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Medicaid, Managed Care, and Health Care Reform: Protecting the Interests of Adolescents in Climate of Cut-backs

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The 1990s witnessed extraordinary changes in the laws and policies that influence the delivery of health care to adolescents. Most developments were beneficial, offering opportunities to expand eligibility for health insurance and to provide more comprehensive services to meet adolescents' specific needs. Health insurance coverage was expanded and the delivery of services was improved. A few developments limited adolescents' access to care or laid the groundwork for later policy changes that could restrict access.

To examine the significance of Medicaid, managed care, and health care reform for adolescents, the National Center for Youth Law (NCYL) and the National Health Law Program initiated a study that was conducted from 1995 through mid-1999 with the support of the Carnegie Corporation of New York. It included a review of the literature on the health status and health care needs of adolescents; legal research and analysis of the laws pertaining to health care; examination of Medicaid managed care contracts and requests for proposals; analysis of Medicaid Section 1115 demonstration

waivers; a survey of adolescent health care professionals; meetings of adolescent health experts; and case studies of several states.

The findings from that study were documented in a detailed report in November 2004 issued by NCYL and the National Health Law Program in collaboration with the Center for Adolescent Health & the Law.¹

Those findings, which inform this article, are newly relevant a decade after the study began because much of the progress seen during the 1990s is currently at risk. At the end of the decade 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. At the same time, there is ongoing concern about the high percentage of the U.S. population, including adolescents, that is uninsured or underinsured, with little consensus on how to address the problem.

In light of both the shift in the policy environment and ongoing concern about the uninsured, it is important to review earlier policy developments

in adolescent health care with respect to Medicaid, managed care, and health care reform. With pressure to constrict access, policymakers and advocates can build on lessons learned from developments in the 1990s as well as from innovations that states created to help other disadvantaged youth thrive.

Following is a brief review of important events before, during, and after the 1990s.²

Before 1990

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

- Enactment of Medicaid in 1965.
- Creation of the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program in 1967.
- 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).
- Revision of EPSDT in 1989 to cover children and adolescents for all medically necessary Medicaid services to diagnose or treat their health problems.

¹ Abigail English, Jane Perkins, and Catherine Teare, *Adolescent Health Care: Medicaid, Managed Care, and Health Care Reform—Lessons from the 1990s* (2004) [hereinafter *Lessons Learned*]. The report is available on the websites of the National Center for Youth Law, www.youthlaw.org; the National Health Law Program, www.healthlaw.org; and the Center for Adolescent Health & the Law, www.cahl.org.

² Each of these developments is discussed in detail in *Lessons Learned*, *supra* n.1.

The 1990s

The expansive trend continued during the 1990s with additional key developments:

- Enactment by Congress in 1990 of a requirement 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.
- Adoption of 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. (See sidebar, “States Innovate to Improve Access and Care for 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. (Continued on page 4)

States Innovate to Improve Access And Care for Adolescents

From 1995 through 1999, five states—California, Massachusetts, Missouri, North Carolina, and Oregon—were studied in depth to identify innovations that benefit adolescents. Research included detailed analysis of each state’s laws, and interviews with 10 to 20 individuals in each state. Interviewees included health care providers, policymakers, and health plan administrators. The five states’ most salient innovations are highlighted here.

Notably, even in these states, significant changes and even retrenchment are underway in the current decade. The innovations identified in each of these states—and others like them elsewhere—can be useful and instructive even in a different climate, but must be understood in the new context. Although budgetary issues are dominant almost everywhere, there are ongoing concerns about health insurance coverage and about efficiency and quality in health care services delivery. Many of the innovations identified here are consistent with extending health insurance coverage to uninsured adolescents and improving the efficiency and quality of health services for this age group. It is in that light that they retain their relevance in the current climate.

California

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

- Beginning in 1988, the state covered “medically necessary pregnancy-related services” for all California residents, including adolescents, regardless of immigration status.¹
- In 1997, California’s Child Health and Disability Prevention (CHDP) program (which operates the screening component of EPSDT in the state) issued new health assessment standards, which emphasized adolescent health issues for the first time.²
- 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 Medi-Cal.³
- 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. Issues included timing and periodicity

¹ 1988 Cal. Stat. 1441 (amending Cal. Welf. & Inst. Code § 14007.5 (West Supp. 1998)).

