The Politics of EPSDT Policy in the 1990s: Policy Entrepreneurs, Political Streams, and Children's Health Benefits

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SINCE 1967, MEDICAID HAS INCLUDED A SPECIAL child health benefit known as the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program.¹ EPSDT was designed to ensure that Medicaid-eligible children receive comprehensive health coverage, not only for services related to acute and chronic medical problems but also for a wide range of preventive benefits. The EPSDT program is notable for its policy significance as the only U.S. entitlement to comprehensive child health services. In a comparative sense, whereas such services are available universally in most countries of Western Europe, EPSDT is the only attempt in the United States to provide a right to comprehensive child health services nationwide.

The EPSDT program was analyzed in its early years by social scientists, resulting in a series of case studies and studies in federalism that attempted to explain the failures of states to implement the federal EPSDT program (Foltz 1982; Thompson 1981; Goggin 1987).

We will examine EPSDT as a national policy issue during the period 1989 to 1997 (table 1). In 1989, the EPSDT program was revitalized with the enactment of a strengthened federal mandate, which the states

¹ 42 U.S.C. §1396d(a)(4)(B); 42 U.S.C. §705(a) (1968).

TABLE 1
A Chronology of the Political Process Related to EPSDT, 1989–97

Date	Political process steps
1989	Enactment of OBRA'89 amendments to EPSDT
Spring 1993	Deliberations begin on draft of Clinton Health Security Plan, including discussion of the role of EPSDT in a national health reform plan
September 1994	End of congressional debate on the Clinton Health Security Act and related legislation
November 1994	Election of Republican-majority 104th Congress, representing major ideological shift to the right of the political spectrum
November–December 1994	Republican governors advance Medicaid block grant proposal with new Republican-controlled Congress
January–December 1995	Medicaid block grant proposals and alternatives for Medicaid reform deliberated in the 104th Congress
December 1995	President Clinton vetoes legislation containing Medicaid block grant that would eliminate benefit guarantees, including EPSDT
February 1996	National Governor's Association reaffirms support for Medicaid reform
March–June 1996	Congressional committees consider alternative Medicaid reform legislation, with EPSDT benefits debated
July 1996	Bipartisan, White House–congressional compromise to drop Medicaid reform, in favor of welfare reform
December–February 1997	Multiple proposals to expand children's health insurance advanced by a bipartisan array of members of Congress and President Clinton
August 1997	New "State Children's Health Insurance Program" signed into law by President Clinton

implemented in various ways. A small piece of the national health reform debate of 1993–94 was devoted to EPSDT and its benefits. More recently, efforts to reform Medicaid and to expand children's health insurance coverage brought the politics of EPSDT into sharp relief.

During 1995 and 1996, the EPSDT program's very existence was threatened by those advocating "Medicaid reform." In 1997 the federal policy debate on children's health insurance included substantial discussion of the value of EPSDT and its comprehensive benefit package. In analyzing the political dynamics of EPSDT policy, we hope to provide insight into the general nature of the politics of child health policy in the United States.

Methodology

The core concepts in this article developed out of conversations we had with each other, which began when the first author, Alice Sardell, interviewed the second, Kay Johnson, who was then director of policy and government affairs for the March of Dimes Birth Defects Foundation. This interview was part of a larger project on the politics of child health policy. The data on which this article is based come from two sources: The first is archival materials, including congressional committee hearings, reports from government agencies and interest groups, interest group newsletters and position papers, and newspaper and legislative journal accounts. These were collected and analyzed by Kay Johnson, who was also a central participant in EPSDT policy making at the federal level, first at the Children's Defense Fund from 1984 to 1991 and then at the March of Dimes from 1991 to 1996. Most of the archival material discussed below are from her personal files.

The second source of data was a series of interviews with policy actors conducted by Alice Sardell during 1996 and 1997. Some of the interviews were done as part of the larger child health policy project before the two authors met, and others were conducted specifically for this study of EPSDT policy. The first set of policy actors interviewed for the larger study were identified by their presence at congressional hearings on child health issues. Other policy actors were selected for interviews on the basis of snowball sampling; those interviewed were asked to identify other persons or groups who were knowledgeable about the policy processes. All of the interviews were conducted solely by Alice Sardell, who, as a university-based political scientist, did not participate in any of the policy processes described here.

Alice Sardell developed the analytic framework and research methods. The research instrument consisted of a group of "question sets" on

one research topic or theme. The questions were focused and specific but open ended; informants were asked about the behavior of political actors or the reasons why a particular course of action was undertaken. Each interview began with a certain number of these question sets, depending on the institutional position of the informant (i.e., interest group staff, congressional staff). When new topics were introduced during the interview, the interviewer added more questions in order to elicit further information on those topics. As the interviews proceeded, questions were added to the research instrument in order to corroborate earlier information and to elicit further discussion of the issue or topic. Those interviewed were asked for any available documents pertinent to the issues discussed. Interviews were tape recorded with the interviewees' permission. All informants were guaranteed anonymity, and so they are identified here only by institutional position. Each interviewee was recontacted and asked to review text containing information that was attributed to them. Alice Sardell analyzed all of the interview data and wrote the sections based on interviews.

The data used in this study come from interviews with policy staff of the following organizations: Families USA, March of Dimes Birth Defects Foundation, National Association of Children's Hospitals, National Governors' Association, and United Cerebral Palsy Associations. Families USA is a national organization focused on health policy, particularly health system reforms to benefit vulnerable populations like elderly and low-income individuals. The March of Dimes Birth Defects Foundation is a voluntary health organization that provides research, education, advocacy, and community services, with the goal of achieving better health for babies and therefore for the next generation of children. The National Association of Children's Hospitals is the government relations and advocacy arm of the trade association formed by a group of children's hospitals from across the country. The National Governors' Association (NGA) was the name given to an organization that developed out of annual governors' conferences, the first of which was held in 1908. The NGA began to focus on national legislation during the 1930s and became an influential national policy actor during the 1960s. The United Cerebral Palsy Associations is a voluntary organization in the health sector, providing education, services, and advocacy to persons affected by this health condition and related disabilities.

In addition, interviews were conducted with senior staff of three congressional offices active on the issue of Medicaid from 1994 to 1996

and staff of four of the six governors who met to negotiate the NGA 1996 Medicaid proposal. Two of these staff members worked for Republican governors; the other two gubernatorial staff members worked for Democrats. All four were involved in the processes at issue and were geographically accessible to Alice Sardell, who conducted the interviews in Washington, D.C.

