BACKGROUND BRIEFING REPORT
WITH SEMINAR PRESENTATIONS

HEALTH CARE REFORM AND CALIFORNIA'S VULNERABLE FAMILIES

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HEALTH CARE REFORM AND CALIFORNIA'S VULNERABLE FAMILIES

An Analysis of the Impact of Health Care Reform Proposals on California's Vulnerable Families and Children

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The California Family Impact Seminar provides nonpartisan information to government officials and policymakers concerning issues affecting children and families in California. CAFIS is a project of the California State Library Foundation, which is committed to preservation of the cultural heritage of California, and is sponsored by the State Library California Research Bureau which performs policy research for the governor and the State Legislature.

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CALIFORNIA FAMILY IMPACT SEMINAR
Promoting a family perspective in policies and programs.

State policymakers are challenged today by a host of family issues and problems that need to be addressed within the context of limited resources. There is a growing body of research on families, and on the numerous programs that seek to address family-related problems. Unfortunately, policymakers often do not have access to this current research and may instead rely on information that is out-of-date, biased, or inaccurate. This problem is exacerbated in California by the loss of state policy analysis resources due to ongoing budget cuts in the legislative and executive branches.

The ***California Family Impact Seminar (CAFIS)*** is a nonpartisan policy research and education project that seeks to provide accurate current information on family issues at state and local levels. ***CAFIS*** forums and briefing papers present cutting edge research on health and social indicators, and the development, implementation, and evaluation of public and private policies and programs.

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- Provide state policymakers with up-to-date, solution-oriented, and objective information on family policy issues from a family perspective;
- Provide a forum for frank and open consideration of various policy dilemmas and policy options;
- Facilitate productive communication among state legislators, legislative policy staff, gubernatorial staff, state agency officials, and state agency policy staff, with program professionals, policy experts, and researchers from throughout the United States; and
- Generate a family-centered approach to information, moving from a categorical program focus on the individual child or parent to one that evaluates the issue or problem and potential solutions within the context of the family.
- Assist policymakers and governing institutions to develop effective family-centered policy.

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Each year ***CAFIS*** holds a series of four to six seminars in Sacramento specifically designed to educate and inform state legislators and executive branch officials and their policy staff and to provide a forum for focused discussion. The current range of issues includes violence, child maltreatment, health care reform, family preservation, foster care, poverty, and literacy. The topics are chosen with guidance from the ***CAFIS*** Board of Advisors and the ***CAFIS*** Steering Committee

Seminars are two hours in length. The first portion of the seminar is devoted to presentations by a panel of recognized experts who discuss research findings and program experiences at the federal, state, and local levels, and review a range of policy options. The presentations are followed up with a question-and-answer period allowing for discussion among the panelists and participants. Each seminar is accompanied by an in-depth Background Briefing Report and followed up with a Seminar Presentation Summary.

CAFIS is a project of the California State Library Foundation and is sponsored by the California Research Bureau, which conducts policy research for both the legislative and executive branches of state government. The 1994 seminar series is supported by grants from the Henry J. Kaiser Foundation and the Stuart Foundations.

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INTRODUCTION

National and state proposals for health care reform range from those that would make modest changes in the current financing and delivery system to others that seek fundamental restructuring of the entire health care system. During this Congressional session, no fewer than 50 bills have been introduced with the goal of modifying the current health care system in some fashion. In California, several state-level health care reform efforts are also under way, each proposing vastly different approaches.

Opinion polls indicate that the general public shares an interest in the topic, with significant proportions indicating a willingness to levy new taxes to pay for better access to needed health care (University of Chicago, 1990). In a series of questions on specific programs, the National Opinion Research Center found that Americans supported by substantial margins additional government spending for health care for uninsured children, as well as preschool programs such as Head Start and services for disabled and chronically ill children.

Without doubt, the outcome of this debate has major implications for virtually all Californians. However, certain individuals, because of their low incomes and/or special health care needs, have a special stake in the resolution. While relatively small in number, some children require special attention in the health care reform debate because their health care needs are special. In addition to routine primary and preventive health care, these children also frequently need specialized equipment and services designed to address their medical, emotional or developmental conditions. Further, they need services tailored to their stage of growth and development provided by professionals skilled in pediatric care.

Unfortunately, vulnerable children far too often do not receive adequate health care either because they are uninsured, cannot afford the cost of care, and/or face other obstacles to the care they need. The national and state movements toward health care reform provide an opportunity to remedy these problems and maximize the level of health care given to vulnerable children. To achieve this goal, health care reform must contain certain features that address the specific needs of this group.

Unless properly designed, health care reform could fail to meet the needs of underserved families with vulnerable children, as well as run the risk of reducing access to care for those who currently receive the care they need. In California, these millions of families generally gain access to health care through means other than the private health insurance system. In many cases, parents or caretakers are either unemployed or are employed by a business that does not offer health insurance for workers and their dependents. Many other families require special health and related services that are not traditionally included in private insurance plans or, because of the extensive nature of the medical needs of one or more family members, are unable to obtain affordable private health insurance. There are also thousands of children in California who rely upon publicly-sponsored programs to meet all of their needs, including health care (such as the approximately 85,000 children in out-of-home care).

Federal, state and local government have a long history of providing health and related services to vulnerable families and children. Public programs evolved out of an identified need for specific services for particular populations: prenatal care for pregnant women; pediatric care for children; and comprehensive, community-based care for the developmentally disabled and the mentally ill. Thus, with the exception of Medi-Cal, each program is geared toward the individual and his or her particular needs and not toward the family as a whole. In an environment of scarce governmental funding, categorical programs have also facilitated cost control by focusing services on a specific population.

The purpose of this report is to focus on the health care reform debate as it might affect vulnerable families and children. The report does not deliberate on the question of whether or not government should be responsible for assuring the availability of health and related services. Rather, based on the supposition that government will continue to insure access, this report examines the impact of national and state health care reform on vulnerable families and on the public programs that serve them.

Chapter I describes California's vulnerable families. Chapter II reviews the public programs operating in California that provide health and related services to individuals who collectively are California's vulnerable families. Chapter III provides an overview of the different approaches to health care reform under consideration in Washington and in California. Chapter IV assesses the effectiveness of various national proposals to meet the needs of vulnerable families based on specific criteria. Finally, Chapter V draws some conclusions about the impact of health care reform on vulnerable families and provides some insights as to the issues of greatest consequence.

CHAPTER I: OVERVIEW OF CALIFORNIA'S VULNERABLE FAMILIES

In the context of health and medicine, the term "vulnerability" is often used to describe individuals who are at risk for health problems due to physiological, environmental or social factors and/or individuals for whom health care is essential for maintaining functioning or life. For children and pregnant women, vulnerability is usually defined by a set of characteristics or conditions that put them at risk for poor health, mental health, and/or developmental outcomes. For the purposes of this report, vulnerable families and children are defined as those who have special or chronic health care needs, who are at risk for health problems because of their social circumstances (regardless of income), or who are at risk for health problems because of poverty and its associated health threats.

Specifically, these populations include:

Low Income Children and Pregnant Women

"Low income" is generally defined in terms of the relationship of family income to the federal poverty level (FPL). As of February, 1994, the FPL is defined as income of $12,310 per year for a family of three. This group includes newly legalized immigrants and refugees and undocumented immigrants. These families -- predominantly women and children -- are at risk because their poverty may result in their inability to find and use timely, appropriate health care. Their lack of access to health care poses subsequent dangers to their health.

Families With Children Who Have Complex Health Needs

This group includes families with children who have acute or chronic illnesses or conditions, children with developmental disabilities, and children with mental illness. These children are considered at risk because their complicated or chronic, often serious, health needs may result in death, disability, or other health, mental health, or developmental problems.

Children With Complex and Often Multiple Social Needs

This group includes children in out-of-home placement (children in foster care, group homes or in the juvenile justice system) and adolescents. Children in out-of-home placement are regarded as at risk because they have been abused or neglected or they exhibit behavior that may be dangerous to themselves or others. Adolescents are often regarded as particularly at high risk for health and developmental problems because of risks associated with exposure to family and community violence, their sexual activity, and alcohol and drug use.

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CHAPTER II: HEALTH SERVICES FOR VULNERABLE FAMILIES

Factors associated with vulnerability are not only descriptive, but also largely determine one's qualifications for health care. Indeed, health services in our current health care system, particularly publicly-financed health services, have been developed in response to specialized health needs. These definitions of vulnerability largely determine who gets health and health-related care, the specific type and level of care available and accessible, by whom these services are provided, and the sources and degree of financial support available and their degree of stability. The major programs that currently serve these categories of vulnerable families and children in California are reviewed briefly below.

Income-Defined Services: Low Income Families and Children

In each of these programs individual or family income is the major eligibility criterion, sometimes in tandem with health or pregnancy status and age. In the case of immigrants and refugees the breadth of services covered is also linked to documentation status.

Federal and State Funded Programs: Medi-Cal, EPSDT, and CPSP

Medi-Cal. California's version of the federal Medicaid (Title XIX) program, Medi-Cal is the primary funder of health care and related services for low income families, with specific attention to serving children, mothers and pregnant women. Federal law requires the program to provide a core of basic services including outpatient care, inpatient hospitalization, physician visits, skilled nursing care, laboratory tests and x-rays, and family planning services. Private and public providers may elect to participate in the Medi-Cal program; Medi-Cal recipients are free to choose their providers from those who elect to participate. Mandated Medicaid services are covered by federal funds with a state match (generally 50:50). The federal government also provides match funding for 31 optional services, of which California now provides 28. Currently there are four major categories of eligibility for Medi-Cal:

> *Categorically Needy*. These are families or individuals who receive cash assistance under either Aid to Families with Dependent Children (AFDC) or the Supplemental Security Income/State Supplementary Program (SSI/SSP). People in this category automatically receive Medi-Cal eligibility cards and have no copay, or "share-of-cost," for their medical expenses. There are approximately 4.1 million eligible people who are Categorically Needy Medi-Cal recipients.
>
> *Medically Needy*. These are families with dependent children who are aged, blind or disabled persons, with incomes higher than the June, 1991 AFDC payment level ($694 for a family of three). People in this category have no share-of-cost if their incomes are between 100% and 133-1/3% of the AFDC payment for their household size. People with higher incomes may be eligible for Medi-Cal if their medical expenses require them to "spend down" their incomes to 133-1/3% of the AFDC payment level. This spend down

is called their share-of-cost. There are almost 1.1 million pregnant and parenting women, children, and aged, blind or disabled adults that receive Medi-Cal as Medically Needy or Medically Indigent.

Medically Indigent. Pregnant women and children under the age of 21 who meet the same income/medical expense requirements as the Medically Needy. There are approximately 8,800 newly legalized immigrants and refugees receiving services under Medi-Cal, and another 390,000 undocumented people receiving emergency services or pregnancy-related care funded by Medi-Cal.

"Nontraditional" Eligibles. Newly legalized and undocumented persons, as well as children and pregnant women who meet various income criteria (e.g., pregnant women and infants to 200% of the federal poverty level).

Eligibility for many people in these four categories is required by federal law; however, eligibility for some populations and categories (e.g., "Medically Needy" families) is provided at the state's discretion as an optional service. In addition, the state at its discretion has expanded the range of services available to several populations (e.g., children and pregnant women, including those who are undocumented).

In addition to these primary categories of eligibility, there are three major Medi-Cal programs designed specifically for vulnerable children and pregnant women. These include:

Early Periodic Screening, Diagnosis and Treatment (EPSDT). EPSDT, the pediatric component of Medi-Cal, provides for regular screening examinations, diagnostic services, and treatment services for children from birth to age 21 who are Medicaid-eligible. Under federal law, children are entitled to all Medicaid-covered services that are identified as medically indicated in the course of an EPSDT screening, whether or not the services are covered in an individual state's Medicaid plan. EPSDT services must be made available to all children from birth to age 21 who are eligible for Medi-Cal.

Medi-Cal "Sensitive Services." This eligibility category permits minor children up to 21 years of age to obtain a Medi-Cal card for specific services including mental health services, alcohol and drug treatment, treatment of sexually transmitted diseases, sexual assault treatment services, pregnancy related services, and family planning. The services are provided confidentially, without regard to parents' income, property or resources, and do not require parental consent.

Comprehensive Perinatal Services Program (CPSP). Funded by Medi-Cal and state funds, CPSP provides comprehensive perinatal services to pregnant and post-partum women with incomes to 200% of the federal poverty level and to their infants to one year of age. CPSP providers may be public or private, are certified to participate in the program, and receive a global fee for the package of services they provide. There is no share-of-cost to recipients.

State Funded Programs: CHDP and AIM

Child Health and Disability Prevention (CHDP). CHDP is an extension of components of the EPSDT program for children who are low income but not eligible for Medi-Cal. The program provides for health, vision, hearing, dental and other assessments and immunizations of children from birth to age 18 in families with incomes to 200% of the federal poverty level. More than three million children are believed to be eligible for CHDP services, although fewer than 40% of these children are receiving these services (Children Now, 1993). Pediatric providers are certified to participate in CHDP. There is no share-of-cost for children to participate.

Access for Infants and Mothers (AIM). This program is designed to provide services to pregnant and post-partum women and their infants to two years of age in families with incomes between 200 and 250% of the federal poverty level who are uninsured and are not eligible for Medi-Cal. AIM is a private health insurance alternative to the CPSP model. Under AIM the state contracts with private insurance plans to provide perinatal health services to pregnant and post-partum women (to 60 days post-delivery) and pediatric health services to the infants up to two years of age. The woman's share-of-cost is 2% of her family income and a $100 fee for the infant's health coverage for the second year.

State and Locally Funded Programs

Proposition 99 Services

The Proposition 99 Cigarette and Tobacco Tax provides funding for primary health care services at the local level for low income, uninsured families and children with incomes up to 200% of the federal poverty level who are not eligible for Medi-Cal. Health services may be provided by individual providers, private or public clinics, or hospitals.

"Section 17000" Services

Section 17000 of the Welfare and Institutions Code provides that counties are responsible for the health and welfare of their citizenry. Over the more than fifty years that this statute has been in place, it has been tested and upheld in the courts to mean that, regardless of a person's ability to pay, counties are the "providers of last resort." Therefore, anyone in need of health care who is not eligible for a program sponsored by the state or federal government or does not have access to health care through other means, can look to the county to meet their need. There is no consensus as to the number of persons currently served in county or county-sponsored health programs. However, it is the providers of last resort that families and children depend upon for care when it is otherwise unavailable.

Status-Defined Services: Families With Children Who Have Special Needs

An array of federal, state and county funded programs exist to serve children with special health needs. It should be noted that these programs are not designed to serve the parents or other children in the family. Eligible children may be recipients of services through several of these programs at one time, as well as obtain their primary health care and other services under Medi-Cal or through private health care insurance. In addition, some of these programs impose income-related eligibility criteria while others do not. The programs discussed below do not represent a complete list of all services for children with special needs. However, they include the major programs that serve large numbers of these children.

Children With Special Health Needs

Children With Acute/Chronic Illnesses or Conditions. These children may receive services through programs such as California Children's Services (CCS) for children with chronic illnesses or physical disabilities as defined by state regulations. State regulations define CCS-eligible conditions including orthopedic conditions, conditions requiring plastic surgery reconstruction such a cleft lip, eye conditions leading to the loss of vision, phenylketonuria (PKU), hemophilia, convulsive disorders that pose medical management problems or problems of diagnosis, neoplasms, chronic pulmonary conditions such as cystic fibrosis, and congenital anomalies.

