DRAFT

## Children's Health Care in the United States

### Poverty

- One in five children lives in a family with income below the poverty level. One out of every four infants and toddlers under age 3 is poor. (National Commission on Children, 1991)

- The rate of poverty among children remains significantly higher than that of any other age group (22.7% for kids vs. approximately 12% for both the elderly and non-elderly adults.) (Department of Commerce, 1994)

- Children comprise about 40% of the nation's poor, even though they represent only a quarter of the population. (Department of Commerce, 1994)

### Health

- Overall, American children are healthier today than at any time in our past. Yet in many areas of health care, progress has slowed or halted altogether. In others, the U.S. is actually losing ground.

- Each year, nearly 40,000 babies born in the U.S. die before their first birthday. Our infant mortality rate is higher than that of 23 other industrialized countries, including Japan, Sweden and France. (Health Unites States, 1993)

- Low birthweight is the leading factor contributing to the nation's poor infant mortality record. Little progress has been made in reducing the overall rate at which babies are born to soon or too small. (National Commission on Children)

- At least 15% of children are affected by chronic and disabling conditions including mental and nervous disorders which limit normal childhood activities. Some of these conditions may have been easily prevented or substantially ameliorated by timely health care and reductions in environmental risk. (National Commission on Children, "Beyond Rhetoric", 1991)

- A recent review of research on adolescent health has found that it is declining, primarily due to violence, pregnancy and drug and alcohol abuse. (Journal of the American Medical Association, 6/6/95)

- In 1992, only 55% of two-year olds had been appropriately immunized. (Children's Defense Fund)

### Poverty and Health

- Children from low income neighborhoods are significantly more likely than children from high income areas to be hospitalized for conditions that could have been prevented by routine ambulatory care. Admission rates for asthma and bacterial pneumonia, for example, are four times higher in low income than in high income areas. (Robert Wood Johnson, 1993)

- Poor and near poor children receive more of their care from emergency rooms, hospital outpatient departments and clinics than do nonpoor and insured children. Using these sources has substantial cost implications: hospital emergency room visits are three to four times the cost of visits to a doctor's office; outpatient visits are double the cost of office visits. (Robert Wood Johnson, 1993)

- Only 29% of poor children had a dental visit in 1989, compared with 43% of nonpoor preschoolers. (Robert Wood Johnson, 1993)

**United States' Health Spending on Children**

- Through such programs as Social Security and Medicare, the nation has significantly improved the circumstances of our elderly. We have not been as generous with our children. In 1993, 22.7% of American children lived in poverty, compared to 12.2% of the elderly. Nearly 100% of our senior citizens have health coverage, while more than a fifth of our children are uninsured. (Department of Commerce, 1994)

- According to a recent article in Fortune magazine

  - In 1990, federal, state and local governments spent over $11,000 on every American over 65, and only $4,200 on each person under 18. (Fortune, Jan 13, 1992, pp 68-72)

  - Senior citizens represent only 12% of the population, but command 54% of federal spending.

**Health Insurance Status of Children**

- The United States ranks among the worst of the industrialized nations in its prioritization of health care for children. The U.S. is the only major industrialized nation that does not provide universal health coverage for children.

- Even with the Medicaid program in place, more than 14% of those under age 18 are uninsured. (Current Population Survey, 1994)

- Between 1988 and 1994, the number of children under age 18 with employer-sponsored insurance fell by nearly 1.2 million. Largely because of Medicaid, these losses did not produce a net increase in the number of children without insurance; however, many are not categorically eligible for public programs and are therefore at risk for financially and physically catastrophic health events. (Holahan et al., 1995)

- Allowing our children to go without health coverage has particularly profound effects, since childhood provides a critical window during which to establish good health practices, detect impairments that can worsen with age, and intervene early to minimize their adverse health impacts.

**Medicaid and Children.**

- One in five American children are covered by Medicaid (Current Population Survey, 1994)

- Since 1984, the federal government has enacted a series of modifications of the Medicaid program, expanding eligibility and improving services. As a result, more low income pregnant women and children are receiving services. Gains are most evident in states where coverage in 1984 was relatively limited. The changes have reduced disparities among states in access to Medicaid services for pregnant women and children. (GAO, 1991)

- As a result of Medicaid expansions, the percentage of children below poverty who were uninsured declined between 1986 and 1990, with the gains concentrated among infants and preschoolers. (Robert Wood Johnson, 1993)

- o Increased Medicaid costs have not resulted from federal requirements to add more low-income mothers and children to the program.
  - According to a recent study by the Urban Institute, mandates for infants, children and pregnant women accounted for only 15% to 20% of 1992-1993 spending growth.
  - Cost increases have been driven primarily by the addition of substantial numbers of elderly, disabled, HIV-infected and unemployed adults as new beneficiaries. These groups tend to incur higher per patient costs than people in young families incur. (Blendon et al., 1993; Urban Institute, 1995)
- o Although adults and children make up nearly three-fourths of beneficiaries, they account for only 27% of Medicaid spending. The elderly and disabled account for the majority (59%) and DSH accounts for the rest (14%). (The Urban Institute, 1995)
- o Children are actually the least costly of all Medicaid recipients. Low income children represented 50.1% of beneficiaries in 1993, yet were responsible for only 15.3% of expenditures. (GAO, 1991; Urban Institute, 1995)
- o Even with today's broader levels of Medicaid funding and welfare assistance, 28% of Medicaid recipients do not have enough money to buy food, 31% to pay their rent or mortgage, and 29 percent to pay their heat and light bills. They simply cannot absorb the costs of needed medical services for themselves and their children. (Blendon et al., 1994)

**List of Sources:**


1) "Beyond Rhetoric: A New American Agenda for Children and Families", Final Report of the National Commission on Children, 1991

2) Census Bureau, Department of Commerce, stats based on March 1994 CPS ( taken from excerpt Jeanne has in her poverty file.

3) Health United States, 1993

4) Robert Wood Johnson, "Access to Health Care: Key Indicators for Policy" prepared by the Center for Health Economics Research, November 1993

5) "The Future of Children" a journal by the Center for the Future of Children. Looked at Winter 1992, Summer/Fall 1993, Winter 1994

5) Holahan, et al. "The Changing Composition of Health Insurance Coverage in the United States," February, 1995

6) Irwin, Brinids et. al., The Health of America's Youth: Current Trends in Health Status and Utilization of Services," University of California at San Francisco, March, 1991

# Clinton Presidential Records
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Booklet, "Bibb County Department of Family and Children Services," 12 pages

# BIBB COUNTY DEPARTMENT

# OF

# FAMILY AND CHILDREN SERVICES

## Children's Initiative
## Family Preservation Outreach

**" Bringing Services to the People "**

Melanne —

Who is the most appropriate person for this group to meet with?

Julie

↓ Michele, Jen Klein

# FAX COVER SHEET

DATE: 2-16-95 TIME: _____

TO: Ms. Patti Solis

OF: Office of First Lady (Agency, Busines, etc.) Washington, D.C. (City & State)

AREA CODE & FAX #: 202 456-2317

REMARKS:

See attached request for an appointment with the First Lady.

This fax is being sent per Mr. Bob Ensley, Macon, GA.

Thank you.

YOU ARE RECEIVING THIS FROM: Marjorie Almand (912) 751-6051
(Name) (Phone No.)

BIBB COUNTY DFCS
456 OGLETHORPE STREET
MACON, GEORGIA 31298-1399

FAX #: 912-751-6578

TOTAL PAGES SENT: APPROVED BY: _____

1 EXCLUDING THIS COVER SHEET SENT BY: _____

**Bibb County Department of Family and Children Services**

456 OGLETHORPE STREET • MACON, GEORGIA 31298-1399

Director
MARJORIE M. ALMAND

Board Members
RANDALL E. DOUTHIT
BRENDA J. HADAWAY
MARTHA W. HOOPER
DONALD C. SHEFFIELD
DR. COLUMBUS WATKINS

February 16, 1995

TO: Ms. Patti Solis

FROM: Mrs. Marjorie M. Almand
Director - Bibb County DFCS

RE: Health Care - Federal Funding

We are requesting an appointment with the First Lady anytime during the week of February 28 - March 3, 1995. We will be attending Child Welfare League where Mrs. Clinton is scheduled to speak on March 1st. There will be approximately eight people in our party.

The purpose of this meeting would be to discuss the following health care programs with the hope of getting some Federal funding:

Immunization Campaign
Substance Abuse Center
Teenage Pregnancies
Health Check Clinic - Only one in the country.

Please let me know if further information is needed. This fax is being prepared per Mr. Bob Ensley.

We are eagerly awaiting your response.

Thank you.

---

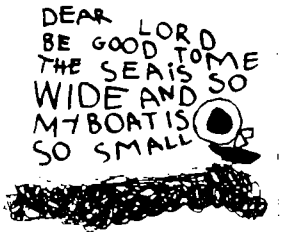
Jen -
How would you like to meet w/ this group? If you're amenable, pls call & say POTUS can't meet, but if they'd like to meet w/ staff, etc... ☺ Nicole

Jennifer Klein -fyi

To be released 11/15/94

# Key Findings from *Wasting America's Future: The Children's Defense Fund Report on the Costs of Child Poverty*

(Beacon Press. November 1994)




Children's Defense Fund

Approximately 15 million children in the U.S. live below the federal poverty line. the highest number in almost three decades. ***Wasting America's Future*** finds that child poverty is an enormous drain on the U.S. economy, with every taxpayer, business, school and hospital sharing the cost. The book estimates that:

- Every year of child poverty at current levels will cost the economy between $36 billion and $177 billion in lower future productivity and employment among poor children.

- These costs to the economy do not include the billions of additional dollars that will be spent because of the greater incidence of special education, crime, foster care, or teenage childbearing resulting from child poverty.

The human costs also are devastatingly high. According to the Kansas Department of Health, low-income children are:

2 times more likely than others to die from birth defects,
3 times more likely to die from all causes combined,
4 times more likely to die from fires,
5 times more likely to die from infectious diseases and parasites, and
6 times more likely to die from other diseases.

Similarly, poor children have been found to be two or more times as likely to suffer from a host of other problems, including stunted growth, severe physical or mental disabilities, fatal accidental injuries, fair or poor health, iron deficiency, and severe asthma.

***Wasting America's Future*** combines existing research across academic disciplines, and adds newly commissioned academic findings, to show that poverty's effects are large and far-reaching. Compared with other problems children face, long-term poverty is often of comparable or greater importance:

- "Family income is a far more powerful correlate of a child's IQ at age five than maternal education, ethnicity, and growing up in a single-parent family," according to one study cited in the book.

- Poverty's effects on child test scores have been found to be independent of mothers' scores on basic skill tests (sometimes called mother's IQ), race, marital status, years of education, and age at birth, or the mother's smoking or drinking habits.

- Single-parent families, race, and parent education levels cannot explain why children who experience poverty are consistently two to three times more likely than their peers who are never poor to become high school dropouts. This pattern is found among Black children and non-Black children, among those with married parents and those with single parents, and among those whose mothers finished high school and those whose mothers did not.

25 E Street, NW
Washington, DC 20001
Telephone 202 628 8787
Fax 202 662 3510

- The U.S. Department of Education reports that the risk of a student falling behind in school increases by two percentage points for every year he or she spends growing up in poverty. Poverty's effects are separate from--and stronger than--those of race, region, having a teen parent, or living in a one-parent home, according to the Education Department study.

- The effects of economic hardship on children cannot be attributed simply to intractable problems of their parents, such as deep-seated cultural or genetic traits or "character flaws." Such unchanging traits by definition cannot explain why problems such as child abuse, family break-up, and infant mortality tend to worsen or improve when economic conditions worsen or improve.

***Wasting America's Future*** traces many of the pathways leading from poverty to ills such as undernutrition, unsafe housing or family stress -- and from there to health problems, behavior problems, lower school achievement and a lifetime reduction in earning potential. Poverty likely hurts children for a wide variety of reasons, including:

- *stress on parents*, which can lead to less effective parenting, marital conflict or break-up, and ultimately to child behavior problems, aggressiveness, learning problems, and delinquency;

- *poor nutrition*, which can cause stunted growth (linked to lower academic test scores), iron deficiency (linked to anemia and deficits in problem-solving, attention span, motor coordination, and IQ), low birthweight, and birth defects;

- *housing problems* such as homelessness (linked to infant mortality, chronic diarrhea, asthma, delayed immunizations, family separation, and missed school), frequent moving (linked to not completing high school), and utility shut-offs (implicated in home fire deaths);

- *worse neighborhoods* with inferior schools, exposure to crime, and exposure to toxic chemicals and pollution; and

- *fewer resources for learning outside of school* such as inferior child care (linked to child stress and behavior problems), fewer extracurricular activities and stimulating family activities (linked to lower school achievement), more onerous home and work responsibilities (linked to lower school enrollment and attainment), and financial barriers to college.

***Wasting America's Future*** documents how many large and small problems accumulate and interact to leave poor children less resilient, more vulnerable, and at elevated risk across-the-board. The number and complexity of poverty's consequences for children suggest that better services for poor children may be necessary but not sufficient. Without a direct strategy to provide better jobs and adequate family income, the book concludes, we are unlikely to remedy the complex effects of poverty on children or reduce the extraordinary costs that poverty now imposes on American society.

Child poverty is not inevitable. As Children's Defense Fund president Marian Wright Edelman notes in her *Introduction*, other countries of comparable wealth have far lower rates of child poverty. The United States can follow a similar path by reducing family poverty through direct job creation, supplements to low wages, affordable child care, increases in the minimum wage, and a national system of child support enforcement and assurance.

Overseen by a distinguished advisory panel chaired by Nobel prize-winning economist Robert M. Solow, ***Wasting America's Future*** suggests that Americans should no longer fear the expense of eliminating child poverty. As Professor Solow notes in his *Foreword*, "Inaction has its costs, too." In fact, writes Solow, "This book is cause for optimism....The evidence in this volume indicates that ending child poverty is, at the very least, highly affordable. More likely it is a gain to the economy, and to the businesses, taxpayers, and citizens within it."

# The Children's Health Fund

To:

From: Irwin Redlener, M.D.
Children's Health Fund

Date: November 10, 1994

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The Children's Health Fund and the Kids First Campaign invite you to attend an important post-election meeting of children's health and advocacy organizations on **November 14th, 1-4 pm.**

In the aftermath of the recent Summit on Children and Health Care Reform, the Kids First Campaign has solicited and received valuable input on the best course of action to ensure that health care coverage for children remains a priority item on the national legislative agenda. This meeting will attempt to focus the resources and expertise of participants on development and strategic implementation of a common ground agenda for children in 1995. The agenda items listed below will be analyzed in discussion groups led by senior staff members of participating organizations.

In addition to your attending, we strongly suggest the senior staff person for communications within your organization also be invited to attend.

**Please RSVP by November 4th** by calling the Children's Health Fund at (212) 535-9400.

DATE/TIME: **November 14, 1994**
**1:00 - 4:00 PM**

LOCATION: National Education Association
1201 16th St. (16th and M St.)