The History of EPSDT

The history of EPSDT is closely intertwined with both the political and legislative history of Medicaid. Created in 1967, the EPSDT program was intended “to discover, as early as possible, the ills that handicap our children” and to provide “continuing follow up and treatment so that handicaps do not go neglected.” Thus was created a sweeping guarantee for comprehensive health coverage unlike any other benefit in American health policy—a program that would locate low-income children, assess their health status, and ensure that they received the continuous and comprehensive medical care they needed.

One of the most important benefits offered under Medicaid is EPSDT. The program defines a special set of benefits (broader than those used for other Medicaid beneficiaries) and services for all enrolled individuals younger than age 21. The central purpose of EPSDT is prevention, and from its inception the program’s mission has been to provide care to children before they become ill or disabled.

Unlike much legislation with broad, sweeping missions and objectives, the EPSDT legal requirements and legislative intent have always been well defined. All children enrolled in Medicaid are entitled to EPSDT benefits. The required benefits changed over time but were specified in the legislation and clarified by federal rules. Since 1989 federal law has mandated coverage of the core components built into the early EPSDT program design: comprehensive, periodic health assessments (screens) of a child’s overall physical and mental health and his or her growth and development; vision, hearing and dental examinations and follow-up care; and any medically necessary treatment that is recognized among the 25 separate categories under Medicaid federal law.

At the same time, the program never has met its objective to ensure that children received continuous and comprehensive medical care. EPSDT participation rates—even for the basic screening examinations—have been low throughout the history of the program. Despite perfor-

mance objectives (now set at 80 percent), participation rates have typically ranged from 25 to 35 percent of eligible children screened (Rosenbaum and Johnson 1986; Keller 1983; Office of the Inspector General 1997).

As the implementation arm of the program, states had clear obligations to carry out performance objectives and, in the early days of the program, they could even be penalized for not doing so. State Medicaid agencies were given the responsibility to inform families about the program, to offer assistance in obtaining screening services, to arrange for transportation, and to assist in organizing follow-up care in the event that a child needed treatment. These duties, which were part of the program for more than 20 years, created challenges and failures in its implementation. For example, because the work of county welfare agencies did not primarily involve health services or health promotion, assigning them the responsibility first of informing families about Medicaid and EPSDT, and then that of enrolling them, was bound to lead to failure. Medicaid agencies, whose primary role was to pay for covered services, were not consistently able to assist families in the ways prescribed.

Apart from its particular weaknesses, EPSDT has also been plagued by certain problems within the structure of the Medicaid program itself. Eligibility criteria were typically set low to keep out all but the poorest children receiving cash assistance, resulting in intermittent enrollment as family income fluctuated, and this created a major barrier to the delivery of comprehensive and continuous care. Another major barrier to EPSDT inherent in Medicaid was the fact that many providers declined to participate in Medicaid because of "low payment, slow payment, or no payment" (Harvey 1990).

However, Medicaid coverage was expanded to include not only children receiving cash assistance but also additional groups of uninsured children in working families during the late 1980s, and Medicaid provider relationships were changed as states began increasingly to purchase more Medicaid managed care during the early 1990s. During the mid-1990s, Medicaid reforms were proposed and for the most part rejected, but sweeping legislation to expand subsidized health coverage for low-income, uninsured children was adopted. Issues related to the EPSDT program were important in both of these policy processes.

The political factors that shaped national EPSDT policy during the last decade are the subject of this article. We use a political science framework in order to analyze the relations among policy issues, political events, and policy outcomes.

A Conceptual Framework for Understanding EPSDT Policy Change

We found John W. Kingdon's framework (1995) very useful in analyzing EPSDT policy, and we will begin with a brief summary of the relevant concepts. Kingdon is interested in explaining "predecision processes," or the question of why some issues get on the governmental agenda at certain moments while others do not. Kingdon focuses on predecision processes like agenda setting and specifying alternatives, rather than on legislative or executive decisions. Although this kind of separation of policy activities into linear stages is conceptually useful, in reality these processes are circular, continuous, and overlapping (Anderson 1979). For example, agenda setting can occur within the context of processes leading directly to legislative decision making. In any case, Kingdon's distinctions between "visible" and "hidden" clusters of participants, and his concepts of "policy streams" and "policy windows," help to explain the politics of EPSDT.

Kingdon argues that a subject is most likely to rise on the decision agenda when three separate process streams—problems, policies, and politics—are joined. The first stream is the process of choosing and defining problems that can be remedied through governmental action.

The second, the policy stream, is the "primeval soup," in which ideas float around and recombine; some policy ideas emerge as viable and well formed and others do not survive. The typical actors in the policy stream are members of a policy community, that is, specialists in a specific policy area who interact with one another from institutional positions inside and outside of government. These are the "hidden clusters." The actors may be staff for congressional offices, interest groups, executive branch agencies, universities, or private think tanks.

While the members of policy communities interact with one another around a set of policy alternatives, the fate of those policy alternatives is, of course, affected by the larger political environment. Kingdon's third stream is the political stream. The political stream is shaped by factors like "public mood, pressure group campaigns, election results, partisan or ideological distributions in Congress and changes of administration" (Kingdon 1995, 145). The political actors are in "visible clusters" and may be legislators, cabinet members, executives (e.g., the President), and other elected officials. These political actors are more likely to be

defining problems and making policy decisions than to be working on specific policy alternatives.

When these separate streams come together, a policy window opens and there is an opportunity for policy action on a given problem. Such an opportunity may be seized on by “policy entrepreneurs”; that is, those individuals inside or outside of government who are willing to invest resources—time, energy, reputation, or money—to achieve a particular policy outcome. Policy entrepreneurs advocate for a definition of a problem or a specific policy proposal within the policy stream, but they also attempt to link problems, policy solutions, and political events so that a policy window will open. Frequently, windows open when an issue captures the attention of government officials, or when there is a change in the political stream (i.e., a new administration or a significant shift in the composition of a legislative body).

The recent political history of EPSDT was shaped by two distinct sets of policy entrepreneurs with dramatically different views of the value of EPSDT as a child health policy. One set of policy entrepreneurs comprised child health advocates; the second, fiscally conservative governors. While other groups (i.e., Congress, the White House, and Medicaid advocates) each had a role to play, these two sets of policy entrepreneurs dominated the politics of EPSDT in the 1990s.

