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THE STATE CHILDREN'S HEALTH INSURANCE PROGRAM

A CASE STUDY

WITH ADDITIONAL MATERIAL

ON DATA NEEDS IN THE AREA OF CHILD HEALTH

prepared by

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A CASE STUDY OF THE STATE CHILDREN'S HEALTH INSURANCE PROGRAM

As the statistics community establishes its goals and objectives for the 21st century, it should include among the issues it considers the realities of the policy process and the increasing desire on the part of policymakers and the general public to know more about what they are buying with their health care dollars. This examination of the development of the Children's Health Insurance Program, its implementation and evaluation, and data concerns in the child health field highlights some of these issues.

The State Children's Health Insurance Program (CHIP), Title XXI of the Social Security Act, was enacted in August 1997. It was Title IV of Public Law 105-33, the Balanced Budget Act of 1997. (Appendix A contains a summary of the provisions of the law.) As is usually true, the provisions of this title reflect a series of politically-based decisions, as well as a thoughtful, but perhaps incomplete review, of the facts. Could more or better data have influenced the writing of the law? Possibly. Are more or better data needed to determine whether the program is operating as expected and whether it could be implemented more effectively? Probably. Are more or better data needed to determine whether the program is affecting children's access to care or their health status? Definitely.

The first section of this case study will examine the development of the CHIP legislation with particular attention to the use of data in that process. The second section will explore the implementation and evaluation of CHIP, especially the use of data in assessing the progress being made towards its objectives. The final section will broaden the scope of inquiry to examine the overall problems of collecting information on children, addressing the question: As fewer

infants, children, and adolescents die, and as those who live experience fewer of the traditional health problems, what information is essential in order to target the remaining pockets of ill health and to move toward examining the “health” status of children?

SECTION I

The Development of the CHIP Legislation

Although Congress resoundingly defeated President Clinton’s proposal for health care reform in 1994, some legislators still felt that the number of uninsured Americans was too high and that the federal government should take action to reduce this number.

Background

A comprehensive approach to health insurance coverage was unthinkable given the earlier defeat. This belief was reflected in the headline on a front page article in The New York Times of November 11, 1996: “New Approach to Overhauling Health Insurance; Step by Step. Administration Learns From Defeat in Congress¹.” The Health Insurance Portability and Accountability Act, sponsored by Senators Kassebaum-Kennedy and passed by the 104th Congress in 1996, was one such incremental step. The Times article suggested that health insurance coverage for some uninsured children and help in paying premiums for workers between jobs might be among the Administration proposals for the next steps. It quoted a General Accounting Office (GAO) report which stated that in 1994 the percentage of children without any health insurance coverage was the highest it had been since 1987, 10 million or 14.2% of children under 18 years of age, figures that were to appear frequently in the next 8 months. The article was accompanied by a map which showed the percentage of children in each state who were uninsured in 1995, with the Census Bureau given as the source.

According to one of the individuals interviewed for this case study (hereafter referred to as informants), most Congress-watchers and many members of Congress, expected that health insurance would be discussed in the 1st session of the 105th Congress and that a small incremental change would be passed in the 2nd session. The particular focus of such legislation was uncertain. But under pressure from the Democratic leadership, in January 1997 Congress moved quickly to consider health care for children. The reasons for this choice are unclear, but could possibly have been predicted on the basis of a series of GAO reports that had been requested by members of Congress, primarily Senator Dodd of the Subcommittee on Children and Families, Committee on Labor and Human Resources, although he did not ultimately submit a bill.. Between February 1995 and February 1997, the GAO sent seven reports to Congress on public and private insurance coverage of children².

These GAO reports were based on numbers generated by the Bureau of the Census's Current Population Survey (CPS), surveys by other governmental and non-governmental agencies, and studies by GAO staff in selected states. They stated what policy experts already knew, that large numbers of children were uninsured, that the number and proportion of children covered by private insurance was decreasing, that the number and proportion of children covered by Medicaid was increasing, and that some states were experimenting with their own health insurance programs for children.

Congressional leaders probably believed that a bill that would improve children's access to health care, whether through insurance or some other mechanism, was the health measure most likely to be passed. They also might have felt that there was public support for such action. On January 16, 1997, the Kaiser Family Foundation had released the findings of a survey

conducted just after the November elections which revealed that 52% of voters supported expanding health coverage to children as the next step in incremental health care reform³. The most popular proposal was tax credits to help parents buy private insurance (40%), followed by a new health care program (31%), and expanding Medicaid (21%). (Appendix B contains additional results of this and other surveys.)

Proposed Legislation

As Congress prepared to open in January 1997, several members were developing bills that would increase the number of children covered by health insurance or in other ways improve their access to medical care. Proposals included block grants, tax credits, strengthening the public health sector, vouchers, Medicaid expansions, and other strategies. (Appendix C contains a summary of some of these bills.)

The bill that perhaps came closest to passage before meeting defeat was the one proposing a Medicaid expansion. It would have increased eligibility for Medicaid and thus covered, with a very generous benefit package, a large number of children who did not meet the eligibility criteria then in effect, which mandated Medicaid coverage of all children under age 6 living in families with incomes below 133% of the federal poverty level (FPL). Children over age 6 and under age 14 were covered up to 100% of the FPL, with the age limit increasing by one year each year and the phase-in of children under age 19 and under 100% of the FPL to be completed by October 2002. Some states were already covering more children under their Medicaid programs.

This Medicaid expansion bill received serious consideration by the Finance Committee, but a series of objections caused its demise. One, and perhaps the most important, was that, once

again, the federal government would be telling the states how to operate an insurance program. Although the original Medicaid legislation, as well as its expansions, had permitted the states some degree of freedom in terms of eligibility, benefits, and provider selection and reimbursement, it had mandated minimum coverage, minimum benefits, and minimum provider eligibility. The states increasingly were demanding more responsibility and authority in regard to use of their own and federal funds, a trend called the New Federalism⁴. The welfare reform legislation had responded to these demands and allowed states considerable flexibility in how they moved families off the welfare rolls. The states wanted this flexibility in regard to children's health insurance as well. This state pressure for autonomy would later complicate the task of assessing CHIP's impact.

The importance that the Congress placed on New Federalism concepts showed clearly in the June 24, 1997 House Budget Committee's report on the Child Health Assistance Program⁵. According to the report, the bill's purpose is "to establish a mechanism enabling States to expand the provision of coverage and services to low-income uninsured children." The report goes on: "Congress has yet to give the States the tools they need to ensure that low-income uninsured children receive the assistance they currently lack." After a discussion of state initiatives to reduce uninsurance, the report notes, "advances in the coverage of children have occurred when States have the flexibility to achieve maximum coverage through the Medicaid program and related initiatives."

In addition, many states were opposed to Medicaid expansion because Medicaid was an entitlement. While the states could try to curtail costs by reducing eligibility, benefits, and provider reimbursement to the federally-mandated minimums and by making enrollment as

difficult as possible within federal guidelines, those who did enroll had to be served. There was no financial cap. If more services were provided than had been budgeted, states needed to appropriate supplementary funds. Many states were vehemently opposed to another federally-mandated entitlement program or to the expansion of the existing one, Medicaid. In addition, some members of Congress were against a Medicaid expansion because they basically did not like, and possibly had never liked, the Medicaid program. According to one informant, these members of Congress would have been willing to terminate the Medicaid program at any time and certainly were not going to vote to expand it.

Another objection came from states that were already experimenting with covering additional children with health insurance using state, local, and private funds. Some of these programs had received considerable favorable publicity. The GAO had described six of these programs in its January 1996 report⁶ and, in May 1997, the National Conference of State Legislatures produced “State Programs for Providing Children’s Health Insurance—A Resource Notebook⁷,” which highlighted twelve such programs, categorized as Public Programs, Medicaid Expansion Programs, Public/Private Partnerships, and Private Programs. These states, and particularly Florida which was experimenting with a state health insurance program for children, Healthy Kids, wanted a federal bill that would enable them to continue and expand the programs that they had already designed and were operating. They felt that the Medicaid expansion would not accomplish that.

According to one informant, Senators Chafee and Rockefeller believed that they had the support of a majority of the Finance Committee members for Medicaid expansion. But ultimately both Florida senators voted against it in Committee because of pressure from Florida

Governor Chiles who wanted more state control over federal health insurance funds in order to assist the state's Healthy Kids program which was experiencing financial difficulties.

Another approach to child health insurance expansion was needed, but as the Balanced Budget Act (BBA) of 1997 came closer to passage, attention shifted from its child health provisions to its Medicare ones. According to several informants, the CHIP bill was written in the House Committee on Commerce and inserted at the last minute and under considerable time pressure. One informant stated that it was two bureaucrats from the Department of Health and Human Services (DHHS) who offered a member of Congress or a Congressional staffer the broad outlines of an alternative approach that might satisfy many of the states, as well as the reluctant members of Congress. A House and a Senate version of a child health insurance bill were reviewed at a House-Senate Conference where, according to one informant, pieces were taken from each to write the bill that is now CHIP.

CHIP pleased most of the states because it allowed them to make the important decisions. Those states which were satisfied with their existing Medicaid program could expand it, while those which were concerned about the entitlement issue could develop an alternative that would not be an entitlement. And the law made it possible for those states that wanted a way to expand their own state child health insurance programs to do so. What the law did not include were funds for the assessment of a program that allowed such diversity in implementation, although the law contained a section on information to be collected.