Another program that serves these children is the High Risk Infant Follow-up Program (HRIF). HRIF is for infants who have been discharged from a neonatal intensive care unit or a community agency and who meet state-defined biological and other risk factors. HRIF eligibility criteria require that infants and toddlers (to age 2 or 3 depending on the program) must be at significant risk for developmental delay following discharge from a neonatal intensive care unit. Biological risk factors include prematurity, required assisted ventilation, neonatal seizures, congenital anomalies, and prenatal alcohol or drug exposure; environmental risk factors include an adolescent mother, concerns regarding infant-parent bonding, environmental chemical exposure, mothers with an educational level of 10th grade or less, and maternal alcohol or drug use. CCS is funded through a combination of federal Title V Maternal and Child Health (MCH) block grant funds and state and county funds. HRIF is funded by the state.

Children With Developmental Disabilities. Children with mental retardation, cerebral palsy, and other conditions, may receive services from Regional Centers, Special Education programs, and the State Developmental Centers. The 21 Regional Centers around the state are private non-profit agencies funded through state contracts to purchase or provide services to prevent or mitigate developmental disabilities. Developmental Centers are residential institutions for the most severely developmentally disabled individuals, including infants and children. Special Education programs to mitigate disabilities are funded through a combination of federal and state education dollars. The purpose of Special Education is to assure that a child receives whatever services are necessary to assure him or her a free and appropriate education.

Children With Mental Illness. These children may receive treatment and case management services from federal**,** state and locally funded County Mental Health services. These are available in addition to psychological and psychiatric services through fee-for-service Medi-Cal (if eligible) and federal and state funded Special Education programs. Residential treatment is provided in state hospitals, group homes, or other psychiatric facilities. For school children diagnosed as seriously emotionally disturbed, the AB 3632 component of Special Education directs the local school, social services and mental health professionals to develop and fund a wide range of mental health services geared at improving the child's ability to benefit from his education. Adolescents are also eligible for mental health services through Medi-Cal under the Sensitive Services program.

Children With Complex Social Needs

Children in Out-of-Home Placement. This includes children in foster care, group homes, and the juvenile justice system. Children in foster care (approximately 85,000 children in California) receive case management and other services through county Child Welfare Services that are intended to improve their access to health care. Most, but not all, children in foster care are eligible for Medi-Cal. Children in most juvenile justice facilities are not eligible for Medi-Cal; their primary health care is often dependent on the largesse of local and state juvenile justice agencies and local public health programs.

Special Services for Adolescents. Youth up to age 21 who are pregnant or parenting may receive case management and support services to improve their access to health and other important services for themselves and their children from Adolescent Family Life Programs (AFLP). AFLP is funded with Federal Title V Maternal and Child Health funds through contracts to local non-profit agencies. As noted above, adolescents also have access to short-term Medi-Cal for limited services through the Medi-Cal Sensitive Services program. School-based clinics and similar programs are also growing in California, aided by recent legislation such as the state's Healthy Start program. AFLP, Sensitive Services Medi-Cal, and school-based clinics are among the very few publicly funded programs now available in California that are targeted to adolescents' special health and social needs.

Tables 1 and 2 illustrate the services available, populations served, eligibility criteria, benefits, financing and delivery system for these major programs serving vulnerable families and children.

Table 1

OVERVIEW OF EXISTING HEALTH-RELATED SERVICES FOR VULNERABLE FAMILIES AND CHILDREN

Population	Program	Eligibility	Benefits	Financing	Delivery System
AFDC-eligible or linked families	Medi-Cal	Based on income and assets	Coverage for medical, dental, vision, mental health, tests, prescription drugs, etc.	Federal Title XIX; state matching funds	Private providers, private and public clinics and hospitals
Pregnant women eligible for Medi-Cal	Comprehensive Prenatal Services Program	Based on income and assets	Enriched prenatal care with supportive services. (This program is a component of the Medi-Cal program.)	Federal Title XIX; state matching funds	Private providers, private and public clinics and hospitals
Children of AFDC-eligible and linked families; children near or below poverty	Early Periodic Screening, Diagnosis and Treatment (EPSDT)	Based on income; serves children up to age 21	EPSDT provides screening, evaluation and treatment	Federal Title XIX; state matching funds	Private providers, private and public clinics and hospitals
Low income children not eligible for Medi-Cal	Child Health and Disability Prevention Program (CHDP)	Based on income; children up to age 21 of families with income up to 200% of FPL	Health, developmental, and mental health screening, diagnosis and treatment according to pediatric periodicity schedule	State tobacco tax funding	Private providers, private and public clinics and hospitals
Low income pregnant women and infants not eligible for Medi-Cal. Children up to age 18 of low income families	Access for Infants and Mothers (AIM)	Children of enrolled mothers, from birth to age 2, to 250% of FPL	Prenatal and delivery services; pediatric care	State tobacco tax funds	Private providers, private and public clinics participating in select HMOs and health plan.
	Prop. 99 County Health Care	Children not eligible for Medi-Cal from families with incomes up to 200% of FPL	Pediatric care	State and county funds	Private providers, private and public clinics and hospitals
Children with acute/chronic conditions	California Children's Services (CCS)	Children with acute or chronic conditions; may be served regardless of family income	Specialty medical services, home health care, medical supplies and equipment, occupational and physical therapy	Federal Title V (MCH), state and county funds	Private providers, private and public clinics and hospitals

OVERVIEW OF EXISTING HEALTH-RELATED SERVICES FOR VULNERABLE FAMILIES AND CHILDREN
(continued)

Population	**Program**	**Eligibility**	**Benefits**	**Financing**	**Delivery System**
Children with acute/chronic conditions (continued)	High Risk Infant Follow-Up Program (HRIF)	Infants and toddlers at risk for developmental delay due to biological or environmental factors; may be served regardless of income	Health and developmental assessments; occupational, physical, and speech therapy; parent support, case management	State funds	Designated programs and providers
Children with developmental disabilities	Regional Centers	Children and adults with developmental disability (state definition with onset before age 18)	Health and developmental assessments, health services if not CCS or Medi-Cal covered, case management, physical and other therapy, counseling	State funds	Designated programs and providers
Children in out-of-home placement	Foster care case management. Most of these children are also eligible for Medi-Cal	Children up to age 18 who require out-of-home placement because of abuse or neglect or risk of abuse/ neglect	Case management through county Child Welfare Services	Federal Title IV-E, Title IV-B funds; state matching funds; additional local funds	County Child Welfare Services caseworkers
Children with mental illness	County mental health	Children who meet definition of serious emotional disturbance	Individual, group and family therapy, case management, residential care, day treatment, inpatient psychiatric hospitalization	Federal Medicaid and Mental Health Block Grant funds, state matching funds, county funds	Private providers, private and public clinics and hospitals
	Special Education AB 3632 services	Children identified by the schools as needing services in order to benefit from their education	Individual, group and family therapy, case management, residential care, day treatment	State and county funds	County-designated public and private providers, clinics and hospitals
Pregnant/ Parenting Adolescents	Adolescent Family Life Program (AFLP)	Pregnant or parenting teens regardless of income	Case management, counseling, support groups, and parenting education	Federal Title V (MCH) funds, state funds	Designated programs

Table 2

FUNDING SOURCES OF PROGRAMS FOR VULNERABLE FAMILIES AND CHILDREN

PROGRAM	FEDERAL SOURCES	STATE	COUNTY
AB 3632 (Special Ed/SED)		X	X
AFLP	Title V (MCH)	X	X
AIM		X	
CCS	Title XIX (Medicaid)	X	X
CHDP		X	X
Child Welfare Services	Title IVE, Title IVB	X	X
County Health Services (Prop. 99)		X	
County Mental Health Program	Mental Health Block Grant	X	X
CPSP	Title V, Title XIX (Medicaid)	X	
EPSDT	Title XIX	X	
Family Planning	Title X (Family Planning)	X	X
HRIF		X	
Medi-Cal (Medicaid)	Title XIX	X	
Regional Centers		X	
Special Ed	PL 94-142	X	X

CHAPTER III: APPROACHES TO HEALTH CARE REFORM

The current deliberations around health care reform are not unique to this place and time. The organization, financing and delivery of health care in this country has been the subject of debate for nearly a century. For example, significant efforts to establish national health insurance date to the period 1915-1920 and were repeated in the mid-1930s, as well as during the Johnson, Nixon and Carter Administrations (Starr, 1992). The creation of the Medicaid and Medicare programs grew directly out of the health care reform debate of the mid-1960s, serving to substitute for more significant reform.

The current national health care reform effort represents the first major undertaking in nearly a quarter century. Now, as in the past, the impetus for reform stems chiefly from two primary concerns: (1) the inability of large numbers of persons to obtain needed health care, and (2) the high costs associated with health care. Between 1980 and 1990, the number of persons without any form of health insurance rose dramatically. Between 1978 and 1989 alone, the number of uninsured Americans increased by 37% (Employee Benefits Research Institute, 1992). By 1991, 36.3 million persons under 65 had no health insurance, public or private (Employee Benefit Research Institute, 1993). In California these numbers translate to six million people without insurance; 17.8% of the state's children are uninsured (Center for the Study of Social Policy, 1993). Because uninsured individuals commonly delay health care until treatment is unavoidable, lack of health insurance can lead to undue harm to the patient as well as higher health care costs. At the same time, health care costs rose from 9.1 percent to 12.2 percent of the gross national product (GNP) (Health Insurance Association of America, 1992). According to the Government Accounting Office (GAO), the United States is projected to spend over 16% of its GNP on health care by the year 2000 (GAO, 1992).

Scores of bills on the subject of health care reform are currently pending before Congress as well as in many state legislatures, offering approaches ranging from modest changes in the current financing and delivery system to more fundamental restructuring of the health care system . This wide variation in approaches to health care reform in part reflects differing views about the nature and extent of the health care “crisis.” That is, while some observers consider it only to be in slight imbalance, others regard the health care system as near the brink of collapse. The specific models proposed generally mirror these views. Perhaps more important, however, are fundamentally differing attitudes towards social issues generally. Indeed, embedded in the health care reform debate are central questions about: (1) the role of government in addressing social problems (such as health status); (2) who should pay for reform; and (3) the degree to which individuals, rather than society, are responsible for meeting individual needs. While many of these debates reflect ideological differences, they translate in practice into very different approaches to health care reform both in Washington and in California.

The Washington Debate

The varying models of health care reform under consideration by Congress fall on a continuum ranging from proposals which seek to maintain while modestly altering the current health care system to proposals which fundamentally change the way health care is financed and administered. When this report was written in mid-May, 1994, five major proposals had been introduced and were receiving the greatest attention. These proposals are described below.

The Affordable Health Care Now Act (Michel plan)

Introduced by Senator Trent Lott (R-MS) and Representative Bob Michel (R-IL), this plan encourages purchase of private coverage through reforms designed to reduce the price of private insurance and expands Medicaid to permit states to subsidize coverage for additional low income residents.

The Managed Competition Act (Cooper/Breaux plan)

Introduced by Senator John Breaux (R-LA) and Representative Jim Cooper (R-TN), this plan encourages purchase of insurance through the use of health alliances, offers other measures to bring down the cost of private coverage and replaces Medicaid with a subsidy system to offset the cost of coverage for low income persons. Employer contributions are not required.

The Health Equity and Access Reform Today Act (Chafee/Thomas plan)

Introduced by Senator John Chafee (R-Rhode Island) and Representative Bill Thomas (R-CA), this plan guarantees universal insurance coverage for all U.S. citizens and legal residents, but retains the Medicaid program to cover certain low-income persons. Individuals not eligible for Medicaid would be required to buy coverage, but no employer subsidies are provided. Individual subsidies would be conditioned on savings in government programs.

The Health Security Act (Clinton Administration plan)

Introduced by Senator George Mitchell (D-ME) and Representative Richard Gephardt (D-MO) and developed by the President's Health Reform Task Force, this plan guarantees universal coverage for all U.S. citizens and legal residents. Benefits are financed through mandatory employer and individual premiums.

The American Health Security Act (Wellstone/McDermott)

Introduced by Senator Paul Wellstone (D-MN) and Representative Jim McDermott (D-WA), this plan guarantees universal health insurance for all U.S. citizens and legal residents through what is known as a single payer plan. Coverage is provided through a government program, with individual, corporate and other taxes in lieu of premiums.

Among the many other bills under consideration is a proposal sponsored by Representative Pete Stark (D-CA). Technically an amendment to the Clinton Administration proposal, Congressman Stark's proposal differs from the original Health Security Act by covering those without employment-based insurance through an expanded Medicare program, rather than insurance premium subsidies. This proposal was voted out of the House Ways and Means Subcommittee on Health and is currently pending before the full Committee.

Since mid-May, Senator Edward Kennedy has promoted his own version of the Clinton Administration plan. This measure was adopted by the Democratic majority of the Labor and Human Resources Committee. Also, Senator Patrick Moynihan is at work trying to craft a bipartisan proposal for consideration by the Senate Finance Committee. While the Kennedy and Moynihan proposals are now in the limelight, there is no individual proposal that, at this point in time, is the lead measure.

Detailed information on each of these bills is presented in Table 3. In addition to describing each proposal in terms of the general approach, this table describes the three dimensions of the plans that are of special importance to vulnerable families and children:

- Populations to be covered;
- The benefits to be provided; and
- Provisions for cost sharing by families.

Tables 4 through 7 assess the impact of each of these proposals for the individual groups that make up California's vulnerable families. Although the fate of these individual proposals is uncertain, this information is still very instructive. Each of these proposals is still awaiting Congressional action; portions have been incorporated in one of the latest committee-approved proposals or are under consideration for inclusion in still other proposals under development.

Health Care Reform In California

At the same time that the President and Congress are acting to achieve health care reform at the national level, efforts are underway for health care reform in California. These reforms include:

- Medi-Cal managed care;
- State-sponsored private insurance reforms; and
- A campaign for a single payer system in the state.

All of the proposals dovetail with plans proposed at the national level. Indeed, both the Small Employer Purchasing Pool Program and the Medi-Cal Managed Care Program have been cited as "dress rehearsals" for implementation of national reform.

Medi-Cal Managed Care

In 1993 the California Department of Health Services (DHS) began implementation of a plan to transform the Medi-Cal program from traditional fee-for-service to managed care. Under managed care, providers are prospectively paid a capitated payment for each enrollee (or patient), for which they are expected to furnish all specified services. This contrasts with the fee-for-service payment system, under which providers are paid a specified amount for each service rendered. The primary group slated for managed care under this plan are families receiving Aid to Families with Dependent Children (AFDC). Over time, other Medi-Cal beneficiaries are expected to be phased in.

Under the DHS plan for Medi-Cal managed care, all AFDC recipients in the state's thirteen largest counties will be in managed care by April, 1995. The thirteen counties are Alameda, Contra Costa, Fresno, Kern, Los Angeles, Riverside, San Bernardino, San Diego, San Francisco, San Joaquin, Santa Clara, Stanislaus, and Tulare, with a total of 2.3 million people eligible for enrollment in managed care. Medi-Cal recipients in these counties will choose among two plans for all personal health care services, including perinatal and pediatric care. These two plans will include:

- A "Local Initiative" plan, developed and implemented by a county's board of supervisors; or
- A "Mainstream" plan, which is likely to be a single HMO selected by DHS through a competitive bidding process.

