coverage that are permissible under Title XXI is presented along with a discussion of the range of the potential benefit packages that could be offered. For more information, contact Regina Graham at the Fox Health Policy Consultants at 202-223-1500.

Heffron, J. Strategies for Advocacy and Public Education Related to the State Children's Health Insurance *Program.* 1998: National Mental Health Association. The National Mental Health Association maintains a State Healthcare Reform Advocacy Resource Center that provides information and technical assistance. For more information, contact Jesse Gately, Manager at 703-838-7524.

Heffron, J., Chamberlain, K., and C. Miller. *The State Children's Health Insurance Program: An Analysis of the Mental Health/Substance Abuse Benefits and Cost-Sharing Policies of Approved State Children's Health Insurance Program Plans.* 1999: National Mental Health Association. This educational booklet details the approaches each state is taking to expand health insurance coverage, as well as their mental health and substance abuse benefits. Copies are available by calling 703-838-7534.

State Options for Expanding Children's Health Insurance. May 1997: National Conference of State Legislatures. This report explores the nature and extent of lack of insurance among children and describes state programs that provide coverage. To order, call 303-830-2054.

State Programs for Providing Children's Health Insurance: A Resource Notebook. May 1997: National Conference of State Legislatures. This notebook serves as a companion piece to the above report and provides more specific information on state programs. To order, call 303-830-2054.



Title V and Children's Oral Health. In press: Association of Maternal and Child Health Programs. This issue brief was developed to highlight the ongoing issue of children's oral health status in this country, the health systems in place to address this issue, and the role of Title V programs and others (e.g., CHIP) in improving children's oral health status. Examples of Title V program involvement are also included as well as recommendations for how Title V programs can strengthen and improve children's dental health programs. Call 202-775-0436 for more information about the brief.

OUTREACH AND ENROLLMENT

The Children's Health Insurance Program - States' Application and Enrollment Processes: An Early Report From the Front Lines. May 1999: Office of the Inspector General, Office of Evaluation and Inspections. This study found that states are taking steps to improve applications and ease the application process for families. However, various factors, including families' misconceptions about immigration and citizenship status, are preventing families from applying for CHIP. OEI recommended that HCFA work with States and Immigration and Naturalization Service (INS) to address these issues. For a copy of the report, visit: http://www.dhhs.gov/progorg/oei.

CHIP and Outreach. 1998: National Conference of State Legislatures. This table provides information about states' outreach efforts under CHIP as of October 1998. For a copy, visit http://www.ncsl.org/programs/health/chipout.htm.

CHIP Implementation Brief: Early Lessons Learned: Outreach and Enrollment. 1998: National Academy for State Health Policy. This brief is based upon a one-day intensive seminar: CHIP-ing Away at the Uninsured: An Intensive on Implementing Title XXI, which was designed for CHIP program implementers and provided lessons on outreach and enrollment shared by states. For more information, e-mail info@nashp.org.

"Covering Kids" Up and Running in 27 States and DC. <u>Covering Kids Partners.</u> Spring 1999. This first issue of the newsletter provides background information on grants awarded by the Robert Wood Johnson Foundation. These grants are for states to work on targeted efforts addressing outreach, simplification and coordination of children's health coverage application and redetermination processes. For further information, visit http://www.coveringkids.org.

Insure Kids Now: The National Governors' Association launched the *Insure Kids Now* hotline in February 1999. The toll-free number, 1-877-KIDS-NOW, connects callers nationwide to existing health insurance call centers in their own states. Parents of children eligible for the State Children's Health Insurance Program and Medicaid can receive information and referrals. For more information, visit: http://www.insurekidsnow.gov.

King, M. *Insuring More Kids: Options for Lawmakers*. 1998: National Conference of State Legislatures. This report outlines the major provisions of the new State Children's Health Insurance Program. It highlights the two major approaches available to states (expand Medicaid or provide another insurance alternative), provides examples of non-Medicaid approaches and compares costs among state programs. It also discusses matching funds, children with special needs, outreach to eligible families and other aspects of the issue. To order, visit: http://www.ncsl.org/public/catalog/cyfcat.htm.