Data Input into the Legislative Process

The rapidity with which the Congress went from consideration of a child health bill to the passage of CHIP (December 1996 to August 1997) left little time for collecting new data or

perhaps for even adequately analyzing existing data. The Robert Wood Johnson Foundation seemed to expect a longer period of discussion. The Foundation had asked the Committee on Children, Health Insurance, and Access to Care of the Institute of Medicine and the Board of Children, Youth , and Families to evaluate the empirical evidence about the relationship between health insurance and access to care, trends in insurance coverage and in the delivery of care to uninsured children, and changes in the provider community that might have an impact on access to care for uninsured and underserved children. Its report was expected to assist the Congress in developing the child health legislation. But the committee only started its work in March 1997 and concluded it in January 1998. The report was published too late to influence the debate⁸.

Congress needed information both to engender support for a child health insurance program and to determine what it would cost. Support from members of Congress and from the general public depended on being able to show that large numbers of children were uninsured and that being uninsured had consequences for their health. (Appendix D contains a discussion of some of the problems in studying these subjects.) Data on the costs of insuring children was needed in order to determine whether the funds available were sufficient for the proposed program or whether cutbacks were needed. The budget agreement reached by the President and Congressional leaders in May 1997 had committed \$16 billion over 5 years to insure 5 million poor, uninsured children. This had risen to \$24 billion by the time the law passed because of the availability of additional funds from the tobacco settlement.

The needed data appear to have come from several sources⁹:

- government reports from the Congressional Budget Office (CBO), the Congressional Research Service (CRS), and the Government Accounting Office (GAO);

- staff- and member-level support from the CRS;
- Congressional committee hearings; and
- fact sheets and other materials from non-governmental agencies.

Government Reports. Both the GAO and the CRS provided the Congress with estimates of the number of uninsured children. These documents relied primarily on the CPS, although there were some references to other data sources. The CPS is conducted by the Bureau of the Census for the Department of Labor. Although the CPS is primarily designed to determine employment data, it has a continuing series of supplements that gather information on a wide range of social and health indicators. The March supplement requests information on insurance coverage during the previous year. The CPS had two major advantages as a source of data for developing the CHIP legislation. First, it could provide data for individual states and, second, it could provide data for recent years. The CPS sampling frame is designed to fill the states' needs for data for their unemployment insurance programs. However, while the number of respondents in each state is large enough for the purpose of determining, with reasonable validity, the number of unemployed in a state, many in Congress and in the health care community were aware that the sample sizes in the smaller states were not adequate for determining the number of children who were uninsured.¹⁰ (Appendix E provides examples of differing estimates of the number of uninsured children based primarily on the CPS data.)

Few, if any informants, cited NCHS's ongoing National Health Interview Survey (NHIS) as an input into decision-making, although for several years the NHIS has included a section on health care coverage in its Family Resources Supplement. While Current Estimates From the National Health Interview Survey, a major source of data on the nation's health, does not include

data on insurance, NCHS could certainly have provided print-outs (and may have done so) of the NHIS data on children's health insurance status. These data, however, would have been less useful than the CPS data because they would have been older and not state-specific. One informant stated that the latest unpublished health insurance data available from NHIS in 1996 would probably have been from 1993.

Data from the Medical Expenditure Panel Survey (MEPS) also was mentioned infrequently by informants. The first issue of MEPS HIGHLIGHTS was issued in May 1997 and thus was available during the deliberations. Although it contained an estimate of the number of uninsured children (11 million) and for a recent period (the first half of 1996), as well as some of their characteristics, MEPS could not provide state-specific data.

Two government agencies provided Congress with information on the health-related consequences for children of being uninsured.. The CRS included a two-page review of the literature on the impact of health insurance on access to health care and on outcomes in a Spring 1997 report to Congress¹¹. The GAO devoted an entire report to a literature review on this subject, but it was not issued until November 1997¹².

The major source of data on the costs of insuring the uninsured children came from the CBO. Some of these estimates, however, seem to have been based on earlier bills, rather than on CHIP per se. On June 16, 1997, the CBO sent Representative Bliley, Chairman of the House Commerce Committee, an estimate of the budgetary effects of the "Child Health Assistance Program," (a block grant proposal). It stated, "After accounting for spending on the provision of direct services and other activities, CBO assumes that states could cover about 500,000 children through new health insurance programs. In addition, CBO estimates that in the process of

enrolling children in these programs, states would identify some children who were eligible for Medicaid and would enroll them in that program. As a result, federal Medicaid outlays would increase by 50.7 billion over the 1998-2002 period; on a full-year equivalent basis, Medicaid enrollment would increase by about 125,000 children annually. Not all of the children newly enrolled in state programs or Medicaid would otherwise have been uninsured, however, so that the net effect of this provision would be to reduce the number of uninsured children by about 380,000.” But estimates of cost and number of children who would be covered changed as the various bills made their way through the legislative process¹³.

Staff- and Member-Level Support from the CRS. The CRS placed its usual role of providing information and analytic assistance to members of Congress, their staffs, and committee staffs on an ongoing basis during the legislative process. Its Spring 1997 report suggested many of the policy questions that interested the Congress and, in a few sentences for each, tried to answer these questions:

- What is the appropriate role for the federal and state governments in providing access to health insurance for children?
- What would the costs to the federal/state and local governments be?
- Who is the target population?
- What types of benefits should be provided?
- What would the costs to the beneficiaries be?
- Would there be adverse selection?
- Would public insurance “crowd-out” private coverage?

Members of CRS’s health insurance team were called upon especially for background

information about which states already had programs for uninsured children, the numbers of children covered, the benefits provided, and the costs of such programs¹⁴. Congress was interested in the various models of providing coverage and concerned about the impact of a federal law on the state programs. CRS staff also assisted Congress in preparing the House-Senate conference report.

Congressional Hearings. Although no hearing appears to have been held on the CHIP provisions as they were finally written, perhaps because they were written so late, several hearings were held on children's health insurance and related matters in March and April 1997¹⁵. The April 18 hearing of the Senate Committee on Labor and Human Resources examined "proposals to improve the health status of children, including S 435 and S 525, focusing on pediatric care, public health, mental health, and substance abuse issues." This hearing was very comprehensive and included testimony from several senators, including the ones sponsoring these bills, Secretary Shalala, a representative of the American Academy of Pediatrics and the National Association of Children's Hospitals and Related Institutions, the executive director of the American Public Health Association, a pediatrician from a children's hospital, and others. The GAO figures were cited again and also the problem of non-enrollment in Medicaid among those eligible. Secretary Shalala spoke in favor of bills that give money to states "so that they can design a program flexibly and put their own identity on it." She also supported allowing children to remain on Medicaid for a full year even if the child was no longer eligible.

Fact Sheets and Other Materials from Non-Governmental Agencies. Many organizations submitted fact sheets to members of Congress which described, briefly, the number and characteristics of children who were uninsured, the benefits of health insurance, and the

problems faced by uninsured children. But these advocacy groups clearly believed that the members of Congress and their staffs were not interested in details or were too busy to consider them. With few exceptions, the material was presented in one or two line bullets usually with no information about the original source of the data or when it was collected¹⁶.

One exception was “Facts About Uninsured Children” prepared in July 1997 by the National Maternal and Child Health Policy Consortium¹⁷, which supported the health insurance proposals. Although this five page document also presented information exclusively in a bullet format, references were provided for all statements. In addition to data on health insurance, the document devoted a page to “The Consequences of Having No Insurance,” (8 bullets on access and service utilization), and “The Health Value of Insurance,” (3 bullets on health, including low birthweight, newborn illness, and hospital admissions and mortality rates). Moreover, a footnote to the studies of consequences stated, “The studies reported in this section rely on cross-sectional data. While longitudinal or experimental data would be preferable, at this time such studies do not exist.”

Another well-documented fact sheet critiqued the health insurance proposals. On June 24, 1997 Citizens for a Sound Economy (CSE) issued a release questioning that 10 million children were without health coverage. CSE noted that the Census Bureau had reported that only 2.8 million children were “chronically uninsured” and that the rest of the 10 million were temporarily uninsured and regained coverage within four months. Moreover, CSE noted that the GAO estimated that 2.9 million uninsured children were already eligible for Medicaid but unenrolled. CSE then divided the CBO’s estimate of the five-year cost of one Senate bill (\$16 billion) by the net increase in the number of children covered (560,000) to arrive at an annual cost per child per

year of \$5,714, “over twice the cost of covering a child with private insurance (\$2,292).” The per child cost of the House bill was calculated to be even higher. CSE also cited CBO estimates of the numbers the proposed program would “force” to lost private health coverage, 245,000 for the House bill and 380,00 for the Senate bill. This issue paper did not use bullets and did provide specific citations.