² Children’s Medical Services, Child Health and Disability Prevention (CHDP) Program Health Assessment Guidelines (1997) (available from California Dep’t of Health Services, Sacramento) (hereinafter *CHDP Guidelines*).

³ Cal. Code Regs. tit. 22, § 51340(e) (West 1998).

⁴ *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).

of health assessments, provision of medically necessary diagnosis and treatment services,⁴ and the inclusion of well-child visits for the 12-21 age group in external quality review reports.⁵

- A Family PACT (Planning, Access, Care, and Treatment) program was created to offer comprehensive confidential family planning services to individuals with family incomes at or below 200 percent of FPL.⁶
- 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. These clinics have been pioneers in adolescent health assessment and health education, efforts to minimize the cost to families for treatment of eating disorders, and minimizing barriers associated with prior authorization (through regional call centers that use protocols developed by adolescent medicine staff).
- Kaiser Permanente has improved confidentiality for California adolescents through strict confidentiality requirements first developed in its teen clinics, distribution of information about minor consent laws, and training of providers.
- California operates a Medi-Cal minor consent program that allows youth up to age 21 to qualify for services for which they can consent independently,⁷ including pregnancy-related care, diagnosis and treatment of 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.⁸ Although these provisions are clear in state regulations, implementation has sometimes been limited, particularly with respect to certain services such as mental health care.

Massachusetts

Massachusetts provided leadership in improving delivery of health care to adolescents through targeted efforts in collaboration with medical providers and others.

- A *Teen Choices* brochure was created to educate adolescents about enrollment in Medicaid managed care and choice of a primary care provider.
- The state issued detailed regulations on preventive services in Medicaid that included provisions of particular importance to adolescents, such as annual exams, adolescent-specific anticipatory guidance, annual pelvic exams and pap smears for sexually active adolescents, STD testing, and Hepatitis B immunizations.⁹ The state publicized these requirements through collaboration with the American Academy of Pediatrics and training of managed care providers.
- 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 use birth control.

- Massachusetts enacted legislation to provide funding for school-based health centers and adopted policies to facilitate use of school-based health centers (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.

- The state 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 percent of FPL (using an income disregard). Ultimately, it 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,¹⁰ 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.¹¹

⁵ Health Services Advisory Group, External Quality Review Organization: *Summary Reports* (June 11, 1998) (available from the California Dep't of Health Services, Sacramento).

⁶ Cal. Welf. & Inst. Code §§ 24000-24027

(1998).

⁷ Cal. Code Regs. tit. 22, § 50063.5 (West 1998).

⁸ Form MC 4026, "Request for Eligibility Limited Services" (Mar. 1996) (available from the California Dep't of Health Services, Sacramento).

⁹ 130 C.M.R. §§ 450.140-450.149.

¹⁰ Mo. Rev. Stat. § 167.600 (1997).

¹¹ Mo. Rev. Stat. § 167.612 (1997).

- The Medicaid managed care contract in the state 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 their 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. Screening levels for adolescents in the state improved.
- The state 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.
- Several initiatives were adopted 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 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; 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 services provided to Medicaid-eligible youth.

(Continued from page 2)

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 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.

The Current Decade

After the economic boom of the 1990s, states began to experience serious financial crises that put intense pressure on their health care budgets. 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 less inclined than in the past to expand or maintain existing health entitlement programs for low-income and vulnerable populations. There have been a few efforts toward reform and expansion at both the federal and state levels, but more common have been modest steps to maintain the status quo, or even move toward significant retrenchment.

In the face of severe budget shortfalls, states are looking to the health care arena—particularly Medicaid but also SCHIP—to trim their budgets. We are also seeing continuing attempts to restructure Medicaid by limiting its entitlement features, efforts that began more than a decade ago. Following are details of these developments.