Child Health Advocates as Policy Entrepreneurs

Between 1984 and 1990, a series of Medicaid expansions had been enacted for children and pregnant women (table 2). These years formed a period of intense activity by a number of institutions and advocacy groups that were defining problems in the area of child health and advocating solutions to them. These included the Children’s Defense Fund, the House Select Committee on Children, Youth and Families, the Institute of Medicine, and the National Commission on Infant Mortality (Sardell 1991). Child health was redefined as a national problem by visible actors, including Representative Henry Waxman (D–CA), Senator Lloyd Bentsen (D–TX), and President Bush. In general, the national mood was sympathetic to children’s issues.

Millions of additional children had been made eligible during those years. A core group of child advocates, acting as policy entrepreneurs,

saw reform of the EPSDT program as a way to improve the benefits those children would receive. One of the advocates recounted this history, using the language of Kingdon: "Several of us realized that there was a window of opportunity to take what was over a 20 years old piece of law and try to put some teeth into it" (United Cerebral Palsy Associations policy staff: interview, May 14, 1997).

Key congressional committee staff were persuaded by the advocates that it was "crazy" to pay for screening if Medicaid was not going to pay for treatment. A bill was introduced and debated at a Senate Finance Committee hearing (Johnson 1989), at meetings of the National Governors' Association (NGA), and by the Health Care Financing Administration Medicaid Technical Assistance Group, which included key state child health policy leaders. The NGA opposed the legislation as an onerous federal mandate. However, the momentum for child health issues in the political stream (including recent large expansions of Medicaid eligibility of children) and the Democratic control of Congress led to easy enactment of this benefit-related provision as part of the Omnibus Budget Reconciliation Act of 1989 (OBRA'89).²

The OBRA'89 legislation sought to address the four critical problems that had plagued the EPSDT program throughout its history (Foltz 1982; Rosenbaum and Johnson 1986; National Health Policy Forum 1989):

- The states failed to set timetables (known as periodicity schedules) for well-child examinations (known as EPSDT screens) that fit with pediatric care standards. In fact, in the mid-1980s, only six states had schedules that met these standards. Moreover, few states had adopted age-appropriate dental, hearing, and vision exam schedules. OBRA'89 codified certain requirements. The states were to establish schedules that met "reasonable standards" (e.g., in the case of medical care, the standard guidelines of the American Academy of Pediatrics); define distinct periodicity schedules for dental, hearing, and vision exams; and permit children to be seen on an "interperiodic" basis when a condition was suspected.
- The states failed to ensure access to treatment and services for conditions diagnosed among EPSDT-eligible children. For nearly 20 years, states had been given the option to expand benefits for

²42 U.S.C. §1396a(43)(A) and §1396d(a)(4) (1989).

TABLE 2
Federal Medicaid Improvements for Children and Pregnant Women, 1984–90

Year enacted	Short/long title of legislation	Major expansions for children and pregnant women ^a
1984	DEFRA/Deficit Reduction Act	<p>Mandate:</p> <ul style="list-style-type: none"> • Coverage of: “qualified” pregnant women who would be eligible for AFDC if their child was born • Coverage of “qualified” infants and children (born after September 1983 and with family income below state AFDC levels), phased in to age five • Automatic coverage for one year provided to infants born to women receiving Medicaid
1985	COBRA/Consolidated Omnibus Budget Reconciliation Act of 1985	<p>Mandate:</p> <ul style="list-style-type: none"> • Coverage of all “qualified” pregnant women who meet AFDC financial eligibility criteria, thereby adding pregnant women in two-parent families • Requirement that states extend Medicaid for 60 days postpartum to women who were covered while pregnant
1986	OBRA/Omnibus Budget Reconciliation Act of 1986	<p>Option:</p> <ul style="list-style-type: none"> • Coverage of pregnant women, infants, and children to age five with family income up to 100 percent of the federal poverty level (FPL) • Streamlined eligibility processes with modified asset tests; short application forms; continuous eligibility for pregnant women; and “presumptive” (temporary) eligibility for pregnant women
1987	OBRA’87/Omnibus Budget Reconciliation Act of 1987	<p>Mandate:</p> <ul style="list-style-type: none"> • Phase-in of coverage for “qualified” children (with family income below state AFDC levels and born after September 30, 1983) extended to age eight <p>Option:</p> <ul style="list-style-type: none"> • Coverage of children to age eight with family income up to 100 percent FPL and • Coverage of pregnant women and infants with income up to 185 percent FPL

1988	MCCA/Medicare Catastrophic Coverage Act of 1988	<p>Mandate:</p> <ul style="list-style-type: none"> • Coverage of pregnant women and infants with income up to 100 percent FPL • Services covered under the Education of All Handicapped Children Act (now Individuals with Disabilities Education Act) that are also covered under Medicaid must be reimbursed by the latter program <p>Option:</p> <ul style="list-style-type: none"> • Extend coverage under more liberal income and resource methods and add pregnant women and children at higher income levels (§1902[r][2])
1989	OBRA'89/Omnibus Budget Reconciliation Act of 1989	<p>Mandate:</p> <ul style="list-style-type: none"> • Coverage of pregnant women, infant and children under age six (born after September 30, 1993) with family income up to 133 percent FPL • Through the EPSDT program, amends the statute to continue previous requirement to cover appropriate medical, dental, vision, and hearing care and adds requirement that states cover medically necessary care and treatment under the federal definition of medical assistance (§1905[a]) to children regardless of whether such services are offered to persons over age 21
1990	OBRA'90/Omnibus Budget Reconciliation Act of 1990	<p>Mandate:</p> <ul style="list-style-type: none"> • Phased-in coverage of all poor children born after September 30, 1983 (reference DEFRA) reaching full coverage of poor children by October 2002; and automatic newborn eligibility requirement strengthened to guarantee continuous coverage of infants born to Medicaid-recipient women throughout the first year of life • Mandates previous option (first enacted in 1986) to provide continuous coverage throughout pregnancy and 60 days postpartum for women and the first year of life for infants.