AGENDA:

I. Substantive Content of Health Reform Legislation for Children

II. Analysis of Political Lansdcape for Health Reform in 1995

III. Message Development and Communications Strategy

KIDS FIRST CAMPAIGN - ORGANIZATIONAL SURVEY RESULTS

Number of Respondents 25

1- Would your organization support a health reform proposal which, in addition to insurance reform measures, would guarantee comprehensive health care to children as the first step in providing universal health care coverage for all Americans?

YES 72% NO 4% UNDECIDED 24%

2- Would your organization support a stand alone health reform proposal which would guarantee comprehensive health care for all children?

YES 80% NO 4% UNDECIDED 16%

3- Would your organization support a health care reform proposal which calls for public subsidies to purchase private insurance for uninsured children?

YES 52% NO 8% UNDECIDED 40%

4- Would your organization support a health care reform proposal which calls for the expansion of Medicaid to increase the number of children eligible for Medicaid coverage?

YES 68% NO 8% UNDECIDED 24%

5- Would your organization support a health care reform proposal which calls for the enrollment of all uninsured children in a federally-administered insurance program like Medicare for the elderly?

YES 60% NO 8% UNDECIDED 32%

6- Would your organization support a health care reform proposal which calls for a combination of public subsidies for purchase of private insurance and Medicaid expansion to increase coverage of uninsured children?

YES 44% NO 12% UNDECIDED 40% NR 4%

7- Would your organization support a health reform proposal that guaranteed comprehensive health care services for children yet did not specify a defined package of benefits for children?

YES 0% NO 56% UNDECIDED 44%

8- Would your organization support a health reform proposal that guaranteed comprehensive health care services for children yet did not specify a defined national standard for all health insurance plans and child health programs?

YES 4% NO 40% UNDECIDED 56%

KIDS FIRST CAMPAIGN - SURVEY RESPONDENT LIST

AMBULATORY PEDIATRIC ASSOCIATION
AMERICAN ACADEMY OF PEDIATRICS
CHILD WELFARE LEAGUE OF AMERICA
CHILDREN'S DEFENSE FUND
CHILDREN'S HEALTH FUND
MARCH OF DIMES
NATIONAL ASSOCIATION OF CHILD ADVOCATES
NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS
NATIONAL ASSOCIATION OF PEDIATRIC NURSE ASSOCIATES AND PRACTITIONERS

AMERICAN ACADEMY OF FAMILY PHYSICIANS
AMERICAN COLLEGE OF NURSE-MIDWIVES
AMERICAN COLLEGE OF OSTEOPATHIC PEDIATRICIANS
AMERICAN PEDIATRIC SOCIETY
ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS
ASSOCIATION OF SCHOOLS OF PUBLIC HEALTH
NATIONAL ASSOCIATION OF SCHOOL NURSES
NATIONAL MEDICAL ASSOCIATION
NATIONAL PERINATAL ASSOCIATION
NATIONAL COUNCIL OF HISPANIC HEALTH AND HUMAN SERVICE ORGANIZATIONS

ADVOCATES FOR YOUTH
FAMILY SERVICE AMERICA
FAMILY VOICES
NATIONAL COUNCIL OF LA RAZA
NATIONAL EASTER SEAL SOCIETY
YMCA OF THE USA

New York Newsday
MONDAY, SEPTEMBER 12, 1994

# Kids Are the Victims of Health-Care Politics

**By Irwin Redlener**

ALTHOUGH A FULL overhaul of the nation's health-care system may not occur in 1994, it is at least likely that a compromise, incremental proposal will be passed by Congress. Something must be done for the many Americans who suffer under unfair insurance practices, who are devastated by medical costs and who never know whether essential medical care will actually be available when it's really needed.

But, whatever we do, the theme should be: Kids first. The fact is that, for the nation's children, the failure of Congress to agree upon ways to make health care secure and affordable for everyone has special meaning. Children, more than members of any other age groups, suffer the lack of access to appropriate medical care in silence.

*Irwin Redlener is president of the Children's Health Fund and chief of community pediatrics at Montefiore Medical Center in the Bronx.*

For as many as one in five American children, the current U.S. health-care system is dangerously unreliable and disorganized. Pediatricians from almost every other industrialized nation are bewildered by the profound inadequacy of our health safety net for kids.

At least 10 million children are among the uninsured in America. Many more are only partially covered; some may have medical insurance but live in physician-shortage areas.

Some children who aren't covered by health insurance will get health care — but not until their medical conditions reach a state of urgency that just can't be ignored. They will be seen in emergency rooms or admitted to hospitals as charity cases, often for problems that could have been prevented if they had appropriate office-based preventive care such as routine childhood immunizations. If Congress does not take steps to guarantee comprehensive and preventive health services for children, here's what we can predict with near certainty:

Too many children will not receive life-saving vaccinations because they don't have a regular doctor or clinic, the main reason childhood immunization rates in the United States are so distressingly low. Public education campaigns or even vaccine giveaway programs simply cannot ensure a sustained high rate of completed immunizations.

Next year, more than 600,000 children without health care will have repeated ear infections. Without comprehensive coverage and access to care, many of these kids will experience chronic infections, hearing loss and learning difficulties in school.

One-half million uninsured children will have chronic medical conditions such as epilepsy, diabetes and juvenile arthritis. These children desperately need regular sources of health care where their cases are known and followed, where complications can be prevented or controlled.

Among the uninsured children, 250,000 will have asthma — many debilitated by poorly controlled respiratory troubles that interfere with learning and physical activity. In fact, hundreds of thousands of other medically underinsured children will have a host of disabling conditions. Who will care for these children if we do not make their medical coverage and access to care secure?

At least 500 kids without health care will be diagnosed as new cases of tuberculosis; 200,000 will have elevated blood lead levels and at least 30,000 will experience documentable child abuse or neglect for the first time.

Some 800 cases of childhood leukemia and other malignancies will be identified among the uninsured. And the earlier these malignancies are discovered, the more likely will treatment be successful. But early diagnosis can best take place if a child is getting regular checkups and parents have a place to call if symptoms develop.

And every uninsured family of a child with cancer faces not only the trauma of life-threatening illness, but also the terrifying prospect of financial ruin in paying for treatment.

What's important to realize is that almost all these childhood health concerns would benefit from preventive care, early detection and timely intervention. These are the kind of comprehensive medical services that should be guaranteed, right now, to every child in the country.

If our officals want to do something meaningful to improve the health and well-being of the nation, they should provide appropriate and comprehensive care to children as a first step. This can be done efficiently and at relatively minimal cost.

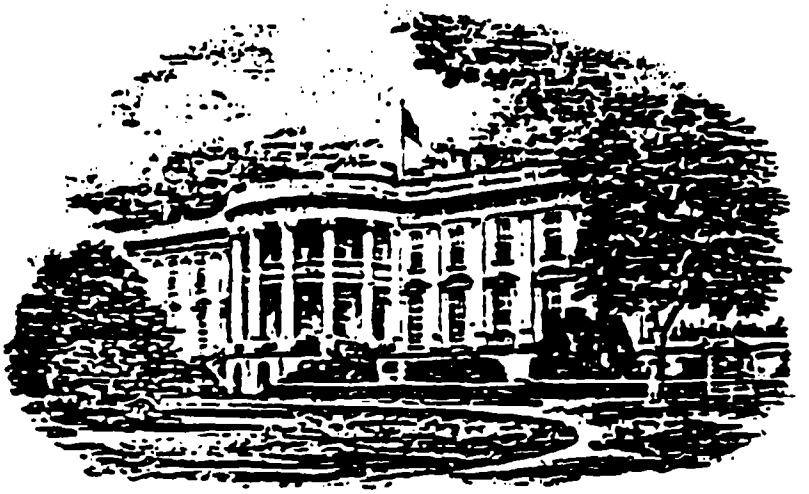
If we fail to act now, many children will needlessly contend with untreated or undertreated medical problems that can undermine their potential to develop or function successfully.

Can our representatives actually give politics a rest and do what's in the best interest of the nation? Let's hope they do the right thing and, if nothing else, at least guarantee insurance coverage and access to appropriate health care for all children.

DATE: _____
TIME: _____

# THE WHITE HOUSE

# WASHINGTON



## FAX COVER SHEET

TO: Marlo Thomas

PHONE: (212) 826 5970 Sabrina Stacy

FAX: (212) 754-2193

FROM: Jennifer Klein

PHONE: (202) 456-2599

PAGES FOLLOWING COVER SHEET: 1

TO: Marlo Thomas
FROM: Jennifer Klein

Here are the points that we discussed earlier. Please feel free to call me at (202) 456-2599 with any questions.

THE PROBLEM TODAY

- 9 million children and half a million pregnant women have no health insurance. Millions more have private insurance that does not cover preventive services -- like immunizations and well-child care.

THE SOLUTION

- We must provide affordable health coverage for all of America's children. And we must ensure that those children get the primary and preventive care that they need -- so that their families don't have to wait until they get sick before seeking medical help. This saves health care costs -- and, more importantly, it improves health and saves lives.

- All children deserve a healthy start, just as all children deserve to grow up in a safe neighborhood, to have a supportive family, and to go to school where they can learn.

FAX TRANSMITTAL # of pages ► 3

| | |
|---|---|
| To Jennifer Klein | From Cheryl Austin |
| Dept./Agency WH | Phone # 690-6051 |
| Fax # 456-2878 | Fax # 401-7321 |

NSN 7540-01-317-7368 5099-101 GENERAL SERVICES ADMINISTRATION

me Took based on yesterday evenings discussion R. VALDEZ 260-1281

Potential Mechanisms for Coordinating with School Health Programs

Draft discussion options

**Background:**

Requests for technical assistance concerning school health provisions raised concerns about the wide range of health care services and programs offered or educationally mandated that are not coordinated with medical care programs. In our meeting of 16 June 94, Judy agreed that the following suggestion was appropriate:

The state/alliance would be required to convene a School Health Resource Partnership including insurers, public and private health care providers and state officials with responsibility for health, mental health, social services, and education. The functions of the partnership could include: (1) identifying unmet health care needs of school-age children; (2) identifying the most appropriate providers of that care; (3) agreeing to linkages among sites and providers; (4) negotiating a menu of services and mechanisms for financial support services that takes into account a variety of factors (e.g., needs for early access, prevention, reducing risk-taking behaviors, reducing barriers to enrollment, promoting cost-effectiveness, meeting health plan requirements); and (5) authorizing health care providers to use a variety of personnel to provide health care in schools. States/alliances would also have the authority to require local partnerships.

**Potential coordination of services options:**

Options for ensuring that the needs of school-age children receive services that are appropriate and coordinated could come through a plan requirements, quality standards, and essential community provider provisions.

Plan requirements (Title I Subtitle E):

Current plan requirements section 1405 subsection (f) contains the following language for compliance with IDEA: (f) Compliance with Treatment of Plans under Individuals with Disabilities Education Act. -- Each plan provided by a carrier shall comply with plans of treatment developed under the Individuals with Disabilities Education Act and other programs for children with special health care needs, notwithstanding -

(1) otherwise applicable prior authorization requirements utilized by the health plan, or

(2) otherwise applicable restrictions on the health care professionals from whom covered items and services may be obtained or the settings in which covered items and services are furnished.

Two modifications could broaden these provisions to include the wider provision of health services in school settings:

Compared OK with S of L language

(1) Replace "shall comply with" to "shall coordinate and integrate services required in";
(2) Replacing the phrase, "other programs for children with special health care needs" to "other programs providing health education and health services for children"

Subsection (c) Specialists as Gatekeepers in section 1405 may also provide an opportunity for increased coordination between medical care and education provided services. Subsection (c) reads:

Any plan that uses a gatekeeper or approval process prior to the provision of health care services shall establish panels of providers who agree to serve as gatekeepers, including specialists in the management of chronic illness or disabilities. In the case of children, such specialists shall be pediatric specialists. Each enrollee who has a chronic disease or diability (as defined under section 7(15) of the Rehabilitation Act of 1973) requiring specialized services likely to last for more than 1 year, may select a gatekeeper from among such providers.

Specialists work in schools

The following modification of this subsection increases school health coordination:

In the case of children, such specialists shall be pediatric specialists who can coordinate treatment plans and services provided in school and other settings under IDEA and other programs for children with special health care needs.

Quality standards (Title I, Subtitle E):

Section 1414. Coordination of Care reads as follows:

A carrier shall establish and implement, with respect to each of its health plans, mechanisms for coordinating the delivery of care across provider settings and over time, including at least mechanisms for -

(1) linking patient registration and medical record information so that it is accessible to all parts of the plan and, consistent with State law, this Act, and other Federal law, assures the confidentiality of patient information,

(2) assisting enrollees to obtain necessary care, including preventive services, and

(3) coordinating the services furnished to an enrollee when more than one practioner or provider is involved.

Modifying the third provision to read:

(3) coordinating the services furnished to an enrollee when more than one practioner or provider is involved. In the case of children, coordination may include treatment plans and services provided in other settings such as schools. OK

Essential Community Provider Certification (Title I, Subtitle F)

The current version of Subpart B- Certification of Essential Community Providers provides for the Secretary to certify ECP status on any health care provider or organization meeting automatic certification and those meeting standards for

certification in section 1583(a). Within Section 1582, however, one of the categories for automatic certification reads:

(10) Provider of School Health Services - A provider of school health services that receives development funds under subtitle E of title III.

Will provide for ECP status for those schools participating in the Title III program. Adding a statement in Section 1583 standards for additional providers would permit the Secretary to certify schools or a subset of schools as ECPs if they are not among the title III grant schools.

Sec 1583 (b) (3) reads:

(3) Other Providers.- Other public and private nonprofit agencies and organizations that -

(A) are located in such an area or providing health services to such a population, and

(B) provide health care and services essential to residents of such an area or such populations.

Modifying the first sentence to read:

Other public and private nonprofit agencies and organizations including schools that --

Would explicitly recognized schools as one of the organizations that could be certified as an ECP for purposes of improving access to care and assuring comprehensive benefits.

To: Jen Fr: Liz Charles

**Regina Birdsell, Dir. Public Affairs & Corp. Dev., Children's Hosp. Los Angeles (CA)**
Coordinates telethon fund raising and cause marketing, media relations for hospital and also involved in organization/production of telethon.

- Prenatal care
- Appropriate care for adults vs. kids when long-term rehabilitation is required
- Coverage throughout treatment in cases like bone marrow transplants

**Amos Brown, Station Manager, WTLC-AM/FM Radio, Indianapolis, IN**
Local telethon co-host for CMN (Riley Hospital for Children). At these radio stations for 19 years. Hosts daily, 90 minute, noontime talk show on AM station. Active in wide range of community activities, boards and committees.