Cuts in Medicaid and SCHIP

Beginning in 2001, the fiscal situation at both the state and federal levels deteriorated dramatically. Many states responded to budget crises by making cuts in their Medicaid and SCHIP programs or planning to do so. Although Congress assisted the states—through 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—they did not renew the first measure and did not repeat the second.

In Medicaid, by FY 2004, all 50 states and DC implemented cost-containment measures.³ These cuts have included limitations in eligibility, benefits, and provider reimbursement, as well as increases in cost-sharing. A report on 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 eligibility⁴; however, all of these strategies have potential to decrease adolescents' access to care.

Many states limited their SCHIP programs as well. A study of policy changes in SCHIP programs in 2003 or

early 2004 found that half of the states 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.⁵ At least six states froze or capped enrollment in their SCHIP programs.⁶ Again, these changes have the potential to adversely affect adolescents.

A survey of 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.⁷ 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.⁸ Because a significant number of adolescents are eligible for 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 risked cutting about 1.2 million to 1.6 million people from Medicaid, SCHIP, or similar state-funded health insurance programs. Almost half of these were children and adolescents.⁹

Although state budgets recovered somewhat in 2004, states were projecting approximately \$40 billion in budget gaps for FY 2005.¹⁰ All 50 states planned to implement cost-containment measures in Medicaid in FY 2005.¹¹ Similar efforts in SCHIP seem likely also, although the program is much smaller than Medicaid so the total savings would be less.

Restructuring of Medicaid and SCHIP

For FY 2004, both the Administration and state governors put forward proposals to modify Medicaid and SCHIP. Although not enacted during 2003, the proposals are likely to resurface. Like the Medicaid restructuring attempts 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 was "time to review and fundamentally rewrite the nation's Medicaid law." For a long time, some governors have been calling for increased flexibility for states and moving "away from entitlement without responsibility."¹² Official policy of the National Governors Association has stated that "it is time to reform Medicaid," and called for greater flexibility for the states,¹³ 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."¹⁴

In 2003, the Administration released the outlines of a proposal of its own 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.¹⁵ While this proposal was not enacted in 2003, in part because the governors ultimately rejected it,¹⁶ it is clear that there will be continuing efforts to restructure Medicaid in ways

³ 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).

⁴ 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).

⁵ 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).

⁶ 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, Washington, DC).

⁷ 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).

⁸ Donna Cohen Ross and Laura Cox, Center on Budget and Policy Priorities, *Beneath the Surface: Barriers Threaten to Slow Progress on Expanding Health Coverage of Children and Families*, October 2004 (available from Kaiser Commission on Medicaid and the Uninsured, Washington, DC).

⁹ 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.

¹⁰ 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).

¹¹ *Supra* n. 3.

¹² Gov. Jeb Bush, Gov. John G. Rowland, and Gov. Bill Owens, *Letter to President Bush and Secretary Thompson*, Jan. 16, 2003.

¹³ National Governors Association, HHS-27: *Medicaid Reform Principles Policy* (effective Winter Meeting 2003-Winter Meeting 2005).

¹⁴ 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.

¹⁵ 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).

¹⁶ Robert Pear, *Governors Seek Aid From Congress and Decline to Back Medicaid Plan*, New York Times, Feb. 26, 2003.

that would eliminate the entitlement feature of the program or modify it substantially to allow states to cut back even further on eligibility and benefits—and, indeed, those efforts have been ongoing in 2005.

After Congress failed to enact a major restructuring of Medicaid proposed in the President's FY2004 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.¹⁷ It seems, however, that the Administration may also be seeking to achieve its goal of turning Medicaid into a block grant indirectly, possibly by approving state waiver requests to create a state-specific global cap on Medicaid funding,¹⁸ and other uses of state waiver authority.¹⁹

Implications for Adolescents

For advocates and policymakers who are concerned about health care access for adolescents, major challenges are represented by the current economic and political climate as well as by recent policy developments:

- Gains in public health insurance eligibility, particularly for older adolescents, could be lost, directly by explicit eligibility limits, or indirectly by measures that would discourage enrollment.
- Some Medicaid and SCHIP cuts could fall disproportionately on benefits of particular importance to adolescents, such as mental health or substance abuse treatment.