Under the two-plan model consumers must be offered a choice of primary care providers participating in the plan's network and must be permitted to change providers if dissatisfied. The Local Initiative must also ensure a role for "traditional safety net providers" such as public hospitals and clinics. Once the two-plan model has been fully implemented in a county, fee-for-service Medi-Cal will be discontinued for AFDC beneficiaries.

In addition, the state's plan for Medi-Cal managed care includes two other approaches to managed care:

County-Organized Health Systems. Two counties, San Mateo and Santa Barbara, already have county-organized Medi-Cal managed care plans. Three additional counties -- Orange, Santa Cruz, and Solano -- are now organizing this type of managed care system, adding 220,000 Medi-Cal beneficiaries to managed care. Under this model, a county-organized health care system is created by the county's board of supervisors to contract with Medi-Cal to administer a county-wide capitated health care system for Medi-Cal recipients.

Geographic Medi-Cal Pilot Program. Sacramento County has organized a geographic-based pilot under which DHS will contract with multiple managed care plans with the goal of enrolling the county's entire AFDC population in managed care. AFDC recipients may select the individual plan in which to enroll.

State-Sponsored Private Insurance Models

At the direction of the California legislature, the state has developed two new programs to provide health insurance coverage to uninsured Californians: (1) the Managed Risk Medical

Insurance Program (MRMIP); and (2) the Small Employers Purchasing Pool Program (known as the "Health Insurance Plan of California"). Both are administered by the state's Managed Risk Medical Insurance Board (MRMIB).

Major Risk Medical Insurance Program (MRMIP). Established in 1991 MRMIP provides health insurance to California residents who are unable to obtain it for themselves or for their families because of pre-existing medical conditions. The program is available to California residents who: (1) are not eligible for employee continuation health benefits under COBRA; (2) are not eligible for both Medicare Parts A and B; and (3) can document that they are unable to obtain adequate private coverage. The program has a 90-day pre-existing condition or post-enrollment waiting period that may be waived by MRMIP in accordance with program criteria. MRMIP will enroll up to a maximum of 16,000 individuals, with $30 million per year designated for support of the program. The program benefit package includes outpatient and inpatient care, preventive services for children, prescription drugs, rehabilitation services, limited mental health care, and durable medical equipment. Subscribers may choose from a variety of plans.

Small Employers Purchasing Pool Program ("Health Insurance Plan of California [HIPC]"). This program, established in 1993, created a health insurance purchasing pool for small employer groups to purchase insurance for their employees. "Small employers" are defined as bona fide licensed businesses with 5 to 50 employees. The minimum employee number will drop to four in July, 1994 and to three in July, 1995. The program, administered by an insurance agency awarded the contract through competitive bidding, has now enrolled more than 2,500 small businesses representing almost 45,000 individuals. Employers are required to pay at least half the premium for an individual enrolled in the lowest cost plan; the employee pays the rest of the premium. An employer may pay more of the premium and/or may cover dependents, but neither is required. The program offers a choice among three PPO (preferred provider organization) plans and eighteen HMO (health maintenance organization) plans, all of which offer the same benefit package. The benefits are comparable to those offered state employees, including perinatal care, well-baby care, home health services, chemical dependency and mental health treatment, prescription drugs, and specialty services like physical, occupational, and speech therapy. The program was initiated by MRMIB with Proposition 99 Cigarette and Tobacco Tax funding and is now self-funded.

Health Insurance Reform

Small Business Insurance. In 1992 a number of important changes were made in state laws that govern health insurance. All insurance companies are now required to offer coverage to businesses with five or more employees. Also, coverage exclusions on pre-existing and on-going medical conditions must be eliminated after six months of coverage. Not addressed by these changes is the premium rate charged, which can be significantly higher than rates paid for employees in larger businesses. As with some of the federal proposals, legislation has been considered that will control the range of rates that can be charged by the private health insurance companies.

Single Payer Initiative Proposal. An effort is underway in California to develop a single payer health care system based on the Canadian health care model. Under this model, health care coverage would be universal for all legal California residents. To cover the cost of coverage, employers and workers would pay a specified amount into a government-operated fund from which health services would also be paid. Under this system, most current arrangements individuals have with health care providers would be maintained, but the role now played by health insurance companies would be absorbed by the single government entity. In theory, eliminating the role of insurance companies and consolidating administrative functions would reduce paperwork and administration, thus achieving cost savings. Supporters contend these savings, coupled with savings in long-term health costs, would be achieved by providing comprehensive coverage to everyone and would help defray the costs of covering the uninsured. Supporters of the single payer system recently completed gathering the required signatures to qualify the initiative for the November 1994 ballot. California’s voters will determine this fall whether a single payer system will be adopted in the state.

CHAPTER IV: HEALTH CARE REFORM AND VULNERABLE FAMILIES

Most of the health care reform proposals now under serious consideration will have special impact on low-income families and children and on children with complex health and/or social needs. For example, the eight million children who currently have no health insurance coverage would undoubtedly benefit from the plans which propose "universal coverage" and "comprehensive benefits." However, some children, particularly those with complex needs, may not be well-served by all or some of the proposals, and may in fact lose some of the benefits to which they now have access under Medicaid and other federally funded programs. Similarly, some high need children with private health insurance may be subjected to unaffordable costs under health care reform if annual caps on out-of-pocket expenses are dropped.

This section analyzes the various health care reform proposals from two perspectives: (1) their likely capacity to address the needs of vulnerable families and children; and (2) their likely impact on the many programs that now serve these populations in California.

Criteria for Assessing Health Care Reform Proposals

In terms of their effects on vulnerable populations, the various national proposals are reviewed from the standpoint of four basic criteria:

- coverage;
- eligibility;
- cost-sharing; benefits; and
- impact on provider supply.

Although a number of features of health care plans are important to children, these four have special significance for vulnerable children and their families. The central questions related to each topic include the following.

Coverage/Eligibility

Are all families and children covered regardless of income, pre-existing conditions, or living arrangements? Medical experts and policymakers agree that access to health care is critical. Currently, pregnant women and children with special health and social needs are excluded from some insurance policies. In order to ensure that all pregnant women and children are covered, health care reform must extend coverage to everyone, regardless of their health status or their pre-existing conditions. In addition, plans should recognize children's special status as dependents of their parents or guardians.

Cost-Sharing

Are provisions made to ensure that out-of-pocket expenses (including both premium payments and copayments) are affordable to low income families? Are provisions made to ensure that copayments are affordable for families with children who require multiple visits? Affordable cost sharing is essential for two groups of vulnerable families: (1) those who are low income and (2) those who have children with special health care needs. Studies show that cost sharing can prevent low income families and children from obtaining essential services, such as preventive health care, as well as treatment for serious health problems (U.S. Congress Office of Technology Assessment, 1993). Therefore, it is critical that cost sharing requirements be designed so they do not create barriers to needed care.

Similarly, cost sharing should not present obstacles for families who have high cost needs. Many children, especially those with special or multiple health problems, require frequent visits to health care providers and/or relatively expensive care. The child with serious asthma or chronic infections, the child with a physical disability who receives physical or other outpatient therapy, or the seriously emotionally disturbed child, for example, all are likely to be high users of services. In order to accommodate these children, plans must keep their premiums, copayments, and family out-of-pocket health care expenses low enough not to deter them from care.

Benefits

Are all needed health services covered in the benefit package? The services that comprise a benefit package can determine the suitability of reform for vulnerable families. Unlike adults, children need routine examinations and early intervention for developmental and medical conditions. Children of low income families may also need additional services, such as those provided through the EPSDT program. Children with complex or on-going health problems may also need special care. The benefit package suitable for children has been defined to include the following:

1. Primary health care that includes outpatient and inpatient care, prescription drugs, and clinical preventive services (immunizations and screenings, evaluation and services for lead exposure, nutrition, dental, hearing, vision, developmental, and mental health) that are provided according to the periodicity schedule recommended by the American Academy of Pediatrics;
2. Pregnancy-related and family planning services;
3. Mental health services;
4. Alcohol and drug services;
5. Home health care;
6. Extended care services including skilled nursing facilities and rehabilitation facilities;
7. Outpatient rehabilitation that includes occupational therapy, physical therapy, speech/language therapy, and respiratory therapy;
8. Durable medical equipment that includes custom-designed devices for children;

9. Case management (as distinct from gate keeping or financial case management);
10. Health education and training for parents and families; and
11. Support services that include transportation and interpretation services. (AB 99 Steering Committee, 1994)

Provider Supply

Are there adequate provisions to ensure availability of appropriate providers? Provider supply issues are important to vulnerable families and children from several perspectives:

Many health experts agree that "essential community providers," the community-based clinics and other providers who have traditionally served the under- and unserved must have a strong role in any new health care system. These providers have demonstrated a commitment to serve low-income families and children, including children with special health and social needs. Community-based providers are also often the source of culturally and linguistically appropriate care for families and children of color and those who are non-English speaking.

These experts also conclude that plans must offer assurance that there will be adequate access to pediatric providers as well as pediatric specialists and regional health facilities. Children with special needs often require access to multiple pediatric specialists (access to providers in adult specialties are not to be regarded as adequate care for children); these specialists must be included in any plans.

Plans must include assistance to areas that have been designated as "medically underserved" if access to care is to be guaranteed, particularly for children with special needs and pregnant women.

Plans must include attention to development of a supply of future providers through such strategies as supporting training of primary care providers, including pediatricians and obstetricians/gynecologists. "Medically underserved" areas are geographic areas with a shortage of health care providers.

The Impact of National Health Care Reform on Vulnerable Families and Children

Given the lack of detail in many of the proposals as well as the fluidity of the decision-making process, the implications of health care reform for low income families and children are difficult to determine. Despite these caveats, some conclusions can be reached about the potential impact of various proposals given their general parameters as originally set forth. Tables 4 through 7, which appear at the end of this chapter, describe the details of the proposals as they address the specific needs of vulnerable families and children and their implications for current programs serving these populations. The following sections identify some of the policy issues that are raised as a result of this analysis.

Coverage/Eligibility

Provisions for coverage vary widely among the five major bills, some potentially resulting in reduced access to health care and others promising universal coverage.

Universal Coverage. The President, in presenting his health care reform to Congress, noted that universal coverage must be assured in any reform proposal submitted to him for approval -- although he is apparently willing to phase that in over a considerable period of time. Three of the five major proposals offer universal health care and would cover all families and children: McDermott/Wellstone (HR 1200), Gephardt/Mitchell (HR 3600), and Chafee/Thomas (S 1770). Although these bills are described as being "universal," none provides for coverage of the undocumented. The Chafee/Thomas plan requires government savings to achieve this universality. The remaining two, Cooper/Breaux (HR 3222) and Michel (HR 3080), are voluntary programs and extend coverage to the extent that individuals elect or are able to purchase coverage.

Populations at Special Risk. In all likelihood, special populations of children will experience access problems under all the plans except McDermott/Wellstone. The Clinton Administration plan, with its detailed coverage provisions, offers a good example for analyzing these potential problems. Populations at potential risk include:

> *Children in foster care.* It is unclear who will be the locus of responsibility for enrolling these children in health plans -- foster parents, biological parents, or the child welfare agency.
>
> *Children and adolescents in juvenile justice facilities.* The bill specifically exempts "prisoners" from coverage; are these children considered "prisoners," and if so, through what mechanism will they receive health care?
>
> *Emancipated adolescents, including homeless children, runaways and "throwaways."* Under the plan, adolescents receive their health care through their parents, from whom these children may be separated. It is unclear through what mechanism this group of adolescents will access the plan. (See the discussion on adolescents below.)
>
> These populations will probably be covered without difficulty under the McDermott/Wellstone plan because the single payer approach provides for coverage of all individuals, unlinking them from employer- or family-based coverage. Because the three remaining plans are not yet very specific about coverage or other details, it is difficult to determine what their impact may be on these groups of children. To the extent that the plans do not significantly alter existing plan-enrollee relationships, existing access to coverage (or lack of it) for these children will probably remain unchanged.

Pre-existing Conditions. The McDermott/Wellstone, Clinton Administration and Chafee/Thomas plans would eliminate exclusions for pre-existing conditions, while the Cooper plan would restrict but not prohibit such exclusions. The Michel plan provides no guarantee of coverage presumably leaving insurers free to enforce health-based exclusions. Lack of protection from exclusions based on health status or pre-existing conditions may leave many children with special health needs at risk of having no coverage for the very conditions that define their special needs status.

Undocumented Immigrants. Three of the plans (McDermott/Wellstone, Mitchell, and Chafee/Thomas) expressly exclude coverage of immigrant children who are undocumented, leaving health care for these families and children the responsibility of the state or counties. The McDermott/Wellstone plan would permit states at their discretion and funding to extend the plan to undocumented people. Interestingly, the two plans that make the least changes in the existing insurance system (the Cooper/Breaux and Michel plans) may leave these families and children with a route to coverage. The Cooper/Breaux plan appears to permit undocumented children to obtain coverage if their working parents receive or can purchase private insurance; the Michel bill is silent on undocumented issues.

Adolescents. Only the McDermott/Wellstone and the Clinton Administration plans offer enough information to speculate about the implications for adolescents. Under the McDermott/Wellstone plan, it appears that adolescents would receive access to health care coverage as individuals. The Clinton Administration plan clearly links adolescents' coverage to their parents' coverage (whether through an employer or government subsidy). For the large and growing group of adolescents who are on their own, including the homeless, runaways, or "throwaways," coverage under the Clinton Administration plan may be difficult or may require that their parents be located, perhaps against the children's will. In either case, the result may be lack of access to health care for these adolescents. If the problem of access to coverage is resolved for emancipated adolescents, subsequent barriers to care may be adolescents' need for premium subsidies and the plan's required copayments, which may simply price care out of adolescents' reach.

Cost Sharing

There is extensive variation among the plans regarding cost sharing, with predictable impact on vulnerable families, particularly for pregnant women and children.

General Cost Sharing Requirements. McDermott/Wellstone, with its reliance on taxes as the funding mechanism, simply eliminates premiums and copayments altogether (with the exception of some long term care services). The other four plans all require premium payments as well as copayments.

Clinton Cost Sharing Provisions. Under the Clinton Administration plan, the premiums of very low income people are paid by the government, but even relatively low income families (i.e., non-AFDC families with incomes below 150% of federal poverty level) will potentially pay at least a portion of the premium, depending on the plan they choose and the availability of government subsidies. There is no copayment for children's preventive services. However, a general copayment of $2 to $10 per visit for treatment services applies. In addition, there are annual caps of $1,500 to $3,000 on a family's out-of-pocket expenses for most services, and a cap of $1,000 per person for prescription drugs.

Cost Sharing Undefined. The Chafee/Thomas and Cooper/Breaux bills require both premiums and copayments but do not define them. Some subsidies would be made to support premiums, but not copayments, for low income people. However, the subsidies are not spelled out in either plan. Under the Michel plan individuals would pay premiums, with subsidies for families with incomes up to 200% of the federal poverty level. Copayments would be required but are not yet defined. None of these three plans specify annual caps on family out-of-pocket expenses, although the Cooper bill recommends establishment of such a cap.