- Infant mortality rate among minorities
- Concern that "preferred providers," "managed care," "regional cooperatives," could have detrimental effect on Black health care providers (i.e. doctors, pharmacists, and others)
- Employer mandates and their probable effect on small minority businesses
- The plan's impact on emergency room visits (as primary care treatment centers)
- Medicare and Medicaid
- Universal coverage (and those who refuse to sign up for such coverage)

**William H. Considine (Bill), Pres. & CEO, Children's Hosp. Med. Ctr. of Akron (Ohio)**
President of one of the nation's top children's hospitals, also a valuable member of CMN's Board of Trustees.

- Excluded coverage for low-income children with chronic, long-term physical, mental and developmental disabilities (Ira Magaziner during recent teleconference at NACHRI annual meeting)
- Children's hospitals to be included in list of essential community providers

**Diane R. Doniger, Trustee, Strong Children's Hospital, Rochester, NY**
Also serves on CMN's Board of Trustees and in line to become board's next Chairperson.

- Role of private philanthropy under universal health care system

**Karen R. Schaler, Co-Anchor/Producer/Reporter, KEVN-NBC, Rapid City, SD**
Has been local host of CMN for past two years. Also hosts local MDA Telethon.

- Impact on Indian Health Services
- Rural health care accessibility
- Medicare/Medicaid and smaller rural hospitals

Mark Woolverton, Comm. Rels. Coordinator, Sacred Heart Foundation, Pensacola, FL
Coordinates telethon in Pensacola for Sacred Heart Hospital. Primarily responsible for all fund raising and cause marketing, but is also involved in organization/production of telethon.

- Financing of the President's Health Care Plan
- Health care costs for premature babies and how rationing included in the Clinton plan may affect these children
- Malpractice reform (as defined in the Cooper Plan)

Incidently, this year's show will be broadcast live from Disneyland on June 4 and 5. It can be seen locally on WUSA-CBS in Washington. Thank you, Patti, for your help in putting this together. I'm sure Mrs. Clinton's remarks will be both enjoyable and enlightening.

Kind regards,

Roger Cook

Roger H. Cook, vice president
Hospital Relations

Children's Miracle Network

Selected Answers to Possible Questions

Most of the questions raised are very straightforward. Here are notes on some of the questions that may be more challenging.

Regina Birdsell

- **Appropriate care for adults vs. kids when long-term rehabilitation is required**

  The President's proposal will expand and improve long-term care options for Americans with disabilities. We recognize that children with disabilities may have needs different from those of adults. Within Federal guidelines, States are given the flexibility to design and define community-based service systems to best meet the needs of children and adults. The plan also includes a wraparound program for Medicaid-eligible children to ensure that they receive a full range of needed rehabilitation services.

  We also recognize that prevention is a central goal of child health services. The plan therefore provides a broad array of clinical preventive services without cost sharing, including prenatal care as well as immunizations, tests and regular checkups for children.

- **Coverage throughout treatment in cases like bone marrow transplants**

  The President's plan does not specify particular treatments within the comprehensive benefit package. The package covers categories of services, such as hospital services or health professional services, and leaves to doctors and their patients -- rather than the government -- intimate decisions about what treatment is medically necessary or appropriate in a particular instance.

  If a treatment is investigational -- like some bone marrow transplants -- a health plan may cover it.

Amos Brown

- **Concern that preferred providers, managed care, regional cooperatives could have detrimental effect on Black health care providers**

  The President's plan guarantees that all health professionals will have a choice of health plans to

join. They may choose to join more than one plan -- for example, both a fee-for-service plan and a preferred provider network. Health plans have an incentive to contract with minority providers in order to best serve their enrollees, who will want to continue seeing the doctors and visiting the clinics that they know and trust.

In addition, the proposal requires that all health plans contract with "essential community providers." These include maternal and child health providers, community health centers, AIDS programs and other community-based providers -- often minority providers who have for so long provided much of the health care in underserved communities.

Finally, the President's proposal specifically prohibits discrimination against health care providers on the basis of race, income, and health status as well as other personal characteristics, and on the basis of the race, income, health status or other personal characteristics of their patients.

William H. Considine (Bill)

- **Excluded coverage for low-income children with chronic, long-term physical, mental and developmental disabilities**

The President's plan fundamentally reforms the insurance market by prohibiting health plans from denying coverage or charging higher rates to individuals with so-called "pre-existing conditions." The plan also eliminates lifetime limits that end coverage just as an individual needs it the most.

The comprehensive benefit package includes a range of services needed by disabled children, including hospital services, preventive services, mental health services, home health care, durable medical equipment and rehabilitation services. Some of the benefits include limitations. We have therefore preserved a wraparound program for Medicaid-eligible children to provide the ongoing supports that they need, including more extensive mental health and rehabilitation services.

We have also created a long-term care program that will expand home and community based services to individuals with severe disabilities. This program will provide support to individuals who can and wish to be cared for

at home or in the community rather than in nursing homes or other institutions.

Karen R. Schaler

- **Impact on Indian Health Service**

  Under the President's proposal, the Indian Health Service and tribal organizations will continue to provide health services to Indian people. The Indian Health Service will expand and improve its facilities to provide the comprehensive benefit package by January 1, 1999. Indians may enroll in health programs of the Indian Health Service or in health plans offered within alliances. While care within the IHS system remains free for the individual, Indians choosing to enroll in an alliance health plan will pay premiums and cost sharing but will be eligible to receive discounts based on income like all other Americans. The IHS will continue to provide a wide array of supplemental services to all Indians -- whether they enroll in an IHS program or an alliance health plan.

might even be excluded because individuals affected by a proposed initiative might "not exist." Public health surveillance of illness events and risk behaviors, dependent on precise measurement, will be thwarted. As it now stands, the epidemiology of many health-related issues for the wonder years can be defined only with great difficulty, if at all. Without absolutely clear age categorization for these years, young people in transition from childhood to adulthood can become lost in a definitional and informational "black hole."

Perhaps most importantly, how adolescent health problems are defined, and who defines them, has implications for the assignment of responsibility for developing appropriate solutions to these problems. It is essential that this be a joint undertaking with representatives from pediatrics, public health, adolescent health, internal medicine, family practice, psychiatry, psychology, nursing, other health care sciences, school health, the college health community, and those in governmental health, education and welfare agencies. A set of commonly agreed on age groupings, definitions, and terms providing uniform data on morbidity, mortality, health, social, and economic status of adolescents and young adults will enable meaningful, shared responsibility *and* accountability for the health of our youth.

*Healthy People 2000* lays out a compelling set of goals and objectives for our nation's health in the year 2000,[10] including many that specifically address the years encompassed by adolescence and youth.[11] However, before we can know that we've attained these objectives and improved the health of our young people, we must get our bearings straight and our definitions clear. When we arrive in the Year 2000 we don't want to wonder...

*"Are we nearly there?... Why, we passed it ten minutes ago!"*[12]

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# Children With Chronic Illness and Medicaid Managed Care

As the nation debates approaches to reforming the health care system, states are conducting experiments of their own designed to improve access to care for low-income Americans, while containing costs, by converting Medicaid programs from fee-for-service to managed care.[1–4] Between 1987 and 1992, states' total enrollment of Medicaid beneficiaries into managed care plans more than doubled.[1] As of February 1993, 36 states were operating one or more managed care programs for Medicaid enrollees.[1] The managed care models adopted by states for Medicaid beneficiaries range from fully capitated, prepayment models whereby plans are at full financial risk for all health services, to models that combine limited risk and fee-for-service reimbursement while controlling utilization through "gate-keeping." These experiments have enormous implications for all parties involved: the federal and state governments, health care providers, and especially the low-income beneficiaries of the Medicaid program.

One group with a special stake in the transformation to managed care is children with chronic illnesses. These children, who require ongoing medical attention, stand to gain much if the experiments are successful. On the other hand, if these experiments fail, the result may prolong or exacerbate their conditions. The stakes are substantial because an estimated 2.5 million children with chronic conditions are enrolled in the Medicaid program (unpublished tabulations from the National Health Interview Survey).

The trend toward greater use of managed care under Medicaid raises several concerns regarding the treatment of children with chronic health problems. One of the biggest concerns is the absence of comprehensive and current data on the effects of Medicaid managed care on children. The most comprehensive evaluation data available come from the Medicaid Competition Demonstrations of the early 1980s. Evaluations of these Medicaid managed care experiments suggest that managed care does not automatically result in improved access to care.[5] In fact, these experiments demonstrated mixed results concerning physician use and quality of care, while find-

Received for publication Jun 29, 1993; accepted Aug 27, 1993.
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ing slight reductions in utilization of emergency departments and inpatient services, and modest reductions in overall costs. These experiments did not target nor separately measure the needs of children with chronic illnesses. Nonetheless, cost containment pressures are pushing wide-scale application of managed care without clear evidence of its benefits for children, especially children with chronic health conditions.

The purpose of this commentary is to identify the essential programmatic elements that must be incorporated into managed care programs to ensure that they result in appropriate access and quality of care. The three specific areas that must be addressed include: the rates paid to plans and providers for the care of chronically ill children, the availability of services and providers needed by chronically ill children, and the quality of care chronically ill children receive.

## CAPITATION RATES FOR MEDICAID ENROLLEES

Medicaid managed care rates are typically set at a figure based on a percentage of average fee-for-service expenditures. In some states these figures are adjusted according to the child's eligibility category, to account for variations in costs associated with different groups of children. For example, most states pay a higher per capita rate for children who are enrolled in Medicaid's Medically Needy program than for children enrolled in the Aid to Families with Dependent Children (AFDC) program, because Medically Needy children tend to experience greater health problems. In contracting with managed care plans, state Medicaid agencies generally seek savings by discounting per capita Medicaid fee-for-service expenditures by 5% or more.

This method of determining rates, although advantageous to states, does not assure that plans and providers are reimbursed adequately for the cost of providing necessary services. For example, the Physician Payment Review Commission reported that Medicaid physician payment levels are equal, on average, to about 64% of Medicare payments and that Medicare reimbursement rates are about 65% of private levels.[6,7] Medicaid payments for inpatient hospital care, according to the Prospective Payment Assessment Commission, are equal to about 63% of private payer rates.[8] Using these data, Sheils and colleagues conclude that Medicaid fee-for-service reimbursement levels would have to increase about 60% for inpatient services and 140% for physician services to match private payer rates.[9]

As a result of low Medicaid capitation rates, few plans—even the most efficient—can afford to provide high-quality comprehensive health care to Medicaid enrollees. Insufficient rates can create a difficult predicament for participating plans and providers by forcing them to withhold care or assume financial losses. Although all children are at risk for avoidable health problems when needed care is not provided, exacerbation or deterioration of health problems are almost assured when chronically ill children are not able to obtain needed medical attention. To ensure that plans and providers have the resources to furnish all necessary care to chronically ill children, rates must be adjusted to reflect the true costs of care.

Raising Medicaid payment levels for children to private payer levels, although not inexpensive, represents a relatively minor expenditure overall. Sheils and colleagues estimate that an additional $39.7 billion would be required in 1993 to bring Medicaid reimbursement rates up to prevailing private levels.[9] Because children account for only about 14% of overall Medicaid expenses,[10] raising Medicaid reimbursement to private levels for children alone would cost substantially less than raising Medicaid reimbursement overall.

Rate setting must not only reflect the costs of providing care to children in general, but also must reflect differences among children. Children with chronic conditions not only use more acute care services than other children, but are also far more likely to use habilitative and rehabilitative services. For example, past studies have shown that children with chronic conditions causing limitations in their usual activities are twice as likely to be hospitalized, consume twice as many physician services, and use six times as many nonphysician professional services as children without activity-limiting chronic conditions.[11] In addition, visit times can be more lengthy for chronically ill children, especially for those children with complex needs.

## AVAILABILITY OF NEEDED SERVICES AND NEEDED PROVIDERS

Depending on the condition and its severity, chronically ill children may require any of a wide range of health services and supports. Federal law recognizes this and stipulates that children enrolled in Medicaid are entitled to case management, rehabilitative services, personal care, psychological counseling, recuperative and long-term residential care, and many other services so long as they are deemed necessary by a physician or other health care provider.[12] Traditional Medicaid benefits for chronically ill children are, in fact, far more comprehensive than those of most private insurance plans. Not all managed care plans, including both private health maintenance organizations and public plans, have the capacity to offer the broad range of services available under Medicaid, nor have within their network the full range of providers that children need.

Explicit procedures are required to ensure that children enrolled in Medicaid have access to the full range of Medicaid reimbursable services. At a minimum, this requires building into contracts language which spells out the range of services to which children are entitled and the plan's obligations to provide them, as well as requirements that plans demonstrate the availability of providers within the plan capable of providing those services. When these services are not offered directly by providers within a plan, provisions must be made to permit receipt of out-of-plan care either through contractual arrangements with out-of-plan providers or on a fee-for-service basis reimbursed by the Medicaid agency. If all services remain within the plan's scope of service but some are provided by an out-of-plan contractual provider,

careful monitoring is essential to ensure that chronically ill children do not face undue barriers in obtaining out-of-plan services. If services are to be provided in the fee-for-service system, care must be taken to ensure that children are not "dumped" on outside providers to reduce expenses within the plan. In either case, out-of-plan services should be provided by recognized child health practitioners. Moreover, explicit contractual provisions must be made that describe how out-of-plan services will be provided and that delineate the plans' responsibilities for assuring children's access to specialty services and for coordinating such care with in-plan services.[4]

More generally, provisions must be made that assure that children with chronic conditions receive proper medical management. At a minimum, proper management includes service coordination and case management. Ideally, these services should be provided by a multidisciplinary team of children's practitioners. By virtue of their size, many managed care systems are in a position to provide the kind of multidisciplinary services these children need, given the proper incentives to do so. However, anecdotal reports suggest such services may not be available to many children enrolled in Medicaid managed care plans. Consequently, explicit procedures are required to ensure that these services, which are fully reimbursable under Medicaid regulations, are provided to chronically ill enrollees.

In addition to ensuring that necessary services are available, provisions are needed to foster linkages between Medicaid managed care plans and existing public programs serving children with special needs. These programs include:

- The Title V Maternal and Child Health Block Grant Program, which includes support for the development of family-centered, community-based systems of care for children with special needs;
- The Child and Adolescent Service System Program (CASSP) of the National Institute of Mental Health, which provides funds for the development of interagency efforts to improve the systems of care for children with severe emotional disturbances;
- The Part H Early Intervention Program of the Department of Education, which supports the planning and implementation of interagency systems that deliver comprehensive, coordinated services to handicapped infants and toddlers and their families; and
- The Part B Special Education Program, also of the Department of Education, which provides funds for special education and related health services to school-age children who, because of their disabilities, require special school instruction.

Services provided by the managed care plans and these public programs should be integrated so that a seamless and coordinated service system can be provided. Ideally, both the plans and the public programs would have mutual responsibility for ensuring this integration, but ultimate responsibility for assuring coordination should rest with the plans.