The memos from staffers to members of Congress also sometimes took an abbreviated approach. A December 1996 memo to a member of Congress who was planning to submit a child health insurance bill included background material in bullet form. The first page dealt with the numbers and characteristics of uninsured children using the 10 million at any time in 1995 and 15 million at some point in time in 1995 figures, plus figures for the member’s state, from a Treasury Department estimate dated 7/94. Of the bullets with citations (not all of them had any), organizations mentioned were Newsweek, the Census Bureau, GAO, CDF, and EBRI. A second page began with the statement, “Insuring children is relatively inexpensive (premiums would likely range from \$500 to \$1000 per child) and has an enormous social and economic payoff.” No source was provided for the dollar figures. Five bullets were then devoted to “The Benefits of Insuring Children.” Three dealt with expenditures (citations were National Association of Children’s Hospitals, American Academy of Pediatrics, and CDF), one with insurance fostering utilization (The Urban Institute), and one with utilization by the uninsured (National Medical Expenditure Survey).

Congressional reports reflected this uncritical approach. For example, a House Budget Committee stated that uninsured children were “less likely to receive the primary and preventive care needed to improve their lifelong health,” and that “leading researchers in the field of

pediatrics have estimated that uninsured children may face lifelong medical expenses that could be as much as 20 percent higher than the cost of care borne by children who regularly receive the coverage or services they need.” No citation was provided.

The Congressional Quarterly in its only full article on children’s insurance between January and August 1997¹⁸, stated “With insurance costs mounting and many smaller companies declining to offer health plans, they (members of Congress) say children are suffering unnecessarily from asthma, acute ear infections, strep throats, and other ailments.”

Summary

The members of Congress probably obtained all the information that they felt that they needed in order to decide that a federal program supporting insurance for low-income children was needed and that CHIP was the best way to achieve it, given political realities. Congress was given data on the number of uninsured children, although there were some differences in the estimates. Also, the numbers of low income children who would actually be affected by CHIP directly or by its Medicaid provisions was not stressed. Congress was also provided some information on the influence of insurance on access, but less on the relationship between obtaining insurance and improving health status, with the focus being on the health problems of the uninsured.

This analysis of the data used in developing CHIP suggests that data were used, but uncritically. There were few references to the possible problems with the CPS data. There was much more emphasis on the total number of uninsured children and much less on the number who might be eligible under the new program for those under 200% of the FPL, a less awesome figure. There was limited discussion of the relative pros and cons of expanding Medicaid or

starting a new program. Clearly some were aware of the problems involved in increasing the number of children who were enrolled in Medicaid or should be enrolled in CHIP, because the legislation requires outreach to eligible families, but this issue was not discussed in much of the material. Allowing the states to decide whether to expand Medicaid, to use a private insurance approach, or to combine these, meant that Congress did not need facts about the problems Medicaid faced in many states or about the limitations of private insurance coverage. The states could be expected to seek such information when they determined how to implement CHIP. Barriers to access aside from the absence of insurance, well described in the literature, were infrequently mentioned by informants or in the material reviewed. And the link between access and health status was either assumed or supported very poorly. Health insurance was assumed to be a good, as indeed it is. Health insurance was assumed to lead to greater access, which is usually true. And outcomes were barely considered.

(This summary is, of necessity, based on written documentation, as well as on interviews. On some of these issues, members of Congress and their staffs may have received individual or group briefings, which were not reflected in the written materials or not recalled by the informants selected for this case study. The author apologizes for any oversights resulting from her limited data sources.)

SECTION II

The Implementation and Evaluation of CHIP

The federal government and the states are investing billions of dollars in CHIP. Will they be able to determine whether this has been a wise investment? Whether some approaches to implementation are more successful than others? What child health problems remain unsolved? The answers to these and other questions will require data.

This section will review what information the federal government requires of the states; some of the proposals for collecting information; possible state and federal data sources to assist in the assessment; and some special issues that may need attention as assessments of CHIP progress. Finally, it will suggest some lessons that can be learned from the CHIP experience to-date.

Information Required by the Federal Government

The same emphasis on state responsibility and authority that resulted in the range of CHIP implementation methods has made it impossible to impose a national evaluation program on the states. While many researchers have commented that the diversity in the state approaches to implementing the CHIP legislation may make CHIP a natural laboratory for determining which approaches are more effective in a variety of areas, this diversity also precludes a national evaluation. No reporting forms are required to be used by all states, beyond those currently in use for Medicaid. Rather the federal government has described the types of information that are required and is leaving it up to the states to determine the specific pieces of information and where they will be obtained. Several non-governmental agencies are assisting the states in meeting the federal requirements.

The federal requirements for states are incorporated into several documents.

State Plans. The legislation required that in order to obtain CHIP funds, each state needed to submit a plan to HCFA explaining how it intended to implement CHIP and requesting approval for the plan. The Application Template provided by HCFA listed several possible performance indicators:

- The extent to which outcome measures show progress on one or more of the health problems identified by the state.

- The HEDIS measurement set relevant to children and adolescents younger than age 19.

(States not utilizing the entire HEDIS set were to specify which measures would be collected.)

- Other child appropriate measurement sets. (These needed to be listed or described.).

State Annual Reports. The legislation (Section 2108a) requires that, starting in 1999, the states must submit annual reports to the Secretary of DHHS. These reports are restricted to the number of children enrolled and financial information . Some of these Annual Reports are now available on the web. They are difficult to aggregate because of the lack of uniformity even in the way they are organized.

State Year 2000 Report. A broader perspective on CHIP will be provided by the states and the federal government in response to the additional legislative requirement that each state submit to the DHHS Secretary by March 31, 2000 an evaluation of its program. (Section 2108b1) These reports will serve as a basis for the report that the DHHS Secretary must submit to Congress by December 31, 2001. (Section 2108b2)

The state evaluations must include:

“(A) An assessment of the effectiveness of the State plan in increasing the number of children

with creditable health coverage.

(B) A description and analysis of the effectiveness of elements of the State plan including--:

(I) the characteristics of children and families assisted under the State plan including age of the children, family income, and the assisted child's access to or coverage by other health insurance prior to the State plan and after eligibility for the State plan ends,

(ii) the quality of coverage provided including types of benefits provided,

(iii) the amount and level (including payment of part or all of any premium) of assistance provided by the State,

(iv) the service area of the State plan,

(v) the time limits for coverage of a child under the State plan,

(vi) the State's choice of health benefits coverage and other methods used for providing child health assistance, and

(vii) the sources of non-federal funding used in the State plan.

(C) An assessment of the effectiveness of other public and private programs in the State in increasing the availability of affordable, quality individual and family health insurance for children;

(D) A review and assessment of State activities to coordinate the plan under this title with other public and private programs providing health care and health care financing, including medicaid and maternal and child health services¹⁹.

(E) An analyses of changes and trends in the State that affect the provision of accessible, affordable, quality insurance and health care to children. “

Also required are a description of any plans the state has for improving the availability of health insurance and health care for children; recommendations for improving the program; and any other matters the state and the Secretary consider appropriate²⁰.

HCFA has contracted with a private firm, Mathematica Policy Research, Inc., to design and conduct a multi-faceted evaluation of CHIP. This evaluation will provide information for

HCFA's required report to Congress and also inform policy makers about CHIP implementation and its effect on health care for children. The evaluation is also expected to be used in Congressional deliberations on the reauthorization of CHIP. The evaluators describe several challengers to the evaluation (and later indicate how they will meet these challenges):

- variability of CHIP programs across states;
- lack of individual-level data in the state-designed programs;
- lack of reliable, state-level baseline data; and
- the difficulty of controlling for other changes that could affect the level of health insurance for and health care use by children.

Unfortunately, the CHIP legislation provided no funds for states to use in their required assessments. In January 1999, Senator Moynihan tried to overcome this deficiency by submitting a bill that would have provided such funds. S.206 would have amended Title XXI "to provide for improved data collection and evaluation of State Children's Insurance Programs, and for other purposes." The CHIP Data and Evaluation Improvement Act of 1999 contained provisions for

- adjusting the CPS to provide statistically reliable annual state data on the number of uninsured children by expanding the sample size in the state sampling units, expanding the number of sampling units in a state, and appropriate verification;
- collecting data on children's health insurance through the State and Local Area Integrated Telephone Survey (SLAITS);
- conducting an independent evaluation of 10 states with approved child health plans;
- standardizing the annual reporting requirements for CHIP;

- auditing a sample of states;
- coordinating CHIP data collection with data requirements under the Maternal and Child Health Services Block Grant; and
- establishing a clearinghouse for the consolidation and coordination of all federal data bases and reports regarding children's health.

In its original form, the bill would have appropriated 9 million dollars in fiscal year 2000 and subsequent years for the first two activities and 10 million in fiscal year 2000 for the 10-state evaluation. According to a member of the Senator's staff, this bill, except for the section on the state reporting requirements, on which Congress will defer to HCFA, has been included in a Senate bipartisan Medicare-Balanced Budget Amendment. Moreover, the House Commerce Committee package has similar provisions, so action in this area is possible.

Proposals for Collecting Information

Many organizations and individuals have proposed ways to collect the information needed for an assessment of CHIP. They agree that many types of data will be needed in order to determine what CHIP has accomplished and how it has done this. Information about some of the required process measures is available in administrative records and HEDIS, but obtaining information on most of the outcome measures, as well as some of the process measures, will need population surveys.

- In 1999, AHCPR and the Health Resources and Services Administration (HRSA) issued a report on the measures and sources of data that 47 states and the District of Columbia proposed to use in their quality and performance monitoring programs²¹. These included:

- o Performance monitoring measures. Most states planned to use all or a limited group of

HEDIS measures relevant to children and adolescents. Some planned to use selected measures from the states' Early and Periodic Screening, Diagnosis and Treatment (EPSDT) programs.