Media Backgrounder: State Children's Health Insurance Program. April 21, 1999: National Governors' Association. This document provides information about total enrollment numbers for the CHIP program and state developments in state outreach and enrollment efforts. For a copy of the backgrounder, visit: http://www.nga.org/Releases/PR-21April1999schip.asp.

Southern Institute on Children and Families: 1997 Annual Report. 1998: The Southern Institute for Children and Families. The Institute's annual report provides background information on improving health access to benefits for low income families and outreach to these families. For further information, visit http://www.kidsouth.org.

State Children's Health Insurance Program: 1998 Annual Report, NGA Supplement. 1998: National Governors' Association. This publication is to be used jointly with the 1998 State Children's Health Insurance Program Annual Report to monitor detailed elements of each state's CHIP plan or amendment. For more information on NGA resources on CHIP, visit http://www.nga.org/Center/Activities/SCHIP.asp.

States Use Innovative Children's Health Insurance Hotlines to Enroll Uninsured Children. February 23, 1999: National Governors' Association. This brief provides results of a survey of all fifty states and provides information on key elements of their children's health insurance hotline. It also provides a summary table listing elements of each state's hotline. For more information, contact Joy Kauffman at 202-624-7854 or visit http://www.nga.org.

Cornell, E. *How States Can Increase Enrollment in the State Children's Health Insurance Program.* May 7, 1998: National Governors' Association. This brief examines the outreach and enrollment opportunities and challenges facing Governors and state health policymakers as they implement SCHIP. It also includes an appendix that highlights the best outreach and enrollment practices of three states. For more information, contact Emily Cornell at 202-624-7879.

Shruptrine, S. and K. Hartvigsen. *The Burden of Proof: How Much is Too Much for Child Health Coverage?* December 1998: The Southern Institute on Children and Families. This report includes information from a poll of 17 southern states and the District of Columbia that was conducted to identify verification questions that states wanted to pose to Health Care Financing Administration. The report includes information about verification requirements at application, verification requirements at redetermination and other issues. For more information, visit http://www.kidsouth.org.

ADOLESCENTS WITH SPECIAL HEALTH CARE NEEDS AND AT RISK YOUTH

Monitoring the Health Status of Hard-to-Serve Children: Lessons for SCHIP Implementation. September 28, 1998: National Governors' Association. This brief describes the unique characteristics and conditions of migrant, homeless and special needs children. It discusses some appropriate quality assurance measures for monitoring the quality of care that they receive and highlights projects using these measures. For more information, contact Mara Krause at 202-624-5380 or visit http://www.nga.org.

Toolkit for Youth Workers: Runaway and Homeless Youth. September 1998: National Network for Youth. This fact sheet provides background information on runaway and homeless youth and services available for these youth, including federal grant programs. For more information, contact National Network for Youth at 202-783-7949 or visit http://www.NN4Youth.org.

BI

Brown, T. *The Impact of the State Child Health Insurance Program (CHIP) on Title V Children with Special Health Care Needs Programs*. January 1999: Association of Maternal and Child Health Programs. This issue brief presents findings from a survey of ten states' Title V Children with Special Health Care Needs Programs and the impact of CHIP on their programs. For more information, contact the author at 202-775-0436 or visit http://www.amchp1.org.

English, A. The new Children's Health Insurance Program: Early implementation and issues for special populations. <u>Clearinghouse Review</u>. January – February 1999; 429-449. The Balanced Budget Act of 1997 gave states options to provide essential health care to children and adolescents from low-income families without health insurance. While almost every state has submitted a children's health insurance program plan, advocates may find significant opportunities for developing the plans to make them more effective and perhaps to help fill some gaps left by welfare reform.

English, A., Kappahn, C., Perkins, J., and C. J. Wibbelsman. Meeting the health care needs of adolescents in managed care: a background paper. <u>Journal of Adolescent Health.</u> April 1998; 278-292. This journal article provides background information regarding the special needs of adolescents in the light of managed care's increasing replacement of fee-for-service reimbursement as the dominant method of health care financing and services delivery for patients. Reprint requests may be addressed to Abigail English, Center for Adolescent Health and the Law, 211 North Columbia Street, Chapel Hill, NC 27514 or e mail: info@adolescenthealthlaw.org.

