

**Adolescent Health Care—
Medicaid, Managed Care, and Health Care Reform:
Lessons from the 1990s**

by

Abigail English *

Jane Perkins †

Catherine Teare ‡

November 2004

Support for the preparation of this report
was provided by the Carnegie Corporation of New York.
The views expressed are those of the authors alone.

* Abigail English is Director of the Center for Adolescent Health & the Law, Chapel Hill, NC. From 1976 through 1998 she was an attorney at the National Center for Youth Law.

† Jane Perkins is Legal Director at the National Health Law Program, Chapel Hill, NC; Los Angeles, CA; Washington, DC.

‡ Catherine Teare was a health policy analyst at the National Center for Youth Law from 1990 through 1999. She is currently Policy Director at Children Now, Oakland, CA.

TABLE OF CONTENTS

Preface	iii
I. Introduction	1
Before 1990	1
The 1990s	1
2000 and Beyond	2
II. Health Status and Health Care Needs of Adolescents	3
III. Medicaid and SCHIP	6
Medicaid	6
The Evolving Roles of Medicaid and Private Insurance	7
Medicaid Eligibility	8
Medicaid Services – EPSDT	11
Screening	12
Diagnosis and Treatment	13
Data Reporting	13
The State Children’s Health Insurance Program – SCHIP	13
SCHIP Eligibility	14
SCHIP Services	15
Beneficial Effects for Adolescents of Medicaid and SCHIP Expansions	15
IV. Health Care Reform	17
National Health Care Reform in 1993 and 1994	17
Health Care Policy Changes in 1995 and 1996	17
Efforts to Restrict Medicaid	18
Federal Welfare Reform Law	18
Mental Health Parity	19
HIPAA – Insurance Portability and Health Privacy	20
1997 – The BBA	21
V. Managed Care – Laws, Contracts, and Waivers	23
Federal Managed Care Laws	23
State Managed Care Laws	24
Medicaid Managed Care	25
Section 1915(b) Waivers	26
Section 1115 Demonstration Waivers	27
Balanced Budget Act of 1997	27

Medicaid Managed Care Contracts – Key Findings	28
Enrollment & Provider Choice	29
Scope of Benefits	29
Provider Networks	30
Cultural and Linguistic Accessibility	30
Confidentiality and Consent	31
Monitoring and Reporting	31
Medicaid Section 1115 Waivers – Key Findings	32
Eligibility	32
Enrollment	32
Scope of Benefits	33
Access to Adolescent Health Care Professionals	33
Confidentiality	33
Monitoring and Reporting	34
VI. What Have We Learned and Where Are We Headed?	35
20 Lessons Learned	35
Recent & Current Experience	38
Cuts in Medicaid and SCHIP	38
Restructuring of Medicaid and SCHIP	40
Implications for Adolescents	41
Appendix A. Voices of the Health Care Professionals	43
Survey of Adolescent Health Care Professionals	43
Benefits of Managed Care	43
Problems with Managed Care	44
Two Meetings of Adolescent Health Experts	44
Health Insurance Coverage	44
Scope of Benefits	45
Managed Care Systems and Procedures	45
Monitoring Service Delivery and Assuring Quality	45
Provider Networks	45
Financing	46
Appendix B. Views from the States	47
California	47
Massachusetts	48
Missouri	49
North Carolina	49
Oregon	50

PREFACE

In 1995, the National Center for Youth Law and the National Health Law Program initiated a study of Medicaid, managed care, and health care reform issues with importance for adolescents' access to health care. The study was conducted from 1995 through mid-1999 with the support of the Carnegie Corporation of New York. The study included a review of the literature on the health status and health care needs of adolescents; detailed legal research and analysis of the laws pertaining to Medicaid, managed care, and health care reform as they affect adolescents; an analysis of Medicaid managed care contracts and requests for proposals; an analysis of Medicaid Section 1115 demonstration waivers; a survey of adolescent health care professionals; two meetings of adolescent health experts; and case studies of several states that included both key informant interviews and analysis of state laws.

The data and analysis from that study have informed this report. Findings from the 1990s revealed important implications of laws and policies for the delivery of health services to adolescents and adolescents' access to care. Both innovations and obstacles were identified and some of each are reported here.

Now, nearly a decade later, the policy climate is different from that which prevailed when we began our study. At the end of the 1990s and in the years immediately after 2000, the policy climate shifted at the federal and state levels, generally becoming less hospitable to expansion of health care coverage, benefits, and access for low income and vulnerable populations, including adolescents. Nevertheless, ongoing concern is focused on the high percentage of the U.S. population, including adolescents, that is uninsured or underinsured, with considerable variation views of the best way to address the problem.

In light of both the shift in the policy environment and the ongoing concern about the uninsured, it is especially important to review earlier policy developments in adolescent health care with respect to Medicaid, managed care, and health care reform. In particular, looking at past developments that were beneficial for adolescents and that may now be at risk of being lost or limited can inform advocates and policy makers in their future efforts to ensure that the health care needs of adolescents are met.

Abigail English
Jane Perkins
Catherine Teare

November 2004

I. INTRODUCTION

The 1990s witnessed rapid developments and extraordinary changes in the laws and policies that influence the delivery of health care to adolescents. Many of the developments were beneficial for adolescents, offering opportunities to expand eligibility for health insurance and to provide more comprehensive services to meet adolescents' specific needs. Indeed, expansion of health insurance coverage and improvements in the delivery of services to adolescents did occur. A few developments, however, either directly limited adolescents' access or laid the groundwork for later policy changes that could restrict adolescents' access to care. In the current era, many of the positive developments for adolescents from the 1990s are at risk.

Before 1990

In the three decades before 1990, key legal and policy developments that provided opportunities to benefit adolescents included:

- The enactment of Medicaid in 1965.
- The creation of the EPSDT program in 1967.
- The expansion in the 1980s of Medicaid eligibility for children and pregnant women based on family income rather than linkage through a welfare or disability program.
- The revision of the EPSDT program in 1989 to provide coverage for children and adolescents of all medically necessary Medicaid services to diagnose or treat their health problems.

The 1990s

During the 1990s, the expansive trends continued with:

- A requirement enacted by Congress in 1990 that states phase in, one year at a time, coverage of all adolescents under age 19 with family incomes at or below the poverty level.
- State-based initiatives to expand health insurance to the uninsured, support safety net providers serving adolescents, and improve the delivery of preventive services to adolescents.
- Inclusion of some adolescent-friendly provisions, including eligibility expansions, in state Medicaid managed care contracts and waivers.
- Enactment of the Mental Health Parity Act of 1996.
- Enactment of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which later resulted in comprehensive health privacy regulations that included some protections for adolescents.
- Enactment of the State Children's Health Insurance Program (SCHIP) in 1997, with the result that eligibility and enrollment of adolescents in public health insurance was expanded, particularly for older adolescents and those with higher family incomes.

Nevertheless, the 1990s also witnessed developments that were actually or potentially restrictive of adolescents' access to care:

- Liberalization of the approval criteria for Medicaid Section 1115 waivers, often with inadequate safeguards for beneficiaries to accompany mandatory enrollment in managed care.
- Attempts to restructure Medicaid that were not enacted but would have modified or eliminated entirely its entitlement feature.
- Enactment of a comprehensive federal welfare law in 1996 that severed the traditional link between cash assistance and Medicaid eligibility and limited access to Medicaid for many immigrants.
- Inclusion in the Balanced Budget Act of 1997 (BBA) of measures allowing states to mandate enrollment in managed care for many Medicaid beneficiaries without a waiver.

2000 and Beyond

In the current decade, after the economic boom of the 1990s, states began to experience serious financial crises that put intense pressure on their budgets for health care. In 2001 and thereafter, pressures on both federal and state budgets and mounting federal deficits began to threaten the integrity of health care programs, particularly Medicaid and SCHIP. This has continued through the first half of the current decade. In addition, political shifts in the Administration and Congress, and in many states, contributed to a climate that was often less inclined than in the past to expand or maintain existing health entitlement programs for low-income and vulnerable populations. Although some efforts toward reform and expansion have continued at both the federal and state levels, they have been few. More common have been modest steps to maintain the status quo, or even significant retrenchment.

Findings from research conducted during the late 1990s about legal developments and targeted initiatives in Medicaid, managed care, and health care reform, and their implications for adolescent health care, can inform future policy making. In particular, these research findings can highlight where gains have been made that have benefited adolescents. In light of recent fiscal and political changes, these gains could be at risk. Research findings can help to identify where efforts need to be redoubled to protect the gains that have been made and, when possible, to build on them in the future.

II. HEALTH STATUS AND HEALTH CARE NEEDS OF ADOLESCENTS¹

Adolescents experience many health concerns and problems, in spite of a widespread perception that they are healthy.² The health issues of adolescence have been extensively documented.³ The major health problems faced by adolescents have been described as “preventable health conditions with predominantly behavioral, environmental, and social etiologies.”⁴ They include injury,⁵ homicide,⁶ suicide,⁷ mental and emotional illness,⁸

¹ Portions of this section appeared originally in Abigail English and Madlyn Morreale, A Legal and Policy Framework for Adolescent Health Care: Past, Present, and Future, 1 *Houston J. Health Law & Pol’y* 63 (2001), and are used here with permission. The data in this section represents recent and current health status data as of the end of the 1990s, when our study was completed, or shortly thereafter. More recent data is available, which indicates improvement in some areas and worsening in others, but does not indicate dramatic departures from the health status of adolescents that prevailed at the end of the last decade.

² See, e.g., Susan G. Millstein, A View of Health From the Adolescent’s Perspective, in *Promoting the Health of Adolescents: New Directions for the Twenty-first Century* 97, 99 (Susan G. Millstein et al. eds., 1993) (explaining that while adolescents generally report themselves as being healthy, they also view their health as poorer than their physicians or parents perceive it to be).

³ E.g., U.S. Dep’t of Health & Human Services, *Health, United States, 2000: Adolescent Health Chartbook* (2000) [hereinafter *Adolescent Health Chartbook*]; Stanford B. Friedman et al., *Comprehensive Adolescent Health Care* (2nd ed. 1998); Ralph J. DiClemente et al., *Handbook of Adolescent Risk Behavior* (1996); Office of Technology Assessment, U.S. Congress, *Adolescent Health, Volume I: Summary and Policy Options* (1991) [hereinafter *OTA Vol. I*]; Office of Technology Assessment, U.S. Congress, *Adolescent Health, Volume II: Background and the Effectiveness of Selected Prevention and Treatment Services* (1991) [hereinafter *OTA Vol. II*]; Office of Technology Assessment, U.S. Congress, *Adolescent Health, Volume III: Cross-Cutting Issues in the Delivery of Health Related Services* (1991) [hereinafter *OTA Vol. III*]; Elizabeth Ozer, et al., *National Adolescent Health Information Center, UCSF, America’s Adolescents: Are They Healthy?* (2d printing 1998).

⁴ David S. Rosen et al., *Clinical Preventive Services for Adolescents: Position Paper of the Society for Adolescent Medicine*, 21 *J. Adolescent Health* 203 (1997).

⁵ *Adolescent Health Chartbook*, supra note 3, at 58 (documenting that motor vehicle traffic-related injuries and firearm-related injuries are the two leading causes of death among adolescents ten to nineteen years of age).

⁶ Bureau of Justice Statistics, *Crime Data Brief: Homicide Trends in the United States: 1998 Update 2* (March 2000) (documenting that homicide victimization rates for teenagers and young adults rose sharply in the late 1980s and early 1990s before falling more recently), available at <http://www.ojp.usdoj.gov/homicide/homtrnd.htm> (last visited May 19, 2001).

⁷ *Adolescent Health Chartbook*, supra note 3, at 38 (documenting that in 1997 suicide was the third leading cause of injury death for adolescents ages thirteen to nineteen and that in

other chronic illness and disability,⁹ poor nutrition,¹⁰ eating disorders,¹¹ dental problems,¹² pregnancy,¹³ sexually transmitted disease (STD),¹⁴ Human Immunodeficiency Virus (HIV),¹⁵ and substance abuse.¹⁶

Regardless of their causes, these health problems among adolescents mean that this age group has a pressing need for a wide variety of health care and related services. Essential services include: preventive services; sexual and reproductive health care; mental health

1999 one-fifth of all high school students reported having seriously considered or attempted suicide during the previous 12 months).

⁸ Ozer et al., *supra* note 3, at 14 (documenting that mental disorders represent nearly one-third of all adolescent disabilities, making them the single largest cause of disability among adolescents). See also, U.S. Public Health Service, Report of the Surgeon General's Conference on Children's Mental Health: A National Action Agenda. Washington, DC: Department of Health and Human Services, 2000.

⁹ Adolescent Health Chartbook, *supra* note 3, at 34 (documenting that in 1997 approximately eight percent of all adolescents ten to seventeen years of age were reported to have some activity limitation due to one or more chronic physical, mental, or emotional health condition).

¹⁰ National Center for Health Statistics, Centers for Disease Control and Prevention, Prevalence of Overweight Among Children and Adolescents: United States, 1999-2002 (noting that sixteen percent of adolescents ages twelve to nineteen are overweight), available at <http://www.cdc.gov/nchs/products/pubs/pubd/hestats/overwght99.htm> (last reviewed Nov. 2, 2004).

¹¹ Martin Fisher et al., Eating Disorders in Adolescents: A Background Paper, 16 J. Adolescent Health 420, 420-25 (1995) (documenting epidemiology and medical complications of eating disorders in adolescents).

¹² Adolescent Health Chartbook, *supra* note 3, at 36 (documenting that during 1988-1994 one-fifth of adolescents ages ten to nineteen years of age had at least one untreated caries lesion or active tooth infection).

¹³ Adolescent Health Chartbook, *supra* note 3, at 62 (documenting that annually more than 900,000 adolescents become pregnant).

¹⁴ The Hidden Epidemic: Confronting Sexually Transmitted Diseases, Institute of Medicine (Thomas R. Eng & William T. Butler eds. 1997), citing Centers for Disease Control and Prevention, Division of STD/HIV, Annual Report 1992 (1993) (documenting that of the twelve million new cases of STDs occurring each year, approximately three million of them are among teenagers).

¹⁵ Office of National AIDS Policy, The White House, Youth and HIV/AIDS 2000: A New American Agenda (2000) (documenting that half of the new infections in the United States every year are in young people between the ages of thirteen and twenty-four).

¹⁶ Adolescent Health Chartbook, *supra* note 3, at 78, 80 (documenting that in 1999 one-half of high school students reported drinking alcohol in the previous thirty days, approximately twenty-eight percent of females and thirty-five percent of males reported binge drinking, and one-half had used marijuana during their lifetime).

and substance abuse services; dental services; treatment for acute conditions; and services to address chronic illness and disability.¹⁷

The health problems and concerns of adolescents are more prevalent and more severe among those adolescents who are characterized as “special populations.” While the term does not have a precise definition, it is often used to refer to a wide range of groups, such as adolescents with a chronic illness or disability; pregnant and parenting teens; immigrant and migrant youth; gay, lesbian, and bisexual adolescents; homeless, runaway, and street youth; and adolescents living in state custody or out-of-home care.¹⁸

Adolescents who are members of these vulnerable groups are likely to need more intensive health services than other adolescents and to have greater difficulty accessing traditional sources of care.¹⁹

¹⁷ Abigail English, Madlyn Morreale, and Amy Stinnett, *Adolescents in Public Health Insurance Programs: Medicaid and CHIP 19 (1999)* [hereinafter English et al., *Medicaid and CHIP*] (available from the Center for Adolescent Health & the Law, Chapel Hill, NC, www.cahl.org).

