STATEMENT ON MATERNAL AND CHILD HEALTH NEEDS UNDER NATIONAL HEALTH REFORM

Good health is essential for children's ability to learn, grow and reach their full potential as members of society. To ensure that our children have good health, all children and pregnant women must have access to a wide range of affordable preventive, acute, tertiary and long term care services. To obtain that access we must make certain that all children and pregnant women are insured. Our failure as a nation to make that commitment results in higher costs, missed opportunities for prevention, unnecessary disability and death.

There is an urgent health care crisis today for well over half of America's 65 million children:

- Over 8 million children and one half million pregnant women have no health insurance;
- 17 million children are uninsured for part or all of the year;
- 19 million children on Medicaid face the prospect of losing benefits because of state fiscal problems;
- Many thousands of children are locked out of the health insurance system because of pre-existing condition exclusions; and
- Millions have private insurance that fails to cover preventive services as well as treatment needed by children with physical and emotional disabilities.

As organizations firmly committed to assuring health security to our nation's children, we strongly urge that:

1) Congress pass and the President sign in 1994 health reform legislation that covers all Americans;
2) Any health care reform plan must include the guarantee of affordable universal coverage and access to care for pregnant women and children on a fast track; and
3) Comprehensive benefits clearly defined by law.

Only legislation that includes such guarantees is acceptable. Otherwise, millions of our children will always be left behind. At this time the legislation that goes furthest in meeting our specific goals for mothers and children is President Clinton's.

BRIDGEPORT CHILD ADVOCACY COALITION (CT)

BRONX PERINATAL CONSORTIUM (NY)

CALIFORNIA ASSOCIATION OF SERVICES FOR CHILDREN

CALIFORNIA MENTAL HEALTH ADVOCATES FOR CHILDREN AND YOUTH

CATHOLIC CHARITIES USA (VA)

CENTER FOR MEDIA EDUCATION/CAMPAIGN FOR KIDS' TV (MD)

CENTER FOR MULTICULTURAL HUMAN SERVICES (VA)

CENTER FOR POPULATION CONTROL

CENTER FOR POPULATION OPTIONS

CHILD ADVOCACY INSTITUTE

CHILD ADVOCATES

CHILDCARE

CHILD AND ADOLESCENT HEALTH POLICY CENTER OF THE JOHNS HOPKINS UNIVERSITY (MD)

CHILD CARE LAW CENTER (CA)

CHILD HEALTH CRISIS STRATEGY GROUP (NY)

CHILD WELFARE LEAGUE OF AMERICA

CHILDREN AWAITING PARENTS

CHILDREN AT RISK (TX)

CHILDREN'S ACTION ALLIANCE (AZ)

CHILDREN'S ALLIANCE (KY)

CHILDREN'S COALITION OF INDIANA

CHILDREN'S DEFENSE FUND

CHILDREN'S EVALUATION CENTER OF SOUTHERN ARIZONA

CHILDREN'S HEALTH FUND

CHILDREN'S HEALTHY START (WA)

CHILDREN'S HOSPITAL MERITCARE (ND)

CHILDREN'S HOSPITAL OF LOS ANGELES

CHILDREN'S HOSPITAL OF MICHIGAN

CHILDREN'S HOSPITAL OF PITTSBURGH

CHILDREN'S HOUSE (NY)

CHILDREN'S SPECIAL HEALTH SERVICES (LA)

CHILDREN'S POLICY INSTITUTE (WV)

CHOICE/CHILDREN'S HEALTH CHOICES (PA)

CITIZENS ADVICE BUREAU (NY)

CITIZENS FOR MISSOURI'S CHILDREN

CITIZENS' COMMITTEE FOR CHILDREN (NY)

CITYMATCH (NE)

COALITION FOR TENNESSEANS WITH DISABILITIES

COALITION FOR HISPANIC FAMILY SERVICES (NY)

COLEMAN ADVOCATES FOR CHILDREN AND YOUTH (CA)

COLEMAN ADVOCATES FOR WOMEN AND CHILDREN

COLORADO ASSOCIATION OF FAMILY AND CHILDREN'S AGENCIES

COLORADO CHILDREN'S CAMPAIGN

COLORADO FAMILY VOICES

COMMITTEE FOR HISPANIC CHILDREN AND FAMILIES

COMMUNITY ACTION PROGRAMS OF EVANSVILLE (IN)

COMMUNITY COORDINATED CHILD CARE (KY)

COMMUNITY COORDINATED CHILD CARE (NJ)

COMMUNITY HEALTH CARE ASSOCIATION OF NEW YORK STATE

CONNECTICUT ASSOCIATION OF CHILD CARING AGENCIES

CONGREGATIONS CONCERNED FOR CHILDREN (MN)

COVENANT HOUSE (NY)

DAY CARE ACTION COUNCIL OF ILLINOIS

DAY CARE ASSOCIATION OF MONTGOMERY COUNTY (PA)

DIOCESE OF ARIZONA

DIXON HOUSE (PA)

DRISCOLL CHILDREN'S HOSPITAL (TX)

EAST COAST MIGRANT HEAD START PROJECT (VA)

EASTERN KENTUCKY CHILD CARE COALITION

EDGEWOOD CHILDREN'S CENTER (MO)

EDWARD C. MAZIQUE PARENT CHILD CENTER (WASHINGTON DC)

EDGEWOOD CHILDREN'S CENTER (MO)

FAMILIES FORUM

FAMILY AND CHILDREN'S SERVICES - DELAWARE

FAMILY AND CHILDREN'S SERVICES - MINNEAPOLIS

FAMILY DEVELOPMENT PROGRAM (NM)