Fox, H.B., Graham, R.R., McManus, M.A., and C.Y. Chen. *An Analysis of States' CHIP Policies Affecting Children with Special Health Care Needs*. April 1999: Maternal and Child Health Policy Research Center. This issue brief examines how state CHIP plans, approved as of January 31, 1999, are structured with respect to eligibility, benefits, plan arrangements, and cost-sharing policies to serve children who have special health care needs. This analysis includes detailed state tables. For a copy of the brief or further information, visit http://www.mchpolicy.org.

Newacheck, P., Marchi, K., McManus, M., and H. Fox. *New Estimates of Children with Special Health Care Needs and Implications for the State Children's Health Insurance Program.* March 1998: Maternal and Child Health Policy Research Center. This fact sheet is intended to provide background material for states to better understand Title XXI coverage issues for children with special health care needs. For a copy of the brief or further information, visit http://www.mchpolicy.org.

Reiss, J. Does Your State's Title XXI SCHIP Plan Promote the Development and Maintenance of Quality Systems of Care for Children with Special Health Needs? Issues and Criteria for SCHIP Plan Review and Analysis. 1998: Institute for Child Health Policy. This policy brief presents CSHCN-related issues and criteria that can be used when reviewing and analyzing CHIP plans. For more information, contact the Institute for Child Health Policy at 352-392-5904 or visit http://www.ichp.edu.

Reiss, J. Promoting Transition of Children and Youth with Disabilities and Special Health Care Needs to Employment and Independence: Health Insurance and Service Integration Issues. April 3, 1998: Institute for Child Health Policy. This brief was a testimony presented at the National Institute on Disability and Rehabilitation Research Public Hearing in Tallahassee, Florida. For more information, contact the Institute for Child Health Policy at 352-392-5904 or visit http://www.ichp.edu.



Schulzinger, R. *Key Transition Issues for Youth with Disabilities and Chronic Health Conditions*. September 1998: Institute for Child Health Policy. This paper describes recent changes in the Supplementary Security Income (SSI) program affecting adolescents, what SSI work incentives are available to them, how they can maintain access to quality health care and benefits during their transition years, and key issues to consider during transition planning. For more information, contact the Institute for Child Health Policy at 352-392-5904 or visit http://www.ichp.edu.

SCHOOL-BASED HEALTH CENTERS

Fothergill, K. *Update 1997: School-Based Health Centers*. Advocates for Youth. This publication provides a summary of the findings from Advocates for Youth's 1996 national survey of school-based health centers. It includes information on SBHC services, staffing, populations served, and financing. Furthermore, changes and trends in the SBHC movement are discussed in this report. To order, visit http://www.advocatesforyouth.org

Guiden, M. School-Based Health Centers and Managed Care. State Legislative Report 23(11): 1-11. 1998: National Conference of State Legislatures (NCSL). This report from NCSL offers policymakers an overview of school-based health centers and the services they provide; a look at managed care and examples of existing collaborative efforts with centers across the states; a discussion on federal action; and the implications for SCHIP. To order, contact the NCSL Book Order Department at 303-830-2054.

Kaplan, D.W., Calonge, B.N., Guernsey, B.P., and M.B. Hanrahan. Managed care and SBHCs: Use of health services. Archive of Pediatrics and Adolescent Medicine. 1998; 52:25-33. The objective of this study was to explore the use of physical and mental health services for adolescents who are enrolled in managed care and have access to a school-based health center (SBHC), compared with adolescents enrolled in managed care without access to an SBHC. The article concluded that SBHCs seem to have a synergistic effect by adolescents enrolled in managed care in providing comprehensive health supervision and primary health and mental health care and in reducing after-hours (emergent or urgent) visits. School-based health centers are particularly successful in improving access to and treatment for mental health problems and substance abuse.