^aSimultaneous Medicaid amendments added mandatory coverage for poor persons over age 65, provisions protecting resources of spouses of persons entering nursing homes, payments for disproportionate share hospitals (DSH), and other changes in asset determination and benefits.

children under EPSDT, including any benefit under Medicaid for which federal financial contributions were available. Few states used this option to furnish special diagnostic and treatment services. Thus, many children had conditions identified in an EPSDT screen, but no payment for treatment was authorized through Medicaid. In 1989 federal law was changed to mandate such coverage, stating that states are required to pay for all medically necessary treatment, whether or not such services are otherwise included under their own state plans.

- Provider participation was limited. Some provider types were excluded from the program (e.g., some states only permitted health department clinics to conduct screens, explicitly excluding private pediatricians; other states precluded the use of psychologists for developmental examinations). OBRA'89 required that states remove limits on participation of licensed, qualified providers.
- States permitted "shadow billing." Private pediatricians were allowed to bill for a routine health exam that did not necessarily meet the EPSDT standards. This visit was then not reported as an EPSDT screen, making it impossible to monitor program performance. OBRA'89 set performance standards that were intended to give states an incentive to count all such visits.

Implementation of OBRA'89: Perception versus Reality

Initially, there was enormous resistance to implementing the OBRA'89 EPSDT requirements. States responded with an avalanche of concerns. A majority of state Medicaid directors and governors believed that the new, mandated benefits, combined with the administrative burdens of tracking and reporting requirements, would be high-ticket items, adding to an already expanding Medicaid cost for states. EPSDT became a frequently cited example of unfunded federal mandates and a target for proponents of state flexibility.

However, states produced little evidence that the EPSDT expansion had substantially affected their Medicaid spending. Two surveys by the American Public Welfare Association, representing the views of Medicaid directors and therefore most likely to be biased in favor of the

states, did not show a significant impact. The first, a 1992 survey of 15 states, found that, although states were reporting higher Medicaid expenditures following OBRA'89, they found it difficult to document that EPSDT service expansions were the cause (versus increases in the number of children enrolled as a result of eligibility expansions) (American Public Welfare Association 1997). In a similar survey of 29 states, conducted in December 1995, 17 states furnished information regarding the cost of benefits expansions, which revealed that a large share of the reported costs was related to financing educationally related therapies or school-based services. Such payments typically were made to education agencies for special education costs and were not necessarily a result of EPSDT requirements under OBRA'89 (American Public Welfare Association 1997).

Moreover, analysis of the recent national trend in Medicaid spending indicates that payments to hospitals serving a "disproportionate share" of Medicaid patients and increased expenditures for older adults were the dominant factors in increased expenditures. Although spending on children increased, it was not in excess of what would be expected, given increased numbers of eligible and enrolled children (Winterbottom, Liska, and Obermaier 1995).

Equally little evidence has been reported regarding a large new administrative burden: states (13 of 29) reported that they had been sued at least once on EPSDT issues. However, over the past 30 years, fewer than 25 cases related to the substantive nature of EPSDT have been decided, and only 8 have been adjudicated since 1989 (Rosenbaum, Teitelbaum, and Sonosky 1997).

Actual implementation of the EPSDT OBRA'89 requirements varied widely among states. Virtually all states made some modifications to their periodicity schedules. States sometimes refused to pay for expanded diagnostic and treatment services, and some states did not modify billing codes to encourage providers to offer services and treatments outside of the regular state Medicaid plan.

Most states failed to reach the performance target of 80 percent screening levels, according to Health Care Financing Administration (HCFA) statistics compiled in 1996. The Health Care Financing Administration reports that the average screening rate went from 31 percent in 1988 to 47 percent by 1992. Moreover, measurement of performance continues to be a problem because of uneven reporting and lack of age adjustment in calculating rates.

There are few studies of the details of OBRA'89 implementation. However, one in-depth study of four states indicates certain potential problem areas and variations in state performance:

1. Not all states had adopted periodicity schedules that complied with the American Academy of Pediatrics standards.
2. The diagnostic and treatment services requirement had little impact, and few changes were made in coverage.
3. Although provider participation increased somewhat, it did not keep pace with growth in enrollment of children.
4. Only one state actively managed the shadow billing problem to recognize the variation in content (i.e., basic and comprehensive) and to count all well-child visits as a part of EPSDT.
5. Outreach and informing activities were increased in an effort to meet performance targets, often done under contract (Gavin et al. 1997).

The implementation of the EPSDT OBRA'89 policies was also affected by the states' transition to Medicaid managed care. By October 1993, 44 states had enrolled at least a portion of their Medicaid populations in managed care arrangements. Children and their parents (i.e., nondisabled, nonelderly Medicaid beneficiaries) were among the most likely candidates for enrollment in managed care (Rivera, Regan, and Rosenbaum 1995).

Despite the fact that OBRA'89 set performance standards, many states enrolling children in Medicaid managed care may require no reporting or encounter data with which to assess performance and adherence to program standards (Rosenbaum et al. 1997). In fact, analysis of 33 contracts that were in effect in 1992 in 25 states (accounting for 97 percent of all Medicaid managed care enrollees) revealed that, although nearly all made reference to EPSDT, roughly one-third were missing a definition of screening, periodic visit schedules, provider qualifications, or reporting requirements (Rivera, Regan, and Rosenbaum 1995). Thus, under Medicaid managed care, states may pay for the EPSDT service as part of a capitated payment but may not have the tools to assess performance.

Evidence suggests that children enrolled in Medicaid managed care are not more likely to receive EPSDT screens. Based on a review of medical records for a national sample of children, the U.S. Department of Health and Human Services, Office of the Inspector General (1997)

estimated that only 28 percent of children in Medicaid managed care receive all of the required EPSDT exams in their state.

Four major problems were addressed through enactment of OBRA'89, but a fifth challenge has since emerged: the rapid growth of Medicaid managed care. As described above, state Medicaid agencies for decades were responsible for outreach, case management, parent informing, provision of transportation assistance, and other support activities. However, because Medicaid agencies are set up to finance medical care, they generally performed such support functions ineffectively. States now frequently delegate these responsibilities to Medicaid managed care plans (Rosenbaum et al. 1997). A report of the Office of the Inspector General found some increase in screening performance levels (i.e., the percentage of eligible children screened) when states inform the plans about the children who are due for EPSDT screens, but the effectiveness of EPSDT outreach, informing, and related efforts by managed care organizations has not been evaluated. OBRA'89 changes were substantial, and its goal was significant improvement in access to, and the outcomes of, Medicaid-financed care for low-income children. However, because the OBRA'89 changes were not fully implemented, they became what one observer called "faux benefits."