- Reimbursement rates and other essential elements in the ability of the programs to provide adolescents with access to providers capable of meeting their particular needs could be further reduced below levels that are already often inadequate.
- The overall integrity of the programs is threatened—represented, for example, by the challenges to the entitlement aspect of the Medicaid program. It is this entitlement feature that enables eligible adolescents to receive a broad range of screening, diagnostic, and treatment services (represented by EPSDT).

Certain groups of adolescents may be at particular risk, especially those whose health care access is already compromised. These include adolescents in state custody, those leaving the foster care and juvenile justice systems, homeless and unaccompanied youth, immigrants, and older adolescents.

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, youth advocates and policymakers will need to analyze carefully their implications for adolescents and move to protect the interests of youth. This is important because adolescents have particular health care needs that impact their health status as a group (*See sidebar, "Health Status and Health Care Needs of Adolescents" p.8*).

Lessons Learned and What We Can Do

The following lessons are based on 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. The findings drawn from each of these diverse sources were remarkably consistent 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 access to needed care.

As advocates and policymakers consider further changes in the health care arena, they may be guided by the following lessons about what improves or impedes adolescents' access to comprehensive health care.²⁰

1. Adolescents' health care needs are often linked to behavioral, environmental, and social etiologies. Any policy development or reform proposals affecting health care for youth should account for this in the service benefit package.
2. Standards of health care professionals with expertise in adolescent health—such as the Guidelines for Adolescent Preventive Services (GAPS) and Bright Futures—have not been consistently reflected in requirements and recommendations for services for this age group. Future requirements and recommendations should incorporate these standards.

¹⁷ National Health Law Program, *Capital Communiqué*, Feb. 24, 2004; Families USA, *The Bush Administration's Fiscal Year 2005 Budget: Analysis of Key Health Care Provisions*, Feb. 11, 2004.

¹⁸ 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.

¹⁹ 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.

²⁰ Extensive references and explanatory materials supporting each of these lessons are included in the full report, *Lessons Learned*, *supra* n. 1.

3. Medicaid is critically important to access for poor and low-income adolescents. As of 2000, Medicaid provided coverage for one in five adolescents age 15 through 20. Thus, future limitations on Medicaid eligibility could have a significant adverse impact on adolescents.
4. The EPSDT component of the Medicaid program is designed to meet the disparate health care needs of limited-income youth; it should remain intact as a pivotal component of their health insurance coverage in the future.
5. EPSDT implementation for adolescents, as evidenced by screening and participation rates, has lagged behind other age groups. Nevertheless, EPSDT provides a strong framework for improving adolescents' access to essential health services. Implementation efforts should be strengthened in lieu of watering down or abandoning the program.
6. Fiscal incentives have encouraged states to establish more generous financial eligibility criteria for Medicaid, and to extend coverage to older adolescents in both Medicaid and SCHIP. Future efforts to encourage health insurance coverage for adolescents may likewise be enhanced by incentives.
7. The enactment of SCHIP was followed by significant increases in health insurance enrollment for adolescents in Medicaid and SCHIP, particularly those in the 15- to 18-year-old age group. This suggests that the availability of federal funds is an effective tool in overcoming the problem of uninsured adolescents. Reductions or withdrawal of such funds could have the opposite effect.
8. Facilitating coverage of the "eligible but not enrolled" adolescent population can be aided by strategies to simplify the application and enrollment procedures. Enrollment efforts should be targeted specifically to adolescents and implemented at health care sites they frequent.
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 specify how adolescents can be targeted, enrolled, and served.
10. With the exception of SCHIP, few health care reform initiatives have included specific provisions addressing the needs of adolescents. In the future, health care reform measures should be carefully scrutinized for potentially adverse implications for adolescents, as well as for opportunities to include elements that would be directly helpful to this age group.
11. Few of the laws governing commercial or Medicaid managed care contain provisions explicitly designed to help adolescents. However, some do contain elements—such as mandated benefits or free choice of family planning provider requirements—that could help youth access needed services. These requirements should be maintained or expanded.
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.
13. Specific protections for adolescents, although rare in past managed care contracts, enhance the likelihood that adolescents will receive the care they need; such protections should be included in future contracts.
14. Options for enrollment in a different health plan or to have a different primary care provider from other family members can help ensure adolescents' access to providers with the interest, training, and experience to care for them.
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.
16. A comprehensive scope of benefits is a critical foundation for assuring that adolescents receive the services they need in Medicaid managed care and other insurance programs.
17. Some health plans require physicians with expertise in the care of adolescents, particularly those who are board-certified in adolescent medicine, to choose between joining the provider network as a primary care provider or a specialist. Such requirements do not allow these physicians to offer the full range of services to adolescents, and should be eliminated by health plans.
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.
19. Some states have adopted—or been