It is important to recognize that many systemic and infrastructural problems exist in our current health care delivery system and that these problems will not be resolved through implementation of Medicaid managed care systems. Chronically ill children who reside in rural areas, for example, are particularly unlikely to have specialty (and in some cases even primary care) services available on a geographically accessible basis. For many inner-city children, such issues as language difficulties, absence of child care, lack of adequate transportation, and a shortage of culturally competent providers capable and willing to serve these populations present major barriers to attaining satisfactory care. It is unlikely, at least in the short term, that the types of financing arrangements being implemented under Medicaid managed care programs will affect these barriers to any significant degree. Additional, separate efforts will be required to deal with these structural health care problems.

## QUALITY OF CARE

Capitation can produce an economic disincentive to provide needed care, especially if capitation rates are inadequate. The resulting defacto rationing at either the plan or provider level can result in inadequate care. However, even if rates are sufficient to cover the cost of care, a built-in incentive remains under capitation to discourage the provision of some services when norms for appropriate treatment are absent or unclear.[13] Because norms for appropriate treatment are poorly defined for many chronic conditions, monitoring quality of care is a difficult but critically important task. Over the long term, this knowledge gap could be addressed through the development of practice guidelines and performance standards for childhood chronic conditions. Concurrently, efforts are needed to monitor compliance with practice guidelines and performance standards. This will necessitate the development of appropriate assessment methods, reporting formats, and systematic methods for analysis of these data.

Even while these guidelines are being developed, provisions must be made to ensure that children obtain high-quality care. The capacity of a managed care plan to provide appropriate treatment for children with chronic conditions will depend on how it is organized.[13,14] Most managed care plans rely on primary care physicians to serve as gatekeepers to specialty services. Evidence from the Medicaid Competition Demonstrations indicates that the proportion of children with a visit to a specialist declined an average of 53% after enrollment in managed care.[5] Although specialty care may have been used inappropriately by children before their enrollment in the demonstration, the magnitude of reduction is cause for concern. Additional data from the American Academy of Pediatrics' Periodic Survey of Fellows indicate that pediatricians report difficulty in referring patients to subspecialists within managed care systems.[15] Families of chronically ill children have also indicated problems obtaining specialist care in managed care systems.[16] In the case of chronically ill enrollees, clear guidelines are needed concerning access to care by specialists. Moreover, it is not sufficient for plans to

simply ensure the availability of specialty or subspecialty care, but rather to ensure that chronically ill children have access to pediatric and not adult specialists.[4]

Medicaid agencies should contract only with plans that incorporate a significant number of local pediatric practitioners within their provider networks. Doing so will increase the likelihood that chronically ill children will be able to maintain ongoing relationships with their doctors. Practitioners who are not part of the managed care system but who have traditionally provided care to Medicaid-eligible chronically ill children for an extended period might also be incorporated into plans as preferred providers. When a lengthy historical relationship exists between a patient and practitioner who is not part of a contracted managed care plan, enrollment in the plan should be voluntary for the child.

Finally, it is critical to have written policies concerning grievance procedures and availability of services. Plans should have written policies that assure access to regular, after-hours, and emergency care, referrals to pediatric specialty care, and information about availability and qualifications of practitioners.[4,17] Written information on how to complain about services and how to appeal plan decisions should be available to all enrollees. An effective and accessible grievance mechanism is a necessary safety valve. A state or local level ombudsman could also be helpful in resolving conflicts and disputes between enrollees and managed care providers.[14] To ensure that managed care plans pay attention to problems reported by enrollees, Medicaid agencies must monitor complaints and be willing to weed out plans with persistent problems.

## CONCLUSION

Incorporating these suggestions would necessitate a significant commitment of funds and other resources on the part of federal and state governments. This level of commitment is necessary if children with chronic conditions from low-income families are to receive appropriate care and their sponsors receive fair value. However, attending to the suggestions made in this commentary—while necessary—will not automatically assure that chronically ill children receive the services they need. All too often the emphasis of Medicaid managed care is on managing costs rather than managing care. It is only through a more enlightened perspective—one that places a greater emphasis on what is best for children and a lesser emphasis on what is best for budgets—that chronically ill children will receive the care they deserve.


## ACKNOWLEDGMENTS

This work was supported in part by the Center for Children with Chronic Illness and Disability at the University of Minnesota and the Maternal and Child Health Bureau, US Department of Health and Human Services.



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# Penicillin- and Cephalosporin-Resistant *Streptococcus pneumoniae*: An Emerging Microbial Threat

ABBREVIATIONS. MIC, minimal inhibitory concentration; CSF, cerebrospinal fluid; LBCMC, LeBonheur Children's Medical Center.

# Health Care Reform and the Special Needs of Children

Health care reform may well address many of the needs of children and adolescents, offering greater emphasis on prevention and providing insurance to the large number of US children currently uninsured. Yet key public health and community health service programs essential to the well being of children and adolescents have gained little attention in the current national health care reform debates. Most discussions focus on insurance and cost containment and fail to address other systemic barriers to health care. Insurance alone will not solve the health problems faced by children and adolescents.

## SPECIAL NEEDS OF CHILDREN AND ADOLESCENTS

Addressing the health risks that children and adolescents face requires combining public and private efforts and community-oriented and personal care services. These risks include the consequences of low birth weight and prematurity, lead poisoning and injuries, child and sexual abuse, and special issues for adolescents, such as sexually transmitted diseases, pregnancy, and substance abuse.[1] Furthermore, the special needs of children with chronic illnesses and developmental disabilities call for complex, integrated, community-based multidisciplinary programs, only parts of which will be supported by national health insurance programs. Finally, children represent the poorest segment of society. With almost one in five US children living in poverty, health care for children has become increasingly framed by the inadequate provision of basic necessities, such as shelter and food, and by poverty's expression as elevated risk for virtually all forms of illness and injury in the daily life of children.[2] The high proportion of children living in disadvantaged communities makes them particularly reliant on local systems of public and community health, arenas of health care delivery that have seriously eroded during the past decade. To address the urgent health needs of children, the national movement toward universal health insurance must be informed by clear delineation of the special requirements of children and must integrate preventive and treatment services with the public health and community programs on which children heavily depend.

Injuries and violence affecting children provide an example of the need for a systemic response beyond insuring access to health services.[3] Programs to prevent injuries and treat their consequences must build on population-based analyses of the problem. These (and other) community problems require approaches that go beyond the use of health facilities and health professionals to define and address them. Although the health care system can provide care for injuries in emergency departments and surgical units, preventive efforts require that physicians and nurses work with public health officials, police, engineers, teachers, and fireman, among others. Many other special needs of children and adolescents fit similar patterns, where responses require a combination of public and private activities: lead poisoning prevention, infectious disease control, and child abuse prevention similarly require a complex array of public and personal health efforts linking disciplines as well.

Received for publication Aug 30, 1993; accepted Nov 10, 1993.
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## PUBLIC HEALTH AND OTHER PROGRAMS FOR CHILDREN

The structure of public health efforts for children and adolescents varies greatly among communities and the states.[4] In the southeast, for example, rural health departments provide substantial amounts of primary care for community residents; in other parts of the country, the provision of direct primary care service is more limited. Public health efforts range from monitoring the state of children's health to immunization programs, lead abatement, efforts to improve birth outcomes, and programs for children with special health needs. Thus, the panorama of public health activity includes standard setting, health monitoring, quality assurance, direct provision of services, and the organization of systems of care to prevent or meet specialized health problems. Increasingly, public health programs have developed partnerships with local residents and private agencies to combat specific problems.

Beyond direct public health efforts, several types of community programs have been important for improving child and adolescent health. Community health centers provide essential health services to higher risk communities, typically linking medical treatment services with preventive services, nutrition services, community health assessment, and community health education, services poorly supported through health insurance. These needs will continue under universal health care coverage. For the large number of children in high-risk communities, especially impoverished ones, community health centers require enhanced funding to meet the needs of children and families effectively. For adolescents, community free clinics, school health programs, and other nontraditional services may be appropriate. Regionalized programs for perinatal care and for children with special health needs have produced better physiologic outcomes for children and have diminished the psychological and economic consequences of illness.[5] Yet regionalized programs require public financial support (beyond that for medical services) for their development and maintenance. The child who is assisted by technology may need a complex array of specialty and primary care physicians, specialized home nursing, social and mental health services, and respiratory therapy, among many others. Such children require access to regionalized systems of care that link high-quality, specialized tertiary care services with community-based primary care services, link the broad array of multidisciplinary services at the community level, and especially link health and educational services for the child. Such systems re-

quire coordination of care and the management of services for children. Health insurance provides little incentive for the development of community-based, coordinated systems of care, and only a small proportion of needed services will be covered through either acute care or projected long-term care benefits.

## BEYOND INSURANCE

Even though these problems are urgent, current reform debate focuses on the too narrow issue of insurance. Insurance mechanisms alone will not assure access to comprehensive health services for pregnant women and children. Medicaid expansion, a cornerstone of several reform proposals,[6–8] has not fully equalized access for poor people. In the mid-1980s, 41% of uninsured women began prenatal care in the first trimester. Medicaid patients had only a marginally better rate of 46%, far short of the 84% rate of privately insured women.[9] Medicaid expansions in Tennessee demonstrated no improvement in early prenatal care, birth weight, or neonatal mortality among the group experiencing the greatest increase in Medicaid coverage (white, married women younger than 25 years with <12 years of education).[10,11] Other reports, however, indicate that service programs that target *nonfinancial* barriers to care (not addressed by typical insurance benefits) have improved prenatal care utilization.[12]

Even with universal insurance coverage, differences in use of health care among socioeconomic strata remain. After controlling for rates of insurance coverage, poor children remain less likely to have a regular source of care than nonpoor children.[13] Among children randomly selected to receive free comprehensive care (paid at market rates) in the Rand health insurance experiment, poor children were less likely to receive preventive care[14] or care for an episode of acute pharyngitis.[15] In Canada, despite well-established universal insurance coverage, dramatic social disparities in child health care utilization, injury, low birth weight, and infant mortality persist.[16–18]

## LESSONS FROM EUROPE

Although European health care systems have evolved in very different social and political climates, the end product has uniformly been far greater commitment to the health of children.[19] Furthermore, European models complement personal health services with some form of community-based public health and preventive efforts. In Norway, nurses operating from community health stations attended by >90% of infants, regularly monitor growth and development, counsel on health promotion and nutrition, and offer prenatal health education.[20] Community-based models of prevention in England utilize home visitors to encourage preventive care, coordinate care for children with special health care needs, and help young mothers develop parenting skills. A computerized registry of all births generates reminders for necessary immunizations.[21] In France, at 8 days, 9 months, and 24 months, the medical history and developmental and immunization status of children are recorded in health certificates with a special note identifying any medical or social risk that requires follow-up. That information is then sent to the local maternal and child health center to ensure follow-up and to a national data bank for epidemiologic purposes.[22] Admittedly, cultural differences pose difficulties in translating European experiences to US programs. Nonetheless, these three countries have all made commitments to universal health insurance, matched by a commitment to community-oriented maternal and child health programs. This comprehensive strategy is associated with lower rates of infant mortality and <5 years mortality in all three countries compared with the United States, even controlling for the influence of race and socioeconomic status on these indicators. Moreover, all three countries spend significantly lower proportions of Gross National Product on health care than does the United States.[23]

## MEETING THE SPECIAL NEEDS OF CHILDREN UNDER HEALTH CARE REFORM

Public health and key community health programs for children and adolescents currently receive support in various ways, although total expenditures for these child health efforts represent <5% of total child health expenditures. The two largest programs are the Title V Maternal and Child Health Program, which serves low income mothers and children and children with special health needs ($1.1 billion per year in federal and state funds), and the Supplemental Food Program for Women, Infants, and Children which provides food vouchers for low-income pregnant women and children ($2.4 billion per year). Smaller amounts of public funds support community and migrant health centers (75% of health center clients are children <18 years of age or women of childbearing age[24]), state and local public health efforts, and community-based preventive care mainly through the Centers for Disease Control (prevention block grant, immunization programs, and lead poisoning prevention).

Health care reform will bring about changes in each of these public programs and efforts. Especially where public health dollars currently support direct medical services, these will likely be replaced by universal health insurance financing. Actual savings from transfer to health insurance likely represent <20% of current program funding. These major programs merit substantial expansion beyond their current level of funding. The 20% savings represents part of the dollars needed. These monies, supplemented with additional dollars, should be redirected to these key child health programs. Meeting the needs of children and adolescents described above will require at least doubling the expenditures for these programs. Equally important, however, is attention to the integration of their efforts with the implementation of national health reform. For example, how will children with special health needs be integrated into the health alliances? How can they be assured access to appropriate multidisciplinary services? How will public health-sponsored programs in injury prevention interdigitate with community health providers? What mechanisms will assure that children and adolescents

in high risk communities receive the range of community-oriented primary care services they need?

The current national interest in health care reform coupled with concurrent public concern for the well-being of children provides a special opportunity to address these issues in a coordinated fashion. Without special provisions, an emphasis on cost containment, particularly amid the intense competitive environment managed competition implies, will likely place new pressures on the delivery of comprehensive child health care in the United States and undermine the impact of expansions in other programs designed to enhance the development and well-being of US children. A program of health care for children and adolescents must include attention to programs that achieve what health insurance alone cannot. Only the purposeful integration of health care financing with community-based programs and public health efforts can ensure that the needs of children will be represented effectively in the fractious struggle to define the character of national health care reform.

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# Financial Access to Care Does Not Guarantee Better Care for Children

The thoughtful and cautionary pieces by Newacheck et al[1] and Perrin et al[2] remind us of how much we have achieved in piecing together care for vulnerable children, how far there is yet to go, and how the transition to the long-overdue health care reform might worsen, rather than improve our present arrangements. In the absence of a rational, planned care system for children, especially for those who are poor or who require extensive services, pediatricians and child advocates in both the public and private sectors have managed to cobble together at least the possibility of decent services for large numbers of children, with some payment to those who provide those services. Of course, huge gaps remain, despite near-heroic efforts by families in the face of public apathy, relentless increases in the proportion of children who are poor, and the disintegration of the traditional communities to which those families have looked for support.

Thus, even with the prospect of universal payment for preventive, therapeutic and rehabilitative services, those who have worked for years to put together the fragile systems of care and those who have studied those systems and their failures have realistic concern about proposed changes. They know all too well that plans which are primarily finance-driven (really, cost–containment-driven) will meet only part of the needs of children and of those who care for and

Received for publication Dec 14, 1993; accepted Dec 16, 1993.
Reprint requests to (A.F.K.) La Rabida Children's Hospital, E 65th St at Lake Michigan, Chicago, IL 60649.

about them. Yes, it is important that there be adequate payment for medical and related services, and that some help is given to parents who now face significant out-of-pocket expenses for the care of their children. Recognition of the need for universal coverage and the elimination of prior–existing-condition restrictions, will help many families who cannot find insurance now, or whose job mobility is restricted because of the potential burdens their chronically ill children may bring to a new employer's insurance plan. And, there are other important provisions in the President's health care reform, which may help to reduce or eliminate the economic segregation from adequate health care services which now accompanies the racial, ethnic, and geographic barriers to access which so many of our children face.