The Potential Burden of Cost Sharing for Low Income Families. Under all but the McDermott/Wellstone plan, premiums and copayments may constitute an economic hardship for many low income families and for families with children with special health care needs who are high users of health services and for whom health expenses may represent a relatively large percentage of family expenses. The lack of an annual cap on medical expenses in the Chafee/Thomas, Cooper/Breaux, and Michel plans is also worrisome.

The Potential Burden of Cost Sharing for Special Needs Children. Cost sharing provisions in each of the plans except the McDermott/Wellstone plan may raise problems with special populations of children in addition to those who are solely low income, such as children in foster care and emancipated adolescents. For example, it is unclear who would bear the premium and copayment costs for children in foster care.

Benefits

The benefits to be provided under health care reform are not specified in three of the five bills, but are to be determined later.

Defined Benefits. The McDermott/Wellstone and the Clinton Administration plans, both of which explicitly identify benefits to be provided, specify relatively comprehensive plans. However, neither is comparable to the benefits now available through the EPSDT program. For example, the periodicity schedule for well-child check-ups is either unspecified (McDermott/Wellstone) or falls short of the schedule recommended by the American Academy of Pediatrics (the Clinton Administration plan). Similarly, neither proposal includes care coordination/case management services. Like the EPSDT package in general, care coordination services are important ingredients in the health care equation for vulnerable children. (See below for a discussion of how case management and other support services might be provided under these two plans.)

Undefined Benefits. The Chafee/Thomas, Cooper/Breaux and Michel plans do not define their benefit package. Both the Chafee/Thomas and Cooper/Breaux plans propose that benefits be set by a national commission. The Chafee/Thomas plan specifies that these benefits would include, at a minimum, preventive services (such as immunizations and screenings), rehabilitation and home care, prescription drugs, "severe mental illness services," and alcohol and drug services. Under the Cooper/Breaux plan, minimum benefits would include preventive services, and current Medicaid services could be continued (with subsidies for extremely low-income people to purchase them) if decided by the commission.

Disadvantages of Undefined Benefits. The "to be decided later" approach regarding benefits is of concern for vulnerable families in general and for the families who have children with special needs in particular. Past experience with the design of health care systems indicates that specific attention must be paid to the special needs of children, who are not just "little adults." Children display health and developmental courses that are far different than those of adults and require access to pediatric medical expertise and unique services. Unless a benefit package is designed with these differences in mind, plans may not meet children's needs.

McDermott/Wellstone Plan. The McDermott/Wellstone plan appears relatively comprehensive and includes most of the benefits vulnerable families need, with the exception of case management, health education, and support services. The plan does not spell out all details, and there may be other services of importance to vulnerable families that are not covered (e.g., some rehabilitation services). In addition, the plan does not specify a periodicity schedule for well-child preventive services. Some limitations on covered benefits also apply, such as mandatory utilization review after 15 inpatient days of mental health treatment or 20 outpatient visits. However, the McDermott/Wellstone proposal also would provide for increased federal funding for preventive and primary services through existing programs such as the Maternal and Child Health Block Grant (Title V), the Preventive Health Block Grant, and others. Therefore, the excluded benefits or support services may be provided through these programs even after enactment of the single payer plan.

Clinton Administration Plan. The Clinton Administration bill has the most detailed benefit package, making it relatively easy to analyze strengths and weaknesses. The benefit package is relatively comprehensive, placing greater emphasis on prevention and primary care than most policies today. As with McDermott/ Wellstone, some important benefits are not specified, including case management, health education and support services for families who have children with special needs. However, it appears that they may be covered by federal block grants that are proposed for continuation after the plan's implementation. Of perhaps greater concern for vulnerable children are limitations on certain covered benefits, including the following:

1. The periodicity schedule for pediatric visits does not match that recommended by the American Academy of Pediatrics, potentially leaving gaps in children's screenings for physical, developmental, and other problems.

2. The plan's outpatient rehabilitation services are generally good for those children with acquired conditions (i.e., those that follow an illness or injury); however, rehabilitation services are not comprehensive for the congenital conditions (e.g., birth defects) that are common among children with special health care needs. In addition, respiratory therapy and audiology services are not covered, although both are critical to assisting a child toward normal health and development. Extended outpatient rehabilitation services (i.e., following each 60-day period of service) would be covered only if the child's function is "improving." Some children may need extensive service before improvement is noted; "improvement" may also be hard to measure in young children whose course of development may be profoundly affected by their illness or congenital condition. Finally, the plan does not include coverage for customized medical devices,

hearing aids, and assistive technologies. These kinds of equipment are not a luxury for children. Rather, they are central to children's growth and development.

3. The plan places limitations on the scope of benefits for both mental health services and alcohol and drug services, including annual visit limits, a requirement that children meet individual health plan criteria in order to obtain these services, and lack of coverage for preventive mental health or alcohol or drug services. These limitations may not serve the needs of children with serious emotional disturbances, adolescents with chemical dependency, or children at risk for either mental illness or chemical dependency.

Provider Supply

Each of the proposals includes language intended to improve access to health care in underserved communities, either by: (1) providing incentives for providers to locate there; (2) authorizing grants to support health care resources; (3) and/or promoting training of health care providers likely to serve underserved communities.

Providers in Underserved Communities. The McDermott/Wellstone and the Clinton Administration plans include funding for essential community providers, funding for primary care provider training including pediatricians, and grants to centers to promote primary care in underserved areas. The Chafee/Thomas, Cooper/Breaux, and Michel plans all include funding for community-based services, for provider training, and medically unserved areas, but are less specific on the details for implementation than the other two plans.

Provisions for Pediatric Providers. All the plans are silent on access to pediatric providers and pediatric specialist services. The McDermott/ Wellstone plan allows choice of all approved providers including specialists, and the Clinton Administration plan provides for a "point of service" option as well as enrollment in fee-for-service plans that would guarantee access to the provider of choice (if the family can afford these more expensive options). "Point of service" options permit plan enrollees to see providers outside their plans, with the enrollee picking up at least part of the additional cost of the service. However, none of the bills specifically address the need to have guaranteed access to specialized providers including pediatric specialists and regional pediatric facilities.

Impact of Managed Care. The plans other than McDermott/Wellstone rely heavily on expansion of managed care. Under existing managed care plans there are documented problems with access to specialty providers for children and adults with special needs. None of these four reform plans include provisions to assure that populations with special needs will have easy access to appropriate providers of primary and specialty care under managed care. Because premiums are lower for HMO plans than for fee-for-service or mixed plans, low income families probably will be affected disproportionately by this situation.

Impact of Health Care Reform Proposals on Programs for Vulnerable Families and Children

Analysis of the impact of reform on special populations and the programs that were established to serve them raises a number of issues that should be considered as policymakers contemplate reform.

Elimination of State-Mandated Benefits

The Clinton Administration, Cooper/Breaux, Chafee/Thomas and Michel plans all override and eliminate state mandates for insurance benefits. (The McDermott/Wellstone plan permits states to develop their own plans with a richer benefit package.) The loss of state mandates is less of a concern with the Clinton Administration plan, whose benefit package is generally comprehensive, although it may be a problem for those families and children whose current coverage is more comprehensive than the Clinton Administration package. However, this override is particularly worrisome in the case of the other three plans, since the benefit packages are not yet defined and ultimately may offer substantially less than many private plans. The override is of particular concern in California from two standpoints:

- First, DHS has committed to a comprehensive system of health care for low income families and children through the managed care expansion that is based on the broad Medicaid benefit package. This service package may be significantly reduced in states under any of the plans except McDermott/Wellstone.

- Second, in the case of the three less comprehensive plans that maintain the existing private insurance system, the override would eliminate California's current legislative obligation of private insurance plans to offer preventive health services to children.

Medicaid Program Fold-In

All of the plans propose changes, often major, to the Medicaid program, with substantial implications for vulnerable families and children.

McDermott/Wellstone Plan. The McDermott/Wellstone plan would eliminate Medicaid as a separate program and integrate all beneficiaries fully into the new national system.

Clinton Administration Plan. The Clinton Administration plan would integrate Medicaid recipients into the new plan but retain supplemental "wrap-around" benefits (such as transportation and case management) for those families receiving cash benefits (Aid to Families with Dependent Children, or AFDC, and Supplemental Security Income, or SSI). Other low-income children and pregnant women now on Medicaid would select among the plans available in their area and be eligible for government assistance in paying the premiums.

Chafee/Thomas Plan. The Chafee/Thomas plan would integrate Medicaid beneficiaries into the health plan by permitting AFDC and SSI recipients to receive assistance to enroll in qualified health plans. Medicaid could remain in place at the state's option, but federal financial participation would be subject to an annual cap.

Cooper/Breaux Plan. The Cooper/Breaux plan would repeal Medicaid and offer subsidized coverage under private health insurance for people with incomes below poverty, subject to federal funding caps. Responsibility for Medicaid services not covered by health plans would be delegated entirely to the state without federal participation.

Michel Plan. The Michel plan would restructure Medicaid to permit states to reduce benefits and establish experimental health delivery models to reduce costs. Federal payments for Medicaid acute care would be capped.

Implications for Vulnerable Families

The loss of existing Medicaid services, including enabling services such as case management and transportation, for low-income families and children, particularly for families who have children with special health care needs, could eliminate their access to services that are widely acknowledged to improve the chances for good health and development. The income status of these families, coupled with their high needs for often expensive medical and other services, render it unlikely that their families will be able to pay for these services or to purchase supplemental health insurance with additional covered benefits.

Implications for Vulnerable Adolescents

Confidentiality of services is a significant concern of many adolescents. The "sensitive services" now available through Medi-Cal guarantee access to confidential and free care for a number of medical services. The services themselves will probably be covered by both McDermott/Wellstone and the Clinton Administration plan, but the confidentiality of these services is not specifically guaranteed in either plan.

State-Operated Programs

The fate of existing state programs under health care reform is uncertain. In part, the outcome will be determined by the final model adopted and the extent to which comprehensive health services are provided through a uniform system. If all (or most) of the essential services are provided through a comprehensive benefits package, the need for specialized, supplementary programs may no longer exist. Conversely, if the benefits offered are limited and/or coverage is not universal, the current methods of patching together health services will persist. The fate of state programs may also be determined by the source of program funding. For example, if federal funds are folded into a national health plan, then these resources will likely not be available for states to use. On the other hand, state funds will be available for use as each state pleases, assuming that health care reform does not restrict states’ ability to supplement the national program. The following sections speculate on the possible implications of national reform on California and its programs.

Impact on Innovative Programs. National health care reform in all its current incarnations offers a means of providing for coverage of personal health care services for individuals. At the same time, many innovative programs have moved toward providing family-centered, coordinated, community-based health care shored up with comprehensive support services such as case management, transportation, and child care. These have demonstrated impressive impact on health outcomes. What will be the impact of reform on these innovative programs, particularly those that draw on existing funding streams such as Medicaid for support, and what will be the impact on future attempts at innovative approaches to health delivery and promotion?

Impact on Non-Health Programs. The services provided by a number of non-health programs are closely linked with health services such as those available through Medi-Cal. These programs will clearly feel ripple effects as a result of the elimination of or major changes in Medicaid. For example, Regional Centers and, more recently, Special Education programs depend on Medi-Cal coverage for health and support services for eligible clients. If Medi-Cal is gone or radically altered, who will bear responsibility for providing these services to children if the services are required under a Special Education Individual Educational Plan?

Planning the Future of Existing Programs. As the state and nation move inexorably toward reform, policymakers and planners must develop and employ a "big picture" overview of the existing service delivery system for vulnerable families and children, including an analysis of why existing programs were created and what they sought to accomplish, whether these programs are working, and if so, whether and how they may be integrated into a new national and state health care system or whether they should be preserved intact as reform proceeds.

Planning for the Reform Transition Period. As the examples above demonstrate, no matter what form of health care reform finally emerges from Congress, it will result in a period of dislocation in California. Services and programs will have to sort themselves out, with attendant impact on their clients or patients and on the state's health and social services delivery system. Policymakers, program administrators, direct service providers and consumers alike will need to plan carefully for this transition period in order to minimize disruption in service delivery to vulnerable families and children.

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CHAPTER V: CONCLUSION

These findings suggest that, while health care reform holds much promise for vulnerable families and children depending largely on the model adopted, improved access to needed health care for these populations is by no means assured. Health care reform may result in new or expanded access for large numbers of families who today are uninsured or underinsured, but to achieve this goal, coverage must be universal, affordable, comprehensive, and ensure access to appropriate providers. It is a measure of how far the health care debate has come that all of the plans reviewed here make some attempt to address these four criteria, although, as noted above, their success varies greatly.

Many analysts have suggested that health care reform at least meet the basic medical tenet "first, do no harm." That is, at minimum, plans should assure that no vulnerable families or children see actual reductions in their access to care. Several of the plans analyzed in this report clearly fail to meet this basic guideline.

Other analysts urge that policymakers seize this opportunity -- the first in over twenty years and perhaps the last for decades to come -- to exercise true vision, to jettison our patchwork of health services and support programs and to instead build a rational, planned, comprehensive and integrated system of health care for all. It is still unclear to what degree even the most comprehensive and detailed existing reform plans can meet this goal.

As this report is written the debate continues in Congress regarding which strategy reform should take, from modest tinkering in existing financing or delivery to fundamental restructuring of the system itself. Whatever route chosen, policymakers must commit to ensuring a healthy future for our most vulnerable families and children.

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CHAPTER VI: SEMINAR

Health Care Reform and California's Vulnerable Families

Tuesday, June 28, 1994
8:30 a.m. - 11:30 a.m.
State Capitol, room 113
Sacramento, California

AGENDA

8:30 - 9:35 a.m.	***Welcome, Introductions and Seminar Overview*** **Anne Powell, M.S.W.** Director, California Family Impact Seminar
8:40 - 9:00 a.m.	***State and Federal Health Care Reform Activities; Major Policy Issues*** **Debra Lipson, M.P.H.** Associate Director, Alpha Center, Washington D.C.
9:00 - 9:15 a.m.	***Health Care Reform Issues for Families with Medically Involved Children*** **Ann McDonald-Cacho** Parent and Volunteer, Family Resources Network
9:15 - 9:30 a.m.	***Health Care Reform Issues for Families with Mentally Ill Children*** **Sandra Goodwin, Ph.D.** Director, California Institute for Mental Health
9:30 - 9:50 a.m.	***Health Care Reform Issues for Low Income Families and Families of Color*** **Paul Simms, M.P.H.** Immediate Past President, Black Caucus of Health Workers, American Public Health Association
9:50 - 10:00 a.m.	**BREAK**
10:00 - 10:30 a.m.	***Question and answer period.***
10:30 - 11:30 a.m.	***Roundtable Discussion*** An opportunity for seminar participants and speakers to explore in greater detail various policy issues relating to health care reform and vulnerable families.

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PRESENTATIONS

M. Anne Powell, M.S.W., CAFIS Director

Introductions and Welcome

Good morning and welcome. Let me talk for a moment about the California Family Impact Seminar. There are two parts to each seminar: the Background Briefing Report and the presentations. The background briefing report provides you with background information that you can refer to later, as a reference document. Because the issue is very fluid, the report is useful in understanding the individual elements of health care reform rather than each proposal in its entirety. While the makeup of each proposal under debate in Washington is constantly changing, the basic elements of health care reform are not.