¹⁸ See English et al., *Medicaid and CHIP*, supra note 17, at 21-22 (tbl. 3) (providing detailed documentation of the demographics and health care needs of these special populations of adolescents).

¹⁹ *Id.*

III. MEDICAID AND SCHIP

Medicaid and the State Children's Health Insurance Program (SCHIP) are critical sources of financing for the health care of low-income adolescents. The similarities and contrasts between the two programs can be traced to their origins: Medicaid as we know it was enacted in the civil rights era of the 1960s (although the antecedents of Medicaid date back even earlier), while SCHIP was created with the more cautious, incremental approach characteristic of the late 1990s. Nevertheless each has played a significant role in moving toward more comprehensive health insurance coverage for adolescents.

Medicaid

Created by Congress in 1965, Medicaid²⁰ is the largest single source of federal funding for health care for low-income individuals in the United States, including women, children, and adolescents. Three decades later, by 1996, at the time our study began, the program covered more than 40 million individuals – about half under age 21 – at an annual cost of more than \$150 billion in federal and state funds.²¹ At that time, adolescents already were an important segment of the Medicaid population: 3.2 million adolescents ages 15 through 20 in 1996, or nearly 9 percent of the beneficiary population.²² More recently Medicaid has played an increasingly important role in coverage for low-income youth. In 2000, when there were 24.3 million adolescents ages 15 through 20 in the U.S.,²³ the Medicaid program covered more than 4.9 million of them or one in five adolescents ages 15 through 20.²⁴ Then and now, adolescents in Medicaid present significant challenges for policy makers, health care providers, advocates, and

²⁰ 42 U.S.C. §§ 1396 et seq; 42 C.F.R. §§ 430 et seq. For a detailed discussion of the requirements of federal Medicaid law related to administration, eligibility, and services, including citations to all pertinent Medicaid statutory and regulatory provisions and cases, see Jane Perkins et al., *An Advocate's Guide to the Medicaid Program* (2001) [hereinafter *Medicaid Guide*].

²¹ The Kaiser Commission on Medicaid and the Uninsured, *Medicaid Facts: The Medicaid Program at a Glance* (September 1998) [hereinafter *Medicaid Program at a Glance*].

²² Health Care Financing Admin., U.S. Dep't of Health & Human Services, *Medicaid Nat'l Summary Statistics for FFY 1996* (tbl. 25), *Medicaid Recipients of Medical Care by Age and by Region and State: Fiscal Year 1996*. Available at: <<http://www.cms.hhs.gov/medicaid/msis/mstats.asp>> (last updated Feb. 24, 1998) (hereinafter *Medicaid Nat'l Summary Statistics for FFY 1996* (tbl. 25)).

²³ U.S. Census Bureau, *Census 2000 Summary File 1 (SF 1) 100-Percent Data* (tbl. P12), *Sex by Age – Universe: Total Population*. Available at: <<http://www.census.gov/Press-Release/www/2001/sumfile1.html>> (last revised May 10, 2004).

²⁴ Centers for Medicare and Medicaid Services, U.S. Dept. of Health & Human Services, *MSIS Statistical Reports for Federal Fiscal Year 2000* (tbl. 2) *Medicaid Eligibles – Fiscal Year 2000 by Age Group: All States*. Available at: <<http://www.cms.hhs.gov/medicaid/msis/msis99sr.asp>> (last modified Sept. 16, 2004).

Medicaid agency personnel in the ongoing process of designing and implementing the Medicaid program at both the national and state levels.

Medicaid is an essential element in assuring the provision of necessary health care to adolescents, particularly those from low-income families. In particular, the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) component of Medicaid represents a broad benefit package offering eligible adolescents comprehensive services.²⁵ To date, Medicaid and EPSDT have not met their promise to adolescents,²⁶ although significant progress has been made.²⁷

During the late 1980s and early 1990s, Congress enacted important expansions in Medicaid eligibility, some of which were of direct benefit to adolescents. Subsequently, however, those expansions, as well as even broader ones undertaken by the states, were seriously threatened. The new federal welfare law, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA), also limited access to Medicaid coverage for certain groups of adolescents, such as some cash assistance recipients, adolescents with disabilities, and immigrant youth. When Congress enacted, in the Balanced Budget Act of 1997, a new State Children's Health Insurance Program (SCHIP), states were given new opportunities and financial incentives to increase Medicaid coverage of adolescents. Ultimately, Medicaid remains a critically important element in access to health care for poor and low-income adolescents, and the program's fate will likely have major implications for this segment of the population.

The Evolving Roles of Medicaid and Private Insurance

As of 1989, one in seven adolescents overall – and one in three poor adolescents – lacked any health insurance at all, including Medicaid coverage.²⁸ From the mid-1980s to the mid-1990s the proportion of adolescents without health insurance remained about the

²⁵ 42 U.S.C. §§ 1396a(a)(10) and (43); § 1396d(a)(4)(B); § 1396d(r). 42 C.F.R. §§ 441.50 - 441.62. See also, Centers for Medicare & Medicaid Services., U.S. Dep't of Health and Human Services, State Medicaid Manual (hereinafter CMS, State Medicaid Manual), Part 5, §§ 5010-5360.

²⁶ Kristi Olson et al., Children's Health Under Medicaid: A National Review of Early and Periodic Screening, Diagnosis and Treatment (1998)[hereinafter EPSDT Review]; Amy Stinnett et al., Children's Health Under Medicaid: A National Review of Early and Periodic Screening, Diagnosis and Treatment – 1997-1998 Update (2001) [hereinafter EPSDT Update 97-98]; Amy Stinnett et al., Children's Health Under Medicaid: A National Review of Early and Periodic Screening, Diagnosis and Treatment – 1999-2001 Update (2004) [hereinafter EPSDT Update 99-01] (available from the National Health Law Program, Los Angeles, CA, www.healthlaw.org)

²⁷ E.g., Madlyn C. Morreale and Abigail English, Eligibility and Enrollment of Adolescents in Medicaid and SCHIP: Recent Progress, Current Challenges, 32 J. Adolescent Health 25 (2003).

²⁸ Paul W. Newacheck et al., Health Insurance Coverage of Adolescents: A Current Profile and Assessment of Trends, 90 Pediatrics 589 (1992).

same, although the proportion with private employer-based coverage was dropping while the proportion with public coverage, especially Medicaid, was increasing.²⁹ This was due to some of the eligibility expansions that occurred in the late 1980s and early 1990s. Further opportunities for expansion came later in the 1990s with the advent of SCHIP, increasing the number of adolescents with public health insurance, including Medicaid.

Looking at the health insurance status of adolescents in the current decade, a recent study found that the percentage of uninsured adolescents ages 10 to 18 had decreased from 14.1% to 12.2%, a small but significant decrease.³⁰ Virtually all of the improvement after 1995 was due to increases in public insurance coverage of adolescents in poor and near-poor families (with incomes under 200% of the federal poverty level). In fact during the same period that health insurance coverage for adolescents declined overall and for those in poor and near-poor families, the proportion of adolescents in middle and higher income families without insurance increased from 4.1% in 1995 to 6.3% in 2002 as the availability of private insurance coverage declined.³¹

Medicaid Eligibility

A major advantage of Medicaid for adolescents as well as other eligible populations is that it operates as an entitlement program: individuals who satisfy the financial and other eligibility requirements are entitled to receive the services provided by the program. Historically, however, the program has not covered everyone living below the poverty level or even all poor children or adolescents, and adolescents have been at a particular disadvantage.

There are two broad categories of Medicaid eligibility: mandatory eligibility groups, which states are required to cover by federal law; and optional eligibility groups, which states may choose to cover.³² Traditionally, Medicaid eligibility was dependent on linkage to a cash assistance program such as Aid to Families with Dependent Children (AFDC) or Supplemental Security Income (SSI). During the 1980s Congress began a process, which continued into the early 1990s, of “delinking” Medicaid eligibility from cash assistance and expanding eligibility for children and pregnant women based on their income in relation to the federal poverty level (FPL) for some mandatory as well as optional eligibility categories.³³

²⁹ Paul W. Newacheck et al., Adolescent Health Insurance Coverage: Recent Changes and Access to Care, 104 *Pediatrics* 195 (1999).

³⁰ Paul Newacheck et al., Trends in Private and Public Health Insurance for Adolescents, 291 *JAMA* 1231 (2004).

³¹ *Id.*

³² For a complete discussion of these categories, see Medicaid Guide, *supra* note 20.

³³ For a list of these eligibility expansions, see GAO, Health Insurance for Children: Many Remain Uninsured Despite Medicaid Expansion, Appendix I, tbl. I.1: A Series of Laws Expanded Medicaid Eligibility for Children (1995) (GAO/HEHS 95-175). The

As a result of a combination of the traditional Medicaid eligibility rules and the expansions of the late 1980s and early 1990s, by the mid-1990s states were either required or permitted to cover numerous groups of adolescents based either on their linkage to a categorical eligibility program such as AFDC, SSI, or Title IV-E foster care and adoption assistance, or on their family income.³⁴ Most notably:

- States were required to phase-in coverage, one year at a time, of poor adolescents through age 18 born after September 30, 1983 and were permitted to cover them more quickly.
- States were permitted, through options provided by Congress (such as the option known as “1902r(2)”) to cover all adolescents in low-income families, even if family income exceeded the poverty level.
- States were required to cover pregnant adolescents with family incomes at or below 133% of FPL and were permitted to cover them up to 185% of FPL.
- States were required to cover adolescents in families with incomes below the AFDC levels in effect on July 16, 1996; (in most states) adolescents receiving SSI based on blindness or disability; adolescents receiving federal foster care maintenance payments under Title IV-E of the Social Security Act; and adolescents receiving federal adoption assistance payments or for whom an adoption assistance agreement is in effect under Title IV-E.

After 1995, the two most important further opportunities for states to expand Medicaid eligibility for adolescents came in 1997, with the enactment of SCHIP, and on a smaller scale in 1999, with the Foster Care Independence Act. SCHIP provided a financial incentive for states to “accelerate” their Medicaid coverage of poor adolescents (mandated in 1990 as a phase-in) and to cover adolescents from families with higher incomes; and numerous states availed themselves of this opportunity.³⁵ The Foster Care Independence Act included an option for states to provide Medicaid coverage to adolescents who had been in foster care on their 18th birthdays.³⁶

The extent to which adolescents actually benefit from the eligibility expansions that have occurred depends both on whether the states have implemented them and whether eligible adolescents are actually enrolled. The federal Medicaid agency reported that in 1994 an estimated 4.7 million children and adolescents could be covered by Medicaid but were

delinking process culminated, in a more negative way, with the enactment of the federal welfare law in 1996.

³⁴ See GAO, *Health Insurance for Children*, supra, note 33; *Medicaid Guide*, supra, note 20.

³⁵ Morreale and English, supra note 27.

³⁶ Abigail English, Madlyn C. Morreale, and Judith Larsen, *Access to Health Care for Youth Leaving Foster Care: Medicaid and SCHIP*, 32 *J. Adolescent Health* 53 (2003).

not enrolled.³⁷ The American Academy of Pediatrics (AAP) estimated that in 2002 4.1 million children and adolescents ages 0 through 18 were eligible for but not enrolled in Medicaid.³⁸ AAP estimates for 1999 suggested that 1.3 million uninsured adolescents ages 13 through 18 were eligible for but not enrolled in the Medicaid program; more recent adolescent-specific data is not readily available.³⁹

Reasons why adolescents who are eligible might not be enrolled include: lack of awareness or misunderstanding of the criteria for Medicaid eligibility, including the potential for obtaining Medicaid coverage independent of cash assistance; unwillingness or inability (e.g. due to lack of transportation) to visit a “welfare office” to enroll; complexity of the enrollment process; inability to obtain necessary financial information from parents; lack of education regarding the need for ongoing health coverage and preventive care for adolescents; and cultural and linguistic barriers.⁴⁰

Strategies for improving enrollment include some further changes in eligibility rules as well as procedural improvements in enrollment processes such as: “outstationing” of eligibility workers at sites other than welfare offices; shortened application forms; elimination of the assets test for pregnant women, infants, and/or children; presumptive eligibility pending a formal determination of eligibility; expedited processing of pregnant women’s applications; mail-in eligibility; and 12 month continuous eligibility for children up to age 19. If targeted specifically to adolescents and implemented at health care sites frequented by adolescents, these strategies could significantly facilitate their enrollment in Medicaid.⁴¹ Indeed, numerous states did adopt some of these approaches,

³⁷ Laura Summer et al., *Millions of Uninsured and Underinsured Children Are Eligible for Medicaid 3* (1996) (available from the Center on Budget and Policy Priorities, Washington, DC).

³⁸ American Academy of Pediatrics, *Children’s Health Insurance Status: Medicaid/SCHIP Eligibility and Enrollment, Characteristics of Medicaid-enrolled and Uninsured Children, State Reports, 2002*, October 2003. Available at: <<http://www.aap.org/research/2003cps.pdf>> (visited Oct. 6, 2004).

³⁹ American Academy of Pediatrics, *Health Insurance Status, Medicaid, State Program and Title XXI Eligibility for U.S. Children Under Age 19, 1999* (updated March 1999) (based on American Academy of Pediatrics’ analysis of 1998 March Demographic File, Current Population Survey and 1999 Projections by Single Year of Age, Sex, Race and Hispanic Origin (Series A), U.S. Census Bureau).

⁴⁰ Jane Perkins & Susan Zinn, *Toward a Healthy Future — Early and Periodic Screening, Diagnosis, and Treatment for Poor Children 1* (1995) [hereinafter *Toward a Healthy Future I*]; Jane Perkins & Sarah Somers, *Toward a Healthy Future: Medicaid Early and Periodic Screening, Diagnostic and Treatment Services for Children and Youth* (2003) [hereinafter *Toward a Healthy Future II*] (available from the National Health Law Program, Los Angeles, CA, www.healthlaw.org).