- o Site of care - ambulatory performance measuring. Most states planned to monitor immunizations, well child care, and adolescent well visits, all of which are included in HEDIS. A majority also planned to monitor dental care (if the plan offers dental benefits), emergency room utilization, and mental health utilization, also all in HEDIS. Fewer states planned to monitor care for chronic conditions, adolescent risk reduction interventions and health behavior counseling, and other measures not in HEDIS.

- o Site of care - inpatient performance measuring. States most frequently mentioned monitoring newborn care, mental health utilization, and asthma admissions and planned to obtain these data through HEDIS or by independent tracking.

- o Consumer satisfaction - The majority of states planned to monitor consumer satisfaction, some using HEDIS's Consumer Assessment of Health Plans Study (CAHPS) survey instrument.

- o Impact on health status - Few states included monitoring of specific child health outcomes.

The authors noted that, "approved CHIP programs will focus heavily on obtaining process measures (primarily utilization data) for both outpatient and inpatient care rather than defining target performance improvement goals or obtaining health outcome measures."

- Halfon, Inkelas, DuPlessis, and Newacheck²² have explored the types of data that will be needed to meet the federal requirements and provided an excellent framework for tracking

CHIP's progress and allowing it to be continuously improved. They suggest that CHIP be evaluated in terms of its impact on access to health insurance, as measured by enrollment and retention of coverage over time, and its impact on access to health services, defined as availability and use of services. Examples are provided of how structural, process, and outcome measures could be used in the enrollment phase. The authors believe that most of the structural measures, such as total expenditures per eligible child, can be obtained from administrative data. However, most of the process measures, such as time elapsed between initial request for coverage and becoming enrolled, would require population surveys. The outcomes measures are almost evenly divided between those that could be obtained from administrative data, such as proportion of children losing Medicaid eligibility who are eligible for and enrolled in CHIP, and those that would require population surveys, such as proportion of families who know about the state's CHIP program. Similarly, in the access phase, the authors list measures of usual source of care and provider choices, physical access, travel and waiting time, coverage of services, availability of services, and utilization of care. A few of these measures could be obtained from administrative data, but most will require patient and population surveys. Specific sources are given for the patient and population surveys, such as NHIS, MEPS, CAHPS, HEDIS, and the Community Tracking Study.

- In October 1998, the American Academy of Pediatrics published a State Children's Health Insurance Program Evaluation Tool²³, the result of a long planning process that had involved many individuals and groups. The Tool consisted of three matrices, one for access indicators (10), one for process indicators (11), and one for outcome indicators (9). For each indicator, the matrix listed target population, recommended data sources, model instruments, and expected

change. The data sources for the access indicators included household surveys, administrative data, employer/employee surveys, new enrollee surveys, and physician and dentists surveys. For the process indicators, administrative data were recommended in most cases but if they were unavailable, household surveys. For adolescents, a survey being developed by the Foundation for Accountability (FACCT) and the National Committee for Quality Assurance (NCQA) was recommended. The data sources for other outcome indicators were administrative data and household surveys, including, for adolescents, the Youth Risk Behavior Surveillance System (YRBSS). An appendix provided information about the major national surveys.

- In August 1999, the NASHP published *Framework and User's Guide for State Evaluation of the Children's Health Insurance Program*²⁴. The Guide was developed by an Evaluation Workgroup over a 5 month period. The Workgroup included the Acting Co-Chair of the DHHS Steering committee on CHIP, as well as representatives of HCFA and the White House, the National Governor's Association, the American Public Human Services Association, and nine states. The Workgroup believed that completing the forms in the Guide would allow states to meet their legal obligations for CHIP reporting, as well as present "an easy-to-read summary of how CHIP is working." The goals of the Evaluation Framework were to:

- o assist states in meeting federal statutory requirements;
- o provide consistency across states in the structure, content, and format of the report;
- o recognize the diversity of state approaches to Title XXI and allow states flexibility in highlighting key accomplishment and progress of their Title XXI programs;
- o build on data already collected by HCFA's quarterly enrollment and expenditure reports; and

o enhance accessibility to information on the achievements of Title XXI.

Concern about unequal state capacity to conduct assessments was shown in a boxed statement on an early page: “With respect to specific program elements covered in this Framework, some States may be able to provide information that is evaluative in nature, while other States may have limited experience and data and therefore will be more descriptive in their responses.”

The Framework is very specific. It shows what information is to be placed where and often how the computer should be used to do this, e.g., right click on the mouse. Although it is not a federal document and its completion is not a federal requirement, the presence of key federal officials on the Workgroup and the fact that drafts were reviewed by key Congressional staff suggest that states would be foolish not to use the forms. The Guide does not indicate where all the information is to be obtained, possibly because the earlier volume in the NASHP reports on CHIP provided that information.

- Starfield²⁵ has suggested that CHIP can succeed only if low-income children are provided with insurance, live in an area with available resources, and achieve both an affiliation and a linkage with a regular source of care that provides adequate primary care services. She has proposed methods for evaluating each of these determinants of improved health status using administrative and survey data.

State and Federal Data Sources for the Assessment of CHIP

The federal agencies and committees responsible for the implementation of CHIP have examined the existing federal data collection systems to determine what each might contribute to the CHIP’s assessment. Several private data systems have also been reviewed, especially the

National Survey of America's Families being conducted by The Urban Institute and the Community Tracking Study being conducted by the Center for Health System Change. Factors to be considered in determining whether the data system is appropriate for CHIP assessments include the sample, data collection methods, interval to report, types of information collected, and cost.

Sample. To be useful, the data collection system would need to have a relatively large sample of families generally or be targeted at low-income families with children under age 19. If only national data were needed, the sample could be selected using the sampling methods employed by the NHIS. If state-level data were essential, a state-based method would need to be developed.

Data Collection Methods. In general, experts believe that information collected by household interviews is more valid than that collected by telephone or by questionnaire. (The exception is very sensitive information and even in these cases, household interviews conducted using computer-assisted methods are providing information that appears to be valid.) However household interviews are very expensive and it may be necessary to use data systems that employ the alternative collection methods, adjusted on the basis of prior experience with such methods. Other considerations in regard to the data collection are its response rate, whether it is ongoing, and whether it can generate data at least on a yearly basis.

Interval to Report. One of the advantages of the CPS at the time that CHIP was developed was its ability to provide information for a recent period. No NCHS survey could match the CPS turn-around time. If the federal government or the states are to use an existing survey for assessing CHIP, it will need to provide reports within a year of data collection.

Types of Information. A wide range of information will be needed to assess the impact of CHIP. As noted earlier, much of it will come from administrative records, but data on insurance status and changes in insurance coverage may need to come from surveys. This would include whether Medicaid-eligible but previously unenrolled children were enrolled in Medicaid, whether CHIP-eligible children were enrolled in CHIP, and whether crowd-out had occurred. Obviously there are some situations where such a shift might occur and not represent crowd-out, such as when the principal breadwinner lost a job that had provided a family health insurance benefit. The data collection system would need to be able to distinguish between valid reasons for changes in the source of child health insurance and crowd-out.

Additional items that would be needed for a comprehensive assessment of CHIP are:

- the characteristics of the care received, including its accessibility, content, comprehensiveness, and coordination²⁶;
- quality of care received - using both objective and subjective measures;
- satisfaction with care received;
- utilization - visits to physicians and dentists for primary care, use of emergency rooms, hospitalization, etc.; and
- health status of the child - using both subjective (e.g., parents' perception of the child's health), and objective (e.g., days of limited activity, including days lost from school, control of chronic illnesses such as asthma or diabetes) measures.

Shortly after CHIP's passage, HCFA, HRSA, AHCPR, and other federal agencies began to investigate what federal data sets might assist the states in their assessment and also which federal data sets might be useful for a national evaluation. The most comprehensive review of

the potential sources was provided by the NASHP in December 1998²⁷. It listed 18 data sources and for each showed in matrix form whether it could be used to measure various aspects of insurance coverage/crowd-out, access to care, quality of care, and program administration. Three tables were provided:

- for data sources that were currently available and valid for use at the state level. These included the Area Resource File System; the Behavioral Risk Factor Surveillance System (BRFSS); the YRBSS; claims or enrollment data for Medicaid or CHIP; state uniform hospital discharge data sets; encounter, survey or chart-abstracted data gathered by managed care organizations for accrediting purposes (if the state was delivering CHIP services through HMOs); data gathered by states for reporting on Title V (these data are discussed in Section III of this case study); the National Immunization Survey (SLAITS); vital statistics; and Special Supplemental Nutrition Program for Women , Infants, and Children (WIC) data;
- for data sources that were available but only useful in selected states. These included the Community Tracking Study, the Health Care and Utilization Project (HCUP), MEPS, and the National Survey of America's Families; and
- data sources that were either not available currently or not useful for state-level estimates. These included the CHAPS, CPS, NHIS, Survey of Income and Program Participation, and SLAITS.

For many of these surveys, additional information about the data source was provided in appendices.

Special Issues Needing Attention

As various governmental and non-governmental agencies have worked on the

implementation and assessment of CHIP, several issues have arisen that may require attention.