The speakers will have about 15 to 20 minutes each to make their presentations. We will then have a period of time for questions and discussion.

Let me begin by defining "vulnerable families." We are, for purposes of this seminar, describing vulnerable families as families who have children with complex medical, social, and other types of conditions, and also low-income families, including families of color who depend upon public programs for their services.

It is not the intent of this seminar to question or challenge the role of government as to whether or not government serves these individuals. Rather, the seminar is based on the premise that the government has chosen to do so. Thus, we will look at how health care reform will interact with state programs.

Debra Lipson, M.P.H.

Debra Lipson is from the Alpha Center in Washington, D.C. Debra will update us on the status of health care reform both in Washington and some of the other states. She will also describe the key policy issues for vulnerable families that we at the state level should be thinking about.

State and Federal Health Care Reform Activities: Major Policy Issues

I will provide some perspective from inside the Beltway on what is going on in health care reform, but I must tell you that I'm not a real insider or else I probably wouldn't be here right now. All the real insiders are on Capitol Hill right now, struggling with what is surely one of the most complex issues that Congress and this country have had to face in a long time. One of the reasons that I agreed to come today is because I am very concerned with what is going on in the states and what the implications are for heath care reform – in whatever shape and form it takes – and what is left to the states to figure out. I think there is going to be much for you to figure out. In fact, Congress is not going to be able to deal with all of the complexities and be able to spell out in great detail for you what the states have to do. What remains for state officials and for people in the community all over the country is to figure out what health care reform means for them.

There are people in Washington who are sympathetic to what states have to deal with. It's just that they aren't always able to translate that sympathy into something that represents tangible help. I can recall just last week that your governor was in Washington, D.C. asking for some help dealing with the tremendous costs associated with providing health and welfare services for illegal immigrants. He received some expressions of support, and sympathy as well, but he didn't really come away with much in hand. I'm afraid that's going to be a portent of what happens with health care reform.

I'm not necessarily going to predict just what that's going to be, but they are not going to be relieving a whole lot of the burden for the states. They are certainly not going to be relieving California of some of the tremendous burdens of Medi-Cal. Nor are they are necessarily going to be providing you any more money to deal with some of the unfunded mandates such as those associated with providing services for illegal immigrants. There is a lot that they are not going to do for the states.

I want to give you some sense of what I think is likely to happen, although, again, I'm not going to make any specific predictions. At least I will outline for you what roles the state governments are likely to have and then identify some of the issues that are important for vulnerable families.

Federal Health Care Reform

There are some common themes in health care reform at the moment. I would say that this represents the nexus around what is likely to happen in Congress over the next several months. There is one thing that everybody at the national level agrees on, and that just about every state agrees on as well – it is very critical to restructure the health insurance market. The current health care market leaves too many people uninsured and makes it too difficult for those who have insurance to continue their coverage, especially if they have existing health problems.

Congress agreed, along with 46 states, that there's got to be some fundamental restructuring of the rules that govern the sale of health insurance, with changes such as a guaranteed renewal of insurance policies and limits on pre-existing conditions, which California has already had some foresight to enact. And I'm not sure how much further, if at all, Congress will go in placing those kinds of restrictions on the insurance industry. But in one way or another, the responsibility of administering these changes will fall on the states. Under the Constitution it is the states that have the authority to regulate health insurance plans.

Most policymakers agree that Congress needs to establish some minimum benefit package to which everybody is entitled. There is this notion that there is some sort of minimum standard out there, but people have a very hard time figuring out what that is. Most proposals have some level of specificity, but there is a lot of disagreement about what should be included. It is clear, though, that a minimum set of benefits needs to be established.

There is also pretty widespread agreement that we need to promote a more efficient health care delivery system that costs less while promoting health and preventing illness more effectively. Many prefer this be done through increasing the use of primary care, by establishing managed care systems. Again, I am mostly talking about the rhetoric that is going on in Washington, D.C., which everybody can sit around the table and agree to in theory.

Another issue under discussion is the need to establish national goals for cost containment. Everybody, when they really look at the numbers, agrees that health care costs are rising too fast, that we must limit this growth, at least for government expenditures on health care. Some say that what we spend in the private sector is also too high, but controlling costs in this sector vis-à-vis regulation is not supported.

Most people feel it is important to give states some flexibility in implementing reform. Everybody in Washington, D.C., recognizes the diversity of communities and states across the country and that whatever national framework is developed, states have some flexibility. Even proponents of the Wellstone and McDermott Plan, the single payer plan, agree that states need some flexibility. At the other end of the spectrum, I would say that proponents of the Michel Plan would agree that states need tremendous flexibility. The need to allow states flexibility in implementing health care reform is recognized across the continuum.

Attempts to reach agreement on specifics break down pretty quickly. It is the quest for the middle ground on which the debate is currently focused: whether and how to reach universal coverage. Obviously, President Clinton has stated very clearly that this is his bottom line, but the question is, by when? Does that really mean a hundred percent of the population, or does it mean something less than that? That is what has taken hold of the headlines over the last couple of weeks. That is where the debate is focused right now.

As soon as you start talking about how we are going to pay for expanded coverage, whether that is a hundred percent or somewhere in between – approximately 85 percent of the population is currently covered – that you run up against tremendous disagreements. Employer mandates are the touchstone for much of the debate right now. Individual mandates are being talked about more and more.

What kind of taxes would we need to pay for expanded coverage? How much savings from Medicare and Medicaid can really be produced and shifted over to pay for expanded coverage for those without any insurance? Whether and how to control Medicare and Medicaid costs. There appears to be unanimous agreement that you have to keep Medicare and Medicaid spending down or possibly even reduce it.

There are a lot of folks who are not necessarily sure that the government really needs to be involved in controlling what the private sector spends on health care. Then, of course, there is discussion as to whether it will be more regulatory approaches or market forces that will control health care costs. These questions and issues really make up most of the debate around containing costs.

The use of purchasing alliances, sometimes known as cooperatives, was considered to be almost an absolute ingredient in the debates earlier this year, and now you don’t really hear about them much any more. Certainly, if they were included in any national health care reform proposal, they would be voluntary. I think at this point there is very little hope for anything that resembles mandatory enrollment in purchasing alliances. I was just talking with representatives from the Health Insurance Plan of California, one of the few existing alliances in the country that is actually up and running. And as successful and important as that effort has been, those in Washington have yet to be convinced that these alliances are needed everywhere.

How to regulate health plans is also up for debate. Certainly the HMO industry would prefer uniform federal rules around this. Insurance commissioners and others believe strongly it must be left up to each state to establish rules and monitor performance. There will be a tremendous amount of discussion about how uniform those rules should be and what kinds of standards and performance expectations will be required of health plans.

Finally, there is the question of how extensive to make the minimum benefit package. Particularly problematic are mental health and substance abuse benefits. Long-term care is one of those missing links in the debate, and we sometimes hear it come up and then disappear again. Our senior citizens are certainly very strong advocates for keeping long-term care benefits in the basic package, but you don’t see the issue surfacing very much in the current debate.

As for universal coverage, I’m not sure I could tell you too much more than what you have read in the papers. These "unknowns" that I have mentioned, plus many, many more beyond this, are just too fluid right now to say exactly what is going to happen. The negotiations over the last several days centered on how to find that middle ground, what kind of compromises would be acceptable to a majority of the people both in the Senate and in the House. You see heroic efforts to try to define what universal coverage is. There are also attempts being made to develop incentives that, rather than imposing mandatory employee benefits, would induce more employers to provide coverage to employees and dependents. If the details cannot be resolved, Congress may provide what it knows best, access to the Federal Employee Benefits Plan.

The bottom line of all of this is: what is the plan going to do, and how is it going to score according to the Congressional Budget Office’s calculations? Just like here in California, there is an incredible focus in Washington, D.C. on what the bottom line is and what the federal government would have to spend. Deficit reduction issues are still going to have a very large effect on what the final package looks like. This is especially true now with the appointment of Alex Rivlin, a “deficit hawk,” as head of the Office of Management and Budget.

As mentioned earlier, California and all the rest of the states are ultimately going to be left holding the bag. This is why the Alpha Center is trying to figure out a lot of the issues that Congress cannot deal with – things Congress cannot develop the political solution for nor fund. Again, it is very likely that Congress will leave a lot of these decisions to the states. States will need to figure out what the best solution would be for each of them individually. This includes deciding how much of a commitment there is to populations that may still be uncovered, and for certain benefits, services and programs which are not covered under a federally prescribed benefits package. This is going to leave a tremendous amount for the states to try and figure out how to fit in, if at all.

Politics are almost driving the debate at the current time. It's the “end game” policies and maneuvering that are going on that really are determining what will happen: Will the Republicans do better by trying to bash the Clinton Plan and anything that looks like it; or, will Republicans be in a better position for the fall elections if they really try to get in there and fashion a compromise?

I wanted to mention briefly what I believe states are going to have to deal with, regardless of the federal plan agreed upon. If health alliances, even voluntary ones, are established then of course states will be expected to try and figure out whether these should be public or private entities, and who should be allowed to enroll in each plan. A lot of the decisions about how alliances are structured will be left to the states. States will also be asked to foster the development of integrated health plans. This is not something that is terribly new here in California, but it is new around the rest of the country. In California there will still be issues as to whether these integrated health plans, HMOs, or other managed care plans will be held to certain quality standards, and their capacity for delivering services to certain populations will be an issue.

If there are any subsidies, then certain states will be asked to figure out how to administer those subsidies, to make sure that things look intelligible for them, and that consumers will be able to apply for and receive the benefits of those plans. A very traditional role that states play right now is assuring financial solvency of health plans. This will not change. If anything, this role will increase, because other factors are coming into the system right now. There are currently many questions being raised about new rules for plans that are now taking on financial risks they had never taken on before.

Insurance and malpractice reforms will most likely be under state jurisdiction. I mentioned insurance reform earlier. Malpractice insurance reforms seem to be a consideration. If there is any effort to control costs, then the states will probably be saddled with that as well.

These are enormous challenges. I have just listed them very briefly. Under each of these, I could go into greater depth. These are incredibly complex and challenging issues, especially the bigger issue of how much flexibility states will have in implementing whatever federal rules are handed down. One of the major challenges is determining how much flexibility is important for local/regional considerations and how much regulation is needed to assure conformity to federal rules.

Don’t expect states to be relieved of any of the Medi-Cal or other financing burdens that they now have. This is the one thing that nobody talks about in Washington, because it’s assumed that the states will be expected to continue to pay for the costs associated with Medicaid services.

State-Level Health Care Reform

Although health care reform is likely to be enacted, it is not expected to be as comprehensive as once envisioned. What can states do without a *comprehensive* national health care reform framework? I think that there are only a few states that are going to "go all the way" to provide universal coverage. At this point, without a national commitment to financing universal coverage, there are very few states that are politically able to enact or implement universal coverage, either through mandates on employers or individuals or through substantial tax dollars.

There are only four states that have enacted any kind of employer mandates: Hawaii enacted a mandate many years ago and is the only state that actually has the legal authority to do so right now; Massachusetts did as well in 1988, but they have essentially delayed and perhaps decided not to implement this law; Oregon and Washington have also enacted mandates. Oregon seems to be backing off from its commitment. And we'll see what happens with Washington State, whether it will be allowed to go forward with employer and individual mandates.

Only a couple of other states have gone the other way and said, "Maybe we don't want to do mandates, why don't we try to get universal coverage through voluntary ways?" But that still costs money. Minnesota and Washington are the only states that have enacted substantial tax increases in order to finance expanded coverage.

You have a ballot proposal here in November that will seek to ensure coverage via a "single payer." I wish the sponsors the best of luck; such efforts have not been successful in any other state. It is very difficult to convince the voters to vote for a single payer system when existing forces that benefit from the current system will put a lot of effort into fighting such proposals.

Very few states can really impose any kind of expenditure limit that binds the health care industry within certain inflationary targets. Vermont is still trying to establish its limit. Minnesota has actually set some targets. Washington State has passed legislation to set these targets. But it is extremely difficult to make them stick. This is as far as states have gone towards achieving the goals of universal coverage and cost containment. You'll see very few states actually achieve those goals. Actually, most states have done some important things without a comprehensive framework. This is the kind of thing that I see across the country right now that represents extremely important steps toward a system that ultimately does provide overall coverage to everyone.

States are promoting changes in health care delivery by trying to expand primary care services, and in certain communities are trying to train more primary care personnel, both physicians as well as nurse practitioners. States are trying to promote more integrated health plans and set new standards, not just to improve health care access, but also to assure that these integrated health plans have some commitment to community standards of quality and coordination with other health services. There are many states that are moving in this direction. Many states are trying to improve the availability and affordability of health insurance through various changes in insurance rules, and through voluntary purchase cooperatives like the Health Insurance Plan of California (HIPC).

Some states are providing subsidies to low-income residents. You still see in many states subsidies for coverage of children. If states cannot come up with any other type of commitment to expanded coverage, most of them are at least able to acknowledge the need to cover low-income children and to make them a priority in this new system. Some of this is funded through Medicaid expansion, some with state revenues alone.

You will also see that states are trying to develop uniform data systems just to be able to get a handle on what they are spending. Most states could not tell you exactly what they are spending. The federal government is trying to work with the states to address this data need. We have some new data from the federal Health Care Financing Administration that for the first time provides some information on what is spent in each state. However, the data does not take into account that many of our citizens cross state lines for mental health care. Also, these data categories don't help state officials to figure out where the money is going and where it is coming from.

All of these efforts at the state level are very important in preparing for national health care reform or doing things that in the meantime move the entire country towards a system of universal coverage and containing costs.

From my experience in going around the country trying to figure out what states need, and by implication, what the federal government needs, a number of things are clear. Obviously, the dedication of policymakers to this issue is essential both from the governor and from the legislature. It is also important to realize that health care reform will not happen all at once. This is a continuing process. Once you think you've done something, just remember that it's going to be back at you sooner rather than later. This is a theme that I want to stress over and over again here: just because Congress enacts something, does not mean that it is going to be the be-all and end-all for the next couple of years. I think many in Congress would like you to believe that, because it is such a difficult issue for them. If they don't see health care reform as an evolving issue, then even more will be left to the states.

The process of raising public awareness and generating debate around some of the hard choices is a critical part of the states' processes toward developing their own health care reform legislation. What you can do in California is not necessarily what states like Arizona or New Jersey can do. Therefore, this leads to the recognition in Congress that there still has to be some flexibility in health care legislation because of the tremendous range in political cultures as well as technical capacities of states. What you have here in California in terms of technical capacity is beyond what states like New Mexico could ever approach. It is important to keep this in mind as a strength for you here in California.

Conclusion

I will highlight a few other important lesson. For those of you here who are discouraged that you're not going as far and as fast as you would like, remember that many of the incremental reforms that you are implementing here at the state level really are the building blocks for a more comprehensive reform strategy. Those small reforms, while challenging in some ways, are probably just the beginning of what would be far more challenging if you were to take it all on at once.