Koppelman, J. and J. Graham-Lear. *The New Child Health Insurance Expansions: How Will School-Based Health Centers Fit In?* 1998: George Washington University. This report is based on a June 1998 Making the Grade and National Assembly on School-Based Health Care-sponsored workshop on the relationship between the State Child Health Insurance Program (CHIP) and school-based health centers. Workshop participants used the health centers' experience with Medicaid managed care as a window for understanding their prospects for negotiating contracts with health plans under SCHIP. Experiences in Colorado and Connecticut were presented as case studies on these evolving issues. For a copy of the report, visit http://www.gwu.edu/~mtg/pub/papers/Oct98/index.html

National Survey of State SBHC Initiatives: School Year 1997-1998. 1998: George Washington University. This summary presents results from a 1998 Making the Grade survey of the 50 states and the District of Columbia to assess the growth of school-based health centers across the country and determine the extent of state policies supportive of that growth. The survey focused on assessing the degree to which widespread changes in the health care system and the retreat from government-supported health services had affected the growth of centers. For a copy, visit http://www.gwu.edu/~mtg/sbhc/98summ.html.



Website. http://www.gwu.edu/~mtg. Making the Grade is a national grant program supported by the Robert Wood Johnson Foundation. Under this initiative, the foundation has made \$17.5 million available to support state-community partnerships to establish comprehensive school-based health centers. On behalf of the foundation, the national program office monitors development of the state programs, provides technical assistance to Making the Grade grantees, and shares information about grantee experience with a variety of audiences. The office can be contacted by calling 202-466-3396.

Website. http://www.nasbhc.org. The National Assembly on School-Based Health Care is a non-profit private association representing school-based health care providers and supporters. Created in 1995, the National Assembly's primary mission is to promote accessible, quality school-based primary health and mental health care for children and youth through interdisciplinary and collaborative efforts. The National Assembly supports its 1200 individual and organizational members by providing community, state, and national advocacy, information and knowledge exchange, networking opportunities, and technical assistance. The office can be contacted by calling 202-638-5872.

ACCESS

Children's Health Insurance Expansions: State Experiences in Developing Benefit Packages and Cost-Sharing Arrangements. February 17, 1998: The Office of the Assistant Secretary for Planning and Evaluation, Office of Health Policy, U.S. Department of Health and Human Services. This report is based on a review of nine states that have undertaken major children's health expansions and their experiences in developing benefit packages and cost-sharing arrangements. For a copy of the report, visit http://aspe.os.dhhs.gov/health/reports/benefits.

CHIP and Cost-Sharing. 1998: National Conference of State Legislatures. This table provides information about states' cost-sharing requirements for families under CHIP as of October 1998. For a copy of this table, visit http://www.ncsl.org/programs/health/chipcost.htm

CHIP Implementation Brief: Early Lessons Learned: Cost Sharing and Premiums. 1998: National Academy for State Health Policy. This brief is based upon a one-day intensive seminar: CHIP-ing Away at the Uninsured: An Intensive on Implementing Title XXI, designed for CHIP program implementers and provides lessons on CHIP and cost-sharing shared by states. For more information, e-mail info@nashp.org or visit http://www.nashp.org

CHIP Implementation Brief: Early Lessons Learned: Employer-Sponsored Health Insurance Using Title XXI Funding. 1998: National Academy for State Health Policy. This brief is based upon a one-day intensive seminar: CHIP-ing Away at the Uninsured: An Intensive on Implementing Title XXI, designed for CHIP program implementers and provides lessons on CHIP and employer-sponsored health insurance shared by states. For more information, e-mail info@nashp.org or visit http://www.nashp.org

Dresing, M., Naff, R., and T.F. Stoller. *Raising the Bar for Quality and Access in Pediatric Delivery Systems: The Experience of the Florida Healthy Kids Corporation*. August 1998. This report is one in a series of technical assistance papers that is intended to help communities and states in their endeavor to provide health insurance and quality healthcare services to their children. For more information, contact the Healthy Kids Corporation at 850-224-KIDS.

Finan, T., and E. Neuschler. Bright Futures and Managed Care Action Brief: Outreach: Private and Public Sector Efforts that Work. November 1998: National Institute for Health Care Management (NIHCM). This brief provides a summary of the key issues and insights of a roundtable forum convened by NIHCM, entitled "Outreach: Private and Public Sector Efforts That Work." At the forum, practitioners from states and the private sector presented and discussed outreach initiatives to enroll children for coverage (under Medicaid and CHIP) and get them receiving care in a medical home. For more information contact NIHCM at 202-296-4426.