EPSDT and the Benefits Debate in Health Care Reform

EPSDT and comprehensive health benefits for children next became a central policy question during the formulation of child health policy for the Clinton Health Security Plan (National Health Policy Forum 1993). The Clinton plan for national health reform did not include EPSDT benefits for all children; instead, it guaranteed EPSDT's comprehensive benefits only to the poorest children, who would remain in Medicaid. Nonpoor children would be served under the standard benefits package of the Clinton plan—a package that was modeled on commercial benefits and was thus less comprehensive than the EPSDT program. It was the Clinton administration's view that children in higher-income, non-Medicaid families could purchase supplemental benefits if necessary (White House letter: May 1993). Actors in the political stream, particularly at the White House, did not propose comprehensive coverage of all children, only of poor children.

An ad hoc coalition of children's advocates—led by the March of Dimes, the United Cerebral Palsy Associations, and Family Voices (an advocacy group comprising parents of children with special health needs)—pushed for a supplemental benefits package (of more extensive therapy, home health care, durable medical equipment, and other services) for children with special health needs in families of any income level. The advocates approached Senators Edward Kennedy (D-MA), Tom Harkin (D-IA), and John Chafee (R-RI), who agreed to look for ways to amend the pending health reform proposals to include supplemental benefits for children through the use of funds from the proposed long-term-care allotment. Children's advocates also met with a coalition of long-term-care advocates (led by the Alzheimer's Association, the American Association of Retired Persons, and the Paralyzed Veterans of America) to structure a new provision in the long-term-care portion of the Health Security Act and to set aside funds for children as part of the long-term-care allotment. These provisions were dropped when the entire health care reform effort lost momentum in Congress in August 1994.

At the end of the congressional deliberations, Christopher Dodd (D-CT) and Senate Majority Leader George Mitchell tried to break through a Republican block on health reform votes by introducing a narrow amendment on child health benefits. This amendment would have required health plans to include preventive care only for one group: pregnant women and infants. The Democrats saw this as an issue for which there would be widespread support. However, the Republicans "saw it differently and argued that the amendment simply would open the door to government intrusion in health care" (Dewar and Priest 1994). Again, the political-stream actors opposed guaranteed health benefits even for just one age group of children: infants.

States were not directly involved in the child health benefits discussion of the national health care reform debate. However, at the state level, between 1989 and 1994, EPSDT became for many governors, particularly Republicans, a major symbol of federal infringement on state autonomy, and a policy that they acted to overturn.

The NGA as Policy Entrepreneur

Since the enactment of Medicaid in 1965, health financing issues have been of central concern to the NGA (Ramsay 1995, 337). From 1991 through 1996, "Medicaid reform" was a top priority for the NGA. The

governors' experience was that Medicaid costs were rising and consuming a larger share of state budgets concurrently with growing opposition to new or higher taxes, which made it increasingly difficult to raise state revenues (NGA policy staff: interview, May 30, 1996).

The NGA position on repealing EPSDT was based on the dual perception that EPSDT was a very costly program and that it, and several other Medicaid issues, constituted a violation of state autonomy within the federal system. One NGA policy staff said, "It's not that we don't want to serve kids . . . but to give the states some opportunities to think through how they would like to determine which optional benefits should be available to kids" (NGA policy staff: interview, May 30, 1996).

In 1994, a policy window opened for the governors most concerned about EPSDT and other "flexibility issues." That window of opportunity was created by the 1994 congressional elections, which shifted control of Congress to the Republican Party and represented a further ideological shift of the House of Representatives to the right of the American political spectrum. A leading priority for the Republican-led 104th Congress was balancing the federal budget. The Republicans viewed reductions in spending for entitlements like Medicaid as one of the ways to move toward a balanced budget. At the same time, Republican governors brought forward their agenda for reductions in federal Medicaid requirements. A policy initiative, labeled "Medicaid reform," was forged out of these two interests. The proposed policy remedy was a Medicaid block grant under which federal spending would be capped and states would have the flexibility to modify Medicaid.

The Republican governors' Medicaid Task Force worked with Republican congressional staff to write legislation that replaced the existing Medicaid entitlement program with a state block grant. "We had tremendous amounts of access and cooperation from the House and Senate in drafting this Medigrant bill" (Governor's staff #2: interview, March 14, 1997). Democratic members of Congress were excluded from this process (Pear 1996).

The Congress intensively debated the merits of a "per capita cap," a pure "block grant," and variations in between. However, the bill that passed the Republican-controlled House was a pure block grant, which left all decisions on eligibility and benefits to the states. In the Senate Finance Committee, Senator John Chafee (R-RI) was able to use his "swing vote" on the committee (of 11 Republicans and 9 Democrats) to add a requirement that states continue the entitlement to Medicaid for

pregnant women and children up to age 13 in families with incomes at or below the federal poverty level. (This still meant a reversal of coverage for many other groups of children and pregnant women who had gained entitlement during the late 1980s. See table 2.) The legislation that came out of the House/Senate Conference Committee and was passed on November 17, 1995, included the eligibility entitlement provision sponsored by Senator Chafee, but left the determination of all benefits for children to the states. This provision would have abolished EPSDT (Fraley 1995, 3540).

At the same time, both the White House and congressional Democrats had heard from many of the constituencies that would have been affected by the health and other social spending cuts in the budget reconciliation package sent to the President (Governor's staff #3: interview, May 15, 1997). On December 6, 1995, President Clinton vetoed the legislation, leaving Medicaid, and thus the EPSDT program, intact.

Even before the actual veto, the dynamics of Medicaid policy had been changed by the reaction of the anti-block-grant forces. Republican governors sought to move forward on Medicaid reform by suggesting to Democratic governors that they work together on a proposal that could win bipartisan support in Congress. Six governors and their staffs (Republicans John Engler of Michigan, Tommy G. Thompson of Wisconsin, and Michael O. Leavitt of Utah, along with Democrats Lawton Chiles of Florida, Roy Romer of Colorado, and Bob Miller of Nevada) and NGA staff met for 100 hours in December 1995 and January and February 1996. These six governors were all members of the nine-member NGA executive committee, and several had been very interested and active on the Medicaid issue (Governors' staffs #2 and #3: interview, March 14, 1997).