⁴¹ See, e.g., *Improving the Implementation of State Children’s Health Insurance Programs for Adolescents: Report of an Invitational Conference Sponsored by the American Academy of Pediatrics, Section on Adolescent Health*, September 26-27, 1999, 105 *Pediatrics* 906 (2000).

although not necessarily in a way that was targeted at adolescents. Nevertheless they may well have contributed to the increased public health insurance coverage of adolescents in the late 1990s; they have also been cut back in some states as budgets tightened.⁴²

Medicaid Services - EPSDT

The key to the importance of Medicaid services for adolescents lies in Early and Periodic Screening, Diagnosis and Treatment (EPSDT). It is EPSDT that provides the basis for eligible adolescents to receive the full range of Medicaid services, and to do so not only episodically in response to acute health problems, but as part of a comprehensive and preventive approach to health care.⁴³ Although EPSDT has not yet fulfilled its promise to adolescents, it offers the means to do so by providing those who are eligible with the right to expect access to a comprehensive set of services. Many of the benefits of EPSDT (for adolescents as well as younger children) have only been realized as the result of court decisions.⁴⁴ Nevertheless, the framework that has been built over nearly four decades currently remains strong and presents a viable basis for Medicaid-eligible adolescents to receive essential care.

Medicaid covers a broad range of medically necessary services, which fall into two groups, mandatory and optional.⁴⁵ For Medicaid beneficiaries under age 21, all mandatory and optional services must be made available if medically necessary.⁴⁶ While all mandatory and optional Medicaid services must be available to Medicaid eligible adolescents under age 21, certain Medicaid services are particularly important for adolescents. These include EPSDT; mental health and substance abuse treatment; family planning and reproductive health care; immunizations; and certain support services, such as outreach, transportation and scheduling, and case management.

Originally enacted in 1967, EPSDT⁴⁷ was significantly strengthened by Congress in the Omnibus Budget Reconciliation Act of 1989 (OBRA '89).⁴⁸ Pursuant to federal EPSDT requirements, states must provide for comprehensive assessment or screening of a child or adolescent's health. In addition, states must cover services necessary to correct or

⁴² See, e.g., Donna Cohen Ross and Laura Cox, Center on Budget and Policy Priorities, *Beneath the Surface: Barriers Threaten to Slow Progress on Expanding Health Insurance Coverage of Children and Families*, 2004 (available from Kaiser Commission on Medicaid and the Uninsured, Washington, DC, www.kff.org).

⁴³ See *Toward a Healthy Future II*, supra note 40, at 34.

⁴⁴ See *Advocates' Guide*, supra note 20, at 4.4-4.5 and n. 46-49.

⁴⁵ See *Advocates' Guide*, supra note 20.

⁴⁶ 42 U.S.C. § 1396d(r)(5). States may limit the scope of non-ambulatory services for the medically needy. See *Advocates' Guide*, supra note 20, at 4.4.

⁴⁷ 42 U.S.C. §§ 1396a(a)(10) and (43); § 1396d(a)(4)(B); § 1396d(r). 42 C.F.R. §§ 441.50 - 441.62. See also 58 Fed. Reg. 51288 (1993) (proposed regulations). CMS, *State Medicaid Manual*, Part 5, §§ 5010-5360.

⁴⁸ Pub. L. No. 101-239, § 6403, 103 Stat. 2106 (1989).

ameliorate health needs identified in the screening process, even if those services otherwise are not be covered under the state's Medicaid plan for adults.

Screening. The EPSDT statute requires that states must provide or arrange for comprehensive health assessments that include four distinct screening components — medical, vision, hearing, and dental — in all cases in which they have been requested.⁴⁹ Certain aspects of the screening requirements, such as laboratory tests for STDs, hepatitis B immunizations as recommended by ACIP, and anticipatory guidance, are particularly critical ones for adolescents.

States must provide screening services at periodic intervals during a child or adolescent's life. The schedule of visit intervals, known as the periodicity schedule, must meet reasonable standards of medical and dental practice, as developed by the state after consultation with recognized medical and dental organizations involved in child health care. Thus, for adolescents, it is reasonable to conclude that the periodicity schedule should correspond to the recommendations contained in professional guidelines such as the Guidelines for Adolescent Preventive Services (GAPS), Bright Futures, and the guidelines of the American Academy of Pediatrics (AAP): in other words, states' periodicity schedules should, at minimum, provide for annual exams during the adolescent years.⁵⁰ There must be separate periodicity schedules for medical screens, and for vision, dental, and hearing services,⁵¹ which may vary from one another. For example, experts in child dental care and the AAP recommend dental visits twice yearly.⁵²

The periodicity schedule for adolescents in many states lags behind the annual checkups recommended by virtually every professional group and compliance with screening requirements is far from adequate. Even if the periodicity schedule in a particular state is inadequate, federal law also requires coverage for “interperiodic screens,” which could be particularly useful, for example in implementing a recent recommendation that all sexually active adolescent girls should be screened twice a year for chlamydia, a sexually transmitted infection.⁵³

⁴⁹ U.S.C. §§ 1396a(a)(43)(B), 1396d(r)(1)-(4).

⁵⁰ Arthur B. Elster and Naomi J. Kuznets, *Guidelines for Adolescent Preventive Services* (1994) (Williams and Wilkins: Baltimore); Nat'l Center for Education in Maternal and Child Health, *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents* (M. Green ed., 1994); American Academy of Pediatrics, Committee on Practice and Ambulatory Medicine, *Recommendations for Preventive Pediatric Health Care*, 96 *Pediatrics* 373 (1995).

⁵¹ 42 U.S.C. § 1396d(r)(1)-(4).

⁵² American Academy of Pediatric Dentistry, Clinical Affairs Committee, *Clinical Guideline on Periodicity of Examination, Preventive Dental Services, Anticipatory Guidance, and Oral Treatment for Children* (revised 2003). Available at <<http://www.aapd.org>> (visited Oct. 11, 2004).

⁵³ Gale R. Burstein et al., *Incident Chlamydia Trachomatis Infections Among Inner-City Adolescent Females*, 280 *JAMA* 521 (1998).

Diagnosis and Treatment. Federal law requires a state to provide EPSDT eligible children and adolescents with “necessary health care, diagnostic services, treatment, and other measures [listed as required or optional Medicaid services]. . . to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services.”⁵⁴ These services must include — in addition to standard medical services — vision, hearing, and dental services.⁵⁵ This federal provision means that, as long as the services a child needs are listed in the federal Medicaid statute as either mandatory or optional services, they must be provided whether or not they are included in the state's Medicaid plan for adults.⁵⁶ Fully implemented, this offers needy adolescents access to a broad range of critically important services including, mental health and substance abuse services, case management, private duty nursing, and rehabilitation services, among others.⁵⁷

Data Reporting. Congress required HHS to obtain participation and screening data from the states and to monitor them to assure that participation rates improve.⁵⁸ Pursuant to this law, the Secretary of HHS set a participation goal of 80 percent of all eligible children for each state as of FY 1995.⁵⁹ By April 1 each year, states must submit specific data showing the success of EPSDT in reaching eligible children and adolescents. Data submitted by the states to HHS in the mid-1990s showed adolescent participant rates to lag woefully behind the rates for other age groups, although some improvements were seen later in the decade.⁶⁰ Nevertheless, the potential of EPSDT to meet adolescents’ needs for prevention, diagnosis, and treatment remains huge.

The State Children’s Health Insurance Program – SCHIP

SCHIP⁶¹ was created in 1997 as Title XXI of the Social Security Act. SCHIP made available to states a total of \$40 billion over 10 years to expand health insurance for low-income children and adolescents.⁶² SCHIP allowed states to expand Medicaid, create separate non-Medicaid state programs, or combine these approaches. States with federally approved state plans receive Title XXI funds at a higher matching rate than the Medicaid matching rate: SCHIP “enhanced” matching rates vary from 65 percent to 84 percent, compared with 50 percent to 77 percent for Medicaid (at the time SCHIP was

⁵⁴ 42 U.S.C. § 1396d(r)(5). For additional discussion of treatment services in EPSDT, see *Toward a Healthy Future*, supra note 40.

⁵⁵ 42 U.S.C. § 1396d(r)(1)-(4).

⁵⁶ 42 U.S.C. § 1396d(a), (r)(5).

⁵⁷ See English et al., *Medicaid and SCHIP*, supra note 17.

⁵⁸ 42 U.S.C. § 1396d(r).

⁵⁹ CMS. *State Medicaid Manual*, § 5360.

⁶⁰ *EPSDT Review*, supra note 26; *EPSDT Update 97-98*, supra note 26; *EPSDT Update 99-01*, supra note 26.

⁶¹ 42 U.S.C. § 1397 et seq.

⁶² 42 U.S.C. § 1397dd(a).

enacted).⁶³ In Medicaid expansion programs, federal Medicaid requirements apply unless the state has obtained a waiver of those requirements, while in non-Medicaid SCHIP programs, states have considerable discretion to design and administer their own programs within some broad federal parameters.

SCHIP Eligibility

In both Medicaid-expansion and state-designed SCHIP programs, states were allowed to cover uninsured children and adolescents who are younger than age 19 living in families with incomes up to either 200 percent FPL or a higher level in states that, prior to SCHIP, had raised their maximum Medicaid eligibility level above 150 percent of the FPL.⁶⁴ It is noteworthy that prior to the enactment of SCHIP, through various Medicaid options, states could already have covered most, if not all, of these adolescents, albeit without the enhanced federal financial match made available by SCHIP.

Some groups of children and adolescents were specifically excluded from SCHIP eligibility, such as those with other health insurance, some incarcerated youth (“inmates of a public institution”), and residents of certain mental facilities (“inmates of institutions for mental diseases”).⁶⁵ However, eligibility was not to be restricted based on disability or denied based on a diagnosis or preexisting condition.⁶⁶ Moreover, states could not claim SCHIP funds if they reduced Medicaid eligibility below June 1997 levels, and could not cover individual children and adolescents who were eligible for Medicaid in their state as of the end of March 1997.⁶⁷ Screening for SCHIP eligibility must identify children and adolescents who are eligible for Medicaid and enroll them in that program.

SCHIP offered a major opportunity for states to offer health insurance to large numbers of adolescents who had previously been ineligible for Medicaid. SCHIP also provided a financial incentive for states to “accelerate” the mandatory Medicaid phase in of adolescents with family incomes at or below 100 percent FPL by allowing them to do so immediately and claim the enhanced SCHIP matching rate.⁶⁸

SCHIP Services

The type of program a state chooses to implement has a significant impact on the scope of benefits. In a Medicaid expansion, the scope of benefits is the Medicaid benefit package, unless the state has received an explicit federal waiver to vary the Medicaid scope of benefits.⁶⁹ In a non-Medicaid state-designed SCHIP program, the scope of

⁶³ 62 Fed. Reg. 62613 (1997); 62 Fed. Reg. 48098 (1997).

⁶⁴ English et al., Medicaid and CHIP, *supra* note 17, at 42.

⁶⁵ *Id.* at 42.

⁶⁶ 42 U.S.C. § 1397bb(b)(1)(B)(ii).

⁶⁷ 42 U.S.C. § 1396d(u)(1)(A) and (2).

⁶⁸ 42 U.S.C. § 1396d(u)(2).

⁶⁹ English et al., Medicaid and CHIP, *supra* note 17, at 65.

benefits is determined by the state within very broad federal parameters: states have the option of offering one of several “benchmark plans” or their actuarial equivalent.⁷⁰

While the mandatory minimum package of benefits in a non-Medicaid SCHIP program is actually quite limited, virtually every state has chosen to offer a benefit package that goes well beyond the minimum. In fact, some states have even chosen to offer a “Medicaid look-alike” package or to include an expanded benefit package for children and adolescents with a chronic illness or disability.⁷¹ The latter approaches have the advantage of providing generous benefits, but the disadvantage of lacking the entitlement feature of the Medicaid program.

Beneficial Effects for Adolescents of Medicaid and SCHIP Expansions

The combined effect of the Medicaid eligibility expansions of the 1980s and 1990s and the opportunities afforded by SCHIP after 1997 were positive for adolescents. The positive developments included both eligibility expansions on paper and increases in actual enrollment.

Looking at comparisons in Medicaid eligibility in March 1997, immediately before SCHIP was enacted, and September 2001, four years after it became effective, we note some dramatic improvements for adolescents. For example:

- The first few years of SCHIP implementation witnessed a doubling in the number of states that exceeded the federal Medicaid eligibility phase-in schedule for poor adolescents, from 23 in 1997 to 46 in 2001.⁷²
- Several states with Medicaid income eligibility thresholds in the 10% to 18% range for older adolescents ages 15 to 18 in 1997 had raised those thresholds to 100% or 200% of FPL by 2001.⁷³

Four years after SCHIP implementation began, states had made significant progress in expanding adolescent’s eligibility for both Medicaid and SCHIP, and in addressing the disparities between eligibility levels for adolescents and younger children. Although states mostly established more generous eligibility requirements in their state-designed

⁷⁰ Id.

⁷¹ Id. at 70; Harriette Fox et al., *An Analysis of States’ CHIP Policies Affecting Children with Special Health Care Needs* (1999) (available from Maternal and Child Health Policy Research Center, Washington, DC).

⁷² Madlyn C. Morreale and Abigail English, *Eligibility and Enrollment of Adolescents in Medicaid and SCHIP: Recent Progress, Current Challenges*, 32S J. Adolescent Health 25 (2003). At the time this comprehensive analysis of eligibility and enrollment of adolescents in Medicaid and SCHIP was completed, the most recent adolescent-specific data available were as of September 30, 2001.

⁷³ Id.

SCHIP programs than in their Medicaid expansion SCHIP programs, advances for adolescents were seen in both. By September 30, 2001, for example:

- A total of 29 states established their income threshold for Medicaid eligibility for all adolescents under age 19 at a level higher than 100% FPL; of these, 13 established a threshold equal to or higher than 200% FPL.⁷⁴
- The number of states that provided the same eligibility standards in both Medicaid and SCHIP programs for all children and adolescents under age 19, including older adolescents ages 15 to 18, increased dramatically, from five in 1997 to 45 in 2001.⁷⁵

Comparisons of the enrollment of adolescents in Medicaid immediately prior to the enactment of SCHIP with enrollment of adolescents in Medicaid and SCHIP combined is difficult due to the different age groupings for which CMS collects and reports data for the two programs. Nevertheless, a positive impact can be discerned:⁷⁶

- During FY 1997, the year SCHIP was enacted, Medicaid served 3.9 million adolescents ages 15 through 20.⁷⁷
- By the end of FY 2001, nearly 4.7 million adolescents ages 13 through 18 had enrolled in Medicaid (at some point during that year) and nearly 1.5 million had enrolled in SCHIP (either Medicaid expansion or state-designed programs).⁷⁸

The expansions in eligibility and enrollment were not the only benefits for adolescents in that were provided through the Medicaid and SCHIP programs in the late 1990s. Other positive developments, at least in selected states, were related to such issues as outreach, preventive services, and family planning services.⁷⁹

⁷⁴ Id.

⁷⁵ Id.

⁷⁶ Id.

⁷⁷ Id.

⁷⁸ Id.

⁷⁹ See, e.g., English et al., Medicaid and CHIP, *supra* note 17; Claire D. Brindis et al., Adolescents and the State Children's Health Insurance Program (CHIP): Healthy Options for Meeting the Needs of Adolescents (1999) (published by the Association of Maternal and Child Health Programs, Washington, D.C., and the National Adolescent Health Information Center, University of California, San Francisco; available at <http://nahic.ucsf.edu>); Harriette B. Fox, Margaret A. McManus, and Stephanie J. Limb, Early Assessments of SCHIP's Effect on Access to Care for Adolescents, 32S J. Adolescent Health 40 (2003).