Need to Monitor Changes in the Health Care System. The impact of CHIP on the health care system seems to be included, albeit vaguely, in sections D and E of the portion of the law that deals with state evaluations of CHIP. These sections deal with the coordination with other public and private programs providing health care and with changes and trends in the provision of health care. But the potential of CHIP to modify the health care system, particularly the safety net providers, might deserve more attention.

Because most Americans are insured and receive their care from private providers, much of the information available from the NHIS focuses on the care received in physicians' offices and in hospitals. Because of the relatively small number of individuals who use the providers in the safety net systems, this and other population-based surveys tend to aggregate these providers in their analyses and request relatively little information about them. Provider surveys have only recently begun to look at some of the safety-net providers, which include health departments, community health centers, hospital ambulatory care centers, and school-based health centers.

More information will be needed in order to assess the impact of CHIP on these providers. It might be expected that use of these facilities will decline as insurance coverage increases, but this was also anticipated when Medicaid was first implemented, i.e., that Medicaid families would flow into the mainstream of American medicine. But this did not happen, largely because Medicaid reimbursement rates were low and thus private practitioners were reluctant to accept patients whose bills were to be paid by Medicaid. The federal government and the states should want to know what happens to safety net providers as a result of CHIP and also of increases in the number enrolled in managed care. Do safety net providers survive? If they do

not, does this reduce access for children? For example, a decline in the number of school-based clinics might reduce access even if the percentage of children in those schools covered by health insurance increased. Also, if some safety net providers are forced out of operation, what happens to the funds that previously supported them?

Crowd-Out. When the CHIP legislation was being developed, members of Congress wanted to make certain that this coverage did not come at the expense of Medicaid or of private insurance. States were not to switch children from Medicaid to CHIP because of its higher rate of federal reimbursement. States were also to prevent crowd-out, i.e., they were not to allow employers to drop family coverage because children's coverage was now available through CHIP and they were not to allow parents to give up private insurance for their children for the same reason. So states not only need to count the number of children insured and determine whether it has increased; they must also show that CHIP has increased the number of previously uninsured children who were now insured. (This is further complicated by the federal government's interest in increasing the number of Medicaid-eligible children who were not currently enrolled in that program. CHIP is to increase the number of insured children both by enrolling in CHIP those not eligible for Medicaid, and also by enrolling eligible but unenrolled children in Medicaid.)

Studies conducted through 1997 of whether Medicaid expansion had caused crowd-out had reached different conclusions. Two (Cutler & Gruber, 1997²⁸; Dubay & Kenney, 1996 & 1997²⁹) found that the expansions had encouraged some families to drop private insurance coverage and accept Medicaid. Three other studies reported no effect (Shore-Sheppard, 1995 & 1996³⁰; Yasci, 1996.³¹) A Minnesota study found that 7.1% of MinnesotaCare enrollees reported

that they gave up existing private insurance to participate in MinnesotaCare: approximately 3% gave up employer-based coverage and 4%, individually-purchased coverage. But 5% of respondents dropped public coverage, mainly Medicaid, to join MinnesotaCare³². A recent Florida study showed limited crowd-out as a result of the Healthy Kids program, but the authors believe that some amount of substitution should be tolerated in order to ensure coverage for low-income children³³. Crowd-out was discussed in the GAO February 1997 report, an EBRI July 1997 Issue Brief³⁴, and the CRS Spring 1997 report. Crowd-out is technically difficult to measure and thought should be given to how best to address this problem.

Need for Baseline Data. In order to assess progress even in such a seemingly simple area as reducing the number of uninsured, states will need information on how many children were insured and under what system during some group of years between 1995 and 1997. No decision appears yet to have been made about what the baseline years should be. CPS, MEPS, and NHIS all provide data at the national level on the insurance status of children in the 1990s. Each of these data sources has advantages and drawbacks. Only the CPS data are available at the state level, but they are considered questionable for small states. Thus, while the states should be able to report the number of children enrolled in CHIP, they will have more difficulty in meeting the legislative requirement for reporting “progress in reducing the numbers of low-income, uninsured children.”

Need for State-Level Data. Most informants believed that assessing CHIP would require states to undertake expensive data collection activities, such as telephone surveys, or the federal government to modify existing surveys or develop new ones. A few informants noted that state officials’ dislike of federal involvement in their matters extended to data collection.

Thus, despite the problems involved in obtaining the information required by the legislation, plus other information that they might need to better understand the law's impact, many states opposed any federal agency telling them what to collect and how. The only current source of state-specific insurance information is CPS and, as noted earlier, the accuracy of its information overall has been questioned and it certainly can not provide valid information for the smaller states.

SLAITS, a relatively new NCHS data collection system originally designed to collect information on children's immunization levels by state, could be expanded to collect insurance data as well. While SLAITS is in the process of being expanded to include information on children with special health care needs for the federal Maternal and Child Health Bureau, it has not been funded to collect data on CHIP.

Other possible sources of state-level data are the Pregnancy Risk Assessment Monitoring System (PRAMS), BRFSS and YRBSS. These are conducted by the states under CDC guidance using a sample and a core set of questions designed by CDC, but with allowance for a limited number of additional questions chosen by the states. BRFSS has never asked about children, PRAMS focuses on the prenatal and postpartum period, and the YRBSS surveys children, seldom a good source of insurance information. Yet, by adding a few questions, each of these surveys might provide additional information about some aspect of CHIP.

Informants who were economists believed that collecting data on the impact of CHIP in all states was unwise and unnecessary, given the needed information. They recommended collecting data in a sample of states, perhaps several for each model of CHIP implementation, namely Medicaid expansion only, private insurance only, and combination; and then using

statistical modeling techniques to extrapolate to the other states and to the nation as a whole. This approach assumes that all the factors that might cause one state to differ from another within each of the implementation models is known, an assumption that can certainly be questioned. For example, most experts expect states to vary considerably in their outreach efforts and this would lead to between state variability that would probably not be captured by the models.

CHIP's Impact on Child Health. Some states have reported that they will monitor state-wide rates of certain variables, such as suicide rates or rates of absenteeism, as a way of assessing the impact of CHIP. This should probably be discouraged because if these rates did not improve, it might be taken as a sign of the failure of CHIP, when actually it would probably be because the CHIP population constituted such a small fraction of the entire population under consideration. Even within a managed care plan, it will probably not be possible to ascribe any changes in health outcomes to CHIP, again because the number of CHIP patients would be so much smaller than the total number of children. On the other hand, if because of CHIP, overall rates of insurance coverage increase for children, including both those enrolled in CHIP per se and those Medicaid-eligible children who were previously not enrolled, an improvement in access-sensitive measures might be expected.

Lessons Learned

Several lessons can be learned from this review of the difficulties in assessing CHIP.

Need to Interest Legislators in Data Collection and Evaluation

Data collection and evaluation received some, but not much, attention in the CHIP legislation. Today, more than two years after the passage of the legislation, there is still no overall plan for evaluating the impact of CHIP, although the NASHP Framework is a good

beginning, the Mathematica evaluation plans will provide much needed information, and the Moynihan bill may provide incentives, if passed. Congress and the administration seem willing to pass the responsibility for evaluating CHIP to the states. Unless action is taken soon, the opportunity will be lost to determine which of the approaches that the states take to increase coverage are more effective. Moreover, one can predict that when it comes time to reauthorize CHIP, members of Congress will complain about the lack of information upon which to make a decision. Action seems to be needed to convince federal and state legislators about the importance of supporting data collection efforts, not only to evaluate CHIP, but also to guide child health efforts generally. (See Section III of this cases study.)

Need to Include Funds for Evaluation

Members of Congress and their staffs need to be aware that collecting, analyzing, and reporting about programs is an expensive procedure. The CHIP legislation requires each state to spend 90% of its federal CHIP funds on insurance, leaving only 10% for all other functions including the mandated outreach to uninsured children. Because of the difficulty in enrolling children, particularly those of the working poor -- a problem already noted at the time of the Medicaid expansions³⁵-- the states are spending most of their money on outreach. This leaves few CHIP dollars for data collection and few states have their own funds set aside for such purposes. Congress has not yet provided funds for the expansion of any of its national surveys to provide the state-level, fast turn-around, comprehensive data needed. SLAITS, which is conducted on a state basis and was prepared to add insurance questions to its basic survey, has not been funded for the increase in questions and respondents that would be necessary for it to be part of a CHIP evaluation. (The Moynihan bill would make this possible.)

Need to Provide Critical Assessments of Data and Studies

It may well be true, if discouraging, that members of Congress only have time to read bulleted material and that they are not interested in the source, age, or possible limitations of the material presented. But members of Congress have several resources that could critically evaluate data and studies, and place their imprimatur on those that should be used to influence legislation. Those House and Senate committees that deal with health matters should, and often do, have staff members with this ability and CRS and GAO staff also can do this. Yet most of the materials reviewed did not critically analyze the subgroups within the category of uninsured children, nor devote much attention to the components (outreach, physician availability, primary care emphasis) necessary to make an insurance-based approach to child health be effective, points that were raised in some literature reviews. (Note earlier caveat on possible limitations of this case study because of data sources.)