The outline of the negotiated plan was adopted by the full membership of the NGA in February. Interviews about the actual negotiations at the "Governors' Table" provide insight into the way that EPSDT was defined as an issue within this institutional arena.

EPSDT at the Governors' Table

EPSDT was defined by both the Democratic and Republican governors at the negotiating table as a "flexibility issue," as were the Boren amendment hospital payment requirements, nursing-home standards, and full-

cost reimbursement for federally qualified health centers (FQHCs). The “Boren amendment,” enacted in 1980 and reauthorized in 1987, required that state Medicaid programs “adequately” reimburse covered costs in “efficiently run facilities” (Serafini 1995). Federally Qualified Health Centers are defined as those federally funded health centers (e.g., community health centers, migrant health centers) or “look-alike” clinics having similar characteristics. Federal law mandates that FQHCs be reimbursed at a level sufficient to cover “reasonable costs.” The NGA viewed these legislative provisions and federal nursing-home standards as interfering with state autonomy. Moreover, it blocked the ability of states to set provider reimbursement levels in several important categories.

In some respects, it is surprising that a child health program like EPSDT would become an NGA priority, given that all child health expenditures account for less than 25 percent of total Medicaid spending and EPSDT is only a fraction of those costs (Health Care Financing Administration data 1996). However, EPSDT, Boren, nursing-home standards, and FQHC were symbolic of the types of federal mandates governors opposed and were critical areas on which they formed a consensus. This unanimity may have been based on the fact that these were provider and benefit issues, not eligibility or federal funding battles. The tension between benefit and eligibility issues will be discussed in further detail below.

There also were some important partisan differences, with the major opposition to EPSDT coming from the Republican governors, who believed that EPSDT, after OBRA’89, had a negative fiscal impact on their state budgets. Governors’ staff recalled: “The Republican governors were absolutely convinced that EPSDT was busting their budgets” (NGA policy staff: interview, May 30, 1996). Some of the Republican governors talked about the need to repeal EPSDT and replace it with an actuarially conceived benefits package similar to those offered by commercial HMOs. In their view, such a package would be the new model of providing services for children (Governor’s staff #1: interview, May 13, 1997; staff #3: interview, May 15, 1997).

EPSDT was less important to the Democratic governors as a policy concern. Staff reported: “They also wanted flexibility on these issues but didn’t believe that they had as important a fiscal impact as the Republicans did.” However, EPSDT was viewed by the Democratic governors as a bargaining chip. Of greater importance to the Democratic governors were the guarantee of individual entitlement to Medicaid and the

formula for federal–state funding. The flexibility issues were viewed as leverage against these more important issues (Governor’s staff #1: interview, May 13, 1997).

The “Governors’ Proposal” presented by the six governors to Congress on behalf of the NGA in February of 1996 called for the repeal of, or redefinition of, the “T” for treatment in EPSDT “so that a state need not cover all Medicaid optional services for children” (National Governors’ Association, 1996, 4). At the same time, they recommended that eligibility be federally guaranteed for pregnant women and children to age six in families with incomes up to 133 percent of the federal poverty level and children up to age 13 in families with incomes at or below 100 percent of poverty (National Governors’ Association 1996, 3). Thus, the governors were restoring to the program certain categories of children and pregnant women whose entitlement would have been ended under the Republican plan vetoed by President Clinton in 1995, but they still wanted to exclude the older, “phase-in” children who were to have been gradually added to the Medicaid program up to the year 2002 (i.e., those children under age 18 with incomes below 100 percent of poverty who were born after September 1983). (See table 2.)

The saliency of eligibility issues was discussed by both Republican and Democratic governors’ staff. Republican staff reported that the Republican governors outside the NGA Task Force meetings were concerned that “we’d gone too far in being prescriptive” by agreeing “to support guaranteed health care for certain populations.” Yet, this staff person said, the Republican governors believed that no bill could pass Congress and be signed by the President without some guarantees for children (Governor’s staff #2: interview, March 14, 1997).

House and Senate members had taken a “hard vote” on the first set of Medicaid provisions in the budget bill that Clinton had vetoed. Clinton had used the “hot button issue, hurting kids, women and older citizens” in his veto message on the bill. His rhetoric was seen as so effective that Senate and House Republicans “felt they had to have prescriptive measures in the Medicaid provisions before they could vote on it again. . . . The kids became the biggest issue” (Governor’s staff #2: interview, March 14, 1997).

Another governor’s staffperson recalled that the proposal to exclude the “phase-in kids” (those poor children born after September 1983, who were gradually becoming eligible for Medicaid), for which the Republican governors had “pushed very hard,” was “a public relations

nightmare” for the White House, the Democratic governors, and even for congressional Republicans. “These were kids who would have been eligible and who were not expensive” (Governor’s staff #1: interview, May 13, 1997).

After the NGA proposal was presented to Congress, the six governors and their staffs continued to meet in order to work on other specific aspects of a bipartisan agreement on Medicaid. However, these other issues, particularly funding formulas, were never resolved (Governor’s staff #2: interview, March 14, 1997). The Democratic governors disclaimed the Medicaid provisions in a second piece of welfare/Medicaid legislation proposed by the Republicans in May (Katz 1996, 1467).

Clearly, EPSDT policy making during the 1990s took place within the context of larger health policy debates, first about national health reform and then about the future of Medicaid. Children’s advocates tried to rally support for comprehensive health coverage of children at all income levels among actors in the White House, in Congress, and among broader-issue coalitions during the health reform debate. During the 104th Congress, advocates for EPSDT were part of a child health coalition that, in turn, was part of a larger group opposing Medicaid block grants. Ironically, the coalition activity that made a place for children in the national health reform debate and then effectively generated pressure to preserve Medicaid as an entitlement program could not be as focused on preserving EPSDT.

The Medicaid Block Grant and Advocacy for EPSDT

Advocacy for EPSDT took place within the context of the larger effort to oppose the creation of a Medicaid block grant. A broad coalition of groups whose constituents would be affected was active in opposing the effort to end an individual entitlement to Medicaid. Their activity was important at two junctures of the policy process.

First, it contributed to the pressure on President Clinton to veto the bill that contained the Medicaid block grant provisions in December 1995. Second, the Clinton veto changed the dynamic in the political stream, pushing the Republicans to compromise on Medicaid. During the policy process after December 1995, children’s advocates worked to influence the policy compromises, focusing on guarantees of eligibility

for children and pregnant women and on preservation of EPSDT. The important institutional arenas during the postveto period were the “governors’ table” and the House Commerce and Senate Finance Committees.