IV. HEALTH CARE REFORM

Important changes in health and welfare law at the federal level that occurred during the 1990s had major implications for adolescents. These included enactment of a comprehensive new welfare law and some incremental health care reform measures related to mental health parity and insurance portability. In addition, several unsuccessful efforts to change the law – by attempting to enact national health care reform legislation, convert Medicaid to a block grant – also had potential significance for adolescents. Ultimately, however, for adolescents the most significant development was the enactment of the State Children’s Health Insurance Program (SCHIP), previously discussed in Section III.

National Health Care Reform in 1993 and 1994

In 1993 and 1994, President Clinton made national health care reform, including health insurance for all, a centerpiece of the policy agenda for his first term, and numerous members of Congress, both Democrats and Republicans, introduced their own proposals.⁸⁰ While none of the plans was ultimately enacted, several would have had specific advantages for adolescents. For example, some, but not all, of the plans included universal coverage for adolescents as well as younger children, a guaranteed benefit package, a supplemental or Awrap around@ benefit package for children and adolescents with special needs, limitations on cost-sharing for low-income children and families, and protection for essential community providers.⁸¹ A decade later, many of these issues remain to be addressed, for adolescents as well as other age groups.

Health Care Policy Changes in 1995 and 1996

The mid-1990s witnessed both restrictive developments and incremental positive reforms. Some of the most restrictive efforts – to restructure Medicaid – did not succeed, but the implications of the new federal welfare law were negative for adolescents. Incremental improvements related to mental health parity and insurance portability.

⁸⁰ E.g., Health Security Act (S. 1757/H.R. 3600) (President Clinton/ Sen. Mitchell/ Rep. Gephardt); The American Health Security Act of 1993 (S. 491/H.R. 1200) (Sen. Wellstone/ Rep. McDermott); Health Equity and Access Reform Today Act of 1993 (S. 1770/H.R. 3774) (Sen. Chafee/ Rep. Thomas); Managed Competition Act of 1993 (H.R. 3222/ S. 1579) (Rep. Cooper/ Sen. Breaux); Stark (Markup of H.R. 3600 by Health Subcommittee of House Ways and Means Committee); Kennedy (Chairman's Mark of S. 1757 for Markup by Senate Committee on Labor and Human Resources).

⁸¹ For a comparison of the provisions of the various plans, see, e.g., Kaiser Commission on the Future of Medicaid, Summary of Major Health Care Reform Legislation (as of December 22, 1993).

Efforts to Restrict Medicaid

During 1995 and 1996, Congress threatened access to health care for poor and low-income populations, including adolescents. In 1995, as part of a bill to balance the federal budget in seven years, Congress passed legislation that would have converted Medicaid to a block grant, thereby eliminating numerous features of the program important to adolescents, particularly its status as an entitlement (meaning that those eligible for the program have the right to obtain services through the program on a timely basis).⁸² Due to a presidential veto that Congress was unable to override, this bill did not become law. Other proposals in 1995 and 1996 to restructure Medicaid, put forward by both the Clinton administration and the National Governors' Association (NGA)⁸³ also were not enacted, but they would have had major implications for adolescents' ability to qualify for Medicaid and to receive necessary benefits under the program:

- All three of the proposals would have ended the Medicaid entitlement as it existed at the time, creating in its place either a block grant or a capped entitlement.
- All three proposals would have allowed states to use mandatory managed care without federal permission in the form of a waiver.
- Eligibility requirements and coverage for adolescents would have been weakened, by eliminating mandatory coverage above age 12, eliminating the required phase-in of coverage for poor adolescents, or creating financial incentives for states to drop optional eligibility categories that benefit adolescents.
- Benefits for adolescents would have been weakened, by eliminating the requirement for coverage of the full scope of EPSDT benefits, limiting the treatment component of EPSDT, or creating a per capita cap that would limit states ability to provide the full scope of EPSDT services.⁸⁴

Federal Welfare Reform Law

A new federal welfare law, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA) was signed into law in August 1996.⁸⁵ It had numerous implications for adolescents' eligibility for Medicaid:⁸⁶

⁸² The Balanced Budget Act of 1995, H.R. 2491, 104th Cong. (1995) [hereinafter the Medigrant bill]. See Cong. Rec. H12557 - H12582 (1995) for the Medicaid provisions of the bill.

⁸³ President Clinton's 1997 Budget Proposal submitted to Congress (Feb. 6, 1996); Outline of National Governors' Association Proposal (Feb. 6, 1996). The NGA proposal was never fully incorporated into a specific legislative proposal.

⁸⁴ For a discussion of the potential harmful effects from these proposals, see, e.g., Paul W. Newacheck, et al., The Effect on Children of Curtailing Medicaid Spending, 274 JAMA 1468 (1995).

⁸⁵ Pub. L. No. 104-193; 110 Stat. 2105 (1996). For a series of articles analyzing the new welfare law, see a special issue of Clearinghouse Review, Vol. 30, Nos. 9-10 (Jan.-Feb. 1997).

- First, the law repealed the Aid to Families with Dependent Children (AFDC) program, replaced it with a new block grant program of Temporary Assistance for Needy Families (TANF), and in doing so altered the long-standing structure whereby eligibility for Awelfare@ was one of the primary ways to qualify automatically for Medicaid.⁸⁷
- Second, the law dramatically altered the eligibility of immigrants for public assistance programs, including cash welfare benefits and Medicaid, severely limiting access to Medicaid not only for undocumented immigrants but also for many living legally in the United States.⁸⁸
- Third, the law changed the eligibility requirements for children and adolescents with disabilities to qualify for Supplemental Security Income (SSI), establishing stricter eligibility criteria that were expected to have a particularly severe effect on children and adolescents with mental or emotional disorders, functional impairments, or multiple impairments no one of which was severe enough to allow them to qualify.⁸⁹

Mental Health Parity

The Mental Health Parity Act of 1996⁹⁰ fell short of providing full parity for mental health benefits, but did address two specific issues: annual reimbursement limits and lifetime caps. Many private insurance plans have lifetime caps of \$50,000 and annual limits of \$1,000 or \$2,000 for mental health benefits.⁹¹ The law addressed these problems by prohibiting an insurer from imposing a lifetime cap or annual limit on mental health benefits if it does not do so for medical and surgical benefits or establishing a lower lifetime cap or annual limit on mental health benefits than for medical and surgical benefits. The law was time-limited and had numerous other deficiencies, but laid the foundation for future efforts to enact more comprehensive mental health parity legislation.⁹²

⁸⁶ National Health Law Program, et al., *The Welfare Law and Its Effects on Medicaid Recipients*, 30 *Clearinghouse Review* 1008 (1997).

⁸⁷ Pub. L. No. 104-193, Title I, §§ 101-116 (amending various sections of the U.S. Code).

⁸⁸ Pub. L. No. 104-193, Title IV, §§ 400-451 (amending various sections of the U.S. Code).

⁸⁹ Pub. L. No. 104-193, § 211(a) (codified at 42 U.S.C. §1382c(a)(3)(C)(i)).

⁹⁰ 29 U.S.C. § 1185a; 42 U.S.C. § 300gg-5.

⁹¹ Bazelon Center for Mental Health Law, *Paying for Parity* (1996) (available from Bazelon Center for Mental Health Law, Washington, DC).

⁹² In the interim existing law was extended until December 31, 2004, pending Congressional action on comprehensive legislation was not enacted in 2003, The Senator Paul Wellstone Mental Health Equitable Treatment Act, S. 486, H.R. 953, 108th Cong. 2d Sess. (2003). Bazelon Center for Mental Health Law, *Legislative Update: First Session of 108th Congress Adjourns with Little Achieved*. <http://www.bazelon.org/takeaction/alerts/12-19-03update.htm>.

HIPAA – Insurance Portability and Health Privacy

The Health Insurance Portability and Accountability Act of 1996 (HIPAA)⁹³ was among the incremental health care reform measures passed in the 1990s after the failure to enact comprehensive national health care reform legislation early in the decade. It addressed two distinct issues: the difficulties in establishing, obtaining, and retaining health insurance for people with high health costs or significant health problems; and the privacy of health information.

Among its other provisions, HIPAA restricted somewhat insurance companies' ability to discriminate against children and adults with health problems by limiting pre-existing condition exclusions, denial of coverage to small employer groups or individuals based on health status or claims experience, and discrimination in premium amount among similarly situated individuals.⁹⁴ The net result of HIPAA was to provide some protections for individuals with pre-existing conditions and the groups that they are part of, but little relief against the high premiums charged by insurers for such individuals and groups. HIPAA theoretically provided some important protections for adolescents, particularly those who have a chronic illness or disability or who live in a family with someone who does. If the family has insurance, it cannot be canceled and the family cannot be excluded from coverage based on the adolescent's or other family member's health problem. For example, if an adolescent becomes pregnant and has costly complications of the pregnancy or gives birth to a premature infant who requires neonatal intensive care, the family's insurance coverage cannot be canceled as a result.

Nevertheless, HIPAA's ability to expand adolescents' access to care was limited in several ways. First, it did little if anything to expand coverage to uninsured children and adolescents. Second, it did little or nothing to make health insurance more affordable because it did not stop insurers from charging exorbitant premiums to discourage people with pre-existing conditions from purchasing a policy or joining a group. Finally, some groups of adolescents C particularly older adolescents and young adults who are graduating from high school or college and moving into jobs C may not be protected by it at all. For example, college students who have been covered by a college health plan may not be considered to have had Acreditable coverage@ and, therefore, may not be protected against pre-existing condition exclusions or be guaranteed coverage and renewal.

HIPAA also contained a provision related to the privacy of health information, which provided that unless Congress enacted legislation governing the standards with respect to the privacy of individually identifiable health information by August 21, 1999, HHS was required to promulgate regulations to do so.⁹⁵ Several health privacy bills were introduced

⁹³ Pub. L. No. 104-191, 110 Stat. 1936 (1996).

⁹⁴ 29 U.S.C. §§ 1182; 42 U.S.C. §§ 300gg-1, 300gg-11.

⁹⁵ Pub. L. No. 104-191, § 264 (1996).

in Congress during 1999,⁹⁶ but none was enacted. There was considerable debate in Congress about whether to include protections for minors. HHS subsequently proposed regulations in late 1999 and promulgated final rules in December 2000,⁹⁷ which were modified in August 2002.⁹⁸ These regulations, known as the HIPAA Privacy Rule, have significant implications for the confidentiality of adolescents' health information.⁹⁹

1997 – The BBA

The leading health care reform initiative of the 1990s with positive implications for adolescents was the creation of the State Children's Health Insurance Program (SCHIP) as part of the Balanced Budget Act of 1997 (BBA). The BBA also contained key provisions related to Medicaid and managed care.

In early 1997, both Democrats and Republicans expressed interest in continuing the incremental health care reform process by enacting legislation which would target expansion of health insurance for some or all of the more than 10.5 million U.S. children and adolescents without insurance.¹⁰⁰ While many pundits and analysts thought it unlikely that health insurance expansion legislation would actually be enacted during 1997, by mid-year momentum was building, and by late June both houses of Congress had enacted a version of such legislation. On August 5, 1997 the Balanced Budget Act (BBA) of 1997 was signed into law.¹⁰¹ The BBA included SCHIP as a new Title XXI of the Social Security Act,¹⁰² offering \$40 billion in new funds to expand health insurance for children and adolescents. SCHIP has been extensively discussed in Section III of this report.

⁹⁶ See, e.g., S. 573, 106th Cong. 1st Sess. (1999), S. 578, 106th Cong. 1st Sess. (1999), S. 881, 106th Cong. 1st Sess. (1999).

⁹⁷ 65 Fed. Reg. 82461 (2000).

⁹⁸ 67 Fed. Reg. 53182 (2002).

⁹⁹ Abigail English and Carol Ford, *The HIPAA Privacy Rule and Adolescents: Legal Questions and Clinical Challenges*, 36 *Family Planning Perspectives* 80 (2004).

¹⁰⁰ See, e.g., *Kids-Only Health Insurance: Health Care Reform's Next Step?*, *Health Policy and Child Health* (Center for Health Policy Research, George Washington University, Washington, DC), Fall 1996, at 1.

¹⁰¹ National Health Law Program, et al., *The Balanced Budget Act of 1997: Reshaping the Health Safety Net for America's Poor*, *Youth Law News*, Vol. XVIII, No. 5, Sept.-Oct. 1997 and *Health Advocate* (No. 190), Fall 1997 [hereinafter *BBA Analysis*] (available from National Health Law Program, Los Angeles, CA or National Center for Youth Law, Oakland, CA).

¹⁰² 42 U.S.C. §§ 1397 et seq. For analysis of the SCHIP provisions of the BBA, see, e.g., Abigail English, *The New Children's Health Insurance Program: Early Implementation and Special Populations*, 32 *Clearinghouse Review* 429 (1999); National Conference of State Legislatures and National Governors' Association, *1998 State Children's Health Insurance Program: Annual Report* (1999) [hereinafter *NCSL and NGA*].

In the BBA Congress also added many significant changes to the Medicaid program and to the requirements for Medicaid managed care. Key provisions with implications for adolescents included:

- *Mandatory managed care.* The BBA authorized states to require most Medicaid beneficiaries to enroll in managed care without obtaining a waiver under Section 1115 or Section 1915(b) of the Social Security Act, albeit with some continuing protections for children and adolescents with disabilities, foster children, and adoptees.¹⁰³
- *Copayments in managed care.* The BBA authorized states to require cost-sharing in Medicaid managed care plans to the same extent that it is allowed in fee-for-service Medicaid programs, although significant limits should continue to apply to pregnant women, children, and adolescents.¹⁰⁴
- *Presumptive eligibility for children.* The BBA gave states the option to implement presumptive eligibility for children under age 19,¹⁰⁵ which would allow preliminary determinations of Medicaid eligibility to be made by health care providers who serve adolescents.
- *Twelve month continuous eligibility.* The BBA gave states the option to implement 12 month continuous eligibility for children up to age 19 in their Medicaid programs.¹⁰⁶

From the perspective of adolescents, the Medicaid program changes enacted in the BBA have mixed implications. Some adolescents with special needs are protected from mandatory managed care enrollment in the absence of a waiver, but most Medicaid-eligible adolescents do not fall into those groups. The imposition of cost-sharing in the form of co-payments in Medicaid managed care plans could create barriers to services for teens, especially confidential services. Medicaid prohibits co-payments for children and youth below age 18 (or 19, 20, or 21 at state option),¹⁰⁷ but for any older adolescent not protected from co-payment requirements, they could be a serious obstacle. At the same time, the implementation of presumptive and/or continuous eligibility could be highly beneficial for many adolescents.

¹⁰³ 42 U.S.C. § 1396u-2.

¹⁰⁴ 42 U.S.C. § 1396o; C.F.R. §§ 447.50-447.59.