Need for State-Level Data

The inability of several major federal data systems, especially NHIS and MEPS, to provide data on a state basis is a major drawback. It is perhaps understandable, given what these agencies appear to believe is their mission, namely to provide data on the health status and the medical care received by the nation as a whole. But responsibility for health and other social welfare programs is increasingly being delegated to the states and, because of this, data need to be available at the state level. Funds should be provided for this by federal and state governments. Moreover, members of Congress want to know how legislation that they pass has affected the lives of the people that they represent; and states and the general public want to know what is happening in their states³⁶. Collecting information at the state level would require

major changes in the current sampling methods and would be very expensive, especially if the data on the smaller states were to be valid. The NHIS sampling frame, on which MEPS depends, can provide state-specific data only for the largest states. According to one informant, it is not just a matter of increasing the size of the NHIS sample in each state, it would require redesigning the way that the sample is drawn. Congress has not shown any inclination to increase funding for the federal data collection agencies. Unless state-level data become available from federal surveys, some states will probably develop their own data collection systems with minimal federal guidance. This may in the long run be more expensive and will not produce data that can be compared across states. The CDC, in its PRAMS and BRFSS, has shown that federal-state partnerships in data collection can produce information that is comparable across states and can be aggregated.

Need to Shorten the Time between Data Collection and Availability of Reports

The NHIS has a long lapse between data collection and the issuance of reports, or even the availability of data from which individuals could generate their own reports. This problem is usually attributed to the absence of sufficient staff members to clean, process, and analyze data, and write reports. But often there has been no great need for rapid turn-around. CHIP and similar programs may make the need for a shorter interval more urgent.

SECTION III

DATA NEEDS IN THE AREA OF CHILD HEALTH

Many federal data systems appear to be adult-oriented. This is unfortunate and unacceptable, and probably has resulted from there being more adults than children and health care for children usually costing less than health care for adults. But the assessment of CHIP, as well as further progress in child health, will require more attention to child health measures. Although some traditional child health measures, such as mortality, have shown improvement in the last decade, children still suffer from preventable conditions, large health disparities by income and minority status continue, and significant numbers of children do not reach their full potential because of chronic physical and mental problems.

An example of the low priority given to child health data is the final report on Leading Health Indicators for Healthy People 2010³⁷. Three sets of indicators were developed based on:

- health determinants and health outcomes - 10 items, one on smoking among youth, most applicable to any age, and one not applicable to children;
- life course determinants - 9 items, several on children and youth (low birthweight, childhood poverty, enrollment in Head Start, alcohol and illicit drug use among youth, and physical assaults among youth and young adults), the remainder applicable to any age; and
- prevention - 9 items, one on childhood immunization, most applicable to any age, and two not applicable to children.).

Only the indicators based on life course determinants show much interest in infants, children, and youth.

Another example of the lack of attention to children's health needs can be found in

HEDIS 99. Only 12 of its 75 quality/access and use indicators are child-specific. Also, only 3 of the 33 indicators of hospital quality and community access in the Healthcare Cost and Utilization Project (HCUP) Quality Indicators apply specifically to children. As noted by Simpson and Fraser (also the source of these numbers), “we cannot expect research on adults to ‘trickle down’ to children.³⁸” This country needs as good, or better, data on children as on adults. Children’s needs may be different, but they are just compelling.

Current Data Systems

Several federal, state, and foundation-supported data systems track the health of infants, children, and adolescents. The federal systems are usually divided into vital statistics, population surveys, provider surveys, and systems based on claims and other administrative data.

The vital statistics system with its information on births and deaths is one, extremely valuable such system. Moreover, it is state-specific and data can be aggregated by even smaller geographical areas.

Among the population-based surveys, NCHS’s NHIS provides much information on children in its ongoing survey and much more in its infrequent child health supplements. Because these data are not available on a state basis, except for the largest states, states and smaller geographical areas must make synthetic estimates if they are to use the data at all. The MEPS, sponsored by AHCPR and NCHS, provides greater detail on health care use, expenditures, sources of payment, and insurance coverage³⁹. Because it uses the NHIS sample, which enables it to link MEPS and NHIS data, MEPS is also unable to provide state-level data. Other surveys with importance for child health monitoring include the National Survey of Family Growth and the National Health and Nutrition Examination Survey.

Provider surveys include the National Hospital Discharge Survey, the National Ambulatory Medical Care Survey, and the National Hospital Ambulatory Medical Care Survey. Administrative data are available through Medicaid claims and other sources.

Several surveys of maternal and child health are conducted by the states in cooperation with the Center for Disease Control and Prevention (CDC). These include BRFSS, YRBSS, and PRAMS (in 18 states). States also collect administrative data about who uses the services they provide and about Medicaid claims. Some states go beyond this and conduct population-based surveys of their residents.

Foundations, particularly the Commonwealth Fund, the Kaiser Family Foundation, and the Robert Wood Johnson Foundation, support private groups to conduct population-based surveys that answer specific questions about children and their families. Several foundations support The Urban Institute's program, "Assessing the New Federalism," which includes the National Survey of America's Families, conducted in over 44,000 randomly selected households in 13 states.

With such a wide range of surveys focusing, at least in part, on the health of children, it is surprising that this case study of CHIP has concluded that there may not be enough data to determine if CHIP meets the objectives established by Congress or anticipated by child health advocates. But the problem, as noted by many child health experts, goes beyond the inadequacy of present health data systems to provide the information needed for CHIP. These systems are also unable to:

- to describe child health as distinct from child ill-health;
- provide information essential to target small groups of children with serious health problems

or deficiencies in their health care; and

- provide the data needed by the federal Maternal and Child Health Bureau to prepare its Congressionally- mandated reports.

(The weaknesses of data systems that were noted in the case history, i.e., absence of state-level data, long intervals between data collection and data availability, and inability to monitor changes in the health care system will not be discussed again here.)

Child Health Not Ill Health

The national focus on health promotion and disease prevention has not been accompanied by the development of indicators that would measure positive health rather than illness or injury. Most of the indicators in the previously-cited report on Leading Health Indicators for Healthy People 2010 still reflect a negative view.

A recent plea for redefining the vision of maternal and child health away from disease prevention and toward health promotion included a section on a data strategy for realizing the new vision⁴⁰. The authors state, “one of the critical steps in redefining the vision toward health promotion and rebuilding the data strategy is reorienting the focus away from negative events, a deficit model, and toward positive attributes, an asset model.” Among the asset-based indicators listed are level of functioning and quality of life.

The need for better measures of child health should be considered in the evaluation of CHIP. Although most of the discussions about evaluation deal with insurance coverage and access, certainly these are not ends in themselves, but rather means to healthier children. The evaluation of CHIP provides an opportunity to consider exactly what the nation is trying to accomplish particularly through preventive health care. (The objectives of care for the sick or

injured child are more obvious.) Presumably children who have received adequate preventive care should enter school with:

- vision and hearing (corrected or uncorrected) adequate for learning;
- no decayed or missing teeth, except those that have fallen out and not yet been replaced;
- no disability or chronic illness that has not already been detected and controlled; and
- weight appropriate to height and age (if not, the reason should be determined).

This list could be extended for this age group and similar lists developed for younger and older children, but these examples should suffice to suggest the type of data that would be needed to determine if insurance and access had made a difference in the life of children, certainly more important than counting the number of child health supervision visits. These particular items of information could be collected during the examinations which many schools require when a child enters school. Thus, the source would be medical records transferred to school records. Other items, such as some measure of the quality of life, might be added to ongoing surveys such as the NHIS.

Children with Special Problems

Although many federal and other surveys have begun to over-sample populations believed to be at elevated risk, such as the poor and certain minorities (African-Americans and Hispanics), there remain vulnerable groups of children about whom little is known. Learning more about them would require over-sampling or special studies.

Some of these children are special because of where they reside. These children are not included in current survey samples or are not identified if included, or there are too few of them in the surveys to make meaningful estimates. Many studies have shown that children in foster

care or in prisons have more health problems than those being cared for in their own homes, yet no survey routinely monitors their health or their health care. Little information is available about children in institutions for the physically or mentally handicapped.

Other children are special because of what their parents do or their parents' legal status. Children in migrant labor families are a high-risk group about which too little is known. The health problems of children in immigrant families and how they change over time needs study⁴¹, particularly because of recent changes in rules about eligibility for federal benefits.

Another group is "children with special health care needs," a term adopted by the Maternal and Child Health Bureau in order to de-categorize and de-stigmatize this group of children who, from the inception of Title V in 1935 when they were called "crippled children," were considered a particular responsibility of the program. It was not until 1998, that an adequate definition of this term was published.

Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally⁴².

The Bureau is now trying to find ways to operationalize this definition so that the number of children with special health care needs can be counted and their health status, insurance coverage, service utilization, service needs, and other concerns can be determined, both overall and specifically for those served by Title V and by managed care organizations. The NHIS has some questions that could be used to suggest a child with special health care needs, such as limitation of activity or specific health conditions, but it is not broad enough to capture all such children nor does it provide enough information for program planning. The NHIS Child Disability Supplement provided additional questions that would identify these children, such as

perceived by parent to have a disability, but this is not an ongoing study. The Questionnaire for Identifying Children with Chronic Conditions (QuICCC) is being tested to determine whether it could be used on surveys to obtain some of the information needed.⁴²

Because these children, who are special because of where they reside, their families' status, or their health care needs, contribute disproportionately to the ill health and poor health care of this nation's children, more needs to be known about them. Statistical experts and program planners need to determine how data can be collected on these small groups of children in a cost-effective manner.