Fox, H., McManus, M., Rodgers, J., and K.B. Hayden. Cost-Sharing Options Under the State Children's Health Insurance Program. March 1998: Maternal and Child Health Policy Research Center. This issue brief is intended to assist state policymakers in structuring reasonable policies for CHIP participants and provides a guide for states in examining the implications of alternative costsharing approaches with respect to such issues as family income, number of eligible siblings and children's health, or disability status. For more information, contact 202-223-1500 or visit http:// www.mchpolicy.org.

Gehshan, S. and J. McDonough. Family Coverage Under the State Children's Health Insurance Program. October 1998: National Conference of State Legislatures. This paper describes the law and current federal guidance on pursuing the family coverage option, and gives an overview of various state approaches that have been proposed to take advantage of the option. For more information, visit NCSL's website at http://www.stateserv.hpts.org

Millions of Uninsured and Underinsured Children are Eligible for Medicaid. January 1997: Center on Budget and Policy Priorities. This report describes the range of policy issues regarding the translation of eligibility for Medicaid into actual coverage. It includes state specific information on the number of children eligible but not enrolled on Medicaid. This report may be particularly helpful to states designing and coordinating the outreach components of their state plan. For more information, call 202-408-1080.

State Challenges and Opportunities in Rural and Frontier Health Care Delivery. September 29, 1998: National Governors' Association. This publication describes the unique characteristics of rural and frontier populations, outlines the barriers to rural and frontier health care delivery, describes some successful state responses to these challenges, and examines new rural health care delivery opportunities for states. For more information, contact Tracey M. Orloff at NGA at 202-624-7820 or visit http:// www.nga.org

States Have Expanded Eligibility Through Medicaid and the State Children's Health Insurance Program. February 10, 1999: National Governors' Association. This update from the National Governor's Association provides information about states' Medicaid and CHIP eligibility levels for children, by age group, and for pregnant women as of October 1, 1998. For more information, contact Mara Krause at NGA at 202-624-5380 or visit http://www.nga.org

Thorpe, K. and C. Florence. Covering Uninsured Children and Their Parents: Estimated Costs and Number of Newly Insured. July 1998: The Commonwealth Fund. This report estimates that CHIP, combined with Medicaid, could reduce the number of uninsured children by 80 percent if states were to enroll all those who are eligibile. For more information, contact Mary Mahon at 212-606-3853 or mm@cmwf.org

Using SCHIP Funds for Health Insurance Premium Contributions: Policy Issues and Operational Challenges. October 15, 1998: National Governors' Association. This issue brief identifies the benefits of coordinating public and private health insurance programs through a premium subsidy approach. It also identifies operational challenges for state policymakers choosing to use SCHIP funds for premium contributions and options to address those challenges. For more information, contact Joan Henneberry at NGA at 202-624-3644 or visit http://www.nga.org

Weinick, R., Weigers, M.E., and J.W. Cohen. Children's Health Insurance, Access to Care, and Health Status: New Findings. <u>Health Affairs.</u> March/April 1998. This journal article presents analysis of data from the household component of the 1996 Medical Expenditure Panel Survey. Findings suggest that children are at greater risk of encountering difficulties with the health care system depending on their race/ethnicity, parents' education, and parents' employment status.

CONFIDENTIALITY

Cheng, T., Savageau, J., Sattler, A., and T. DeWitt. Confidentiality in health care: A survey of knowledge, perceptions, and attitudes among high school students. <u>JAMA</u>. 269 (11): 1404-1407. 1993. This journal article presents findings from a study of high school students that addressed confidentiality issues in health care. The study found that a majority of adolescents have concerns they wish to keep confidential and a striking percentage report they would not seek health services because of these concerns.

English, A., Matthew, M., Extavour, K., Palamountain, C., and J. Yang. *State Minor Consent Statutes: A Summary.* 1995: Center for Continuing Education in Adolescent Health. This publication is available for the Center for Adolescent Health and the Law. The authors are currently working on an updated version of this publication. The Center for Adolescent Health and the Law works to create a legal and policy environment that promotes the health of adolescents and their access to health care. The Center conducts research, analyzes legal and policy issues, prepares publications, provides training and technical assistance, and engages in advocacy. Contact Abigail English at the Center for more information at info@adolescenthealthlaw.org or call 919-968-8870.