The operational tests that I mentioned before are extremely complex. We've seen in many of the states that are participating in the Robert Wood Johnson Foundation state initiative on health care reform programs, that just getting something up and going can be extraordinarily difficult and complex. If you think it is difficult at the state level, just try to imagine what it is like in Washington, D.C., where the federal bureaucracy is huge and there is often lack of communication between agencies. These are all important things to keep in mind.

These are the issues that will be left to you to decide, and these are things I want to highlight as you see what comes out of Congress over the next weeks or months. Look at the benefits package and see what is included and what is left out, what happens to all the supplemental services that you have struggled to get Medi-Cal to pay for over the last several years, in terms of medically necessary support of services that may not be considered medical care in the basic benefits package. That is going to be a clue to you to figure out what comes next in terms of the state programs and services. We need to figure out which of those kinds of programs fit in, and whether they will they be fundable under any kind of a uniform benefit package. Many of these programs are very vulnerable in the current health care equation, because there is very, very little discussion in Washington, D.C. about those kinds of programs and what happens to them.

Financing issues are, obviously, extremely important – the timing, the coverage requirements, who gets covered and when. I just read a Congressional Research Service analysis that said employer mandates, if they take effect, are most likely to hurt workers at or near the minimum wage. It is families that are living on minimum wage incomes that are most likely to be hurt if employer mandates come along. It's sort of a double-edged sword. On one hand the family is entitled to coverage and on the other hand, those families and their employers are most likely to be hurt because of the more limited ability of those employers to alter benefits and wages.

It is very important to determine what kinds of incentives and problems there might be for low-income families. The level of subsidies to low-income families is also very important. A study that was just released in June 1994 looked in more detail at how those subsidies would work for low- or near low-income families earning between 100 and 200 percent of the poverty level. Some of those subsidies may actually provide disincentives to work or to increase income because that might then take away some of the benefits. Again, these are very important issues to think about in terms of how they affect the coverage that low-income families may currently have, as well as how they might affect families that don't have any coverage whatsoever.

This is a whole set of issues that I don't have time to discuss now, but maybe we will get a chance to get into them later. The kinds of systems or Medicaid reforms that are going on here in California and in other states, and which are likely to be included in some form or another in national health care reform, are influenced by the impact of capitated payments and the availability of services. Access and quality in capitated plans will either be enhanced or compromised for vulnerable families. These are very difficult issues to sort out, with valid arguments on both sides.

It is extremely important to try to apply some level of objective analysis to what happens and be cognizant that there are going to be some who are helped and some who are hurt.

Pooling and boundaries for community rating is another important issue. What is a community? If you are going to move towards community rating, whether or not this is pure community rating, how big does that region get? Does it exclude some areas that may have more low-income families or more minority families? Is Medi-Cal going to be part of that community rating pool? All of these issues have tremendous implications for the coverage and rates that low-income families are expected to pay.

Finally, there are health system reforms that are occurring in the private marketplace that will affect the availability of providers and facilities. The consolidations between some of the large health plans and hospital systems have tremendous implications for the more community-based and nontraditional providers of services that low-income and vulnerable families depend on.

Ann McDonald-Cacho

Ann McDonald-Cacho came to our attention late yesterday afternoon when our second speaker informed us that she would not be able to be here today. Ann is here with her husband, Bernard, and their son, Philip, who has complex medical needs. Ann recently testified before Congressman Waxman's hearing on health care reform concerning families with special medical needs. Her family is not to be a "low-income" family, and is not eligible for many services public programs. Ann's family represent more of the mainstream concern around how issues such as health care reform and parenting with a special child come together. Due to the fact that Ms. McDonald-Cacho just last night consented to speak today, she has no specially prepared remarks. Instead, she is going to share with us the testimony that she presented to Congressman Waxman.

Health Care Reform Issues for Families with Medically Involved Children

I just want to preface my talk a little bit. I'm going to basically read my testimony, which I have presented in the past. We are here as a picture of a vulnerable family, but the idea behind this talk is that we are all vulnerable. This could happen to anyone at any time. We all will require medical care at some point in our lives. And so I am just trying to present a picture that is not special interest, it is just that we know what health care needs to look like. I hope health care reform comes out this way. If it doesn't come out this way federally, maybe the state can integrate some of these ideas.

"I am Ann McDonald-Cacho from Berkeley, California. Supporting me in this effort is my husband Bernard Cacho and our eight year old son, Philip. Thank you for allowing us to share about our experience in accessing health care for Philip. We are honored to be heard by an audience sensitive to this issue.

"We hope to present a picture for you in order that the “debate” over health security will result in meaningful legislation that will truly provide lifetime health security for our family and the millions of families like ours – families whom you may never hear, see, or know because they are broken and silenced by the present “system,” who have not the voice, language, education, finances, or empowerment to have escaped the despair of trying to cope with extraordinary concerns in a health care system whose delivery I can describe in the politest of terms as “bizarre” and in the most personal terms as “dangerously indifferent.”

"Much as we are all tempted to pretend that our family will magically escape a medical crisis, this kind of collective denial serves no purpose other than to perpetuate a society of “us,” the healthy, versus “them,” the sick. One day we were “us.” The day after Philip’s birth asphyxia, we became “them.” This is the real world with real risks. People get sick, people get injured, and closing our eyes to this does not make the truth go away, even in America.

"We are grateful for those working to establish a health care system where the Cacho family is free to join the “risk pool” of humanity, rather than being artificially confined to a risk pool of three individuals – Ann, Bernard, and Philip – with no purchasing power and no alternatives. One third of our pool, Philip, requires aggressive, attentive, long-term medical intervention that no insurance company in the United States would touch with a ten foot pole, unless contractually bound to do so before Philip’s condition existed.

"We thank President Clinton for taking up this issue for all Americans. There are critical principles of the President’s Health Security Act we applaud, which must be preserved:

- Universal coverage with a guaranteed/specified comprehensive benefits package. This is critical to families caring for a loved-one with a disability. Security we hardly dared dream about until now.

- The elimination of exclusions for preexisting conditions. Our horror stories with our insurance company, one of the largest in the United States, would make any person cut and run for their lives. Tragically, for us, there is no one to run to.

- Coverage with no lifetime cap on benefits coupled with a mandated community-rated premium. This means the difference between financial impoverishment and maintaining a modest family lifestyle.

- Home and community-based long-term services, with limits on out-of-pocket expenses. Please recognize the efforts we as parents expend relentlessly, each day, to care lovingly for our children at home, as long as we are able. Families like ours are the ultimate expression of “family values.” And please recognize that our children need the security to survive our passing.

"Let me briefly describe our lives. And by doing that, attempt to have you understand the level of fear involved living under this kind of vulnerability. Keep in mind that none of us are immune. None of us.

"Philip’s care requires 24-hour-per-day, on-call, hands-on assistance by Bernard or me. My husband cares for Philip while I work. I care for Phil before 9 a.m. and after 6 p.m. Caring for Philip means we work 40 hours per week just to supply his meals and drinks -- the total time commitment for the average person’s full time job. Caring for Philip means we are there to assist him in dressing, toileting, and bathing. Caring for Philip means we adapt all of Philip’s curriculum into augmentative communication formats he can access. Caring for Philip means we are adapting, adjusting, and transporting his equipment. Caring for Philip means driving to and participating in each of Phil’s various weekly therapies and doctors appointments. Caring for Philip means we have never been away from him for more than three hours in almost nine years. All of this can be accomplished with love. None of it can be sustained when the system is beating you down at every turn. One income is our family’s choice. The only alternative, institutionalization, for the benefit of another income, is unthinkable.

"I am self-employed. We are self-insured by Metropolitan Life Insurance Company. People say we are lucky to be insured at all. We are, I guess, but at what cost and for how long? Our family health insurance premium has grown from $270 per month in 1985 to $902 per month in 1994 – from $3,200 per year to $10,800 per year. $10,800 per year.

"However, Met Life’s risk exposure is quite limited and remains static. A $50,000 maximum benefit per person, per illness, per year is secured on an “exception basis.” Surgeries and hospital stays are fixed to an antiquated pre-1985 maximum cost schedule for the life of the policy. Met Life attempted to assert we’d bought a $50,000 per person lifetime maximum benefit policy – obscene even by industry standards and contrary to their own literature and written clarification of their own representative. They became enlightened when we hired legal help. Given Philip’s early intensive care needs, he would have been dropped from their “protection” after less than one year of life.

"Our premium is now 334 percent of its original cost nine years ago. Physical, occupational, and speech therapy costs are 133 percent of 1985 hourly rates. The split on undisputed claims is 80 percent insurance reimbursement to our 20 percent out-of-pocket copayment. No threshold exists for 100 percent insurance reimbursement. Financially alone, this is a recipe for disaster for our family and has undoubtedly doomed countless others. This is health care crisis. And it gets worse.

"In spite of our insurer’s limited exposure, we have found it necessary to obtain attorneys on four separate occasions to protect benefits “guaranteed” in the insurance contract and those protected by California law. The most recent attorney fee amounted to $5,000 in 1993. This battle over medical necessity of physical, occupational, and oral-motor/feeding therapy drained us for a year and four months, with reimbursements held pending outcome. Our family’s outlay for unreimbursed medical claims averaged close to $1,000 per month. Of course, our premiums of $750 per month in that year were duly collected throughout this extended period. We were paying $1,750 per month for 16 months plus attorney fees to be denied coverage. Get Met It Pays.

"We finally “won” if that is the proper term to use. When faced with California law, Met Life’s “cost-containment consultant,” his actual title, did not have a leg to stand on. How many families tragically joined the ranks of the uninsured through experiences such as ours? How many could not fight? How many?

"By the way, for those who believe in safety nets:

- The California Department of Insurance refused to review our case when they heard we had already talked with a private attorney. You might think it would be in this state’s financial interest to pursue these cases when the most likely outcome of insurance companies divesting themselves of their legal obligations to their policyholders results in that financial burden being shifted to the state via the CCS system or other state services.

- Our Regional Center case worker felt badly for us but had no ideas for help.

- Sadly, neither the Disability Rights Education and Defense Fund (DREDF) nor Protection and Advocacy (PAI) took an interest, although we know personally that similar experiences for other families are growing with increasing alarm.

- California Children’s Services will not reimburse for private therapies and now no longer deducts insurance premiums from family income in their eligibility formula. In essence, as I struggle harder, to earn more, to meet ever increasing premiums, Philip comes closer and closer to the brink of CCS ineligibility for any medical equipment assistance -- even though on average, Met Life directly takes from one-half to one-third of my family’s yearly income.

- The maximum allowable income tax deduction for self-employed persons for health insurance premiums was 25 percent and if my understanding is correct, zero for this year, compared to the 100 percent deductibility privilege of small business and corporations. A killer, especially in light of the dismal standing we have with regard to any purchasing power.

"I hope you haven’t forgotten Philip’s needs in all this. This is the most critical element of our presentation.

"We have survived the torment of the present system so far and have researched possible escape routes. Selling our California home, moving to Wisconsin, where life is cheaper and the care for children like Philip is exceptional. The support of extended families in Wisconsin under an extended Medicaid program [Katie Beckett eligibility waiver – (TEFRA 134)] which California has written but never implemented) is in line with a 1990’s understanding of the type of care crucial to kids with disabilities and with an understanding that we all benefit by allowing families the security to enable them to care for the children they love at home.

"Will we be okay when reform becomes a reality? Can we breathe a sigh of relief? No. The incredible reality is, the way the Health Security Act is currently written, if not amended -- and I believe Senator Kennedy's mark corrects some of these omissions – Philip and children whose medical needs stem from sometime between conception and birth – children with Down's syndrome, spina bifida, cerebral palsy, epilepsy, to name a well-known few – will not be afforded the health security guaranteed for children whose conditions result from illness or injury after birth.

"To have done everything right, to have worked so hard, to have come so far, we and families like ours cannot weather a blow like this. By some twist of cruel logic or sanctioned indifference, an entirely new subclass of Americans will have been created. This cannot stand. The ramifications are horrifying. Our children and their needs must be included in any reform that becomes law. Health care reform that brings rationality to the system but ignores the needs of children like Philip is no security at all.

"Let me touch on some of Philip's complex, preventative, and proven needs which we have fought long and hard for:

- Ongoing physical therapy: for the purpose of preventative rehabilitation, to avoid progressive deterioration of his condition – hip dislocation, contractures, compromised lung function, scoliosis, chronic life-long pain.

- Ongoing occupational and speech therapy: for his feeding dysfunction, avoiding aspiration, related pulmonary complications, preventing the need for hospitalizations for pneumonia, or gastrostomy surgery. For learning to use assistive technology for wheelchair mobility, voice-output communication, and writing, environmental control.

- Durable medical equipment: which allows Philip the freedom we enjoy, to interact with his surrounding world, travel safely, perform daily functions, and to prevent further deterioration of his condition. (power wheelchair, custom seating insert, adaptive potty seat, adapted bathing seat, prone stander, orthotic braces and splints, adapted automobile child-safety restraint system, van lift, and repair and growth modifications for this equipment.)

- Of course, long-term care: services and family support that limits out-of-pocket expenditures, which the Clinton Health Security Act currently does not, and emphasizes family and/or user-directed consistent personal-assistance services.

"Early in Philip's life, Philip's neurologist gravely explained Philip's CT scans to Bernard and me with tears in her eyes at his prognosis. This same doctor, several years later, could not believe Philip was the same child. Despite the severity of Philip's brain insult and resulting spasticity, his little body is in great condition. This is true because Philip works harder with more good humor than any kid I know. This is true as a direct result of the ongoing involvement of caring medical specialists – his pediatrician, pediatric rehabilitation specialist, orthopedist, orthotist, pediatric neurologist, pediatric dentist, allergist, rehabilitation engineers, and specialists in the field of augmentative communication, oral-motor, occupational and physical therapy. Access to these specialists are not frills or luxuries to Philip. They are absolutely essential to his health care.

"Unless America aspires to become the Romania of the west, we must make sure this horrible omission of protection for our children is fixed. Twisted bodies, throwaway children, and hopeless painful lives are not defined at birth – they are made. They are made by not applying accepted and knowledgeable medical practices. They are made by gatekeepers who can live with themselves when choosing a dollar over quality of life. They are made when families are forced, by overwhelming incentives, by a society that chooses to value the "us's" and not the "thems," to give up their own children in financial desperation.

"How many of us wouldn't be outraged if a family chose to give up the "normal" sibling to institutional or foster care so that they could give their child with special needs the extra care he or she required? Or chose to abort the "normal" fetus in the womb for the same reasons? Our easy tolerance for these desperate decisions for children with disabilities speaks volumes.

"Has "all men are created equal" become a cliché? Did our forefathers define a time window for getting in on this equality thing? Is it only for those who can buy it? Should our kids, those with congenital medical challenges, just kindly step out of the health security line? No. All of us need the protection of health security. Some will need it more than most, or earlier than most. But as you look around this room or within your own family, can you pick out who? Neither could my husband and I. One day we were "us." The next day we were "them."

"We have a precious chance now to end the separations that separate us only from our own humanity."

Sandra Goodwin, Ph.D.

Dr. Goodwin is the director of the California Institute of Mental Health. She will discuss health care reform and the needs of families with children that have mental illness.

Health Care Reform Issues for Families with Mentally Ill Children

I would like to share with you some of the pretty clear ideas we have in California about what does work for kids with serious emotional disabilities and their parents.