Data Needed by the Federal Maternal and Child Health Bureau

The Maternal and Child Health Bureau, which administers Title V of the Social Security Act, is mandated to provide information about the health of children in the individual states and the nation. Title V requires that states submit annual reports including:

Status of maternal and child health

- rates of low birthweight infants and of maternal, infant, neonatal, and perinatal mortality;
- the number of children with chronic illness and the type of illness;
- the proportion of infant born with fetal alcohol syndrome;
- the proportion of infant born with drug dependency;
- the proportion of women who do not received prenatal care during the first trimester of pregnancy;
- the proportion of children, who at their second birthday, have not been vaccinated against measles, mumps, rubella, polio, diphtheria, tetanus, pertussis, Hib meningitis, and hepatitis B.

Services

- the number of individual served by the state under Title V (by class of individuals);
- the proportion of each class of such individual which has health coverage;
- the types of services provided under Title V to such individuals within each such class;
- the amounts spent under this title on each type of services, by class of individuals served; and
- the number of pregnant women who were provided prenatal, delivery, or postpartum care under Title V or were entitled to such care under Medicaid; and

- the number of infants who were provided services under this title or were entitled to such care under Medicaid.

Some of the required health status items are easy to obtain from birth certificates, such as mortality, low birthweight, and prenatal care. The immunization data are now available through SLAITS. But neither fetal alcohol syndrome nor drug dependency is adequately reported on birth certificates and, in fact, these conditions may not become apparent until after the birth certificate is completed. Although states encounter relatively few problems in counting the numbers of individuals whom they serve (unduplicated counts and definitions of “serve” can cause problems), other health service items are more difficult to obtain. As indicated in the CHIP case history, the proportion of children with health insurance coverage is only reliably available for the largest states, as is the number of pregnant women and infants eligible for services under Medicaid (as distinct from the number who are enrolled).

In addition, in order to meet its obligations for monitoring state use of Title V funds, the Maternal and Child Health Bureau defined performance and outcome measures about which each state needed to provide information in its current Application/Annual Reports. A Guidance⁴³ published in December 1998 listed eighteen performance measures. Some only required counts of services, percentages of individuals receiving specified services, or data that could be obtained from vital statistics. But others needed data that would be more difficult to obtain such as:

- Percentage of children with special health care needs (CSHCN) who have a “medical/health home.” (This requires knowing the number of CSHCN, not just those served by Title V and then determining whether they have a medical/health home.)

- Percentage of third grade children who have received protective sealants on at least one permanent molar tooth. (Here again, the state may know how many children received this

service from the state, but information on all children would seem to be required.)

- Percentage of mothers who breastfeed their infants at hospital discharge. (Only states with PRAMS can probably provide this information with any validity.)

- Percentage of newborns who have been screened for hearing impairment before hospital discharge.

- Percentage of children without health insurance.

- Percentage of potentially Medicaid eligible children who received a service paid by the Medicaid program.

The Guidance also listed six outcomes measures all of which were based on mortality data and could be obtained from death certificates.

The Maternal and Child Health Bureau, in collaboration with the Association of Maternal and Child Health Programs, has been developing a series of health status indicators to be required in the states' Year 2001 Application/Annual Reports. An August 1999 version of these indicators, which have been pilot-tested but not finalized, included the following:

Access indicators

1. Ambulatory care sensitive conditions. The rate per 100,000 hospitalizations for asthma in children less than age 20.

2. Adequacy of primary care. The percentage of Medicaid enrollees and of CHIP enrollees turning 15 months old during the reporting year who received at least one well-child visit.

3. Oral health screening. The percentage of third grade children receiving an oral health screening during the year.

4. Medicaid and CHIP eligibility level. The percentage of poverty level for eligibility in the state's Medicaid and CHIP program for infants, children, and pregnant women.

5. Comparison of health status (low birthweight, infant deaths, first trimester prenatal care, adequacy of prenatal care) between the Medicaid population and the entire state population.

Environmental Indicator

6. Elevated blood lead level. The percentage of all children under age 6 with known elevated blood lead levels.

Family Support Indicator

7. The percentage of confirmed and probable child abuse cases among children less than 18 years old.

Infrastructure Indicators (State MCH data capacity - not relevant here)

Injuries Indicators

9. Fatal unintentional injuries. The rate per 100,000 unintentional deaths for children aged 12 months through age 9 years and for those age 10 through age 19 of fatal injuries due to motor vehicle crashes.

10. Nonfatal unintentional injuries (Same as above for nonfatal.)

Prevention

11. Adequacy of prenatal care. The percentage of women with a live birth whose ratio of observed to expected prenatal visits is greater than or equal to 80% (Kotelchuck index).

12. Interpregnancy intervals. The number of women with a repeat pregnancy occurring within 18 months of a previous pregnancy.

13. Sexually-transmitted diseases. The rates per 1,000 women age 15 through age 19 and age 20 through age 44 with a reported case of chlamydia.

14. Neural tube defects. The rate of neural tube defects per 10,000 live births.

Risk

15. Low birthweight. The percentage of live births weighing less than 2,500 grams (for all and among singleton births.)

16. Very low birthweight. (Same as above for those under 1,500 grams.)

17. Adolescent tobacco use. The percentage of adolescents age 15 through 19 who use tobacco.

A planning committee recommended that some of these indicators be “core”; other be

considered “developmental, i.e., states would not be required to collect this information until it was determined that appropriate data sources were available in all states; and others be dropped. The committee felt that additional indicators should be developed that address adolescent drinking, intentional injuries including homicide, smoking cessation among pregnant women, maternal mortality, adolescent mental health, and physical disabilities and transition issues for children with special health care needs.

Clearly additional state-specific, timely data will be needed if the states are to fulfill the legislative and the Bureau requirements for Title V. These data may come from additions to federal surveys, state surveys, or state administrative records developed to meet these data requirements. In addition, thought should be given to changing these requirements to move them away from the prevention of negative occurrences and towards measures of health.

Child Health Supplements to the NHIS

These data collection problems have not been caused by an absence of interest in the issue among child health experts or many members of the executive branch of the government. Federal committees meet to discuss data needs, studies of indicators of child well-being have been funded, and this section has reviewed several proposals for new measures, yet this case study suggests data inadequacies.

One approach, which has not yet been mentioned, is to improve the Child Health Supplements to the NHIS. These remain a major source of information about child health, but most child health experts believe that they are fielded too infrequently and do not include many important questions. One informant suggested that the NCHS appoint a panel of experts to review the child health supplement, and presumably the NHIS as well, to consider what items

should be included on an on-going basis.

Summary

The implementation of CHIP provides an opportunity to examine the adequacy of the nation's data system in terms of learning about children, their health care, their health status, and their unmet needs. The data systems, and particularly the surveys, currently available do not appear adequate to the task of evaluating CHIP or learning more about children's health in the 21st century. The need for developing new indicators of child health and for learning about populations of children with unique health care needs is particularly urgent. Advances in these areas should lead to improvement in the data collected by the states about Title V and other child health services.

ENDNOTES

1. Pear R. New Approach to Overhauling Health Insurance; Step by Step. Administration Learns From Defeat in Congress. The New York Times, November 11, 1996.

2. The report numbers and dates of these reports are:

Uninsured and Children on Medicaid (GAO/HEHS-95-83R, February 14, 1995)

Health Insurance for Children. Many Remain Uninsured Despite Medicaid Expansion

(GAO/HEHS-95-175, July 19, 1995)

Medicaid and Children's Insurance (GAO/HEHS-96-50R, October 20, 1995)

Health Insurance for Children. State and Private Programs Create New Strategies to Insure Children (GAO/HEHS-96-35, January 18, 1996)

Health Insurance for Children. Private Coverage Continues to Deteriorate (GAO/HEH)-96-129, June 17, 1996)

Medicaid and Uninsured Children, 1994 (GAO/HEHS-96-174R, July 9, 1996)

Employment-Based Health Insurance. Costs Increase and Family Coverage Decreases (GAO/HEHS-97-35, February 24, 1997)

3. Kaiser Family Foundation 1/16/97 survey - cited in Blendon RJ, Young JT, McCormick MC, Kropf JE. Americans' Views on Children's Health. JAMA 1998;280:2122-2127.

4. See discussion of New Federalism in the May/June 1998 issue of Health Affairs and response by Spitz and response to him by Well, Wiener, and Holahan in the November/December 1998 issue.

5. Committee on the Budget, House of Representatives. Balanced Budget Act of 1997. Report to Accompany H.R. 2915. June 24, 1997. (Report 105-149)

6. General Accounting Office. Health Insurance for Children. State and Private Programs Create New Strategies to Insure Children (GAO/HEHS-96-35, January 18, 1996).

7. National Conference of State Legislatures. State Programs for Providing Children's Health Insurance—A Resource Notebook. Washington, DC, May 1997.

8. Edmunds M, Coye MJ (editors). American's Children. Health Insurance and Access to Care. Washington, DC, National Academy Press, 1998.

9. This section of the case study is based on publicly-available government documents, reports of several non-governmental organizations, journal articles, the material in the files of one Congressional aide, and the reports of informants provided during in-person interviews conducted between Fall 1998 and Spring 1999, over a year after CHIP's passage.