The ad hoc coalition against the Medicaid block grant was led by Families USA, an organization with particular interest in health system reform (Ramsay 1995, 209–10). Included in this coalition were senior citizens groups, religious groups, advocates for persons with disabilities, hospital and nursing-home associations, professional associations, counties, public employee unions, and children’s advocacy groups. These groups cosigned letters to members of Congress and the White House and met with the President, White House staff, and congressional members and staff (Families USA policy staff: interview, April 23, 1996). The broad anti-block-grant coalition concentrated on pressuring the President and the Democratic Caucus to “stand fast” on preserving the Medicaid entitlements for its constituent populations. The goal of these activities was to defeat the block grant proposals of the Republican congressional majority (Congressional staff: interview, May 15, 1997).

During the post-veto-policy process, advocacy groups met regularly with staff of congressional opponents of the block grant (most notably, Representatives Henry Waxman [D-CA], John Dingell [D-MI], and Senator Bob Graham [D-FL]) to share information and coordinate strategy. One of their strategies, carried out in the summer of 1996, was to offer amendments to the second Republican block grant proposal during the House Commerce Committee and Senate Finance Committee “mark-up” process. Many of these amendments were focused on preserving Medicaid entitlements and services for specific constituencies, in order to make the block grant concept more concrete to members of Congress (e.g., an entitlement for elderly Alzheimer’s patients needing nursing-home care) and to force a vote directly on these constituency group concerns (Congressional staff: interviews, May 15–16, 1997). Republican and Democratic governors’ staff and congressional staff reported that advocacy for Medicaid constituents made the enactment of a “pure block grant” politically “uncomfortable for governors and Members of Congress alike.”

Within the broad coalition of groups seeking to preserve Medicaid as a federal entitlement, the primary goal of most children’s advocates was to maintain federal guarantees of eligibility for children and pregnant women: that is, to prevent a reversal of the entitlement gains that had been won during the 1980s. Efforts to preserve federal guarantees of

comprehensive services for children through EPSDT was led by the National Association of Children's Hospitals (NACH) (Serafini 1995, 233).

The issue of access to appropriate services for children had become very important to NACH during the health care reform debate in 1993 and 1994 and in the context of expanded use of Medicaid managed care by states. Ironically, this group did not take a position on the Medicaid block grant proposal because many of the board members of its constituent children's hospitals supported the effort to balance the federal budget. However, it did take the position that if Medicaid became a block grant, it had to be structured with appropriate guarantees for medically necessary care for children. Together, a group of children's hospitals and parents advocating for children with special needs through Family Voices had identified conservative Republican members of Congress who would agree to sponsor or support amendments in the Commerce and Finance Committees. These amendments would require that states continue to provide children with access to all medically necessary care (i.e., maintain the treatment requirements of EPSDT). In the House Commerce Committee, Dr. Gregg Ganske, a Republican Representative from Iowa, proffered such an amendment, but it lost in a very close vote. In the Senate Finance Committee, Senator Charles Grassley, also an Iowa Republican, made it clear to Chairman Roth (R-DE) that he would support an amendment sponsored by Senator Chafee. Chairman Roth, wanting to avoid this vote, incorporated the requirement into the Medicaid proposal that passed the Senate Finance Committee (NACH, policy staff: interview, May 16, 1997).

Ultimately, all of this process was moot. The legislative activities at the end of the 104th Congress were overwhelmed by a political stream of election-year concerns.

"Medicaid Reform" and the Political Stream

Although the nature of the Medicaid program was still being debated by the NGA Task Force and congressional committees, Republicans were deciding whether to separate the welfare and Medicaid provisions of the 1996 budget legislation. President Clinton was signaling that he would sign welfare reform but not a Medicaid block grant. Many Republican legislators wanted to pass welfare reform and bring that achieve-

ment to their constituents when they ran for reelection. Others in the Republican Party believed that enacting welfare reform would be perceived as an accomplishment of the Clinton administration and would harm Senator Dole's campaign. The Republican governors wanted Medicaid and welfare reforms to remain linked (Governor's staff #2: interview, May 14, 1997). The concerns of Republican governors about Medicaid policy—including repeal of EPSDT—were swallowed up by a wave from the political stream, the ultimately compelling concern with reelection. The Republican leadership decided to drop the Medicaid provisions so that welfare reform legislation could be enacted, thereby limiting the impact of Republican governors as policy entrepreneurs.

In the end, the governors' efforts to enact Medicaid block grant legislation failed. However, Medicaid reform would return as an issue in the 105th Congress and take the form of increased options to states that wished to mandate enrollment in Medicaid managed care and contract with a variety of managed care organizations without a federal waiver. The Balanced Budget Act of 1997 makes these and other significant changes to Medicaid.³ Moreover, the political pressures both in favor of guarantees for health coverage of children and against EPSDT as a benefit standard also continued into the 105th Congress.

Creating a New Children's Health Insurance Program

In the 105th Congress, child health was a highly visible issue. Following the success of the Health Insurance Portability and Accountability Act, as a bipartisan compromise under the leadership of Senators Nancy Kassebaum (R-KS) and Edward Kennedy (D-MA), the President and congressional leaders advanced a number of proposals to expand children's health coverage. Eight major proposals were introduced, ranging from a new Medicare-style entitlement for all children to a major Medicaid eligibility expansion to a state block grant.

This issue moved quickly from the policy stream to the political stream, and policy entrepreneurs had to struggle to keep up in a political process that lasted only seven months.

³P.L. 105-33 (105th Cong. 1st sess.).

The result was a new State Children's Health Insurance Program (SCHIP)⁴ and the largest single commitment to coverage for children since the enactment of Medicaid in 1965 (Rosenbaum et al. 1998). Over the next five years, \$24 billion was authorized for use by states to expand Medicaid or otherwise provide coverage to children whose family income is below 200 percent of the federal poverty level. Unlike Medicaid, which is an entitlement to individual children, SCHIP was created as an entitlement to states. In addition, states were given enormous flexibility, particularly in defining benefits..