McCabe, M.A. Involving children and adolescents in medical decision making: Developmental and clinical considerations. <u>Journal of Pediatric Psychology</u>. 21(4): 505-16. 1996. This paper reviews the developmental and clinical considerations, and provides recommendations, for determining particular children's level of involvement in making medical decisions. The paper also describes the distinct roles for pediatric psychologists in this process.

Weithom L.A., and S.B. Campbell. The competency of children and adolescents to make informed treatment decisions. <u>Child Development</u>. 53: 1589-1599. 1982. This article presents results from a study to test for developmental differences in competency to make informed treatment decisions at four age levels (9, 14, 18, and 21). The findings from the study do not support the denial of the right of self-determination to adolescents in health-care situations on the basis of a presumption of incapacity. Further, children as young as nine years old appear able to participate meaningfully in personal health care decision making.



QUALITY ASSURANCE AND EVALUATION

Children's Health Insurance Implementation: Beginning the Discussion on Quality and Performance Measurement. ASTHO Access Brief VII. 1999: Association of State and Territorial Health Officials. This Brief is the first in a series of documents on the subjects of data assessment, quality assurance, and performance measures related to the Children's Health Insurance Program (CHIP). This Brief in particular is designed to examine some of the issues related to the definition of quality and performance measures and to suggest possible avenues for state and community-level discussions. For further information, visit http://www.astho.org

Edmunds, M. and M.J. Coye, Editors. *Systems of Accountability: Implementing Children's Health Insurance Programs*. 1998: National Academy Press. This publication presents a framework and recommendations for designing systems of accountability for CHIP as states take a variety of steps to reduce the number of uninsured children. This book is available for viewing at http://www4.nas.edu/IOM/IOMHome.nsf

Rader A., Pernice, C., and T. Riley. *Evaluating CHIP: A "How To" for States (Vol. I) State* and *Federal Health Data Sources: An Inventory for CHIP Evaluators (Vol. II)*. December 1998: National Academy for State Health Policy. Volume I includes speaker materials (including case studies and proposed state methodologies for CHIP evaluation) and related resources for NASHP's December 1998 comprehensive workshop on "Evaluating CHIP: A 'How To' for States." Volume II provides an inventory of health data sources and addresses their utility in evaluating the success of CHIP. Call 207-874-6524 or visit http://www.nashp.org to order.

State Children's Health Insurance Program Evaluation Tool. 1998: American Academy of Pediatrics. This tool provides 30 indicators that measure the impact of Title XXI on three closely linked dimensions of quality assessment of health care: access, process, and outcomes. For copies of the document, contact Beth Yudkowsky at 800-433-9016, ext. 7946 or visit http://www.aap.org/research/reshome.htp

LINKAGES

Issues in Developing Programs for Uninsured Children: A Resource Book for States. March 2, 1998: The Office of the Assistant Secretary for Planning and Evaluation, Office of Health Policy, U.S. Department of Health and Human Services. This resource book contains reference information on nine states that established children's health insurance expansions prior to enactment of Title XXI. It is intended to provide relevant information for states as they design their own children's health insurance programs. For a copy of the report, visit http://ape.os.dhhs.gov/health/reports/resource/toc.htm.

Many Streams Make A River: Proceedings of the National Conference on Community Systems-Building and Services Integration. September 14-15, 1997: Maternal and Child Health Bureau. This publication provides a reference for communities working to sustain systems-building and services integration at the local level and informs health policymakers and decisionmakers about the contributions of community initiatives for achieving systems reform in health policy. For copies of the report or videotape proceedings, contact the National Maternal and Child Health Clearinghouse at 703-356-1964.

State Children's Health Insurance Program. American Public Health Association. This newsletter provides information for public health professionals about the potential impacts of SCHIP on public health programs. It also provides key areas where public health programs can collaborate with SCHIP. For more information, visit http://www.apha.org.

Geshan, S. *State Options for Expanding Children's Health Insurance*. May 7, 1998: National Conference of State Legislatures. This report provides state examples of the various options for expanding children's health insurance through CHIP. For more information, contact http://stateserv.hpts.org.