We've been busy back in Washington trying to share those ideas during the health care reform debate, with some success. I would like to take this opportunity to share those same ideas here. For some of you it is a reminder of what we're doing in public systems in this state that works, and for some of you, it will probably be new. I also have a feeling that I'm going to sound awfully bureaucratic and clinical after such a well-done personal kind of testimony, but I suppose we have to look at all aspects of how to go about making national health care reform work and how to make it work in this state.

I'm going to focus on seriously emotionally disturbed children (SED) and their parents. I'm not going to focus on individual bills. I guess that is done in the background paper well, and besides, as it was explained earlier, it is so fluid right now, who knows what it is going to look like in the final analysis. But there are some things that we really want to see in whatever health care reform package comes down.

I'm also going to talk just briefly about advocacy strategies from the state of California's perspective. I think this is a very good audience to do that with. I've never been involved with Washington, D.C. or what happens inside the Beltway until just recently, and I was sort of astounded by the contradictory attitudes that people there have about California. On the one hand they will talk about California as being really important: it's a big state; some of the key figures in Washington now are Californians who are obviously important to this administration; and we have a huge Congressional delegation.

At the same time, there is an attitude that permeates Washington, D.C. -- what they refer to as "ABC," Anywhere But California. That attitude seems to stem from the notion that California is too big, too complicated, very flaky, and couldn't organize its way out of a paper bag. Besides that, even if the state could figure out how to do anything, it would cost too much money. So with all of these underlying attitudes, it is pretty difficult sometimes to promote some of our California ideas. But I think we are getting more successful in that discussion.

The perspective I would like to describe is primarily from a public mental health services perspective. For SED kids, that is pretty appropriate because given the nature of SED, these kids generally tend to be involved in public mental health systems.

Who are they? Who are seriously emotionally disturbed children? Who am I talking about when I use that term? Actually in California we have it defined in statute; it describes what an SED child is and designates them as a target population for public mental health services in California. They are kids who, first of all, have serious clinical symptoms and a psychiatric diagnosis, such as serious depression. These symptoms have to be severe in intensity. They have got to be long in duration and to the point that they impact the child's ability to function in everyday life – things like being able to perform in school, to make social relationships, and to interact in the family. They are disorders so severe that the child literally is disabled on the basis of their psychiatric disorder.

That is who they are. Now I want to just look at what the impact of national health care reform discussions are around kids with these kinds of problems and their families. When the health care reform task force began, there was a mental health work group chaired by Mrs. Tipper Gore. I just want to take a minute and say, thank you, Tipper Gore, wherever you are. She really ought to become the patron saint of mental health when this is all over. The fact that mental health began as part of the debate and today is still an active part of the debate in Washington, D.C. is phenomenal. I think we owe it in no small degree to Tipper Gore's advocacy in many different ways. Her ability and access to people has been remarkable. She really, with a lot of help, has been able to promote mental health in a way that no one else has ever been able to do.

The final product that came out of the work group was really very good. It was well thought out. It was based on what is becoming more and more the model for mental health services in the United States as well as in California. It works and it is cost effective. It is a model that is very,

very comprehensive and has flexible benefits. It sounds odd, but one of the ways that insurance companies have tried to contain costs is the absolute opposite of what needs to be done. We need a very broad benefit with lots of alternatives, very flexible, but it has to be delivered in a managed system. It would be controlled by supply-side controls like controlling the amount of money, but not the benefits that are available. By doing so, you can very effectively control costs and provide very effective services.

None of that in a real sense ended up in what the administration finally presented to Congress. There were lots of compromises between what the work group did, what the President accepted, and what was finally written into the legislation. One of the reasons for that is that once that concept hit the federal actuarials, there was a lot of disagreement on the cost-containment mechanisms.

The Health Care Financing Administration (HCFA) and later the Congressional Budget Office (CBO) disagreed about the cost effectiveness of this design. First, they were using 1985 data. There were significant expenditures in the 1980s on mental health. However, there have been significant changes – reductions – in expenditures over about the last five years. Yet they took the 1985 data and just projected it forward. They said, "We don’t believe that this mechanism of managing the costs works, so, instead, we will calculate the cost of this benefit by itemizing the cost of each benefit as though fully utilized, and not offset the cost based on savings gained by managing the care." When you do that, you end up with this enormous estimated cost. None of these cost estimates were ever made public because of all the disagreements about their accuracy. To make a long story short, they ended up with a very truncated benefit with a promise of full benefits at some future time.

One of the difficulties that we have with health reform is that any benefit structure that is appropriate for children in the general population is not going to serve kids with serious emotional and physical difficulties. For these kids, for SED kids, the benefit structure is important. Equally important is the service delivery model. That is what we have been preaching back there over and over again: service delivery, service delivery, service delivery. Without that, without the health care benefit in the context of the service delivery system, it is ineffective for kids with SED problems.

In California we are very convinced, based on well-documented, well-researched work of our public programs, that a system of care service for kids is critical to the success of these children. When I say “system of care,” it is really a fairly simple concept – harder to implement, but conceptually easy. Mental health services must be delivered in collaboration with medical services, rehabilitative services, educational, and wrap-around services that are designed to meet the individual needs of that child.

In order to have any impact, to really help kids with serious emotional disturbances, you have to address all the services that impact that child’s life: education, juvenile justice, child protective services, all those pieces. Mental health care, when provided in a vacuum, is not nearly as effective as when provided in this system of care.

In California we developed this model, known as the "Ventura Model." California's statutes are based on that model. That model has now been expanded in California to twelve counties in the state. Not very much, but I want to tell you something. Under the pressure of the budget problems we've had in this state, and the continuing economic recession, to be able to not just retain these programs, but expand them, is amazing. Beyond that, there are counties that have no funding for it at all, but almost every single county in this state is working to implement portions of this model.

We are convinced by the evidence that systems of care provide positive outcomes for children and their families. It helps children to remain at home in their families. It reduces the need for out-of-home care. It increases success in school. It avoids the length of behavior problems, avoids unnecessary hospitalization, and avoids juvenile justice placement. This model is now adopted by the Federal Center for Mental Health Services, a federal center set up to promote the improvement of mental health services in all states. This program is directly relevant to the national health care debate.

With the pressure to reduce the costs of whatever is produced, there is continual discussion to eliminate mental health services altogether, in particular, to eliminate mental health services to children with mental health problems. But our experience is clear. Targeted mental health services organized into community-based systems of care will reduce short-term and long-term costs. We have learned that human services are interdependent, and mental health services will improve outcomes and reduce costs in special education, juvenile justice, and social services, as well as reduce the need and costs within mental health for local and state psychiatric hospitals.

Again, I want to give you a couple of quick examples. In 1993 and 1994, the cost of California's 15,000 court wards and dependents placed in group homes exceeded $500 million. In the test counties where there is a fully implemented system of care, those counties spent only 42.8 percent of previous costs on this type of out-of-home care as the rest of the state. In those test counties, 40 percent or more of the children previously placed out-of-home can be successfully were maintained in the community and with their families.

What does that mean for national health care reform? Any national health care reform package must require, or at very minimum permit, each state to plan and provide an organized, integrated system of care for children with serious emotional disturbances. This is also true for adults with serious mental illnesses, although that is not our subject today.

That specialized system of care needs to be based on certain principles. The plan that states produce must include a flexible range of clients and the integration of any health care plan benefits into a single system of care. There have been some real difficulties with the way the programs have been written up until now. The National Health Security Act takes benefits away from children with these problems. This occurs when they take the Medicaid dollars and put them into a limited benefit which does not provide for their care. So under the National Health Security Act, these kids actually lose benefits.

There are no provisions in the National Health Security Act or in most of the bills to assure that any benefit that is provided to these kids, whatever limit is place on it, is integrated with other kinds of services. Instead, they are set up in a separate system. To be effective, the system of care must require interagency coordination with key human service agencies. It must provide integration with whatever state or federal long-term care plans are available. It must have clear, accountable outcome measures.

We have made some progress in discussions with Congressional members about these issues. Congressman George Miller has been particularly responsive and introduced language providing these elements into the bill that moved out of The House of Representatives' Committee on Education and Labor, language that is based on California systems. That language also, as with most of the mental benefit, received bipartisan support in votes, which is not true of most of the bill that moved out. That same language was picked up by Senator Kennedy and is now part of Senator Kennedy’s bill. We will be continuing to push to see that this kind of language gets included in all of the legislation.

Department of Health and Human Services Deputy Secretary Phil Lee, who is a Californian, is supportive and has agreed to insure that these provisions are included in their bill. Congressman McDermott and the supporters of the single payer bill have agreed that if their bill moves at all, they will integrate that same kind of language.

We are having some success. However, one of the things you often hear said about these issues is that it is a great opportunity, but a horrible risk. I mean, we could win it all or we could lose it all. But whatever the benefit level, our point is, the mental health benefit can’t be provided in a vacuum; it must be a part of a system of care because that is what works for kids and their families.

Paul Simms, M.P.H.

Paul Simms is going to talk about issues relating to low-income families. Mr. Simms is the immediate past president of the Black Caucus of Health Workers and is Deputy Director of Community Health Services in San Diego County.

Health Care Reform Issues for Low Income Families and Families of Color

It is a pleasure to share some thoughts with you. I run a health services program in San Diego, California and what I am going to share with you is a compilation of our experience and some thoughts about our work. It is important to do a little debunking of mythology early up.

In reviewing data about Medi-Cal enrollers, enrollees, and users per month from 1980 to 1992, the numbers reflect when the California economy turned sour, and you can also see when undocumented aliens became eligible for Medi-Cal. The data also tells us about the relationship between the eligibles per month and the users per month: that gap is widening, not narrowing.

Therefore, it would be mythology for anyone to suggest that capitation of the Medi-Cal program would be undesirable.

When you look at the cost per Medi-Cal eligible versus the cost per user, what you see are significant increases in the rate of use. But you do not see parallel increases in the rates for nonusers – only for eligibles. So again, not only is the relationship between eligibles per month and users per month widening, but if you were to apply standard health care economics analyses to these data and you were in the private sector, you would discover that the monthly cost per users versus eligibles is also widening.

Last year I had the good fortune to be president of the National Association of African American Public Health Officials. During this same period, Dr. Richard Busher, also from San Diego, was the president of the National Association of African American Physicians. He and I led a group of delegates to the White House to discuss health care reform. We did not go alone. We took with us representatives of the black nurses, social workers, NAACP, Urban League, and Congressional Black Caucus. The message delivered was that it is absolutely essential that the White House understand that what is going on in health care has got to be driven by data.

I was so pleased with what was said earlier by Ms. Lipson, because you cannot have good policy in this country without good information. You cannot have good information in this country without good data. So it is illogical for us to talk about managed care systems and placing large numbers of people at risk – poor or middle class – without having a good data base from which to learn.

I am personally enrolled in managed care. How many of you are enrolled in managed care? It drives me crazy. I have a better than average education and I can’t figure out how to get through the case master. So when we talk about doing that to Medi-Cal populations, it seems to me we are talking about great leaps of faith. What it is we have faith in, I’m not quite so sure. In looking at this issue of eligibles and user costs, however, if you were the private sector, you would say, "I need to figure out how to get some of that market." That is the attractiveness that you currently see up and down California, particularly in the large counties, around Medi-Cal managed care.

We told the First Lady all she needed to do was to keep having public hearings around the country, and when the occupancy rates in hospitals in San Diego hit 50 percent, declare a victory and change the subject. Why? Because reform is already underway. You have to understand what the market is designed to do. The market responds to potential risk. It’s a risk-responsive system. The threat of national health reform has caused the system to respond already. In 1988, occupancy rates in the county of San Diego were in the mid-70s. A CEO conceptualizing hospital bed construction would have been akin to visions of sugarplums.

In 1994 we have a brand new UCSD hospital on the Thornton campus with 125 beds. Occupancy has not yet exceeded 30 patients. That is like an albatross. But that is a reflection of changing the incentives in the market. Let’s think about it this way. You’re a delivery system. You’re a physician or a hospital. You are used to fee-for-service reimbursement. So when you start, your bank is empty. Every time you provide a unit of service, you get a little more money. So the proclivity of the system's performance is to do more. That's fee-for-service.

In managed care, in capitated environments, the system's incentives are reversed. You start out, the bank is full, and every service you provide, your bank goes down a little bit. There is a great quote in this regard. I was at the University of Michigan when Dr. McClure stated this: "Systems of people perform in a manner that they are structured and rewarded to perform. Poor structure begets poor incentives. Poor incentives begets poor performance." So when you are looking at poor performance, don't blame the messenger. It's how the messenger is rewarded. What managed care does is invert the incentives. Unfortunately, managed care does not address some of the human dynamics in health care.

Let us now talk for a minute about the relationship between price and cost. From 1980 through about 1986, the number of health plans in the United States significantly increased. Then all of a sudden the number dropped off. In terms of the actual number of HMO's, there has been and continues to be a reduction. Can anybody speculate on what's going on here? The reason is mergers.

How are the mergers occurring? The mergers are being forced by controlling prices. Premium has no relationship to increasing costs. Premium increases are controlled. They are controlled as a function of someone's agenda. If you understand the agenda, you understand how you design systems to respond to market forces. These are market forces at work here. That's all this is.

Now, what is the greatest fear that counties have right now in terms of Medi-Cal managed care? Until 1982, when the medically indigent adults were in the State's Medi-Cal program, there were annual increases in the allocation of the state budget to medically indigent adults. Responsibility for serving medically indigent adults was then transferred to counties. State funding for this population then flattened out between 1986 and 1989, after which funding was significantly reduced. This is called shift and shaft – you shift the responsibility to the county, and you somehow can't keep pace with inflation and demand. This is our great fear with Medi-Cal managed care. We have provided this information to the judge in the County of San Diego v. the State of California lawsuit, which is now on its way to the appellate court.

Let's talk about what we said at the White House. We said that the delivery system is the same, whether it's private and right or public and left. It doesn't matter. There are insurers who have relationships with employers who cover consumers and they access health care systems. Or there are fiscal intermediaries, as in Medicare and Medicaid, who respond to and have relationships with government payers who cover eligibles through the Medicaid or Medicare system.

Has anyone in this room seen a Medi-Cal application? Has anyone in this room tried to fill one out? For those of you who have not done it and you have some involvement in this process or some relationship to access or outcome, you should go try it. Wear your standard attire, don't go out in a tie. Go into the Medi-Cal office, and try to apply for Medi-Cal. It is a tribute to the Elizabethan forefathers. I don't want you to miss that point. When we start talking about access, we have designed certain kinds of systems that put certain spins on the interface between the patient and the system. That is the nexus, the synapse, which we must understand and control in mobilizing if we are going to change some of what we do.

The problem for us in the public sector is that we are so woefully fragmented. I now run Physical Health Service and Public Health Service combined in San Diego County. Physical Health Service used to be separate from the Health Department. I ran it from 1980 to 1994. On January 1, 1994, Public Health Service and Physical Health Service were consolidated and placed in the Health Department.