¹⁰⁵ 42 U.S.C. § 1396r-1A.

¹⁰⁶ 42 U.S.C. § 1396a(e)(12).

¹⁰⁷ 42 U.S.C. § 1396o.

V. MANAGED CARE – LAWS, CONTRACTS, AND WAIVERS

The term “managed care” is a broad one that has been used to refer to a diverse set of health insurance and health care delivery structures and arrangements. In its current manifestations, managed care has evolved over several decades from several distinct models. Among the most familiar are the health maintenance organization or HMO, the preferred provider organization (PPO), and the point of service plan (POS). Over time, these models, once distinct, have begun to evolve into increasingly varied approaches often incorporate elements from. Current models of managed care include numerous variations with respect to whether they are risk-based, whether they limit enrollees to a specific panel of providers, whether they use primary care providers as gatekeepers, and the type and extent of utilization controls they use. These models, or elements of them, have been represented among both commercial and Medicaid managed care plans. They will continue to evolve, and those evolutions will include varied implications for adolescents.

The numerous laws that regulate the organization, financing and quality of managed care do not, for the most part, focus on adolescent health. However, they do affect adolescents along with other users of health care. The managed care laws that are most relevant for adolescent health care include the Federal HMO Act, state laws restricting HMO networks, state mandated benefits laws, ERISA, and the statutory, regulatory, and contract provisions that govern Medicaid managed care.

Federal Managed Care Laws

Two federal laws significantly affect the provision of health care to adolescents through managed care plans: the Federal Health Maintenance Organization (HMO) Act and the Newborns’ and Mothers’ Health Protection Act. These two pieces of legislation provide a noteworthy contrast between the more comprehensive approach to health policy-making that occurred in the late 1960s and 1970s and the targeted, often single-issue policy approach that emerged in the late 1990s.

The Federal HMO Act¹⁰⁸ is the most comprehensive federal scheme, to date, for the advancement of managed care. Requirements for an HMO to be federally-qualified under the Act pertain to enrollment and the scope of services among other issues. For example, the HMO must enroll persons who are “broadly representative of the various age, social, and income groups within the area it serves” and it cannot expel or refuse to re-enroll any member because of health status or needs.¹⁰⁹ In addition, the HMO must offer at least a basic set of services, some of which are of particular relevance to adolescents such as treatment and referral for abuse of alcohol and drugs and preventive services, including immunizations, well child care, periodic health evaluations, and family planning

¹⁰⁸ 42 U.S.C. § 300e et seq (1991). The Health Maintenance Organization Act of 1973, Pub. L. No. 93-222, 87 Stat. 914 (1973).

¹⁰⁹ 42 U.S.C. § 300e(c)(3) and (4) (1991).

services.¹¹⁰ The HMO must make these services available and accessible with reasonable promptness and must assure continuity.¹¹¹ As of the mid-1990s, approximately two-thirds of HMOs were federally-qualified.¹¹²

More than 20 years after passage of the federal HMO Act, as part of a new wave of reactions to restrictions on services being imposed by insurers, President Clinton signed the Newborns' and Mothers' Health Protection Act of 1996 to end the managed care problem of "drive-by deliveries."¹¹³ The law requires insurers to pay for minimum stays of between 48 and 96 hours as determined by an attending health care provider in consultation with the mother of the newborn. By the time this legislation was enacted, the majority of states had already enacted minimum stay legislation.¹¹⁴ Nevertheless, this mandate would be of significant benefit to adolescent mothers and their infants.

State Managed Care Laws

State legislatures have moved with increasing frequency to regulate managed care, enacting both general HMO statutes and responding to specific "hot button" issues. States have also passed mandated benefits laws, some of which specifically address care that is important for adolescents. All states and the District of Columbia have enacted some laws regulating the HMO industry.

Examples of state efforts of significance for adolescents' access to care include laws to ensure that HMOs cannot inappropriately limit participation in provider networks such as "any willing provider" laws and other measures to avoid discrimination against providers who serve high-risk patients and to assure the availability of sufficient numbers and types of providers.¹¹⁵ The state regulatory laws are far from comprehensive, however, and have a "hit or miss" quality, although a few states have demonstrated leadership.¹¹⁶

Of particular significance for adolescents, are the mandated benefits requirements that many states impose either on HMOs specifically or on all health insurers. Specific requirements that could be helpful to adolescents pertain to preventive services (e.g.,

¹¹⁰ 42 U.S.C. § 300e-1 (1991).

¹¹¹ 42 U.S.C. § 300e(b)(4) (1991).

¹¹² Patricia Butler & Karl Polzer, *Private-Sector Health Coverage: Variation in Consumer Protections under ERISA and State Law* 56 (1996).

¹¹³ Newborns' and Mothers' Health Protection Act, Pub. L. No. 104-204, 110 Stat. 2874 (1996) (included as part of the appropriations bill for the Departments of Veterans Affairs and Housing and Urban Development).

¹¹⁴ American College of Obstetricians and Gynecologists, *State Legislation and Regulations Requiring Insurance Coverage for Postpartum Care* 1995, at 2 (1996).

¹¹⁵ Paul P. Cooper III and Kylanne Green, *The Impact of State Laws on Managed Care*, 10 *Health Aff.* 161, 162 (Winter 1991); National Ass'n of Insurance Commissioners, *Model Acts* (1996) (available from NAIC Publications Department, Kansas City, MO).

¹¹⁶ Center for Health Care Rights, *I Consumer Protections in State HMO Laws* xi (1995).

well-adolescent exams), reproductive health care (e.g. contraceptive coverage), and treatment for chronic and life-threatening disease (e.g. sickle cell treatment or coverage of diabetes self-management).¹¹⁷

The reach of state mandated benefits laws and other state health care reform efforts is limited by ERISA,¹¹⁸ which “preempts” or overrides much state legislation directed at the health insurance industry and which has been interpreted broadly by the courts. Although ERISA allows states to regulate commercial insurance, it does not allow such regulation of employee health benefit plans in which employers assume the risk and self-insure.¹¹⁹ This means that many adolescents with private insurance are covered under health insurance plans that are beyond the reach – and potential benefits – of state regulation. This is particularly noteworthy, given that only minimal health insurance protections are contained in ERISA.

Medicaid Managed Care

The legal authority for managed care entities to participate in Medicaid dates back to the early days of the program. However, regulation of HMOs and prepaid managed care plans through the Medicaid statute and regulations, beginning in the mid-1970s, provided some protection for beneficiaries such as the right to disenroll and prohibitions against discrimination on the basis of health status or needs.¹²⁰

Since the early 1980s, Congress and successive Administrations tried to encourage increased enrollment of Medicaid beneficiaries in managed care plans. During the 1980s and 1990s states were granted two main types of waivers to further the use of managed care. These were known as “Section 1915(b) waivers” and “Section 1115 waivers.” In 1981 and again in 1997, Congress passed sweeping legislation to this end. The Omnibus Budget Reconciliation Act of 1981 (OBRA 81) broadened the ability of states to establish mandatory managed care programs through the use of Section 1915 freedom of choice waivers, thus replacing the existing authority which already allowed managed care demonstration projects. The Balanced Budget Act of 1997 (BBA) allows states to require most Medicaid populations to enroll in a managed care program without first having to obtain a waiver.

¹¹⁷ Aspen Systems Corporation, *Health Maintenance Organizations: State Law Compliance Guide* 26-33 (1996).

¹¹⁸ Employee Retirement Income Security Act of 1974, 29 U.S.C. §§ 1001-1381 (1985).

¹¹⁹ Butler & Polzer, *supra* note 112.

¹²⁰ 42 U.S.C. § 1396b(m)(2)(A)(vi). The Balanced Budget Act of 1997 allowed states to require beneficiaries to remain in a managed care plan for at least one year. 42 U.S.C. § 1396v(a)(4).

Section 1915(b) Waivers

Section 1915(b) waivers, authorized in OBRA 81, created a mechanism to allow states to require individuals to enroll in Medicaid managed care plans.¹²¹ Prior to 1981, enrollment in managed care had been voluntary for most Medicaid beneficiaries or allowed through experimental Section 1115 waivers (discussed below). States have mostly used these waivers to compel enrollment of women and children, including adolescents. With the passage of the BBA in 1997, a waiver was no longer required for states to compel managed care enrollment except for certain populations, such as children with special health care needs.

Section 1915(b) authorizes four different types of managed care programs, of which the most familiar restricts beneficiaries to receiving services, other than emergency services, from or through a designated provider. Restriction of provider choice is not allowed to substantially impair access to medically necessary services, however,¹²² and the implementing regulations for Section 1915(b) waivers required states to document in a waiver request and maintain data regarding, among other issues, the effect of the waiver in terms of access to care and quality of services.¹²³ Of significance for adolescents, some provisions of the Medicaid statute cannot be waived, such as the right of beneficiaries to freely choose a provider for family planning services.¹²⁴

As of the beginning of FY 1998, 40 states and the District of Columbia held one or more Section 1915(b) program waivers, featuring primary care case management and risk-based or capitated systems or both. Initially, these waivers mostly included families and children and generally excluded disabled populations, but by 1998 a majority of states included disabled populations and more than one third targeted individuals with behavioral health care needs.¹²⁵

Section 1115 Demonstration Waivers

Under Section 1115 of the Social Security Act, a state may apply for a waiver to implement a “demonstration project.”¹²⁶ Section 1115 was intended to allow states to test experimental innovations and not merely “copy what other states have done.”¹²⁷

¹²¹ 42 U.S.C. § 1396n(b) (1992).

¹²² 42 U.S.C. § 1396n(b)(2) (1992).

¹²³ 42 C.F.R. § 431.55(b)(2)(i)-(iii) (1996).

¹²⁴ 42 U.S.C. § 1396n(b) (1992).

¹²⁵ Health Care Financing Admin., Freedom of Choice Waiver Quarterly Report (1st Quarter 1997) [hereinafter HCFA Quarterly Report]; National Health Law Program, Survey of States (March 1996). Current information about the status of pending and approved waiver applications in each state is available at <<http://www.cms.hhs.gov/medicaid/waivers/waivermap.asp>> (last modified Sept. 16, 2004).

¹²⁶ 42 U.S.C. § 1315 (1991).

In 1993, however, after discussions with the National Governors' Association, the Clinton administration moved to streamline the waiver process, shorten the time for approval, and approve waivers that were similar to one another.¹²⁸ The new policy was announced in a Notice in the Federal Register.¹²⁹ The Notice indicated an intention to approve projects that preserved or enhanced beneficiary access to quality services and to disapprove or limit those that create constitutional problems or violate civil rights.¹³⁰ The Notice also indicated an intention to consider cost neutrality over the life of the project,¹³¹ thus virtually eliminating the possibility of true benefit expansions.

During the mid-1990s, 19 states and the District of Columbia were awarded section 1115 Medicaid waivers.¹³² These waivers typically included the use of mandatory risk-based managed care programs. A number of them also extended Medicaid eligibility to population groups that were previously not covered. Due to their similarity to one another, they have sometimes been referred to as “cookie-cutter” waivers.

Balanced Budget Act of 1997

The Balanced Budget Act of 1997 (BBA) allows states to require beneficiary enrollment in managed care entities without first obtaining a waiver of the freedom of choice provisions of the Medicaid statute. It also relieved states of the obligation to operate the program uniformly statewide and to provide comparable benefits statewide and within eligibility groups.

Of significance for adolescents, the BBA continues to require states to obtain waivers before requiring managed care enrollment for certain children under age 19 with special needs including, several groups of children and adolescents with disabilities, as well as foster children or those receiving adoption assistance.¹³³ The BBA also delineated a set of consumer protections for all Medicaid beneficiaries, including adolescents, who are

¹²⁷ Memorandum from David Ellwood, Assistant Secretary for Planning and Evaluation, U.S. Dep't of Health and Human Services, Bruce Vladeck, Administrator, Health Care Financing Admin., and Laurence Love, Deputy Assistant Secretary for Program Operations, U.S. Dep't of Health and Human Services, to Donna Shalala, Secretary, U.S. Dep't of Health and Human Services 2 (June 22, 1993).

¹²⁸ Id.

¹²⁹ 59 Fed. Reg. 49249, 49251 (1994).

¹³⁰ Id. at 49249 and 49251.

¹³¹ Id. at 49149.

¹³² Health Care Financing Admin., Comprehensive Health Care Reform Demonstrations (Feb. 4, 1998). Current information about the status of pending and approved waiver applications in each state is available at <<http://www.cms.hhs.gov/medicaid/waivers/waivermap.asp>> (last modified Sept. 16, 2004).

¹³³ 42 U.S.C. § 1396u-2.

enrolled in a managed care entity.¹³⁴ In addition, the implementing regulations included some important protections for beneficiaries. Examples of statutory and regulatory protections that have particular importance for adolescents are a statutory requirement that MCOs must comply with the Mothers' and Newborns' Protection Act and the Mental Health Parity Act of 1996¹³⁵ and a regulatory requirement that managed care organizations inform enrolled beneficiaries of the services available to them, including family planning services.¹³⁶

Medicaid Managed Care Contracts -- Key Findings

Expansion of requirements for Medicaid beneficiaries to enroll in risk-based managed care programs was accompanied by reliance on contracts to define the rights and responsibilities of managed care organizations (MCOs), state purchasers, and, to some extent, enrollees. These Medicaid managed care contracts create new and enforceable rights, building on the existing array of legal requirements that are in place to protect Medicaid beneficiaries. In addition to creating new rights, the contracts also serve to inform MCOs of existing state and federal laws. The contract is often the legal document with the greatest impact on day-to-day operations so the extent to which it addresses issues in a way that benefits adolescents is important in assuring that adolescents' needs are met in Medicaid managed care.

A review was completed of Medicaid managed care documents from 38 states – a total of 71 model Medicaid managed care contracts and requests for proposals were reviewed, whose effective periods fell somewhere between 1991 and 1999, with most having effective dates in the mid-1990s.¹³⁷ The review looked at a standardized set of issues in each document pertaining to enrollment, scope of benefits, provider networks, cultural and linguistic accessibility, confidentiality and consent, and monitoring and reporting. The results of this review revealed that while most provisions of the contracts and requests for proposals would have at least an indirect impact on adolescents, few states included adolescent-specific or adolescent-friendly provisions. Nevertheless a few states did include varied provisions that could be positive for adolescents. The review also highlighted concerns that need to be addressed by contract or other mechanisms in the future.

¹³⁴ 42 U.S.C. § 1396v(b).

¹³⁵ *Id.*

¹³⁶ 42 C.F.R. § 310.

¹³⁷ The George Washington University Center for Health Services Research & Policy conducted a long-term study of Medicaid managed care contracts that also looked at provisions that affect adolescents. Further information about the study is available at <<http://www.gwu.edu/~chsrp/>>.