As the two accompanying articles suggest, the adequate financing of an inadequate or misconceived delivery system will not guarantee better care for children, especially those with chronic disease or disability. In fact, the transition, unless carefully planned, may worsen their plight, as established federal and state programs and funding streams are eliminated in the anticipation of new financing mechanisms; indeed, if cost-containment becomes the dominant force, new arrangements which arise may result in reduction of necessary services, a scenario by Newacheck et al. They report on certain hazards for children with complicated chronic problems in some of the existing managed care systems, in which appropriate pediatric subspecialty referral and continuing availability of related services such as physical therapy may be denied to control "out-of-plan" costs. Their concern that such problems not be built into new managed care programs in Medicaid or its replacement as health care reform unfolds is realistic and appropriately cautionary.

Although their commentary identifies some of the important issues which threaten the care of children with chronic illness in managed care systems (and these are not just problems of Medicaid managed care plans), they do not offer changes in those systems, whether fee-for-service or managed care plans, that could go a long way toward insuring better care for children with chronic illness. Their suggestions are addressed at either guaranteeing better reimbursement for the physicians or the availability of specialty services for the children. Unquestionably, the costs and absence of payment for services can be (and often are) deterrents to optimal care; yet, the organization of those services may be more important. And, the social and demographic circumstances of the children and their families may be more important yet. Thus, even though I do not argue with the need to bring payment rates for children's services to a level more like the private fee-for-service sector, I believe that leveling reimbursement alone will NOT assure better and more comprehensive services. For the child in a rural or semirural community, specialty services are often simply not available—in fact, for the rural poor, even primary care services are not available—at any price! In dense urban areas, although the services may exist, poverty, inadequate transportation, unavailable housing and day care, racism, and class discrimination among providers can be greater barriers to the attainment of satisfactory care than reimbursement levels.

The authors' cautions about Medicaid managed care systems apply to *all* existing and proposed managed care systems, particularly those encouraged under the Clinton Health Plan, which presumably would replace Medicaid. In targeting the many emerging Medicaid managed care proposals for their caution, the authors risk leading us to imagine that the hazards exist only in those programs; in fact, they are hazards in any of the managed care proposals and systems now before us or in existence. It is not only Medicaid programs that put chronically ill children and their families at risk—it is our global approach to their care. True, if new Medicaid programs adopt the worst practices of the private sector in pursuit of cost-containment, we will have taken a great step backward and, ironically, done little to reduce the immense Medicaid budgets now so worrisome to so many governors and state legislatures.

Any discussion of reform in services for chronically ill and disabled children must emphasize the importance of effective case management in improving services for children with chronic illnesses and disabilities. Were I designing sweeping reimbursement change, my proposal would include mandated, paid-for case management for all children with special health care needs. Several examples of such successful case management systems exist, notably some of those created by state Title V agencies or with their encouragement. These demonstrations repeatedly have shown reductions in morbidity and in overall costs of care to insurers. The modest additional national cost for case management would be repaid manyfold in reduced hospitalizations and office or clinic visits, and in improved outcomes and functional status of the children. Furthermore, pediatricians with whom I speak, both those in independent practice and those in managed care organizations, are nearly unanimous in their desire for help in the case management of children with complex problems who need multiple services.

Indeed, managed care organizations and state-initiated Medicaid case management programs should be ready for such a mandate. As an example, the recently inaugurated Medicaid managed care program for pregnant women and children ages 0 through 5 years in Illinois, called Healthy Moms/Healthy Kids, has a separately funded case management program for preventive, medical, and related services; this model promises great benefits for children with special health care needs as well. Similarly, private-sector managed care organizations, utilizing their existing information and financial management systems and specialty provider capabilities, have the potential to set up targeted case management for children with special needs. The numbers of children and families who would require such services are small in comparison with the much larger numbers of adults and the elderly which such managed care organizations presently cover; the cost increment would be relatively small, particularly in comparison with the potential savings. (Case management for the elderly

in those organizations also has proved to have merit, both for improving outcomes and reducing costs, especially those of hospitalization.) As Perrin et al point out, even relatively simple and familiar home-visitor programs have tremendous potential for improving services and reducing morbidity and cost. Such services can often be provided by specially trained community workers working alongside traditional professionals in a very cost-effective manner.

There are many other existing examples and demonstrations of the possible changes in service delivery systems which can improve the quality of services to children with chronic illnesses; these will need to be pursued even in a better funded environment. Clearly, different solutions will have to be sought in different regions of the United States, among differing populations, and in the wide variety of new financing schemes. We should not come away from the discussion of Newacheck et al with the impression that if we do all they recommend, the problems of medical services to children with special needs will be solved. Without accompanying changes in service delivery coordination, the major barriers to many of these children's optimal health care will remain unaddressed, and their plight little improved. And, although short-term costs may be moderated, long-term costs of continuing morbidity and lost opportunities for these children as productive citizens will continue to grow. Many, if not most, of the services which children with special health care needs require do not fall into the realm of direct medical services; some are in the loosely defined "public health" sector, whereas others have been put together from bits and pieces of public and private maternal and child health and social service programs. Even with universal insurance, free of "prior existing condition" clauses, these children and their families will still need to work tirelessly to find and keep the necessary services unless attention is paid to the system of care delivery on which they depend. Those of us who care for and about this large, growing group of children must remain committed to them in the political as well as in the medical arena. The need for our advocacy on their behalf will not go away with health care reform; indeed, the reform process demands heightened vigilance and creativity.

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# Childhood Lead Poisoning in the '90s

Lead is an extremely toxic metal: even a single atom of lead, once in the human body, binds to a protein and induces some damage; the greater the exposure, the more serious the effects. Lead has no physiological function; any amount of body lead reflects environmental pollution.[1]

In the 1990s, in the United States, is lead poisoning a devastating environmental threat to our children or is childhood lead poisoning a threat of the past? Probably neither of these statements is correct. It may be worthwhile to look at the current situation in detail.

In the 1970s, before efforts were made to reduce environmental lead, common effects in children of the widespread environmental contamination with lead were encephalopathy and even death. In 1976 the National Health and Nutrition Examination Survey (NHANES II) 1976–1980 study estimated the average blood lead level for the entire US population at 16 μg/dL.[2] Preliminary data from the ongoing NHANES III study indicate that the average blood lead level of the US population is now <4 μg/dL. For comparison, an average blood lead level of 3 μg/dL was observed by us in children living in the pristine air of the highlands of the Himalayas, far away from industrialization and civilization.[3] Even for children of low socioeconomic class living in upper Manhattan, the average blood lead level, that was 19 μg/dL just a few years ago, has now declined to 5 μg/dL.[4] Clinically overt lead poisoning has essentially disappeared, and it is now so rare that it can probably be called a threat of the past. We have gone a long way toward elimination of environmental lead and of severe childhood lead poisoning.

What is the cause of this decline? It would be gratifying to this author to think that it resulted from the widespread screening of US children, utilizing the erythrocyte porphyrins test developed in his laboratory. The real reason for the nationwide decline of blood lead, instead, is the reduction of lead from many sources, and, most of all, the near-complete elimination of lead from gasoline. In the heated arguments at the Environmental Protection Agency for the revision of the air quality standard for lead in the 1980s, none of us who argued for a lower standard anticipated that the effect of removing lead in gasoline was going to be so extensive. It is ironic that the removal of lead from gasoline was decreed to protect not the children, but the automobile's catalytic converter. On the other hand, the reduction of blood lead levels with the reduced environmental contamination with lead confirms the ancient saying, . . . *an ounce of prevention* . . . . The removal of lead has reduced background exposure and thus reduced the blood lead level of all US children; it has made them much less likely to attain lead levels associated with overt toxicity. Certainly,

Received for publication Nov 15, 1993; accepted Jan 20, 1994.
PEDIATRICS (ISSN 0031 4005). 

the tragic situation of the 1970s has been largely remedied. The reduction of childhood lead poisoning represents a rare triumph against manmade ills. All those who contributed to this goal should be justly proud.

In view of this incredible success, should we now ignore the residual environmental lead? Although the environmental situation has improved, several studies indicate that subtle, but measurable, effects of lead are detectable even at extremely low levels. This was predictable based on our understanding of the toxicity of lead. It has been known for years that there is no threshold for the effects of lead, when searched by refined biochemical techniques. The pioneer work of Hernberg, in Finland, demonstrated that the enzyme δ-aminolevulinic acid dehydratase is damaged at any level of lead exposure.[5] The accumulation of δ-aminolevulinic acid underlies some of the neurological toxicity of lead. Excess δ-aminolevulinic acid is excreted in the urine, and excess erythrocyte protoporphyrin accumulates in the red blood cells with an exponential increase in relation to blood lead levels.[6]

Several epidemiological studies have shown that some adverse effects of lead on the neuropsychological function are also detectable at low levels of exposure. The initial study of H. Needleman in this area[7] became the center of controversy at the hearings for lead air quality standards at the Environmental Protection Agency; those acrimonious arguments continued in various forums. Needleman's work, however, has been vindicated by the fact that his observations have essentially been confirmed by other independent investigators. These issues have been critically reviewed recently by the National Research Council.[8]

Although there is no doubt that detectable adverse effects of lead are demonstrable at very low levels, two questions must now be addressed: (1) at what level of exposure do the adverse effects of lead become trivial, and (2) what measures, if any, should be taken to reduce exposure to lead, in view of the current situation?

There is substantial epidemiological evidence of adverse effects of lead at blood levels <20 μg/dL.[8,9] Harvey has argued, however, that "evidence that BPb levels <20 μg/dL at age one year cause a clinically important decrease in intelligence and increase in neuro-behavioral problems by the time the child enters school is lacking."[10] We know that the neurobehavioral effects of lead tend to be permanent and prudence advises that, when in doubt, to consider the adverse effects as potentially permanent. On the other hand, one cannot ignore that the adverse effects of very low lead exposure are certainly minor.

Can we tell our education-conscious parents that a loss of 2 to 3 IQ points is trivial? Our society undoubtedly has the responsibility to protect all our children from every avoidable threat. But, *what is the best approach to optimally protect our children from lead poisoning*? This is the crucial question. As in any other case, some consideration should be given to cost/benefit ratio. This should not be limited to its pecuniary aspect; parental anxiety, validity of intervention, and disruption of life should be also weighed against potential benefits of screening.

The Centers for Disease Control (CDC) published an ambitious "Strategic Plan for the Elimination of Childhood Lead Poisoning"[1] in 1991. This document made it clear that the most urgent priority in the United States is the correction of the thousands of dwellings in which lead paint represents a constant hazard for children. However, the same document already contained the self-fulfilling prophecy that the blood lead level for intervention was going to be decreased further by a forthcoming CDC experts committee. There is no doubt that the residual sources of lead should be eliminated, if the residual risk of lead is to be eradicated. Yet, given the opportunity, the CDC chose not to focus on the cause of lead poisoning, but on its potential victims. A committee of experts (including the author) was assembled by CDC and was charged to make a recommendation, without regard to practical considerations such as cost and or effectiveness. As a result, a well-meaning, but abstract recommendation was made to lower the threshold blood lead level for intervention to 10 μg/dL.[9] An ambitious, expensive program thus has been launched for the universal screening of all children, whether living in a lead-laden environment or not.

To make matters more complex, current technology can not adequately measure with accuracy blood lead levels in the 10 to 15 μg/dL range. Even in the best laboratories the error of the measurement is at least 2 to 3 μg/dL. This high degree of inaccuracy requires that a blood lead level in this range be reverified soon, and often the classification must be revised downward.

On the other hand, even if the blood lead level were 10 to 15 μg/dL, its detection would accomplish no useful purpose for the individual child. In that range, the demonstration of minor effects of lead requires large numbers of children and sophisticated techniques of detection and analysis.[8] Yet, with the current recommendation, pediatricians must explain to petrified parents that their child has been found by screening to have lead poisoning, as defined by CDC, the custodian of US health. The same wording, lead poisoning, is used indiscriminately for a child with a blood lead level of 11 μg/dL as for a child with a blood lead level of 110 μg/dL. In most human illnesses in which there is a continuous degree of severity, this is acknowledged to the patient by the physician (moderate hypertension, severe hypertension, etc). In the CDC statement, instead, lead poisoning becomes an all or none phenomenon; but the recommendations for management are quite different, depending on its severity. Similarly, adverse effects of lead are grouped together indiscriminately, regardless of their impact. These broad definitions result in catastrophic statistics about lead poisoning, without distinguishing how many of the children counted are indeed significantly affected.

It seems that we have not learned from our experience in this area. The reduction in blood lead levels in the United States has resulted not from extensive screening, but from the removal of the most

important sources of environmental lead. Screening is critical only in the high-risk areas, but is very inefficient in communities without lead exposure. Instead of testing all the children and declaring many of them poisoned, it would be more logical today to test all the houses in which children live that were built before lead-based paint was eliminated. Several communities have laws mandating window guards in all apartments where young children live or are moving in. It would be more effective if state legislatures, instead of decreeing mandatory screening of all children <6 years, voted instead to establish mandatory inspection of all dwellings built before 1950 in which those children may live. State and federal funds would be better spent to help home owners and landlords remedy the residual lead risk, rather than undertaking the expensive and useless screening of children who are not at risk.

The situation has been well synthesized recently by Oski, "It would be prudent to spend the money on prevention rather than detection."[12]

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**FAX SHEET**

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**NUMBER OF PAGES (Including cover sheet)** 1

**MESSAGE:**

March 13, 1994
TO: Ad Hoc Working Group on Children's Supplemental
FR: Kay Johnson/Vivian Gabor

Based on our discussion yesterday, the following "talking points" will help to guide our discussion this afternoon with Congressional staff. These are for use by advocates, not for circulation to Congress. The meeting, convened by Deborah Von Zinkernagel, will be in G-59 Dirksen Senate Office Building from 4:00-5:00 pm.

PRINCIPLES AND ASSUMPTIONS

- Children's health needs are different from those of adults.
  - Children often need services different in scope, intensity, and duration.
  - Prevention is a central goal of child health services -- both primary prevention of disease and disability, as well as prevention of secondary effects.
  - A small number of children have chronic, serious disabilities and illness; for others, the need varies by age, condition, and effectiveness of early intervention.
- No child should lose coverage or benefits as a result of health care reform.
  - Entitlement and protections in existing Medicaid law must be protected -- for current and future recipients.
- The EPSDT benefit package is comprehensive and has been time-tested.
  - It uses pediatric care standards.
  - EPSDT has proven effective in states where it was well implemented.
- There are problems in child health that could be addressed through health care reform.
  - Gaps in coverage and provider availability, especially for children with disabilities.
  - Problems in managed care for children with special needs.
  - Financial barriers for uninsured children.
- Children's components of Health Security Act can be improved and integrated.
  - Title I benefits do not address many needs of children.
  - Title II provisions could be strengthened and coordinated.
  - Title IV wrap-around is limited and confusing in structure.
- We accept the Clinton Administration's position that a supplemental, "wrap-around" benefit package is needed for children with special needs.