10. Congress relied on the CPS for determining the number of children who would ultimately be insured under the program, and thus the ultimate cost of the program. In addition, it decided to

use the CPS to determine state allocations, “a determination of the number of low-income children (and of such children who have no health insurance coverage) for a State for a fiscal year shall be made on the basis of the arithmetic average of the number of such children, as reported and defined in the 3 most recent March supplements to the Current Population Survey of the Bureau of the Census before the beginning of the fiscal year.”

11. Fuchs B, Hearne J, Lyke B, Purcell P. Health insurance for Children: Legislation in the 105th Congress. CRS Report for Congress, 1997. (97-385 EPW)

12. General Accounting Office. Health Insurance. Coverage Leads to Increased Health Care Access for Children. (GAO/HEHS-98-14), November 1997.

13. On July 7, 1997 Faulkner & Gray’s Medicine & Health cited a June CBO estimate of a 460,000 net drop in uninsured children on the basis of the House Commerce Committee’s block grant proposal. The newsletter stated, however, that the CBO estimated that the Senate \$24-billion bill would increase the number of children who would receive health care coverage to more than 2.7 million from 1998 to 2002. “But several offsetting factors, especially ‘crowding out’ of existing private coverage, show the initiative still falling far short of the 5-million target in the Clinton Administration’s budget agreement with Congress.” The newsletter stated that “CBO estimates that about 40 percent of the kids who would receive new coverage will have been previously insured, reducing a gross total of 2.79 million to 1,670,000 previously uninsured children the Senate bill would cover.”

14. Congressional Research Service. General Distribution Memo.

15. These included:

- Subcommittee on Health and Environment, House Committee on Commerce - March 11 - “Medicaid Reform: The Governors’ View.” The Governors of Utah and Nevada testified, as did a representative of the GAO, of the Kaiser Family Foundation, and a former HCFA director. The proposed legislation was not discussed.
- Senate Finance Committee - March 11 - “Medicaid Reform.”
- Subcommittee on Health, House Ways and Means Committee - April 8 - “Children’s Health Coverage.” A GAO representative testified on “Health Insurance for Children,” using information from earlier GAO reports.
- Senate Committee on Labor and Human Resources - April 18 - “Improving the Health Status of Children.”
- Senate Finance Committee - April 30 - “Increasing Children’s Access to Health Care.”

16. Typical fact sheets supporting the proposal were

- A Fact Sheet issued by the Democratic Policy Committee, United States Senate, gave the 10.5 million uninsured children in 1995 figure, three bulleted descriptions of the characteristics of uninsured children for which EBRI and the CRS were cited, and five bulleted descriptions of children’s health problems, only two of which mentioned insurance for which CRS, GAO and CDF were cited.

- A CDF fact sheet provided these and other examples of the benefits of insuring children, but without any citations.

- The director of government affairs of Families USA, was quoted as saying, “The lack of health insurance limits children’s access to health services, and lack of health services hurts children. This epidemic must be taken seriously.”

17. The National Maternal and Child Health Policy Consortium included Georgetown University, Johns Hopkins University, the federal Maternal and Child Health Bureau, the University of California at Los Angeles, and the University of California at San Francisco.

18. Hosansky D. Concern for Uninsured Children Has Not Led to Agreement. Congressional Quarterly, April 12, 1997 (pages 850-852).

19. In September 1998, the Association of Maternal and Child Health Programs issued an AMCHP Fact Sheet entitled, “Title V Performance Measures: A Tool for Assessing the Quality of Care Under SCHIP.” AMCHP suggested that the performance and health outcome measures required of states under the Maternal and Child Health Services Block Grant might be used in the evaluation of CHIP.

20. The Senate version of the bill did not include this list, only requiring states to provide an annual assessment of the program’s operation that included a description of progress in providing health insurance coverage for low-income children. The House’s list was incorporated into the law as a result of the House-Senate conference. See: Balanced Budget Act of 1997. Conference Report to Accompany H.R. 2015. July 30, 1997. (Report 105-217)

21. Wolfe WJ, Torres NP. Strategies for Performance Monitoring and Quality Assessment of the New State Children’s Health Insurance Program (CHIP): A Comprehensive Overview. (no further information given)

22. Portions of this framework were presented at a May 1998 meeting sponsored by the American Academy of Pediatrics and at a September 1998 meeting on “Learning from CHIP II. Critical Issues in Research Across States,” sponsored by AHCPR. They have been elaborated in two articles published in 1999:

Halfon N, Inkelas M, DuPlessis H, Newacheck PW. Challenges in Securing Access to Care for Children. Health Affairs 1999;18 (2):48-63.

Halfon N, Inkelas M, Newacheck PW. Enrollment in the State Child Health Insurance Program: A Conceptual Framework for Evaluation and Continuous Quality Improvement, The Milbank Quarterly 1999;77(2):181-204.

23. American Academy of Pediatrics. State Children’s Health Insurance Program Evaluation Tool. Elk Grove Village, IL, October 1998.

24. National Academy for State Health Policy. Framework and User's Guide for State Evaluation of the Children's Health Insurance Program. Portland, ME, August 1999.
25. Starfield B. Evaluating the State Children's Health Insurance Program: Critical Considerations. Annual Reviews of Public Health (in press)
26. For an excellent discussion of methods for measuring these concepts, see Starfield B. Primary Care. Concept, Evaluation, and Policy. New York, NY, Oxford University Press, 1992.
27. Rader A, Pernice C, Riley T. State and Federal Health Data Sources: An Inventory for CHIP Evaluators. Portland, ME, National Academy of State Health Policy, December 1998.
28. Cutler DM, Gruber J. Medicaid and Private Insurance: Evidence and Implications. Health Affairs 1997; 194-200.
29. Dubay LC, Kennedy GM. The Effects of Medicaid Expansions on Insurance Coverage of Children. The Future of Children 1996; 12-161.

Dubay LC, Kennedy GM. Did Medicaid Expansions for Pregnant Women Crowd Out Private Coverage? Health Affairs 1997:185-193.
30. Shore-Sheppard LD. "Stemming the Tide? The Effect of Expanding Medicaid on Health Insurance Coverage." Unpublished manuscript, November 1995.

Shore-Sheppard LD. "The Effect of Expanding Medicaid Eligibility on the Distribution of Children's Health Insurance Coverage." Unpublished manuscript, May 1996.

Yazisci EY. "Medicaid Expansions and the Crowding Out of Private Health Insurance." Unpublished manuscript, November 1996.
32. Call KT, Lurie N, Jonk Y, Feldman R, Finch MD. Who Is Still Insured in Minnesota? Lessons from State Reform Efforts. JAMA 1997;278:1191-1195.
33. Shenkman E, Bucciarelli R, Wegener DH, Naff R, Freedman S. Crowd out: Evidence from the Florida Healthy Kids Program. Pediatrics 1999;104:507-513.
34. Employee Benefit Research Institute. Expanding Health Insurance for Children: Examining the Alternatives. Issue Brief, Number 187, July 1997.
35. Selden TM, Bantnin JS, Cohen JW. Waiting in the Wings: Eligibility and Enrollment in the State Children's Health Insurance Program. Health Affairs 1999;18(2):126-133.
36. In reviewing the materials in one Congressional aide's files, this writer (who thought she was familiar with most acronyms) was at first confused by the use of two letter acronyms. After a while she realized that the aide was providing information about the number of uninsured in the

member of Congress's home state. Incidentally, it was a very small one, so the information was probably not very accurate. But this experience made it clear that members of Congress were influenced by what they could learn about their own state.

37. Chryvala CA, Bulger RJ.(editors). Leading Health Indicators for Healthy People 2010. Final Report. Washington, DC, National Academy of Science, 1999.

38. Simpson L, Fraser I. Children and Managed Care: What Research Can, Can't, and Should Tell Us about Impact. Medical Care Research and Review 1999;56:13-36.

39. The MEPS report on health insurance, access to care, and health status (Weigers ME, Weinick RM, Cohen JW. Children's Health, 1996. Rockville, MD, Agency for Health Care Policy and Research, 1998. [MEPS Chartbook No. 1. AHCPR Pub.No. 98-0008]) notes that future MEPS data will address additional aspects of children's health care including the impact of managed care, use of specific services, use of preventive services, amounts paid for health care and sources of payment, additional measures of health status including health conditions and functional limitation, changes in children's health insurance, and amounts families pay for private health insurance coverage.

40. Petersen, DJ, Bajalieh M, Alexander GR. Maternal and Child Health Promotion: Redefining the Vision and Rebuilding the Data Strategy to Promote the Health of the Nation's Children and Families. Washington, DC, Maternal and Child Health Information Resource Center, June 1999.

41. Institute of Medicine. From Generation to Generation: The Health and Well-Being of Children in Immigrant Families. Washington, DC, National Academy Press, 1998.

42. McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff JP, Strickland B. A New Definition of Children with Special Health Care Needs. Pediatrics 1998;102:137-139.

42. Stein REK, Westbrook LE, Bauman LJ. The Questionnaire for Identifying Children with Chronic Conditions: A Measure Based on a Noncategorical Approach. Pediatrics 1997;99:513-521.

43. Maternal and Child Health Bureau. Guidance and Forms for the Title V Application/Annual Report. Rockville, MD, June 4, 1998.