Enrollment and Provider Choice

The enrollment process is fundamental to assuring access to appropriate care. In that process, adolescents may encounter distinct problems related to choice of MCO, choice of provider, enrollment for those in foster care or living apart from their families, and the transition of pregnant adolescents and those with chronic conditions or disabilities from fee-for-service to risk-based managed care. If adolescents are compelled to enroll in the same MCO or to have the same primary care provider as other family members, their access to providers with interest, training, and experience in caring for them can be limited or precluded entirely. This is because not all MCOs include providers with adolescent-specific expertise, and because the most appropriate primary care provider for an adolescent may not be the most appropriate one for other family members. Key enrollment and provider choice provisions (some found in only one state) that are positive for adolescents include:

- Explicit permission for each family member to select a primary care provider of his or her own. (Pennsylvania)
- Unrestricted access to non-network family planning providers without prior permission from a gatekeeper. (majority of states)
- An obligation to explain to members' that family planning services are available to minors and are confidential. (Iowa)
- A requirement to allow automatic and unlimited changes in plan and provider as often as necessary to accommodate placement changes of children in state custody or foster care. (Missouri)
- Mandatory outreach to homeless children. (Pennsylvania)

Scope of Benefits

A comprehensive scope of benefits is the critical foundation for assuring that adolescents receive the services they need in Medicaid managed care as in other health insurance plans and programs. Key contractual issues that affect the scope of benefits for adolescents pertain to basic services, prescription drugs, EPSDT services, medical necessity, and national standards of care. Key scope of benefits provisions (some found in only one state) that are positive for adolescents included:

- Supplementation of the basic benefits package to include disability management education, instruction on diabetes care (six states), nutrition services for eating disorders (Vermont), home-visiting for new mothers and high risk pregnant women (Delaware, Minnesota, New York, Utah), and substance abuse counseling for adolescents (New York).
- Specification that HIV prevention education, pre-test counseling, and HIV testing with informed consent should be provided to adolescents. (New York)
- A requirement to provide specialized services for adolescents and adolescent development (Vermont), age-specific anticipatory guidance (Texas), and age-specific anticipatory guidance including elements required by EPSDT and recommended by the AMA Guidelines for Adolescent Preventive Services. (Massachusetts)

- An obligation to provide EPSDT services in accordance with federal law (many states), but only occasionally listing all covered services. (North Carolina-Mecklenberg County)
- Comprehensive definitions of medical necessity for children and adolescents explicitly referencing EPSDT legislative language (Pennsylvania, New York, North Carolina-Mecklenberg County) and a requirement that medical necessity determinations be made by the treating provider. (North Carolina-Mecklenberg County)
- A requirement that MCOs meet national professional standards of care, relevant to adolescents, established by health care agencies and professional organizations, such as GAPS, Bright Futures, AAP, ACOG, Advisory Committee on Immunizations, and the Preventive Services Task Force, professional mental health organizations, the Centers for Disease Control and Prevention (CDC), the Substance Abuse and Mental Health Services Administration (SAMHSA), and others. (Fifteen states re one or more standards)

Provider Networks

A significant concern is that adolescents generally will not have access to providers with the training and experience to care for them. Key provider network issues for adolescents pertain to access to specialists and inclusion of essential community providers. Key provider network provisions (some found in only one state) that are positive for adolescents included:

- An obligation for an MCO to provide directly or by contract access to specialists for care appropriate to adolescent enrollees (North Carolina-Mecklenberg County) or to pediatric specialists (several states).
- A requirement to contract with essential community providers where necessary to ensure the availability of health services to traditionally underserved populations (Maine) or some encouragement, short of a contractual requirement, to do so (several states).
- Detailed specification of the required coordination of service, including behavioral health services for severely emotionally disturbed children and adolescents. (Texas)
- A requirement to contract or coordinate services with school-based health centers (at least 15 states) or to subcontract or have referral and care coordination arrangements with family planning providers. (at least five states)
- Encouragement to include teen clinics in the provider network. (North Carolina-Mecklenberg County)

Cultural and Linguistic Accessibility

An important element of ensuring that all eligible adolescents, regardless of race, ethnicity, or national origin can access primary care providers and services is the cultural and linguistic accessibility of those providers and services. This issue will become increasingly important as minority adolescents becoming a larger proportion of the youth

population over the next 10 years. About half of states recognized this and took at least preliminary steps to address it. Key cultural and linguistic accessibility provisions (some found in only one state) that are positive for adolescents included:

- A requirement to provide information in the enrollee's primary language about how to access primary care services. (Minnesota)
- A requirement to ensure or make an effort to ensure that non-English speaking beneficiaries have available one or more primary care providers who can provide services and speak to the beneficiary in his or her primary language, or otherwise to exempt the beneficiary from enrollment. (Massachusetts, Nebraska)

Confidentiality and Consent

For adolescents with privacy concerns or who have health needs related to sensitive issues such as sexually transmitted disease (STD), substance abuse, or mental health, assurances of confidentiality and the opportunity to give their own consent for care can be critical elements of access. Some states addressed this, although many did not. A variety of federal and state laws protect provide consent and confidentiality protection for adolescents, but often MCOs are unaware of these laws, which emphasizes the importance of contractual provisions that highlight the importance of these issues. Key confidentiality and consent provisions (some found in only one state) that are positive for adolescents included:

- A requirement of confidentiality for STD (five states) or family planning (six states), and other services for which minors may give consent (Kentucky, Washington).
- Specification that parental consent must not be required for services that minors may consent to under state law. (Washington)
- Inclusion of model language for informing beneficiaries about the availability of confidential services for minors. (Montana)
- A requirement to suppress listing of reproductive health and mental health or chemical dependency services on the explanation of medical benefits (EOMB) forms for all adult and minor beneficiaries. (Minnesota, Washington)

Monitoring and Reporting

Unless MCOs report data about the services adolescents receive, such as EPSDT screening, states are unable to monitor adequately the provision of services. However, few of the contracts actually required MCOs to report that EPSDT participation information that states are obligated to submit to the federal government. Key monitoring and reporting provisions (some found in only one state) that are positive for adolescents included:

- A requirement for MCOs to ensure that even greater than the federally required percentage of EPSDT eligibles receive at least one EPSDT screening during the year. (Maine).

- An obligation for MCOs to track comprehensive EPSDT screens by age. (Pennsylvania)
- Imposition of financial withholds for failure to provide and report EPSDT screens. (at least six states)
- A requirement for MCOs to report information regarding the care of pregnant women by age group, including 10-12, 13-14, 15-17, 18-19, and 20-24. (Hawaii)
- A requirement to report the prevalence of obesity among beneficiaries age 12 and older to further Healthy People 2000 goals. (Hawaii)

Medicaid Section 1115 Waivers -- Key Findings

In order to assess the implications for adolescents of the policies regarding Section 1115 Medicaid waivers that were implemented during the early 1990s, an in-depth review was completed of Medicaid Section 1115 managed care/expansion waivers for which approval had been granted to 16 states by HHS by July 1996. Waivers in five additional states that received approval after that date were given a more limited review. The review looked at a standardized set of issues for each waiver reviewed in-depth including eligibility, enrollment, scope of benefits, access to adolescent health care professionals, confidentiality, and monitoring and reporting. Common elements in many of these waivers included implementation of mandatory risk-based managed care and expansion of Medicaid to additional beneficiaries.

Eligibility

In using Section 1115 waivers to expand eligibility to the uninsured, states faced difficult trade-offs that were significant for adolescents. Due to the need to achieve budget neutrality (as required by federal policy), to the extent that a state chose to include a broader range of low-income adults, fewer adolescents might be covered to higher income levels. Most of the states did choose to expand eligibility but few targeted adolescents except to the extent that they were included within the general population with incomes under a certain level. TennCare extended eligibility to anyone in the state who is uninsured or uninsurable and not eligible for an employer or government health plan, regardless of family income, with an enrollment cap once a certain level of enrollment is reached. MinnesotaCare covered individuals with family incomes below 275 percent of the FPL. The DC waiver was targeted at children and youth under age 22 with chronic illness and disabilities.

Enrollment

Although several states used their waivers to lock-in enrollment in a managed care plan, only a very few provided a corresponding guarantee of eligibility (six months, for example). In this regard, enrollment procedures can be critical in assuring access for adolescents. Few states, however, even mentioned adolescents in the context of enrollment, much less emphasized adolescent-friendly enrollment processes. Among the rare exceptions, one state (Oklahoma) allowed adolescent members to select any qualified provider for family planning services and pregnant women (including

adolescents) to select their own maternity care provider, and another state (Delaware) allowed parents to choose a separate plan for a child or adolescent than for other family members.

Scope of Benefits

Most of the Section 1115 waivers maintained the traditional scope of Medicaid benefits for their populations of Medicaid beneficiaries who were eligible at the time the waiver was granted and some did so for their expansion populations. A notable exception was one state (Oregon) that received a waiver of the requirement to provide medically necessary treatment services (the “T”) under EPSDT for both traditional and expansion populations. Moreover, several of the waiver states offered a more limited benefit package for expansion populations, excluding some services of considerable importance to adolescents, such as EPSDT (Florida, and Hawaii for 19 and 20 year olds not in state custody, Tennessee for some EPSDT services, Vermont for adolescents over age 17), dental care (Florida, Massachusetts), and long term mental health care (Florida). Only a few states focused on EPSDT in their waivers, although some of the later approvals (Maryland, Oklahoma) were conditioned by HHS on their doing so and a few states did so from the outset (e.g., Delaware, Massachusetts).

Access to Adolescent Health Care Professionals

Key providers for some adolescents include safety net providers, school-based health clinics, and family planning clinics. Most of the Section 1115 waivers did not specifically require MCOs to contract with safety net providers, although a few encourage or “expect” them to do so and a very few did require such contracts. A few states discuss school-based health services in their waiver documents (Delaware, Massachusetts, Oklahoma). At least one of these states emphasized coordination and linkages between MCOs and school-based health clinics (Massachusetts). Although Section 1915(b) waivers cannot limit beneficiaries’ choice of family planning provider, Section 1115 waivers can, and some states chose to do so, while at least one (Oklahoma) explicitly allowed adolescents to select any family planning provider whether or not it is part of the health plan’s network.

Confidentiality

Little discussion of confidentiality was included in the waiver documents apart from references to Medicaid regulations and the State Medicaid Manual.¹³⁸ A few states included provisions to protect confidentiality such as omitting references to family planning services from notices sent to beneficiaries homes (Massachusetts, Vermont) and in some of its later approvals (Alabama, Delaware, Kentucky) required states to delineate how confidentiality for beneficiaries, particularly adolescents, will be maintained.

¹³⁸ 42 C.F.R. § 431.300 and State Medicaid Manual Part 11.

Monitoring and Reporting

The Section 1115 waivers generally envisioned both internal and external monitoring of the participating MCOs, but only one state (Massachusetts) included an advisory committee dedicated to adolescent health. Another state (Ohio) described a process for monitoring care for children and adolescents in foster care or protective placements. A few states listed some performance measures of particular importance to adolescents such as ESPDT and teen pregnancy rates (Delaware), smoking cessation and weight loss programs (Rhode Island), and at least one state listed numerous additional performance and improvement measures of importance for adolescents such as STD screening and treatment, mental health and chemical dependency services, among others (Vermont).

Taken together, the statutory and regulatory provisions regarding managed care and the provisions of Medicaid managed care contracts and Section 1115 Medicaid waivers provide a “mixed bag” for adolescents. Although there is no coherent pattern of provisions suggesting a comprehensive awareness or a targeted focus on adolescents, there are a variety of provisions that if implemented would benefit this age group. Moreover, if some of the provisions that appeared in only one state, or a small number of states, were extended more widely, they could improve adolescents’ access to appropriate and essential services.

VIII. WHAT HAVE WE LEARNED AND WHERE ARE WE HEADED?***20 Lessons Learned***

This project resulted in a diverse set of findings from analysis of a wide variety of data sources: health services research; federal and state laws, including statutes, regulations, agency policies, and court decisions; Medicaid managed care contracts and waiver documents; key informant interviews; meetings of experts; and a survey of adolescent health care professionals. Findings drawn from each of these sources showed remarkable consistency in their conclusions about the health and health care needs of adolescents and the roles of Medicaid, managed care, and health care reform in assuring adolescents' access to needed care. The study focused primarily on a particular time period: the 1990s. The information about that time period offers some insights or "lessons" that can be instructive now and in the future as advocates and policymakers consider and implement further changes in the health care arena, which may either improve or impede adolescents' access to comprehensive health care.

LESSON 1

Adolescents' health care needs are often linked to behavioral, environmental, and social etiologies. Any policy development or reform proposals affecting health care for adolescents should account for this in the service benefit package or this segment of the population will not adequately be served.

LESSON 2

To date, the standards of health care professionals with expertise in adolescent health have intermittently, but not consistently, been reflected in requirements and recommendations for screening and treatment services for the adolescent age group. Future requirements and recommendations would be more effective in ensuring that adolescents' needs are met if they incorporate these standards.

LESSON 3

Medicaid is a critically important element in access to care for poor and low-income adolescents: as of 2000, Medicaid provided coverage for one in five adolescents ages 15 through 20 in the United States. Future limitations on eligibility in the Medicaid program could have a significant adverse impact on adolescents.

LESSON 4

The EPSDT component of the Medicaid program is designed and targeted to meet the disparate health care needs of limited income youth and it should remain intact as a pivotal component of their health insurance coverage in the future.

LESSON 5

EPSDT has not yet been fully implemented for any age group, but implementation for adolescents, as evidenced by screening and participation rates, has lagged behind implementation for other age groups. Nevertheless, EPSDT continues to provide a strong framework for improving adolescents' access to essential health services and

implementation efforts should be strengthened in lieu of watering down or abandoning the program.

LESSON 6

Fiscal incentives have provided an impetus for states to establish more generous financial eligibility criteria for Medicaid, and to extend coverage to older adolescents in both Medicaid and SCHIP, enabling a larger proportion of adolescents to qualify for public health insurance. The success of future efforts to encourage health insurance coverage for adolescents may be enhanced by the inclusion of fiscal incentives.

LESSON 7

The enactment of SCHIP was followed by significant increases in health insurance enrollment for adolescents in Medicaid and SCHIP, particularly older adolescents in the 15 to 18 year old age group, suggesting that the availability of federal funds is one effective tool in overcoming the problem of uninsured adolescents. Reductions or withdrawal of such funds could have the opposite effect.

LESSON 8

Strategies for improving future enrollment of adolescents in public health insurance programs will be more likely to succeed if they include a broad range of elements to simplify the application process and facilitate enrollment. If targeted specifically to adolescents and implemented at health care sites they frequent, these procedures could be even more successful in facilitating coverage of the “eligible but not enrolled” segment of the adolescent population.

LESSON 9

In past decades, private employer-based health insurance has not broadened coverage for adolescents, and in recent years that coverage has declined significantly. Any future reform proposals focusing on private health insurance will need to account for how adolescents can be targeted, enrolled, and served.

LESSON 10

With the exception of SCHIP, few of the health care reform initiatives introduced or enacted in the past decade included specific provisions addressing the needs of adolescents, but many of them had or would have had major implications for adolescents and their health care access. In the future, health care reform measures should be carefully scrutinized for potentially adverse implications for adolescents and for opportunities to include elements that would be helpful to this age group.