COMPONENTS OF PROPOSAL

- Supplemental benefits should be an entitlement for all children.
  - Not a new categorical program.
  - Similar to "Medi-gap" insurance approach
  - Extend the EPSDT benefit package to all children.
- Families and states would share in the cost of this program.
  - Income adjusted cost-sharing for families.
  - States would contribute based on the Title II formula.

Administered by a state agency with expertise in the care of children.
  - Coordination for individual children, with alliances and health plans.
  - Development of family-centered, community-based system of care.
  - State designates agency, similar to Part H.

# SPECIFICATIONS FOR A SUPPLEMENTAL CHILD HEALTH PROGRAM AMENDMENTS TO THE HEALTH SECURITY ACT

The following specifications are for a supplemental benefit program for children with special needs. Benefits would be in addition to care and services covered in the Health Security Act, Title I (the comprehensive benefit package). Eligible children would include any child with a special need for health services outside of the Title I benefit package. Children include individuals under age 21. Services would be financed on an income-adjusted basis, similar to the Title II long-term care program. The program would be established as an entitlement and administered by a qualified state agency under uniform federal standards regarding eligibility, benefits, relations to health plans, payment principles, and other methods of administration. As a condition of state certification and participation in regional alliances, health plans would be required to participate in the new program and comply with program requirements.

**Overall drafting structure:** A new Part under Title II, Subtitle B, of the Health Security Act. The program would create a supplemental (wrap-around) program for children based on the following provisions of the Health Security Act:

- Extend to all children the services under the Medicaid wrap-around program for "children with special needs" (§ 4222);
- Leave in place the federal/state Medicaid "long-term care" benefits (§ 4221), with required coordination through the supplemental program; and
- Strengthen the component of the new Title II long-term care program targeted to children, with required coordination through the supplemental program.

## I. SUPPLEMENTAL CHILD HEALTH PROGRAM

### A. Purposes

(1) to provide coverage for health and related services not covered under the guaranteed benefit package that are used by children with physical and/or mental illnesses, disorders, conditions, or disabilities.

(2) to monitor and assess the appropriateness and quality of health care furnished to children with special needs by health plans and other providers, regardless of whether benefits are paid for through the comprehensive benefit package or as a supplemental service.

(3) to provide support for and monitoring of systems of care for children with special needs that assures: (a) provision of care and services in family-centered, community-based settings; (b) access to medical and other pediatric

primary and specialty providers, including family practice physicians and multi-specialty facilities with expertise in on the care of children with special needs; (c) continuity of care without regard to whether payment for such care and services is financed out of the comprehensive (Title I) or supplemental benefit package; (d) coordination of health and related services funded under this part with educational, social, nutritional, and remedial services and programs for children with special needs; (e) individual planning for transitional services as the child enters adulthood at age 21.

B. **Financing:** Federal-state financing plus family contributions through cost sharing based on family income (as defined below, item C).

(1) General federal and state revenue redirected from Medicaid expenditures for the population under 21 for items and services not in the guaranteed benefit package. Such funds would include current federal/state expenditures under various waiver and demonstration programs authorized under Title XIX for children with special needs, plus certain Medicaid funds in the Health Security Act identified in § 4222 (wrap-around benefits for poor children)

(2) A surcharge on health plan payments (similar to that in Title III, §3104).

Assumptions (for cost-estimation purposes only):

- Federal-state contributions based on the matching formula contained in Title II, § 2108;
- Use 1994 as base year for Medicaid spending.

C. **Cost sharing:** Use the sliding fee schedule from the Title II long-term care block grant. No deductibles. Title II, § 2105 schedule for cost sharing defines no cost sharing for persons with income less than 150 percent of poverty and cost sharing in the form of coinsurance, based on a sliding scale, for the remaining persons.

Sliding scale:

(1) 10 percent per service, with a cap on total cost sharing at $500, for income 150-199 percent of poverty;
(2) 20 percent per service, with a cap on total cost sharing at $1000, for income 200-249 percent of poverty;
(3) 25 percent per service, with a cap on total cost sharing at $1,500, for income 250-399 percent of poverty;
(4) 25 percent per service, with a cap on total cost sharing at 7.9% of adjusted gross income, for income at or above 400 percent of poverty.

**D. Eligibility:** Children under age 21 for whom items and services not covered in the comprehensive benefit package are medically necessary and appropriate (as defined below). No categorical definition of a child with special needs should be set.

The target population would include, but not be limited to, children who receive services or qualify:

- o for SSI on the basis of disability;
- o as children with special health care needs under the Title V Maternal and Child Health Services Block Grant;
- o under the Child Mental Health Services Grant program
- o through Parts B or H of the IDEA, with need for related services;
- o under the Developmental Disabilities Assistance and Bill of Rights Act;
- o under child welfare programs (Title IV B or E of the Social Security Act);
- o through the juvenile justice system; and
- o under current Medicaid eligibility standards.

No child for whom a service not included in the comprehensive benefit package is medically necessary and appropriate shall be denied such service solely on the basis that such child is not described by one of the forgoing categories.

**E. Benefits:**

(1) Medically necessary or appropriate items and services described under § 1905(a), 1915, 1929, or 1930 of the Social Security Act that are not covered under the comprehensive benefit package.

(2) Medically necessary or appropriate items and services described under § 1905(a) that are also included in the comprehensive benefit package but that are not sufficiently covered under Title I to be considered medically appropriate for children.

(3) Care coordination and case management, as defined in § 1905(a)(19) of the Social Security Act.

(4) Other services approved by the Secretary of HHS.

The term "medically necessary or appropriate" means coverage sufficient to promote healthy growth and development, prevent or ameliorate illness or disability, achieve or maintain developmentally appropriate function, or prevent institutionalization.

**F. Provider participation:**

Providers certified by the state agency administering the program under standards developed in consultation with: other state agencies responsible for children with chronic illness and disability, including but not limited to state health, mental health, developmental disability/mental retardation, special education, and child welfare agencies; providers with expertise in the care of children with special needs; and consumers.

Health plans should have clearly defined relationships with the supplemental program and its providers to ensure quality, continuity, and coordination of care, as well as an efficient child health delivery system.

Health plans may seek certification as participating providers for one or more covered services. Providers located in school or other community settings must be included on that basis, so long as they meet provider qualification standards.

**G. Provider reimbursement:**

- fee schedule negotiated by state agency with providers, in accordance with statewide alliance fee schedule as developed for children with special needs or other fee schedules for services not covered under health plan benefits.
- special all-inclusive capitation payments for overall care and management.
- Secretary to develop standards for global and fee-based payments.

**H. Administration:**

- By state agency with expertise in care and management of programs and services for children with special needs;
- Federal-State match for both medical and administrative costs.
- Uniform federal standards regarding eligibility, benefits, relations to health plans, payment principles, and other methods of administration to be developed by the Secretary of HHS.

## II. LONG TERM CARE SERVICES FOR CHILDREN

A. Long term care services for children, as part of the Title II new long term care program, should remain with modifications as follows.

(1) Change the definition of eligibility for children to eliminate the institution or hospital test and to require the Secretary to develop a standard of "comparable severity."

(2) Change the definition for minimum mandated personal assistance services to include "family support services and such services as are developmentally appropriate" This could be done for infants, young children, and adolescents or limited to children under age six (as now defined in the Health Security Act).

(3) Require that services provided to children under the new long term care program be coordinated through the agency administering the supplemental child health program.

(4) Clarify that participation in the long term care program would not disqualify a child for services under the child health supplemental program (with the supplemental program as payer of last resort).

**Bright Futures National Guidelines for Health Supervision for Infants, Children and Adolescents**

| Periodicity/age | All children/adolescents | If at risk: see notes |
|---|---|---|
| Prenatal | n/a | n/a |
| Newborn | Metabolic and Hemoglobinopathy<br><br>Hearing screening (once prior to three months) | |
| First week | Hearing screening (once prior to three months) | Assess lead exposure risk #1 |
| One month | Hearing screening (once prior to three months) | Assess lead exposure risk |
| Two month | | Assess lead exposure risk |
| Four month | | Assess lead exposure risk |
| Six month | | Assess lead exposure risk<br><br>If high risk, lead screening<br><br>Hematocrit/hemoglobin #2 (if needed for WIC) |
| Nine month | | Assess lead exposure risk<br><br>Hematocrit/hemoglobin at 9 or 12 months #3<br><br>Tuberculin (PPD) 9 or 12 months #4 |

| | | |
|---|---|---|
| One year | Lead screening #1<br><br>Tuberculin (PPD) #4<br>(12 or 15 months) | Assess lead exposure risk<br><br>Hematocrit/hemoglobin at<br>9 or 12 months |
| Fifteen month | Tuberculin (PPD)<br>(12 or 15 months) | Assess lead exposure risk<br><br>Tuberculin (PPD) |
| Eighteen month | | Assess lead exposure risk |
| Two year | Lead screening | Assess lead exposure risk<br><br>Tuberculin (PPD)<br>Hyperlipidemia assessment #6 |
| Three year | | Assess lead exposure risk<br>Tuberculin (PPD) if at risk<br>Hyperlipidemia assessment |
| Four year | | Assess lead exposure risk<br>Tuberculin (PPD)<br>Hyperlipidemia assessment |
| Five year | | Assess lead exposure risk<br>Tuberculin (PPD)<br>Hyperlipidemia assessment |
| Six year | | Assess lead exposure risk<br>Tuberculin (PPD)<br>Hyperlipidemia assessment |
| Eight year | | Tuberculin (PPD)<br>Hyperlipidemia assessment |
| Ten year | | Tuberculin (PPD)<br>Hyperlipidemia assessment |

| | | |
|---|---|---|
| 11, 12, 13, & 14 year | Pap smear if sexually active #8<br><br>Chlamydia test: annual screening of adolescents who have had sexual intercourse.<br>For males, urine dipstick for leukocytes may be sufficient if asymptomatic | Hematocrit/hemoglobin #7<br><br>Tuberculin (PPD)<br><br>Pap smear if condyloma accuminata as (HPV) as children #8<br><br>Syphilis (VDRL/RPR): screen If history of other sexually transmitted disease(s) and/or living in a high prevalence area #9<br><br>Hyperlipidemia assessment<br><br>HIV assessment #10<br><br>Psychosocial assessment #11 |
| 15, 16, & 17 year | Tuberculin (PPD) Once between 14-16 #5<br><br>Pap smear if sexually active<br><br>Chlamydia test: annual screening of adolescents who have had sexual intercourse.<br>For males, urine dipstick for leukocytes may be sufficient if asymptomatic | Hematocrit/hemoglobin<br><br>Tuberculin (PPD)<br>Pap smear if condyloma accuminata as (HPV)<br>As children<br><br>Syphilis (VDRL/RPR): screen If history of other sexually transmitted disease(s) and/or living in a high prevalence area<br><br>Hyperlipidemia assessment<br><br>HIV assessment<br><br>Psychosocial assessment |

| | | |
|---|---|---|
| 18, 19, 20, & 21 year | Pap smear if sexually active<br><br>Chlamydia test: annual screening of adolescents who have had sexual intercourse.<br>For males, urine dipstick for leukocytes may be sufficient if asymptomatic. | Hematocrit/hemoglobin<br><br>Tuberculin (PPD)<br><br>Pap smear if condyloma accuminata as (HPV) as children<br><br>Syphilis (VDRL/RPR): screen If history of other sexually transmitted disease(s) and/or living in a high prevalence area .<br><br>Hyperlipidemia assessment<br><br>HIV assessment<br><br>Psychosocial assessment |

**Bright Futures National Guidelines for Health Supervision for Infants, Children and Adolescents**

Note #1

HCFA policy requires states to perform a verbal risk assessment for every child ages 6 months to 72 months of age. If all the answers to the questions are negative, the child is considered to be at low risk, but must receive blood lead screening by blood test at 12 months and again at 24 months.

Note #2

Anemia screening (if certification is needed for the special supplemental food assistance program for women, infants and children (WIC))

Note #3

Additional hematocrit or hemoglobin screening at 9–12 months if the following risk factors are present:

- Low socioeconomic status
- Birthweight under 1,500 grams
- Whole milk given before 6 months of age (not recommended)
- Low-iron formula given (not recommended)

Note #4

Tuberculin test (PPD) if the following risk factors are present for infancy and early and middle childhood:

- Low socioeconomic status
- Residence in areas where tuberculosis is prevalent
- Exposure risk to tuberculosis
- Minority or immigrant status

Note #5

Tuberculin test (PPD) if the following risk factors are present for adolescence

- Low socioeconomic status
- Exposure risk to tuberculosis ie homeless shelter
- Residence in areas where tuberculosis is prevalent
- Annually for adolescents with a history of incarceration
- Minority or immigrant status

Testing at 14-16 years of age is recommended.

Note # 6
National Cholesterol Education Panel recommends selective screening of children in the context of regular health supervision for children over two years of age and adolescents in the following groups:

> "(1) children whose parents or grandparents have a history of coronary or peripheral vascular disease before the age of 55 years should have a serum lipid profile that includes determination of low density lipoprotein (LDL) cholesterol value. Blood should be drawn after a 12-hour fast.
> (2) children whose parents have a blood cholesterol level greater than or equal to 240 mg/dl should be screened for total blood cholesterol level (nonfasting).
> (3) children and adolescents with several risk factors for future coronary vascular disease (e.g. smoking, hypertension, physical inactivity, obesity, and diabetes mellitus) whose family history cannot be ascertained may be screened at the discretion of the physician for a total blood cholesterol level."

Note #7

Hematocrit/hemoglobin screening for adolescence
Screen females periodically during adolescence, especially those with moderate to heavy menses, athletes, chronic weight loss, nutritional disorders.

Note #8

Pap smear
Annual screening in sexually active females and for those with condyloma accuminata (HPV) as children.

Note #9
Sexually transmitted diseases
Gonorrhea (screening may not be cost-effective for all populations.) It depends on the prevalence in the community. Chlamydia: annual screening of adolescents who have had sexual intercourse. For males, urine dipstick for leukocytes may be sufficient if asymptomatic.
Syphilis (VDRL/RPR): screen if history of other sexually transmitted disease(s) and/or living in a high prevalence area.

Note #10
HIV
Screen with informed consent and pre- and post-test counseling if history of sexually transmitted diseases, history of intravenous drug use, sexual intercourse with partner with risk factors, having exchanged sex for drugs or money, males who have sex with males, homeless adolescent, or if requested by adolescent.

Note #11
Psychosocial
Screens (psychosocial as well as blood, urine etc.) Regarding self-image, depression/anxiety, suicidal issues, abuse, multiple stressors, peer interaction, sexuality, substance use.