In Physical Health Service, there were four separate medical records. In Public Health Service, there were seven separate medical records. I haven't gotten to mental health. We can't get those records, because they are all confidential. There are 11 separate medical records systems. They set up one for sexually transmitted diseases, one for child health and one for immunizations. So if any elected official were to ask any senior official in the San Diego Health Department, how many patients were being served, we would answer that question with how many visits we provided. This is Bureaucratic Learning 101: answer the question that you have the data for, not the question you were asked. How many families have we served? There is no way to answer that question.

I don't care whether you're talking about health or health and corrections or health and corrections and social services, for African American men the best access to health care is in the prison. They are not Medi-Cal eligible. There is no foundation providing any care. One of the driving problems is that we are now thinking about welfare reform and health reform separately, as if they were separate, when, in fact, you can't have welfare reform without health reform and vice versa. Fifty percent of the African American children born in this country in 1993 were born to single parents. Not 15 percent , 50 percent.

People are walking around loosely with this term "managed care." We argue that it ought to have a scientific definition. This is ours, what we use in the county of San Diego. If you're going to have a managed care system, you are going to have a funding mechanism, you're going to organize providers, you will control eligibility and enrollment – these are separate processes by the way, that I will get into in a minute. There will be management of patient access and assured patient and provider satisfaction. They will be tied together centrally, and I don't care whether or not you're talking about mental health services or services to children, women of childbearing age, or adults, the model applies.

For the County Medical Services (CMS) program in 1983, we implemented this model. So when we started addressing prenatal access in 1988, we developed the same model. You ultimately get a cylinder where you've got tiered services tied together with a single integrated family index. By the way, we didn't use the county uniform universal identifier. We used the county's Department of Social Services' (DSS) Medi-Cal number. Who said we had to use this number? As soon as you put in a DSS identifier, you link the family on the health side with the welfare department. So all of a sudden you can start thinking about how families and move in and out of the system.

This was our argument to the President, that the primary care system ought to be the system around which it is all built. Right now we have integrated systems being designed around hospitals. Now that is an appropriate model for hospitals. If you had an occupancy rate of 75 percent in 1988 and you've got 45 percent in 1994, you are going to figure out how to not join the pterodactyls in the La Brea tar pits. You want to get the money so you can control the indirects and overheads. That is 25 to 30 percent of the game. Arguably, you could build that same capacity around the least resource-consumptive unit of care, the unit of care that will provide access and early diagnosis. We argue that this is the primary care system. We further argue that access to substance abuse treatment should not come down a separate corridor or separate department. It should come through a coordinated primary care system.

The Regional Center for the Study and Prevention of Violence says if you have a cardiac event, after the event is over you can go to the cardiac rehabilitation center. Why is there any difference between that event and an act of violence? If you are a victim of an act of violence, what is the first thing you want to do: more violence? Regarding this business about drive-by shootings – everybody is so concerned about drive-by shootings – it’s nonsense, absolute nonsense. The data suggests that you’re at greatest risk if you have a gun in your home. It is 43 times more likely to be used on one who is related to you by blood or marriage.

The concern is not out in the street, not at the 7-Eleven Store. The concern is in your own home, between your family and your friends. And alcohol. Alcohol is the contaminant. In a week we will announce the creation of a division of Violence and Injury Prevention in the county of San Diego. We’re going to spend a year and a half developing the strategic plan, and I tell you right now, it’s going to be impressive. We’re going to, first of all, weed stuff out so we understand the problem we are to solve. There is an African proverb that says, "If you know the beginning well, the end will not trouble you." Well, the end is troubling a lot of people. We have gone back to some fundamentals in terms of how to build a system. That is what I do in San Diego. I build delivery systems.

How many of you in this room are social workers? Remember when the social workers were taken out of the eligibility process about 15 years ago, and the eligibility function was diminished to almost a clerical function? In other words, the revenue that is being shared at that desk is about $50 to $100 more for the person behind the desk than for the person in front of the desk. I don’t want you to miss that. That’s very important in the dynamics. You have to go sit and apply for Medi-Cal to understand the judgment that occurs at that table. This says that we need to up the ante at the point at which the eligibility determination is made. These workers need to figure out who ought to be linked to low-risk, independent, solo practice, IPA (Independent Physicians Association) type primary care systems versus those persons whose needs require an organized system of nutritionists, social service support, and substance abuse. This is not rocket scientist stuff, by the way. This is just regular people who are working in the Health Department saying, "If it was our money..."

The problem is you are talking about 37 million people nation wide, with an annual health care cost of about $3,000 per person on average, including mental health. You’re talking about $100 billion – do you take the $100 billion and you send it down the existing system? I believe absolutely not. What would you do differently? Well, there are different issues around system organization. And we would have to figure out how to mobilize the American people to take greater responsibility over their own health care.

This primary care model includes physicians and nurses and nurse practitioners and mental health professionals. It is absolutely unthinkable to separate out mental health service. Absolutely unthinkable. Contemptible, at best. You would have case management systems. And those case management systems would manage prime diseases, assure medications required, do the follow-up, facilitate training the patient, and provide patient education. Then there are community health advocates, which is where you put injury prevention. And you include home assessments.

I cannot stress enough the importance of the data coming out of On Lok (a senior program in San Francisco). On Lok demonstrates that if you send someone into the home to provide any kind of assistance and you do an injury assessment, you can reduce hip fractures to a population over 65 by 60 percent. And you know what happens to an elderly person when they fall and break their hip. Where do they go? They go to a long-term care facility for the rest of their life. So it is possible to prevent institutionalization. How do we get active about prevention? I feel that this is the role of the Health Department.

This business about data. There needs to be a complete client record. You then put a summary of it in a regional information data base that everybody has got to participate in. Kaiser Permanente doesn’t have the whole delivery system, although they do have 40 percent of the market in San Diego. They have some of the best data about their enrollees. They don’t want to take any indigents. I created an indigent funding pool in San Diego County and everybody got all upset. I said we were just going to charge 2 percent on every discharge to pay for indigent care. If you applied 2 percent on every hospital discharge, then San Diego would have a $2 million operation, a significant amount of money. We would use the money to redistribute. This is not novel. This is how it works in Minnesota and Florida.

The fact of the matter is there are people who are providing leadership in revenue sharing. I mean, that is essentially what you’re talking about, shifting the risk for adverse outcomes that anybody can experience from individuals to society. That is what the President is attempting to do. That is what the First Lady is attempting to do. You know those jokes they used to tell about the First Lady, in January and February and March of last year, they aren’t telling any more jokes, are they? They realize she is deadly serious.

And the negotiations that have to occur, that’s okay. I was in the civil rights movement. I know how it occurred. Take a step. Take one lunch counter at a time. Ultimately you get them all. Don’t try to get them too quickly, but keep a vision as to what it is you are attempting to do. In the end the vision is a unified public health and social services delivery system. That is where we are heading.

Some of you have asked what is going on in San Diego with regards to Medi-Cal and managed care. This is what is going on in San Diego. What we’ve attempted to do is to say that there ought to be managed care for Medi-Cal patients, but we want to do the watching. We don’t have a hospital. We are not confused by having a thousand employees we have to keep employed. Our role and mission is to protect the public’s health.

Now that’s got three different corridors. One corridor is to make sure that the health plans are all certified competitively. While I am in Sacramento today I will stop by the California Medical Assistance Commission (CMAC) to talk about a relationship, because we will get geographic managed care (GMC). There were some things done wrong in geographic managed care. One of the most significant problems was the lack of local presence. What we are going to say to CMAC is let us do the site visit, let us compile the data, we will evaluate quality, and we will relate collaboratively with the state and local health plans and be the patient advocate. You see, patients need advocates once you place the system at risk, because you are now rewarding the system for doing less.

Traditional providers also need advocates. The economics of large managed care systems will force them into oblivion. In Sacramento County, there was not talk of an African American or Hispanic American physician. Why? Because it is the way incentives in managed care are structured.

The state statutes say the California Department of Health Services controls the system. The health plans will get 98 percent of the money. I don’t need 10 percent to run the system. I don’t need 5 percent. Our oversight and monitoring data collection, quality assurance, and region follow-up can be done in 2 percent. If I can’t do it with 2 percent, then there’s something wrong. That’s the standard we have got in place right now. That is what the negotiation is going to look like.

It starts out with a limited number of plans. How many of you are familiar with the Los Angeles trauma system? The site visit team recommended that there be 9 or 10 hospitals designated as trauma hospitals in L.A. County. Politics took over, and now there are 24 trauma hospitals in L.A. County. Now what’s happened? They've started back toward 9 or 10. Except that the communities that lost the trauma centers were the communities that had large numbers of victims of gun shots and stabbings – that’s code for poor people. So you have ultimately a negative impact in terms of emergency care for those communities who are victims of poor policy. What we have said is, you need to have an adequate number of plans to assure participation. But two of the four – we say at this point we are looking at four plans – two must be traditional physician and/or clinic based. Two must be hospital and health plan based.

Regarding the Primary Care Case Management providers (PCCMs) applications in the pipeline, they should be approved because they are based among African American and Hispanic American and Vietnamese American physician providers. If you don’t do that, the large hospital systems won’t give them room to play. There’s enough data to support that conclusion.

Start with AFDC linked Medi-Cal. Medi-Cal-covered services, health promotion and prevention, ought to be a hallmark. And we are talking in San Diego about the integration of public health and private sectors. It’s very simple. Why can’t we integrate public health and private practice? Why can’t we integrate public health and managed care? Dr. Ross, the county Health

Department director, has said this represents his policy, that children and families will be first, and we will work collaboratively with them.

We started a trauma system in 1983. We released a report last week on preventable deaths. In 1992 in San Diego county we took a baseline. Anytime you do anything important in this arena where you have the poor people and middle class people and five counties possibly involved, you do baseline. We have reduced preventable deaths in the county of San Diego by 91 percent. 91 percent. And it is published in the Journal of the American Medical Association (JAMA). The people who did it ought to win an award, because it doesn't get much better than that.

On July 15 the Rand Corporation is coming to the county of San Diego. We are going to design a study to do a baseline for the AFDC population before we place them all at risk. That is what we would expect out of each other, and so that is what we are going to do for them. The hospitals have agreed to use the trauma system quality assurance mechanism for the managed care plan. We call it Healthy San Diego.

All administrative costs will be capped, our side and theirs. You heard me right. The state is going to love that. Eligibility, enrollment, designation, oversight monitoring, standard setting, community health plan. We've got to figure out how to change health related behavior. I was talking to Phil Lee, Department of Health and Human Services Deputy Secretary, in September 1993. He gave me the data on the Zuni tribe and how the whole community has embraced a behavior to stop hospital admissions associated with diabetes. We can do the same thing. We can use black churches. This separation of church and state, it's specious when you start talking about health care. So we are going with a whole different approach to the delivery of health care from the bottom up, from the community. That is where we're headed with the Medi-Cal initiative in San Diego.

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HANDOUTS

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BIOGRAPHIES

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Debra J. Lipson

Ms. Lipson has served as an Associate Director at the Alpha Center since June 1993. In that capacity, she organizes and conducts health policy workshops for senior state and local health officials under a contract with the U. S. Agency for Health Care Policy and Research, User Liaison Program. She also manages the Center's work on maternal and child health issues, including consultation to the U.S. Maternal and Child Health Bureau in the development of a strategic plan. Ms. Lipson also monitors and provides technical assistance to state officials on comprehensive health care reform strategies, including grantees under the Robert Wood Johnson Foundation's *State Initiatives in Health Care Reform*.

Ms. Lipson has fifteen years of experience in health policy analysis and local health program development and management, with expertise in Medicaid, state programs for the uninsured, primary care services, and maternal, child and adolescent health programs. Prior to the Alpha Center, she was a health policy consultant for a wide range of public and private organizations, Assistant Director for Programs and Policy at the Children's Defense Fund, and Senior Research Associate at the Intergovernmental Health Policy Project at George Washington University. She received her Masters in Health Services Administration from the University of Michigan School of Public Health.

Ann McDonald-Cacho

Ann McDonald-Cacho is the Creative Director of McDonald Advertising, a freelance advertising and design firm. Prior to starting her own business in 1982, Ann was an art director at Foote, Cone, Belding & Honig Advertising in San Francisco. She received her Bachelor of Fine Arts degree from the California College of Arts & Crafts in Oakland.

Personally and more importantly, Ann and her husband Bernard Cacho are the parents of Philip, who is nearly nine years old and has spastic quadriparesis cerebral palsy. Their parenting involves securing a joyful, creative and healthy life for Philip. Ann and Bernard have served various community support organizations, such as United Cerebral Palsy, the Family Resource Network of Alameda County, and the Center for Accessible Technology in Berkeley. Thanks to Philip, his parents are able to extend knowledge, expertise, and peer support to families facing similar challenges and illustrate to the public at large the critical need of educational, medical, and family support services.

Sandra Naylor Goodwin, Ph.D.

Sandra Goodwin is currently the Director of the California Institute for Mental Health, a not-for-profit public interest foundation organized under the auspices of the California Mental Health Directors Association. Dr. Goodwin is deeply involved in development a county-based managed care system for the delivery of Medi-Cal mental health services. She is also currently involved in analysis and advocacy of national health care reform in the context of California's mental health system.

As the Principal Consultant to the California State Assembly Committee on Health from 1989 to 1993, Dr. Goodwin specialized in mental health, developmental disabilities, and substance abuse issues. She is an expert on the California legislative process. She was instrumental in the development and implementation of California's realigned and reformed public mental health system.

Dr. Goodwin served as the Director of Mental Health and Substance Abuse Services for Placer County from 1982 to 1988. She has extensive knowledge and experience in both clinical treatment methodologies and in planning and policy development at the county and state levels.

Paul B. Simms, M.P.H.

Paul Simms is Director of Community Health Services for the County of San Diego. He has been employed with the County in various administrative and management capacities for the past 22 year.

Mr. Simms administers Community Health Services (all Physical and Public Health Services) for San Diego County. He is responsible for the:

- 323-bed Edgemoor Geriatric Hospital;
- Emergency Medical Services Agency (which includes the San Diego Trauma System);
- Division of Primary Care Services;
- County Medical Services Program, which is a managed care program for indigent adults;
- Health services to correctional institutions (except the County Jail);
- Maternal and Child Health Services;
- Communicable Disease Services;
- California Children's Services;
- Public Health Education;
- Public Health Nursing;
- Vital Records and Statistics; and
- Related grant development, research and health planning functions.

These programs represent a budget of $115 million with 1,100 employees.

Mr. Simms received his Masters Degree in Public Health from the University of Michigan with an emphasis in Medical Care Organization, 1993.

He is the recipient of numerous awards, including:

- The Drotman Award, American Public Health Association for demonstrated leadership as a young professional in public health, 1989;
- The Mickey Leland Award, National Medical Association, 1991; and
- 1993 Partnership Award from the MERCK/National Managed Health Care Congress

Mr. Simms is also very active in numerous national, state, and local organizations and activities:

- Member of the March of Dimes Birth Defects Foundation of San Diego Board of Directors, 1993 to present;
- Member of the American Public Health Association Governing Council, 1991 - 1993;
- Chairman of the California Black Infant Health Leadership Committee Medi-Cal Access Subcommittee, 1989 - present;
- Immediate Past President, Black Caucus of Health Workers of the American Public Health Association, 1994 - 1995;
- Adjunct Faculty Lecturer, University of Michigan, School of Public Health, 1987 to present.

Dr. Simms is married and the father of four year old twin girls and a 2 year old son.

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