The politics of EPSDT were a factor in this debate. The central issues and actors in the Medicaid block grant debate remained constant during the formulation of this new children's program. The states were instrumental in setting the tone and pace of the debate (Burns 1997; Johnson and McDonough 1998). The content of policy discussions was largely derived from the experience in the more than half of the states with some type of children's health insurance program, particularly that of the five large states (Florida, Massachusetts, Minnesota, New York, and Pennsylvania) with experience in this area.

From the outset, there were two divergent approaches: Medicaid versus a block grant program. Many groups, including the NGA, the Children's Defense Fund, and the American Academy of Pediatrics initially supported the proposal for a large new state block grant program. This proposal was viewed by many as having the greatest chance of passage both because it had bipartisan support through its cosponsors Senators Orin Hatch (R-UT) and Edward Kennedy (D-MA) and because it would be financed with new tobacco tax revenues. The Hatch-Kennedy bill also tried to guarantee the EPSDT benefits package in the state grant approach. The NGA favored a block grant approach with the fewest possible federal requirements and no minimum benefits package, in part because about half of the states had already established programs with varying structures.

Other policy entrepreneurs favored Medicaid expansion with its individual entitlement and guaranteed EPSDT benefits. Senators Chafee and Jay Rockefeller (D-WV) introduced bipartisan legislation that would build on the current Medicaid program by giving states enhanced federal support to expand coverage to additional children—at state option.

⁴Under the Balanced Budget Act, the "State Child Health Insurance Program" was created by adding Title XXI to the Social Security Act.

Those supporting the Medicaid approach argued that it made sense because it supplied opportunities to use an existing administrative structure, to guarantee EPSDT benefits, and to increase leverage in health care purchasing achieved by creating a larger pool of covered children (English 1997; Weil 1997).

In the political stream, these two approaches were blended. A compromise on the much debated benefits also was struck.

The benefits debate focused on two questions:

1. Should there be a minimum standard?
2. Should standards be based on EPSDT or on a commercial package?

At several points the EPSDT benefits package was on the table, but it never garnered sufficient votes to become part of the final legislation. Opposition from the governors was again a primary factor, as the NGA's negative position on the OBRA'89 expansions still affected its outlook. They argued that comprehensive benefits would be too expensive and that more children could be covered if a slimmer benefits package were permitted (Nather 1997). The Republican governors, joined by conservative Democratic governors, revived their views that EPSDT should be replaced by an actuarially conceived benefits package based on a commercial model.

The view that coverage should be purchased from private insurers and with benefits similar to standard commercial packages was accepted by the Republican-controlled Congress. Moreover, after passage of the legislation, the House Commerce Committee prepared an implementation guide, which argued again that states can reach children more effectively through a separate, non-Medicaid, state program because they can trim the benefits package to keep costs down (U.S. House of Representatives, Commerce Committee 1997; Bureau of National Affairs 1997).

The possibility of using EPSDT as the standard for benefits in the new program was lost in committee before the budget bills came to the House and Senate floors. The House agreement listed only four broad basic categories of benefits, whereas the Senate bill referenced a modified version of the Federal Employee Health Benefit Plan, Blue Cross/Blue Shield option. In a demonstration of the degree to which EPSDT was rejected, when seven benefits options were on the table during the final negotiations, six were commercial variations and the last was "all

Medicaid services except EPSDT” (Nather 1997). Even after passage of the final legislation, some Republican governors expressed disappointment about the fact that any standard was set for benefits in the new child health insurance program (Baltz 1997).

Although EPSDT remains this year as the benefit standard for children in the Medicaid program—an estimated 25 percent of all U.S. children—it will not be the standard for spending under a new children’s health insurance program in which the federal government will invest \$24 billion over the next five years.

Advocating for Benefits in the Political Stream

Our data suggest that one important variable affecting the politics of EPSDT was the relative saliency of eligibility and benefit issues in children’s health policy. While children’s advocates tried to express the value and importance of comprehensive child health benefits, their message was not central to the debate once the issues returned to the political stream and were being debated by Congress. The evidence presented by child advocates about the value of EPSDT to children did not have an impact on the political process after the OBRA’89 legislation because of a shift in the political stream resulting from the 1994 election, which gave Republican governors the opportunity to push for state autonomy in the form of a Medicaid block grant. When children’s advocates joined a larger coalition whose goal was to preserve the federal entitlement to Medicaid, or when they actively pushed to expand subsidies for children’s health insurance, they were focusing on eligibility, and their successes were related to that issue.

It may be that it is more complicated to communicate the effect of reversing benefit expansions than to describe the effect of reversals in eligibility. The EPSDT provisions of Medicaid law encapsulate the nature of benefits to be provided to children. Eligibility, not benefits, was the topic when participants discussed “throwing children off the program” and when votes were held for or against coverage of a particular population, as on the amendments offered in the Senate Finance and House Commerce Committee in June 1996. Even the Clinton administration’s Health Security Plan, which provided for a basic benefits package to all children, only would have guaranteed comprehensive

EPSDT benefits to the poorest children on Medicaid. When it came to eligibility expansions and creation of a new State Children's Health Insurance program, the policy decision was to use commercial standards as benchmarks and to give states flexibility.

Coverage of children as a population may be a more politically salient issue than the topic of child health benefits. Whereas many polls—like those conducted by Robert Blendon and his colleagues at Harvard University and those prepared for the Coalition for America's Children—show that the majority of Americans support efforts to provide health coverage for children, there is no evidence of support for a standard child health benefit package. This may be because there is no standard package outside of Medicaid and EPSDT. Because the U.S. public accepts the wide variations in personal and family employer-based health coverage, it is difficult to communicate the importance of a standard benefit package or the fact that reducing benefits is a problem.

Moreover, some of the general public, actors in the policy stream, and actors in the political stream hold the view that providing minimum benefits for many children is more desirable than guaranteeing comprehensive benefits for the most disadvantaged children. Underlying this equity issue is the categorical nature of American health benefits policy generally, with its historic distinctions among “deserving” and “undeserving” populations.

The importance of a set of preventive and comprehensive health services for children was widely accepted within the child health policy community but was not accepted by enough of the higher-level, or “visible,” political actors to become part of the new children's health insurance legislation. Kingdon's work is especially useful in highlighting the different roles of these two sets of policy actors: the policy community as the “hidden clusters” and the more visible clusters, such as elected officials.

If creating a political window requires having the problems, policies, and politics in alignment, then doing so for wider use of EPSDT's comprehensive child health benefits package may be an unattainable policy goal.

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