# Meeting Children's Long Term Care Needs Under the Health Security Act's Home and Community-Based Services Program

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January 1994

For the Child Health Consortium

# Meeting Children's Long Term Care Needs Under the Health Security Act's Home and Community-Based Services Program

## I. The Problem

Children represent only a small and comparatively low cost segment of the disabled population. In 1991, only six percent of children under 18 years old – or 3.8 million nationwide – were limited in their ability to perform usual activities such as school or play due to chronic conditions. This compares to 32 million adults with limitation in their activities caused by chronic conditions. In addition, because almost all children with chronic health problems live with and are cared for at home by their families, their long term care costs are substantially less than those of adults. We estimate noninstitutional long term care expenditures for the 3.8 million children with limitation in their activities to range from $1 to $2 billion in 1992 dollars.[1,2]

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[1] No current nationally representative data are available for estimating expenditures for long term care for children. The lower figure is based on the 1991 National Health Interview Survey estimate of 3.796 million children with limitation in their activities due to chronic conditions and expenditure data on children with limitation in their activities from the 1980 National Medical Care Utilization and Expenditure Survey (Newacheck P and McManus M: Financing Health Care for Disabled Children, *Pediatrics* 81(3). 1988). Long term care expenditures were calculated as expenditures for nonphysician professional services and medical supplies and equipment for children with limitation in their activities in excess of expenditures for the same services for children without limitation in their activities — all updated by the medical care component of the Consumer Price Index to 1992 dollars. Prescribed medications, hospital and physician care were excluded since these services are considered acute care. If differential medication, hospital and physician care expenses were included, the additional cost would be $4.8 billion, rather than $1.0 billion. It is important to note that expenses for certain long term care services, such as respite care and home modifications are excluded from these estimates. In addition, significantly fewer children now reside in institutional settings than was true in 1980. Factoring in expenses for their noninstitutional care would raise our estimate of LTC costs. Taken together, expenditures for excluded services and deinstitutionalized children could add another billion dollars to our lower estimate, resulting in an estimated range of $1 to $2 billion.

[2] Expenditures for institutional care are estimated to be $1.75 billion. This figure is based on preliminary 1990 census data which indicate that about 40,000 children were in health-related institutions that year, including mental hospitals, intermediate care facilities, skilled nursing facilities, and various hospital wards. Long term care costs were calculated assuming average Medicaid expenditures of $120

Although the costs of caring for this population are modest, especially compared to adults, a significant proportion of children who require long term care services either fail to obtain such care or receive services on a piecemeal and poorly coordinated basis.[3] In the absence of a cohesive system of care capable of meeting children's long term care needs, inefficiency and waste result, as well as uneven access to needed services.

The Clinton Administration plan for health care reform, the Health Security Act (S. 1757), could improve coverage of needed long term care services for disabled children. The legislation provides at least five paths for obtaining long term care services. First, outpatient rehabilitative services, home health care, extended care inpatient services, mental health services and durable medical equipment would be covered in a limited manner through the basic benefit package that is to be offered by alliance health plans. Second, a new state-administered program for home and community-based long term care services is to be created. Third, the legislation encourages the development of private long term care insurance. Fourth, a new federally financed program would be created which allows most children now eligible for Medicaid to continue to receive long term care services not covered by the basic benefit package or a state's home and community-based services program. Fifth, public health programs, such as the Title V programs for children with special health needs, may continue to provide services for disabled children. In addition, initiatives to improve access to health care services for medically underserved populations may

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[2]cont. per day of care for skilled nursing facilities and intermediate care facilities for 1990, updated by the medical care component of the Consumer Price Index to 1992 dollars.

[3] See: Perrin J, Shayne M, Bloom S: *Home and Community Care for Chronically Ill Children.* New York: Oxford University Press, 1993; Newacheck P: Adolescents with Special Health Needs: Prevalence, Severity, and Access to Health Services. *Pediatrics* 84(5), 1989; and Newacheck P: Poverty and Childhood Chronic Illness. Institute for Health Policy Studies Working Paper, University of California, San Francisco, January, 1993.

provide certain enabling services such as transportation, community outreach, patient education and other services.

This paper is focused primarily on the new home and community-based services program. We briefly describe the program and discuss issues related to eligibility, benefits, cost-sharing, phase-in, and program administration. Recommendations in each of these areas are presented in the final section of the report.

## II. State Programs for Home and Community-Based Services for Children with Disabilities

The Health Security Act would provide universal coverage of preventive and acute care services shortly after enactment. Some long term care services, although limited in scope and duration, would also be covered by all alliance health plans. However, because of the high costs of meeting the long term care needs of an estimated 36 million Americans with some degree of disability,[4] the bill specifies the creation of a new home and community-based services program to be phased-in over a seven year period beginning in 1996.

States would be given substantial latitude in designing this new home and community-based program, which would be coordinated with the alliance health plans and other related programs, including Medicaid, the Individuals with Disabilities Education Act, the Title V Maternal and Child Health programs, and other public programs serving disabled persons. Every state would be required to provide personal

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[4] This figure is based on an estimate of 35.5 million persons in the civilian noninstitutionalized population with limitation of activity due to chronic conditions (Adams PF and Benson V: Current Estimates from the National Health Interview Survey. 1991. National Center for Health Statistics. *Vital Health Stat* 10 (184), 1992).

assistance services under the program. Other home and community-based services such as case management, respite care, assistive devices, habilitative and rehabilitative services could be provided at the discretion of each state. Services included in the basic benefit package for alliance health plans and institutional care offered by Medicaid could not be covered under the home and community-based service programs. The home and community-based care programs are envisioned to supplement both the alliance basic benefit package and the institutional services provided by Medicaid.

The proposed home and community-based services programs provide an excellent foundation for meeting the long term care needs of America's adult disabled population; that foundation, however, only partially addresses the long term care needs of children. Disabled children have very different needs and treatment goals from those of disabled adults. Although home care for many elderly people may have a rehabilitative focus, it usually is provided to diminish the need for institutional or hospital services, or at least to postpone the time when institutional services may be needed. In contrast, although many home care services for children are aimed at reducing hospitalization, the major goal of home care for children is habilitation, with the focus on integrating children into the community and supporting their growth and development into full participating members of society. These distinctions between adults and children have important ramifications for the design of home and community-based care programs for children, including provisions for eligibility, benefits and administration.

## III. Eligibility for Long Term Care Services

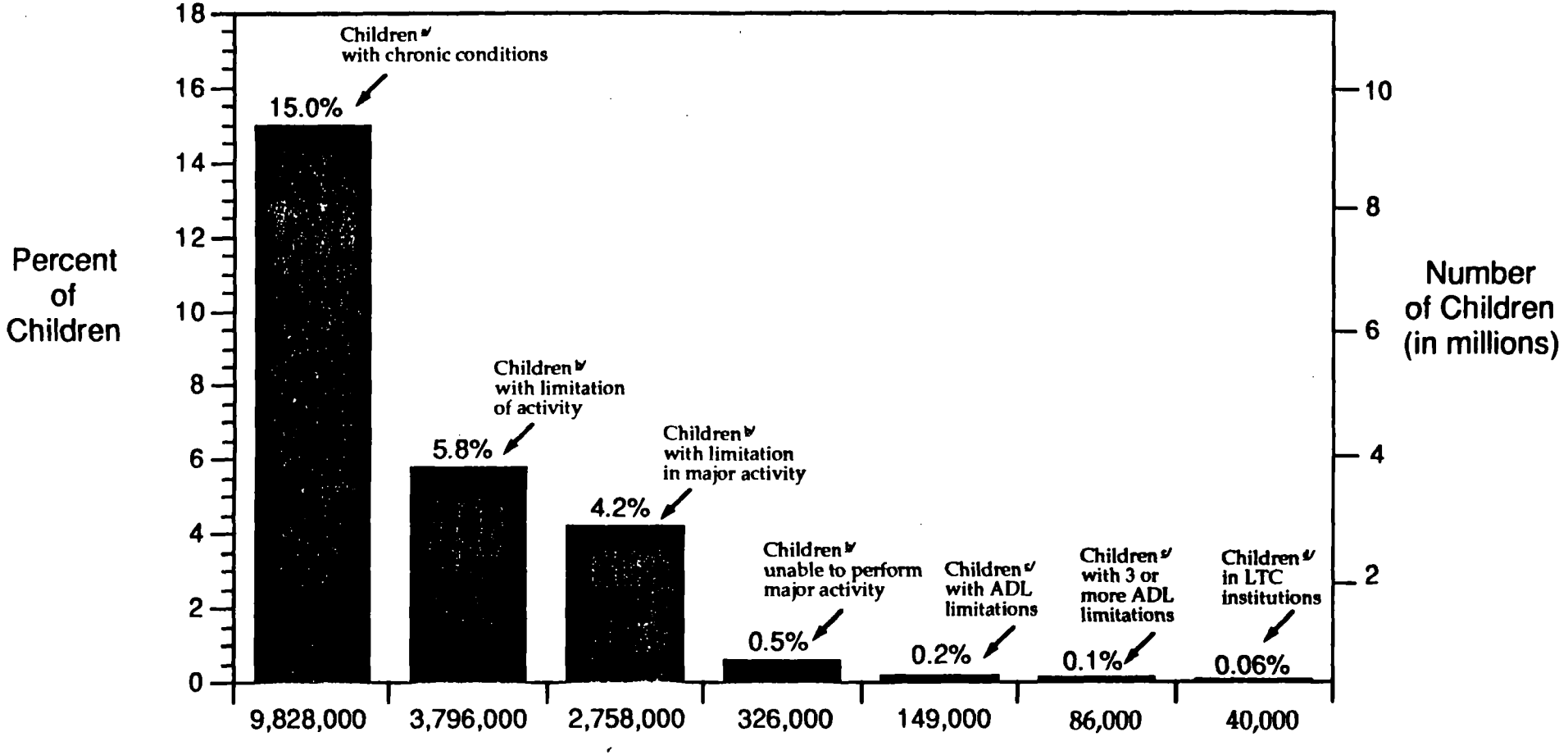
Under S. 1757, eligibility for the new home and community-based services programs would be based entirely on physical and mental functional status; states would not be permitted to exclude individuals based on income, age, or the nature of

their disabling conditions. A person would be considered disabled if he or she requires assistance or supervision in three or more activities of daily living (ADLs), has a severe cognitive or mental impairment in conjunction with a need for assistance in at least one activity of daily living, or is severely or profoundly retarded. Because it is particularly difficult to measure need for assistance in the activities of daily living for very young children, a separate provision for children under age six is included. Children in this age cohort would be deemed eligible if they would require institutional care were they not to receive the services provided under the new state programs.

These eligibility provisions would result in few children gaining eligibility. For example, the requirement stipulating a need for assistance in three or more activities of daily living to gain eligibility for home and community-based services would be met by only a tiny fraction of children with chronic health problems. Data from the National Health Interview Survey indicate fewer than 100,000 children are reported by their families to need assistance in three or more activities of daily living. Yet, an estimated 3.8 million children experience limitations in their usual activities due to chronic health problems. This estimate includes more than 300,000 children so severely disabled that their families report them to be *unable* to engage in school or play activities appropriate for their age cohort. Clearly, the ADL criterion is a very restrictive one that would exclude many needy children from coverage (see Figure 1).

Rather than creating new and potentially inappropriate eligibility criteria, the program could adapt the method now used to establish eligibility for children under the Supplemental Security Income (SSI) program. SSI eligibility for children is based on both diagnostic and functional status criteria. In recent years, these criteria have been modified to include disabled children with a variety of physical and mental conditions. The approach relies partially on diagnostic criteria, but for children not meeting these

## Figure 1
## Chronic Conditions and Disability for Children under 18 Years Old




Sources:
- [a] composite estimate from multiple sources
- [b] original tabulations of the 1991 National Health Interview Survey
- [c] original tabulations of the Home Care Supplement to 1979-80 National Health Interview Survey
- [d] preliminary estimate based on 1990 Census

criteria it also provides an individualized assessment of how the child is developing and functioning compared to other children of the same age. A positive eligibility determination requires that the child's condition limits his or her ability to function independently, appropriately, and effectively in an age-appropriate manner—taking into account cognitive abilities, communicative abilities, motor skills, social skills, and self-care abilities. Hence, the currently-used SSI eligibility scheme provides a comprehensive definition of childhood disability applicable regardless of the specific condition causing disability.[5]

As of November 1993, 718,000 children under 18 years old received SSI disability benefits.[6] Were the income and resource restrictions eliminated from the program, we estimate up to 2 million children would meet SSI's disability criteria.

## IV. Services Included in the Home and Community-Based Care Programs

Under S. 1757, the only mandatory benefit that states must provide is personal assistance services. States are granted discretionary authority to provide a variety of other home and community-based services, including case management, homemaker chore assistance, respite services, assistive devices, habilitative and rehabilitative services, and home health services. However, there are no minimum scope or duration standards for any of these services. Consequently, many children could lose long term care benefits they now have through private health insurance. One nationwide survey of small, medium, and large employers found that 69% of employers offered group

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[5] See *The Advocate's Guide to SSI for Children*. Mental Health Law Project, 1992; Perrin J and Stein R: Reinterpreting Disability: Changes in SSI for Children. *Pediatrics* 88, 1991.

[6] Personal communication from Aaron Prero, Office of Research and Statistics, Social Security Administration, January 1994.

coverage that included comprehensive home care benefits for children (including occupational, speech, physical and respiratory therapies, social work, skilled nursing, and home health aid services).[7] To ensure that children do not lose coverage, long term care benefits for children should encompass a range of community-based medical and social services. Standard benefits should include the following services, to the extent they are not covered under the basic comprehensive benefit package offered by alliance health plans:

- Long term occupational therapy, speech-language pathology services, respiratory therapy, and physical therapy;
- Care coordination or case management services;
- Specialized nursing services, including in-home nursing care;
- Psychotherapy and collateral mental health services related to the treatment of chronic health problems;
- Custom-designed durable medical equipment, prosthetic, orthotic and adaptive devices, including assistive technology;
- Home adaptations;
- Personal assistance services in conducting the activities of daily living;
- Respite care for family care takers; and
- Patient and family education and training related to a child's treatment needs.

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[7] This survey was conducted in 1987 and represents the most recent published data available on private health insurance benefits for chronically ill children. See Fox H and Newacheck P: Private Health Insurance of Chronically Ill Children. *Pediatrics* 85(1), 1990.

## V. Cost Sharing Provisions

S. 1757 includes cost sharing provisions for long term care services that are scaled to family income. The schedule, which is based on the official federal poverty level adjusted for family size is as follows:

| Poverty Level | Coinsurance Rate |
|---|---|
| less than 150% | 0% |
| 150% to 199% | 10% |
| 200% to 249% | 20% |
| 250% or more | 25% |

This cost sharing schedule provides excellent financial protection for low income families. However, other families will be exposed to potentially catastrophic long term care expenses because there is no cap on out-of-pocket expenses. Since most private health insurance plans now cap annual out-of-pocket expenses for covered services, many families will lose protection against catastrophic expenses under the Health Security Act. The cost-sharing schedule may also create distorted financial incentives for families with severely disabled children; parents may find it necessary to reduce their workforce participation or turn down advancement opportunities in order to qualify for zero cost sharing.