the site of—particularly important innovations to improve coverage and service delivery for adolescents. These innovations should be more widely reported to encourage their adoption in other states.

20. The 1990s innovations in law, policy, and practice that have been beneficial for adolescents are dependent on both political will and expenditure of public funds. They are at risk in the current decade.

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Health Status and Health Care Needs of Adolescents¹

Despite a widespread perception that adolescents are healthy, they experience a well-documented array of health concerns and problems.² Most of these are “preventable health conditions with predominantly behavioral, environmental, and social etiologies.”³ They include injury,⁴ homicide,⁵ suicide,⁶ mental and emotional illness,⁷ other chronic illness and disability,⁸ poor nutrition,⁹ eating disorders,¹⁰ dental problems,¹¹ pregnancy,¹² sexually transmitted disease (STD),¹³ HIV,¹⁴ and substance abuse.¹⁵

Because of these health issues, adolescents need a wide variety of health care and related services. Essential services include: preventive; sexual and reproductive; mental health and substance abuse;

dental; acute care; and chronic illness and disability services.¹⁶

“Special populations” of vulnerable adolescents experience more prevalent and more severe health problems. These groups may include: 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.¹⁷ Adolescents who are members of these vulnerable groups are likely to need more intensive health services than other youth and to have greater difficulty accessing traditional sources of care.

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. This section represents data as of the end of the 1990s, when the study that informed the findings highlighted in this article was completed, or shortly thereafter. More recent data 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). 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).

³ David S. Rosen et al., *Clinical Preventive Services for Adolescents: Position Paper of the Society for Adolescent Medicine*, 21 *J. Adolescent Health* 203 (1997).

⁴ *Adolescent Health Chartbook*, *supra* n. 2, at 58.

⁵ Bureau of Justice Statistics, *Crime Data Brief: Homicide Trends in the United States: 1998 Update 2* (March 2000), available at <http://www.ojp.usdoj.gov/homicide/homtrnd.htm> (last visited May 19, 2001).

⁶ *Adolescent Health Chartbook*, *supra* n. 2, at 38.

⁷ Ozer et al., *supra* n. 3, at 14). 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.

⁸ *Adolescent Health Chartbook*, *supra* n. 2, at 34.

⁹ National Center for Health Statistics, Centers for Disease Control and Prevention, *Prevalence of Overweight Among Children and Adolescents: United States, 1999-2002*, available at <http://www.cdc.gov/nchs/products/pubs/pubd/hestats/overwght99.htm> (last reviewed Nov. 2, 2004).

¹⁰ Martin Fisher et al., *Eating Disorders in Adolescents: A Background Paper*, 16 *J. Adolescent Health* 420, 420-25 (1995).

¹¹ *Adolescent Health Chartbook*, *supra* n. 2, at 36.

¹² *Adolescent Health Chartbook*, *supra* n. 2, at 62.

¹³ *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).

¹⁴ Office of National AIDS Policy, *The White House, Youth and HIV/AIDS 2000: A New American Agenda* (2000).

¹⁵ *Adolescent Health Chartbook*, *supra* n. 2, at 78, 80.

¹⁶ 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). (discussing the ways in which Medicaid and SCHIP are able to address adolescents’ needs and provide coverage for these diverse services).

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