LESSON 11

Few of the laws governing either commercial or Medicaid managed care contain provisions that are explicitly designed to be helpful to adolescents, but some do contain elements such as mandated benefits or free choice of family planning provider requirements that could help adolescents access needed services. These requirements should be maintained or expanded.

LESSON 12

Beneficiary protections included in the Balanced Budget Act of 1997 (BBA) responded to the experiences of Medicaid managed care in the 1980s and 1990s and should be maintained in the future. Many of the protections, while not adolescent-specific, could help this age group.

LESSON 13

Specific protections for adolescents, although rare in past managed care contracts, can enhance the likelihood that adolescents will receive the care they need and should be included in future contracts.

LESSON 14

Options for enrollment in a different health plan or to have a different primary care provider from other family members can be an essential element in ensuring that adolescents have access to providers with the interest, training, and experience in caring for them.

LESSON 15

Special protections, such as allowing multiple changes in health plan or provider, are needed to accommodate placement changes and other special characteristics of children or adolescents in state custody.

LESSON 16

A comprehensive scope of benefits is a critical foundation for assuring that adolescents receive the services they need in Medicaid managed care as well as other insurance programs.

LESSON 17

Requiring physicians with expertise in the care of adolescents, particularly those who are board-certified in adolescent medicine, to choose between joining a health plan's provider network as a primary care provider or a specialist does not allow them to offer the full range of comprehensive services to adolescents that they have been trained to provide. This requirement should be eliminated by health plans.

LESSON 18

In their Section 1115 Medicaid waivers, states were more concerned with major system reforms than with assuring services for low-income adolescents. Future waiver activities can address this deficiency.

LESSON 19

Some states have adopted in policy, or been the site of, particularly important innovations for improving health insurance coverage and service delivery to the adolescent population. These innovations should be more widely reported to encourage their adoption in other states.

LESSON 20

The 1990s witnessed numerous changes and innovations in law, policy, and practice that were beneficial for adolescents by expanding their eligibility for health insurance coverage, increasing their enrollment in public health insurance programs, including protections for them in managed care contracts and waivers, and improving delivery of services to them. These changes and innovations are dependent on both political will and expenditure of public funds and they are at risk in the current decade.

Recent and Current Experience

Experience in the current decade has provided important lessons as well. One recent lesson is that in the face of severe budget shortfalls, states look to the health care arena, particularly Medicaid but also SCHIP, to trim their budgets. Another recent lesson is that efforts to restructure Medicaid by limiting its entitlement features, which began more than a decade ago, are continuing today. These developments, among others, have placed at risk many of the gains that were made for adolescents during the 1990s.

Cuts in Medicaid and SCHIP

Beginning in 2001, the fiscal situation at both the federal and state level deteriorated dramatically. At the state level, many states responded to budget crises by making cuts in their Medicaid and SCHIP programs or planning to do so. Measures enacted by Congress to assist the states in dealing with their budget crises – such as a temporary increase in the federal matching rate for Medicaid and a one time reversal of the provision that unused SCHIP funds must revert to the federal Treasury – the first was not renewed, and the second was not repeated.

In Medicaid, by FY 2004, all 50 states and DC implemented cost containment measures.¹³⁹ These cuts have included limitations in eligibility, benefits, and provider reimbursement, as well as increases in cost sharing. A report looking specifically at the effect of Medicaid cuts on children in FY 2003 and 2004 found that states were more likely to lower or freeze pediatric provider payments or impose greater utilization controls than to reduce children's income or categorical eligibility,¹⁴⁰ although all of these strategies have potential to decrease adolescents' access to care.

A substantial number of states limited their SCHIP programs as well. A study that looked at policy changes in SCHIP programs in 2003 or early 2004 found that one half of states

¹³⁹ Vernon Smith et al., Health Management Associates, and Robin Rudowitz and Molly O'Malley, Kaiser Commission on Medicaid and the Uninsured, *The Continuing Medicaid Budget Challenge: State Medicaid Spending Growth and Cost Containment in Fiscal Years 2004 and 2005, Results from a 50-State Survey*, October 2004 (available from Kaiser Commission on Medicaid and the Uninsured, Washington, DC).

¹⁴⁰ Harriette B. Fox et al., *Children Not the Target of Major Medicaid Cuts But Still Affected by States' Fiscal Decisions*, June 2004 (available from Maternal & Child Health Policy Research Center, Washington, DC).

made policy changes and that 20 of these states instituted cost-cutting measures that included some limits on eligibility and enrollment and many increases in cost sharing.¹⁴¹ At least six states froze or capped enrollment in their SCHIP programs.¹⁴² Again, these changes have the potential to adversely affect adolescents.

A survey looking at eligibility, enrollment and renewal, and cost sharing policies in Medicaid and SCHIP in 2002 and early 2003 found a slowing and even a reversal of prior trends to expand eligibility and simplify enrollment.¹⁴³ A similar study of the subsequent period, from April 2003 through July 2004, found that while eligibility levels were relatively stable, the reintroduction of procedural barriers to coverage intensified.¹⁴⁴ Because a significant number of adolescents are eligible but not enrolled in Medicaid and SCHIP, these procedural barriers are problematic for them.

A report in late 2003 found that states had adopted policies that were cutting about 1.2 to 1.6 million people off Medicaid, SCHIP or similar state-funded health insurance programs, of whom almost half were children and adolescents.¹⁴⁵

Although state budgets recovered somewhat in 2004, states are projecting approximately \$40 billion in budget gaps for FY 2005.¹⁴⁶ All 50 states have already planned to implement cost containment measures in Medicaid in FY 2005,¹⁴⁷ and cost containment

¹⁴¹ Harriette B. Fox and Stephanie J. Limb, SCHIP Programs More Likely to Increase Children's Cost Sharing Than to Reduce Their Eligibility or Benefits to Control Costs, April 2004 (available from Maternal & Child Health Policy Research Center, Washington, DC).

¹⁴² Donna Cohen Ross and Laura Cox, Out in the Cold: Enrollment Freezes in Six States' State Children's Health Insurance Programs Withhold Coverage from Eligible Children, Dec. 10, 2003 (available from Kaiser Commission on Medicaid and the Uninsured).

¹⁴³ Donna Cohen Ross and Laura Cox, Center on Budget and Policy Priorities, Preserving Recent Progress on Health Coverage for Children and Families: New Tensions Emerge, July 2003 (available from Kaiser Commission on Medicaid and the Uninsured, Washington, DC).

¹⁴⁴ Donna Cohen Ross and Laura Cox, Center on Budget and Policy Priorities, Beneath the Surface: Barriers Threaten to Slow Progress an Expanding Health Coverage of Children and Families, October 2004 (available from Kaiser Commission on Medicaid and the Uninsured, Washington, DC)

¹⁴⁵ Leighton Ku and S. Nimalendran, Center on Budget and Policy Priorities, Losing Out: States Are Cutting 1.2 to 1.6 Million Low-Income People from Medicaid, SCHIP and Other State Health Insurance Programs, Dec. 22, 2003

¹⁴⁶ Nicholas Johnson and Bob Zahradnik, Center on Budget and Policy Priorities, State Budget Deficits Projected for Fiscal Year 2005 (Feb. 6, 2004); Donald Boyd and Victoria Wachino, Is the State Fiscal Crisis Over? A 2004 State Budget Update (January 2004) (available from Kaiser Commission on Medicaid and the Uninsured, Washington, DC).

¹⁴⁷ Vernon Smith et al., Health Management Associates, and Robin Rudowitz and Molly O'Malley, Kaiser Commission on Medicaid and the Uninsured, The Continuing Medicaid

efforts in SCHIP seem likely also, although the program is much smaller than Medicaid so the total savings to be gained from it are at a lesser scale.

Restructuring of Medicaid and SCHIP

For FY 2004, both the Administration and the state governors put forward proposals to modify Medicaid and SCHIP in light of the current economic situation. While not enacted during 2003, they are likely to resurface in future years. Like the Medicaid restructuring proposals that were not enacted in the mid-1990s, these proposals could have significant adverse effects for adolescents.

In 2003, several governors told the Administration that it is “time to review and fundamentally rewrite the nation’s Medicaid law;” increased flexibility for states and moving “away from entitlement without responsibility” have been key features for a long time of what some governors are calling for.¹⁴⁸ Official policy of the National Governors Association states that “it is time to reform Medicaid,” and calls for greater flexibility for the states,¹⁴⁹ although the governors have also urged Congressional leadership to “oppose any provision that is intended to restrain or curb the growth of the Medicaid program.”¹⁵⁰

In 2003, the Administration released the outlines of its own proposal for restructuring Medicaid. The proposal would have given states a choice: remain with the Medicaid program as it is currently structured with no new federal funds; or receive additional federal funding for seven of the next ten years, but accept a “capped” annual federal allotment, in effect a block grant.¹⁵¹ While this proposal was not enacted in 2003, in part because the governors ultimately rejected it,¹⁵² it is clear that there will be continuing efforts to restructure Medicaid in ways that would eliminate the entitlement feature of the

Budget Challenge: State Medicaid Spending Growth and Cost Containment in Fiscal Years 2004 and 2005, Results from a 50-State Survey, October 2004 (available from Kaiser Commission on Medicaid and the Uninsured, Washington, DC).

¹⁴⁸ Gov. Jeb Bush, Gov. John G. Rowland, and Gov. Bill Owens, Letter to President Bush and Secretary Thompson, Jan. 16, 2003.

¹⁴⁹ National Governors Association, HHS-27: Medicaid Reform Principles Policy (effective Winter Meeting 2003 – Winter Meeting 2005).

¹⁵⁰ Gov. Paul E. Patton and Gov. Dirk Kempthorne, Letter to Hon. Bill Frist, Hon. Thomas A. Daschle, Hon. J. Dennis Hastert, and Hon. Nancy Pelosi, Mar. 20, 2003.

¹⁵¹ National Health Law Program, The Administration’s Proposal for Medicaid: Block Grants Revisited, n.d., (available at <http://www.healthlaw.org/pubs/200302.blockgrants.html>); Melanie Nathanson and Iris J. Lav, The Bush Administration’s Medicaid Proposal Would Shift Risks and Costs to States, Feb. 12, 2003 (available from Center on Budget and Policy Priorities, Washington, DC); Families USA, Preliminary Analysis of New Bush Proposal to Block-Grant Medicaid, Feb. 12, 2003 (available from Families USA, Washington, DC).

¹⁵² Robert Pear, Governors Seek Aid From Congress and Decline to Back Medicaid Plan, New York Times, Feb. 26, 2003.

program or modify it substantially to allow states to cut back even further on eligibility and benefits.

After Congress failed to enact a major restructuring of Medicaid as proposed in the President's FY 2004 budget, the FY 2005 budget did not include a specific legislative proposal. However, the budget did contain statements suggesting that the Administration continued to be interested in enacting some form of a Medicaid block grant.¹⁵³ It seems, however, that the Administration may be seeking to achieve its goal of turning Medicaid into a block grant indirectly, such as by approving state waiver requests to create a state-specific global cap on Medicaid funding¹⁵⁴ and other uses of its waiver authority¹⁵⁵

Implications for Adolescents

For advocates and policy makers alike who are concerned about health care access for adolescents, major challenges are represented by the current general economic and political situation as well as by specific recent policy developments:

- First, the gains in public health insurance eligibility, particularly for older adolescents, that have been made over the past several years could be lost, directly by explicit eligibility limits or indirectly by other measures that would discourage enrollment.
- Second, as Medicaid and SCHIP benefits are restricted, some cuts could fall disproportionately on benefits of particular importance to adolescents, such as mental health or substance abuse treatment.

¹⁵³ National Health Law Program, Capital Communique, Feb. 24, 2004; Families USA, The Bush Administration's Fiscal Year 2005 Budget: Analysis of Key Health Care Provisions, Feb. 11, 2004.

¹⁵⁴ Families USA, Disturbing Medicaid Development in New Hampshire, Feb. 20, 2004; Kaiser Commission on Medicaid and the Uninsured, Section 1115 Waivers at a Glance: Summary of Recent Medicaid and SCHIP Waiver Activity. See also, Cindy Mann, Health Policy Institute, Samantha Gill and Jocelyn Guyer, Kaiser Commission on Medicaid and the Uninsured, Section 1115 Medicaid and SCHIP Waivers: Policy Implications of Recent Activity, June 2003 (available from Kaiser Commission on Medicaid and the Uninsured, Washington, DC); Cindy Mann, Georgetown University Institute for Health Care Research and Policy, The New Era of Medicaid Waivers, available at www.kaisernetwork.org/health_cast/uploaded_files/Cindy_Mann_Council_Presentation.pdf.

¹⁵⁵ Cindy Mann, Health Policy Institute, Samantha Gill and Jocelyn Guyer, Kaiser Commission on Medicaid and the Uninsured, Section 1115 Medicaid and SCHIP Waivers: Policy Implications of Recent Activity, June 2003 (available from Kaiser Commission on Medicaid and the Uninsured, Washington, DC); Cindy Mann, Georgetown University Institute for Health Care Research and Policy, The New Era of Medicaid Waivers, available at www.kaisernetwork.org/health_cast/uploaded_files/Cindy_Mann_Council_Presentation.pdf.

- Third, reimbursement rates and other essential elements in the ability of the programs to provide adolescents with access to providers who are capable of meeting their particular needs could be further reduced below levels that are already often inadequate.
- Finally the overall integrity of the programs – represented, for example, by the entitlement aspect of the Medicaid program – is threatened. It is this entitlement feature of Medicaid that enables adolescents who are eligible a right to expect that they can receive a broad range of screening, diagnostic, and treatment services (represented by EPSDT) that go far toward adding up to comprehensive care.

As measures for addressing the current challenges are considered, the needs of specific groups of adolescents may be at particular risk. For example, groups of adolescents whose health care access is already compromised include, among others, adolescents in state custody, those leaving the foster care and juvenile justice systems, homeless and unaccompanied youth, immigrants, and older adolescents. Their needs should not be forgotten.

Ultimately, the fate of public health insurance for adolescents will be determined as part of a larger picture: the restructuring of Medicaid, Medicare, private insurance, and the overall system of health care financing. As these developments move forward, careful analysis of their implications for adolescents and advocacy to protect adolescents' needs will be required. Lessons from the 1990s document ways in which past policies have helped this age group and thereby point to the risks of failing to build on these policies or abandoning them altogether. In doing so, these lesson can help to inform the analysis of the implications for adolescents of current and new policy proposals.

APPENDIX A: VOICES OF THE HEALTH CARE PROFESSIONALS

Responses to a survey of the membership of a multi-disciplinary society of professionals who care for adolescents and the discussions in two invitational meetings of adolescent health experts revealed similar concerns among the survey respondents and meeting participants. They also reflected many of the issues that emerged from analysis of laws and of Medicaid managed care contracts and waivers. The findings are also consistent with findings from subsequent studies.¹⁵⁶

Survey of Adolescent Health Care Professionals

In 1995, the National Center for Youth Law and the National Health Law Program conducted a survey of the membership of the Society for Adolescent Medicine.¹⁵⁷ The survey was designed to elicit information about the perceived effects of managed care on the delivery of those services. The survey respondents were diverse in terms of professional training, services provided, health care site, adolescent population served, and level of knowledge and experience with respect to managed care. Of those providing direct services, most had experience with managed care and reported that their practices had been affected by prior authorization, capitated/prepaid managed care, and/or other utilization control practices.