Establishing an annual out-of-pocket expense limit for long term care represents a reasonable approach to averting these unintended consequences and would be consistent with the treatment of out-of-pocket expenses in the alliance health plans. A single cap on out-of-pocket expenses or a variable cap related to family income could be instituted.

## VI. Phase-In Considerations

The home and community-based care program would be phased-in over a seven year period beginning in 1996. During the phase-in, the Health Security Act provides for continued provision of long term care services for Medicaid eligible children. These children could continue to receive needed institutional and noninstitutional long term care services while the new home and community-based care programs were being designed and implemented. However, no provision is made for children in families with incomes above Medicaid eligibility levels. Most of these children have employer-based private health insurance that often covers a broad array of noninstitutional long term care services.[8] Since the basic benefit package to be provided by alliance health plans covers few long term care services, many children will lose coverage they now have for long term care services during the phase-in period.

Two actions can be taken to ameliorate this loss of coverage. First, language in the bill could be amended to permit coverage of certain long term care services for all children with chronic conditions, regardless of the origin of those conditions. Currently, S. 1757 restricts coverage of several of the services included in the comprehensive benefit package for the alliance health plans to provision following an illness or injury. This restriction applies to rehabilitative services, home health care, and extended care services. This restriction would exclude children with congenital chronic conditions and impairments from receiving these services. Removing this restrictive language would help assure families that they could continue to receive needed therapies and services for their chronically ill children under alliance health plans.

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[8] Fox H and Newacheck P: Private Health Insurance of Chronically Ill Children. *Pediatrics* 85(1), 1990.

Second, other long term care services needed by children could be provided by extending the Health Security Act's federally funded program for poverty level children with special needs to all disabled children, regardless of family income, during the phase-in period.

## VII. Development of State Plans

The Health Security Act would require each state to submit a detailed plan for its home and community-based services program. This plan would provide a blueprint for addressing eligibility, services, provider certification and reimbursement, cost-sharing, quality assurance, and administration. Federal funding would be contingent on approval of the plan by the Secretary of the Department of Health and Human Services (DHHS).

Other than a stipulation barring states from limiting eligibility based on age, the President's proposal contains no provisions to ensure that states will address disabled children's needs in an age- and developmentally-appropriate fashion. As indicated above, the goals of home and community-based care differ for adults and children. In addition, the provider networks that serve children have evolved differently from those that serve adults. Moreover, because the number of disabled children is small in comparison to disabled adults, their needs are likely to be poorly represented in a program that does not distinguish the interests of various age groups. For these reasons, states should be required to address the distinct needs of children in their plans.

Consistent with the provisions of S. 1757, each state should be required to submit a plan for providing home and community-based services for children that would specify eligibility determination procedures, services to be provided, types of eligible

providers and requirements for participation, provider reimbursement methods and payment rates, and quality assurance and safeguards. States should be required to demonstrate family participation in design of their home and community-based services programs for children and specify provisions for ensuring consumer choice regarding providers and covered services. States should also be required to specify procedures for coordinating services delivered through the new program and existing programs such as Medicaid, the Individuals with Disabilities Education Act, and other federal and state programs serving disabled children. Similarly, the methods for coordinating children's services between the new program and the alliance health plans should be specified in the plan.

## VIII. Implementation

Creating home and community-based service programs in every state represents a significant undertaking. Development of strong federal guidelines could help assure successful program implementation across states. In this regard, DHHS could extend planning grants and technical assistance for program development to all states as soon as possible and to approve state plans only after federal guidelines for eligibility, service delivery, and quality assurance were met. DHHS could commission an advisory panel composed of policymakers, providers, parents and other experts to assist in the design of guidelines for eligibility determination, service delivery, quality assurance, and administration.

## IX. Conclusion and Recommendations

Assuring adequate coverage of needed benefits, as well as developing community-based mechanisms for delivering and coordinating such care is a critically important undertaking. Since relatively few children experience severe chronic health

problems and because many of their expenses are now met through public programs, the added public sector costs of providing comprehensive home and community-based services should be relatively low.

While the home and community-based services program contained in S.1757 provides an excellent foundation for improving access to long term care services, several changes could be made that would greatly enhance the program's usefulness for disabled children. These include:

- Uniform application of age and developmentally appropriate eligibility criteria in all states, those such currently used in the SSI program;

- Development of a mandatory benefit package that includes noninstitutional long term care services needed by children, rather than adult-oriented services to cover services not included in the alliance health plan;

- Protection for families against loss of long term care services currently covered under private health insurance during the phase-in period; and

- Requiring states to design their programs for home and community-based services in a manner that will assure equitable provision of services to disabled children.

# MEETING CHILDREN'S DEVELOPMENTAL AND CHRONIC CARE NEEDS UNDER THE HEALTH SECURITY ACT

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February 1994

# MEETING CHILDREN'S DEVELOPMENTAL AND CHRONIC CARE NEEDS UNDER THE HEALTH SECURITY ACT

Assuring the healthy development of children from birth through adolescence requires that children have access not only to comprehensive preventive and primary care but also to a variety of developmental and chronic care services to treat the physical, emotional, behavioral, and developmental problems they may experience. Currently, such services -- which include, among others, ancillary therapies for the purpose of maximizing functioning, extended home health care unrelated to acute care hospitalization, respiratory therapy, and custom-designed medical devices -- are reimbursed under Medicaid and frequently under traditional private health insurance plans as well.

President Clinton's Health Security Act offers a wide array of benefits, many of which represent substantial improvements over what currently exists. First, a standard benefit package would be available to all Americans. Second, individuals and families would not be subject to coverage limitations due to pre-existing conditions. Third, several benefits would be added that previously have not been covered by many private plans, including clinical preventive services, prescription drugs, mental illness and substance abuse services, vision care, dental care, and extended care services.

Yet, despite these improvements, under President Clinton's national health reform proposal many of the developmental and chronic care services required by children would only be available to those who are Medicaid eligible. Both the proposed Program for Poverty-Level Children with Special Needs and the proposed residual Medicaid program

would serve only AFDC, SSI, and other children who are currently eligible for Medicaid. In addition, the proposed state Program for Home- and Community-Based Services for individuals with disabilities would serve only a small subset of severely impaired children, and the private purchase of community-rated supplemental health insurance coverage is not likely to be financially feasible for any but the wealthiest families. This would leave many privately insured children with more restrictive benefit packages than they now have (see attached table on the appropriateness of benefits for children under the Health Security Act). Even those children who could meet the eligibility criteria of the proposed programs would be forced to rely on an uncoordinated maze of benefits and service systems. Therefore, including a comprehensive package of developmental and chronic care services as part of the basic benefit package for all children is essential.

Any health reform effort must meet a child standard of care[1], one that recognizes and supports children's unique service requirements for healthy physical and emotional development. While only a small proportion of children are likely to need developmental and chronic care benefits, and many may require them only for relatively short periods of time, having access to these services as part of the comprehensive benefit package would make enormous differences in the lives of individual children, better preparing them to function as healthy and productive adults.

To meet a children's standard of care we recommend enhanced benefits, income-

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[1] Principles of law and policy that support treating children's health coverage separately from those of adults is presented in Jameson E and Wehr E: Drafting national health care reform legislation to protect the health interests of children. Stanford Law and Policy Review Journal. Vol. 5:1, Fall 1993.

based cost-sharing provisions, and federal and state administrative responsibilities to oversee the Health Security Act components related to children. These recommendations are briefly described below and will be further elaborated and justified in a subsequent paper.

**Enhanced Benefits for Children**

A children's enhanced health benefit package should be established to provide appropriate health insurance coverage for children's developmental and chronic care needs for all families with cost-sharing requirements based on their ability to pay. This new benefit package for children would substitute for the proposed programs for children called for under the Health Security Act, including the Program for Poverty-Level Children with Special Needs, the residual Medicaid program, and the children's portion of the Program for Home- and Community-Based Services for individuals with disabilities.

Enhanced children's benefits should include services that are not listed in the comprehensive benefit package as well as those that are included but subject to limitations. The following benefits should be available, as necessary, without day or visit limits and should be delivered in offices, clinics, schools, homes, and other settings appropriate to children.

1. Clinical Preventive Services:

    - Additional preventive health visits, as medically necessary, to provide screening and counseling for children at risk for physical, emotional, behavioral, and developmental problems or conditions.

- Family planning services and services for pregnant adolescents.[2]

2. Mental Illness and Substance Abuse Services:

   - Preventive outpatient mental health and substance abuse services, including services for children with a suspected mental health or substance abuse problem or those at risk for mental health problems due to physical health, child abuse, or other biological or environmental risk factors.

   - Additional outpatient, inpatient and residential treatment, and intensive nonresidential treatment, mental health and substance abuse treatment services based on reasonable standards of medical practice developed in consultation with recognized medical organizations involved in mental health and substance abuse care that the individual should receive such treatment.

3. Home Health Care

   - Home health care services, including full-time nursing services and personal care services as well as the services included in 1861 (m) of the Social Security Act, for children who require this level of care to treat an injury, illness or other health condition, consistent with an approved plan of care and subject to a 60-day re-evaluation.

4. Extended Care Services

   - Skilled nursing facility and rehabilitation facility services for children who require this level of care to treat an injury, illness, or other health condition, with coverage extending past 100 days only as an alternative to hospitalization.

5. Outpatient Rehabilitation Services

   - Occupational, physical therapy, speech-language pathology and audiology services, and respiratory therapy services for children for the purpose of improving or maintaining age-appropriate functioning, subject to a 100-day re-evaluation.

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[2] We are recommending that family planning services and services for pregnant adolescents be included as a clinical preventive service to assure that there would be no cost-sharing obligations for these services. Alternatively, the proposed Health Security Act could be revised for all family planning services.

6. Durable Medical Equipment and Assistive Devices

    - Prescribed hearing aids and custom-designed durable medical equipment, including prosthetic devices, orthotic devices, and health-related assistive technology for children.

7. Health Education and Training

    - Health education and training for families of children with physical, emotional, behavioral, or developmental conditions who require these services to achieve treatment goals.

8. Case Management

    - Multidisciplinary case management for all children with severe or chronic health care needs, and those with emotional, biological, or environmental risk factors.

**Cost-Sharing**

Although no family should be charged an additional premium for this enhanced child health coverage, families should contribute to the cost of services based on their ability to pay. Sliding-scale fees should be set so as to assure that families with incomes up to 150 percent were not charged for services, and those with incomes between 150 and 300 percent of poverty were charged no more than 10 percent. Maximum annual out-of-pocket liability for these and all other covered benefits in the comprehensive benefits package should be limited to no more than $3,000 for families with incomes between 150 and 300 percent of poverty. At the highest end, cost-sharing requirements might be limited to $7,500. In addition, for all families, cost-sharing requirements for mental illness and substance abuse services for children should be the same as those established for physical health treatment services.

**Administration**

Oversight for all children's services would be provided by a designated child health agency at the federal and state levels. Alliance plans would be responsible for making enhanced children's benefits available as part of the guaranteed comprehensive benefit package.

The federal child health agency would assist the National Health Board in updating the benefit package for children, developing a pediatric risk adjustment system, encouraging pediatric delivery system developments and innovations, and monitoring and evaluating the impact of health care reform on children. It also would staff a child health services advisory committee that would be established by the National Health Board. In addition, the federal agency would provide a major role in quality assurance by assisting the National Quality Management program in assuring that children's benefits are consistent with pediatric norms of care, treatment protocols, and provider standards.

The state child health agency would be charged with certifying that plans meet pediatric practice guidelines, establishing policies regarding essential community provider designation for centers of excellence and other organized care arrangements specializing in children's services, and ensuring that the alliances' risk adjustment mechanisms adequately meet federal standards and account for differences in children. The state agency would also provide financial incentives to health plans for the early identification and appropriate referral of children's health problems. In addition, it would provide stop-loss protection when a plan's per-child outlays for services reach a specified reasonable amount.

## APPROPRIATENESS OF BENEFITS FOR CHILDREN UNDER THE HEALTH SECURITY ACT

| HEALTH SECURITY ACT BENEFITS | APPROPRIATENESS OF BENEFITS FOR CHILDREN |
|---|---|
| 1. Hospital services | Benefit is appropriate. |
| 2. Services of health professionals | Benefit is appropriate. |
| 3. Emergency and ambulatory medical and surgical services | Benefit is appropriate. |
| 4. Clinical preventive services | Periodicity schedule is less than recommended by the American Academy of Pediatrics and the federally funded Bright Future's Project. |
| 5. Mental illness and substance abuse services | Health professionals would not be able to provide treatment for mental illness and substance abuse problems unless the health plan in which the child is enrolled determines that such treatment is necessary based on its own criteria.<br><br>Preventive mental health visits would not be available to children with a suspected mental health or substance abuse problem or to children at risk for mental health problems due to physical health, child abuse, or other biological or environmental high-risk factors.<br><br>Annual visit limits (30) on psychotherapy, collateral services, and substance abuse counseling and relapse prevention would restrict use of needed mental health and substance abuse services. Additional visits would only be available to individuals in lieu of a higher level of care.<br><br>Copayments and coinsurance would not be applied toward any annual out-of-pocket limit on cost-sharing, creating substantial financial burdens for families. |
| 6. Family planning services and services for pregnant women | Copayments and coinsurance would discourage use of family planning and prenatal care services among adolescents. |
| 7. Hospice care | Benefit is appropriate. |

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| 8. | Home health care | Full-time nursing services would not be covered, only part-time or intermittent nursing care. Personal care services also would not be covered.<br><br>Home health care would only be covered following an illness or injury and as an alternative to hospital, skilled nursing, or rehabilitation facilities. |
| 9. | Extended care services | Extended care services would only be covered following an illness or injury and as an alternative to hospitalization. |
| 10. | Ambulance services | Benefit is appropriate. |
| 11. | Outpatient laboratory, radiology, and diagnostic services | Benefit is appropriate. |
| 12. | Outpatient prescription drugs and biologicals | Benefit is appropriate. |
| 13. | Outpatient rehabilitation services | Occupational therapy, physical therapy, and speech-language pathology services would only be covered following an illness or injury, and only to restore functional capacity or minimize limitations as a result of an illness or injury.<br><br>Respiratory therapy and audiology services would not be covered.<br><br>Extended outpatient rehabilitation services, after each 60 day period, would only be covered if function is improving. |
| 14. | Durable medical equipment and prosthetic and orthotic devices | Hearing aids, customized medical devices, and assistive technologies would not be covered. |
| 15. | Vision care | Benefit is appropriate. |
| 16. | Dental care | Benefit is appropriate. |
| 17. | Health education classes | Health education classes would not meet the needs of families who require education and training related to childrens' treatment goals. |

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| 18. | Investigational treatments | Benefit is appropriate. |
| 19. | Other | Case management would be covered only for individuals with a diagnosable mental health and substance abuse problem. |

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