At the time of the survey, respondents were four times as likely to say that, in their experience, managed care was an impediment to the delivery of services to adolescents as they were to say that it had improved the delivery of services to this group. Nevertheless, benefits as well as impediments were identified.

Benefits of Managed Care

Some of the perceived benefits of managed care identified in the survey, each by a small minority of respondents, were:

¹⁵⁶ E.g., Margaret A. McManus et al., *Is the Health Care System Working for Adolescents? Perspectives from Providers in Boston, Denver, Houston, and San Francisco*. Washington, DC: Maternal and Child Health Policy Research Center (2003); Harriette B. Fox, et al., *Private Health Insurance for Adolescents: Is it Adequate?* 32S J. Adolescent Health 12 (2003); Harriette B. Fox et al., *Early Assessments of SCHIP's Effect on Access to Care for Adolescents*, 32S J. Adolescent Health 40 (2003); Brindis et al., *supra* note 79.

¹⁵⁷ The Society for Adolescent Medicine (SAM), established in 1968, is a multi-disciplinary organization of health care professionals dedicated to furthering the health of all adolescents. A majority of SAM members provide health care services to adolescents. In June 1995, we mailed a four-page survey to all members of the Society for Adolescent Medicine (SAM) living in the United States. In September 1995, we sent a second mailing of the survey to all original recipients who had not yet responded. Of the 1147 individuals to whom we mailed the survey, 432 responded, for a response rate of 37.6 percent.

- Increases in access to preventive care.
- Improved coordination of services.
- Enabling adolescents to choose their primary care provider.
- Greater protection of confidentiality (in staff model HMOs).
- Benefit packages more appropriately tailored to adolescents.

Problems with Managed Care

Although a wide range of perceived problems with managed care for adolescents were cited by survey respondents, some common themes drew the greatest attention, with half or close to half of the respondents citing:

- Obstacles in assuring access to mental health services.
- Obstacles in assuring access to other services related to eating disorders, sexual and reproductive health, and services for chronic illness or disability.
- Exclusion of providers who served adolescents from managed care networks.
- Inappropriate denials of care through the prior authorization process.
- Financial incentives that discourage referrals for necessary care.
- Inappropriately low capitation rates and risk adjustment.

Two Meetings of Adolescent Health Experts

In 1996, the National Center for Youth Law and the National Health Law Program convened two invitational meetings to identify problems affecting the financing and delivery of health care to adolescents, and to discuss innovations to address those problems.¹⁵⁸ Although the experts identified a broad range of both obstacles and potential solutions, in the discussions at these two meetings the problems were more salient. Issues discussed included health insurance coverage, scope of benefits, managed care systems and procedures, monitoring service delivery and assuring quality, provider networks, and financing.

Health Insurance Coverage

Meeting participants identified a range of problems related to insurance coverage for adolescents. With respect to Medicaid, many of the comments focused on barriers that prevented adolescents from enrolling in the first place (lack of information about options, burdensome application procedures), led to their becoming ineligible after a short period of eligibility (due to fluctuations in family income), or limited their access to adolescent-appropriate care when they were enrolled (by not allowing them to select their own managed care plan or primary care provider). Adolescents in foster care were identified

¹⁵⁸ The first meeting was held in San Francisco, California on May 13-14, 1996, and the second in Washington, D.C. on May 29-30, 1996. Participants included adolescent health care providers, clinic administrators, consumer advocates, government agency administrators, health plan personnel, health services researchers, and policy experts.

as at particular risk for not being enrolled in Medicaid or, if enrolled, not being adequately monitored and served. More generally, participants noted that college age adolescents often fall between “the cracks” – no longer eligible for public insurance but not yet covered under an employer-based or other plan.

Scope of Benefits

Meeting participants noted, with respect to Medicaid, a number of ways in which adolescents’ needs are not well served, such as inadequate implementation of the EPSDT benefit, inadequate availability of behavioral health services, and particular limitations on EPSDT treatment services for youth with special health care needs. Participants also noted numerous benefit-related limitations in commercial managed care plans and commercial insurance, such as limited coverage of preventive services and behavioral health services, and burdensome scrutiny of certain claims, especially those for behavioral health services and substance abuse treatment. Participants also expressed concern about limitations in coverage of benefits important to adolescents resulting from insurers’ reliance on a purely “medical” model, as well as a failure by insurers to use adolescent-specific medical standards and practice guidelines in defining the benefit package or deciding whether services are covered within the package.

Managed Care Systems and Procedures

Meeting participants identified a variety of ways in which managed care systems are not designed and operated to be adolescent-friendly. For example, most health plans do not target education and outreach efforts to adolescents and their use of utilization reviewers without expertise in adolescent health issues affects the appropriateness of approvals and denials. Noting a problem not limited to managed care, participants emphasized that some providers are unwilling to record sensitive information in charts because of confidentiality concerns and some adolescents avoid managed care providers fearing that they will reveal sensitive information to parents.

Monitoring Service Delivery and Assuring Quality

Participants were largely in agreement that both for Medicaid and in managed care plans data are lacking in at least two different important respects. First, the absence of adolescent-specific outcome data impedes the determination of priorities for reporting and monitoring; and second, data are lacking on services actually delivered by Medicaid providers and managed care plans to adolescents, which also makes monitoring difficult. Moreover, inaccurate reporting by health plans occurs in part because of inconsistencies in tracking data across different care sites. Ultimately, the appropriate care of adolescents is hampered by these deficiencies.

Provider Networks

A major area of concern for meeting participants, many of whom were adolescent health care providers themselves, was the way in which provider networks in managed care

arrangements failed to address appropriately the needs of adolescents. Meeting participants identified several categories of health care providers and sites that have encountered barriers to their inclusion in managed care provider networks, ranging from teaching hospitals, health departments, community youth clinics, school-based health centers, and other safety net providers. In addition, adolescent medicine specialists, including those who are board-certified in adolescent medicine, often are compelled to choose between participating in a managed care plan as a primary care provider or as a specialist, which does not allow them to offer the full range of comprehensive services to adolescents that they have been trained to provide. For these and other reasons, adolescent-focused providers are in short supply in many Medicaid systems and, although Medicaid managed care has improved access in some states but in others it has only capitated the existing, inadequate panel of providers. Of particular concern for meeting participants were the adolescents who need access to a multi-disciplinary treatment team, as many of the professionals who would be appropriate members of such a team are often left out of provider networks.

Financing

Echoing information that has been highlighted in other studies regarding Medicaid for younger children and adults, and in lawsuits around the country, meeting participants emphasized that capitation rates for adolescent services are inadequate, and rate setting methodologies are not yet adequate to adjust for the increased care required by adolescents with special health care needs. In addition, they noted that adolescents face personal financial and access barriers as health plans increasingly require co-payments.

APPENDIX B: VIEWS FROM THE STATES

Several states were the subject of intensive case studies. These case studies included detailed analysis of each state's laws and key informant interviews with between 10 and 20 individuals in each state, including health care providers, policy makers, and health plan administrators. The focus was on identifying innovative policies and practices that benefited adolescents. The most salient from the five study states – California, Massachusetts, Missouri, North Carolina, and Oregon – are highlighted here.

California

California was home to a broad range of laws, policies, and practices that either directly or indirectly facilitated access to essential health care for adolescents.

- Beginning in 1988, California covered “medically necessary pregnancy-related services” for all California residents, including adolescents, regardless of immigration status.¹⁵⁹
- In 1997, California's Child Health and Disability Prevention (CHDP) program (which operates the screening component of EPSDT in California) issued new health assessment standards, which emphasized adolescent health issues for the first time.¹⁶⁰
- In response to several lawsuits, California issued regulations explicitly mandating coverage of all services required under EPSDT, whether or not they are otherwise covered under the Medi-Cal program in California.¹⁶¹
- Following strong criticism from HHS about the inadequate delivery of EPSDT services in California's Medicaid managed care programs, the state's Department of Health Services took steps to educate Medi-Cal managed care plans about timing and periodicity of health assessments and provision of medically necessary diagnosis and treatment services,¹⁶² and to include well-child visits in the 12-21 age group in its external quality review report.¹⁶³

¹⁵⁹ 1988 Cal. Stat. 1441 (amending Cal. Welf. & Inst. Code § 14007.5 (West Supp. 1998)).

¹⁶⁰ Children's Medical Services, Child Health and Disability Prevention (CHDP) Program Health Assessment Guidelines (1997) (available from California Dep't of Health Services, Sacramento, CA) (hereinafter CHDP Guidelines).

¹⁶¹ Cal. Code Regs. tit. 22, § 51340(e) (West 1998).

¹⁶² MMCD Letter No. 96-07 from Joseph A. Kelly, Chief, Medi-Cal Managed Care Division, to Health Plans, PCCM Plans, and COHSs (July 5, 1996); MMCD Letter No. 96-12 from Joseph A. Kelly, Chief, Medi-Cal Managed Care Division, to Prepaid Health Plans, PCCM Plans, COHSs, & Geographic Managed Care (Dec. 3, 1996) (available from the California Dep't of Health Services, Sacramento, CA).

¹⁶³ Health Services Advisory Group, External Quality Review Organization: Summary Reports (June 11, 1998) (available from the California Dep't of Health Services, Sacramento, CA).

- California created a new Family PACT (Planning, Access, Care, and Treatment) program that offers comprehensive confidential family planning services to individuals with family incomes at or below 200% FPL.¹⁶⁴
- Kaiser Permanente, a group/staff model HMO, operates teen clinics in California that are widely viewed as models for the delivery of adolescent health services under managed care. Although there are few of these teen clinics, they have been pioneers in adolescent health assessment and health education, efforts to minimize the cost to families for treatment of eating disorders, and minimizing the barriers associated with prior authorization through regional call centers that use protocols development by adolescent medicine staff.
- For many years, California has operated a Medi-Cal minor consent program that allows youth up to age 21 to qualify for those health services for which they can consent independently,¹⁶⁵ including pregnancy-related care, diagnosis and treatment, STDs, HIV testing, drug and alcohol counseling, sexual assault care, and outpatient mental health services. Minors can apply for these services without parent or guardian consent, by completing a brief enrollment application, available in English and Spanish.¹⁶⁶ Although these provisions are clear in state regulations, implementation has sometimes been limited, particularly with respect to specific services, such as mental health services.
- Kaiser Permanente has improved confidentiality of care for adolescents in California through strict confidentiality requirements first developed in its teen clinics, distribution of information about minor consent laws, and training of providers.

Massachusetts

Massachusetts provided leadership at the state level to improve delivery of health care to adolescents, including some targeted efforts in collaboration with medical providers and others with respect to managed care and school-based health centers.

- Massachusetts created a *Teen Choices* brochure specifically designed to educate adolescents about issues related to enrollment in Medicaid managed care and choice of a primary care provider.
- Massachusetts issued detailed regulations on preventive services in Medicaid that included several provisions of particular importance to adolescents, including annual exams, adolescent-specific anticipatory guidance, annual pelvic exams and pap smears for sexually active adolescents, STD testing, and Hepatitis B immunizations.¹⁶⁷ Massachusetts publicized these requirements through collaboration with the American Academy of Pediatrics and training of managed care providers.

¹⁶⁴ Cal. Welf. & Inst. Code §§ 24000-24027 (1998).

¹⁶⁵ Cal. Code Regs. tit. 22, § 50063.5 (West 1998).

¹⁶⁶ Form MC 4026, “Request for Eligibility Limited Services” (Mar. 1996) (available from the California Dep’t of Health Services, Sacramento, CA).

¹⁶⁷ 130 C.M.R. §§ 450.140-450.149.

- Some HMOs in Massachusetts worked to improve sexual and reproductive health services for teens, by for example, asking them to fill out a reproductive health questionnaire at each visit, or providing special support for teens who choose to use birth control.
- Massachusetts enacted legislation to provide funding for school-based health centers and adopted a range of policies to facilitate use of SBHCs as satellites of primary care providers for Medicaid billing purposes. However, the need for a prior referral from the primary care provider on a per-service basis impeded delivery of Medicaid managed care through SBHCs.

Missouri

Missouri adopted several policy level initiatives that could benefit adolescents directly by expanding their access to health insurance, school-based services, and community providers, and by requiring managed care plans to implement confidentiality protections.

- Missouri adopted one of the broadest eligibility expansions in its Section 1115 waiver, providing coverage for children and adolescents with family incomes at or below 300% FPL (using an income disregard). Ultimately, Missouri coordinated its 1115 waiver and SCHIP plan.
- Missouri pioneered the use of EPSDT and administrative case management to focus on enrollment, preventive and screening services, and health education through the schools. A School Health Initiative,¹⁶⁸ enacted in 1993, encouraged schools and school districts to provide EPSDT services directly, and to refer children and adolescents to community providers for preventive and primary care. However, school personnel were prohibited from referring students for contraceptive services without affirmative parental approval.¹⁶⁹
- In Missouri, the Medicaid managed care contract required plans to have written confidentiality policies and procedures, including for some adolescent services, such as STD appointments.

North Carolina

North Carolina adopted policies to increase and improve health assessments of adolescents in Medicaid and to facilitate adolescents' use of providers, including SBHCs, with training and experience in care for this age group.

- North Carolina made focused efforts to improve its Health Check (the screening component of EPSDT) program by recruiting more providers, increasing fees, streamlining billing, and improving notification of beneficiaries and their families. North Carolina did improve its screening levels for adolescents.

¹⁶⁸ Mo. Rev. Stat. § 167.600 (1997).

¹⁶⁹ Mo. Rev. Stat. § 167.612 (1997).

- North Carolina worked to bring its standards for health assessments in line with the AMA Guidelines for Adolescent Preventive Services (GAPS).
- North Carolina allows family members including adolescents, to select their own provider within a plan.
- North Carolina adopted several key initiatives to expand state support for school-based health centers, comprehensive adolescent health centers, and adolescent pregnancy prevention. Several school-based and school-linked health centers in North Carolina have been models for the rest of the state and even for other states. North Carolina adopted a policy allowing SBHCs that meet certain criteria to bill Medicaid directly as long as they report services provided to a student's primary care provider.

Oregon

Although Oregon attracted significant attention for some of its efforts to extend Medicaid coverage to the entire population of poor individuals and families, it did not include measures that were of particular benefit to adolescents. However, Oregon did provide some leadership in the school-based health clinics arena.

- As early as 1985, Oregon included a line item in the state budget for a School-Based Health Center Program and funding for the program continued to increase through the mid-1990s.
- Oregon SBHCs were among the first to develop a protocol for billing Medicaid for the services they provide to Medicaid eligible youth.