FAMILY AND CHILDREN'S SERVICES - MINNESOTA

FAMILY DYNAMICS (NY)

FAMILY FOSTER - BASED TREATMENT ASSOCIATION (NY)

FAMILY SERVICE AMERICA

FAMILY VOICES - GEORGIA

FAMILY VOICES - ILLINOIS

FAMILY VOICES - OHIO

FAMILY VOICES - SOUTH CAROLINA

FAMILY VOICES - WASHINGTON

FAMILY VOICES - WISCONSIN

FEDERATION FOR CHILDREN WITH SPECIAL NEEDS (NM)

FIRST UNITARIAN UNIVERSALIST CHURCH (MI)

FLORIDA CENTER FOR CHILDREN & YOUTH

FOR LOVE OF CHILDREN (FLOC)

GEORGIA ALLIANCE FOR CHILDREN

GEORGIA CHILD CARE COUNCIL

GEORGIANS FOR CHILDREN

GREATER COLUMBUS SPINA BIFIDA ASSOCIATION (OH)

HATHAWAY CHILDREN'S SERVICES (CA)

HAITIAN COMMUNITY HEALTH PROJECT (NY)

HAMILTON CENTERS (IN)

HAVEN COUNSELING CENTER/KERN CHILD ABUSE PREVENTION COUNCIL (CA)

HAWAII ADVOCATES FOR CHILDREN & YOUTH

HAWAII EARLY INTERVENTION ASSOCIATION

HAWAII EARLY INTERVENTION COORDINATING COUNCIL

HAWAII FAMILY VOICES

HEALTHY MOTHERS, HEALTHY BABIES OF GEORGIA

H.U.S.H. COALITION

INDIANA ADVOCATES FOR CHILDREN

JUVENILE LAW CENTER (PA)

KANSAS CHILDREN'S SERVICE LEAGUE

LAWYERS FOR CHILDREN (NY)

LOS ANGELES CHILD GUIDANCE CLINIC (CA)

LOUISIANA STATE PARENT COORDINATOR

MARCH OF DIMES BIRTH DEFECTS FOUNDATION

MARYLAND COMMITTEE FOR CHILDREN

MASSACHUSETTS ADVOCACY CENTER

MASSACHUSETTS CHILD WELFARE LEAGUE OF AMERICA EXECUTIVES GROUP

MASSACHUSETTS FAMILY VOICES

MATERNITY CARE COALITION (PA)

MENTAL HEALTH ASSOCIATION IN TEXAS

METRO-DADE CHILDREN'S SERVICES COUNCIL (FL)

MICHIGAN CITIZENS FOR AMERICA'S CHILDREN

MICHIGAN HEAD START CHILD DEVELOPMENT ASSOCIATION

MINISTRIES (NJ)

MISSISSIPPI PARENTS AND FAMILIES NETWORK

MONTANA WOMEN'S LOBBY

MOORE COMMUNITY HOUSE (MS)

MOTHER'S UNITED FOR MORAL SUPPORT (WI)

MOTHERS PROTECTING CHILDREN (CT)

MUSCULAR DYSTROPHY ASSOCIATION

NATIONAL ASSOCIATION FOR FAMILY CHILD CARE (VA)

NATIONAL ASSOCIATION OF CHILD ADVOCATES

NATIONAL ASSOCIATION OF CHILD CARE RESOURCE & REFERRAL AGENCIES

NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

NATIONAL ASSOCIATION OF COUNTIES

NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITIES

NATIONAL ASSOCIATION OF ELEMENTARY SCHOOL PRINCIPALS (VA)

NATIONAL ASSOCIATION OF HOMES & SERVICES FOR CHILDREN

NATIONAL ASSOCIATION OF SCHOOL NURSES (VT)

NATIONAL ASSOCIATION OF SCHOOL PSYCHOLOGISTS

NATIONAL ASSOCIATION OF ELEMENTARY SCHOOL PRINCIPALS

NATIONAL ASSOCIATION OF STATE ALCOHOL AND DRUG ABUSE DIRECTORS

NATIONAL BLACK NURSES ASSOCIATION

NATIONAL CONSULTANTS OF STATE SCHOOL NURSE CONSULTANTS

NATIONAL CHILD ABUSE COALITION

NATIONAL COMMITTEE TO PREVENT CHILD ABUSE

NATIONAL COUNCIL OF NEGRO WOMEN

NATIONAL DENTAL ASSOCIATION

NATIONAL EASTER SEAL SOCIETY

NATIONAL EDUCATION ASSOCIATION

NATIONAL HEAD START ASSOCIATION

NATIONAL HEALTH & HUMAN SERVICES EMPLOYEES UNION (1199)

NATIONAL MEDICAL ASSOCIATION

NATIONAL ORGANIZATION OF STATE ASSOCIATIONS FOR CHILDREN (OH)

NATIONAL PEDIATRIC HIV RESOURCE CENTER

NATIONAL PERINATAL ASSOCIATION

NATIONAL URBAN LEAGUE (NY)

NATIONAL WOMEN'S LAW CENTER

NATIONAL YOUTH ADVOCACY PROGRAM (OH)

NEBRASKA FAMILY VOICES

NEW HAMPSHIRE ALLIANCE FOR CHILDREN

NEW HAMPSHIRE GUIDANCE FOR CHILDREN AND YOUTH (NH)

NEW JERSEY FOSTER PARENT ASSOCIATION

NEW MEXICO ADVOCATES FOR CHILDREN & FAMILIES

NEW YORK STATE PUBLIC HEALTH ASSOCIATION - LONG ISLAND REGION (NY)

NNK PRESCHOOL (NJ)

NORTH CAROLINA CHILD ADVOCACY INSTITUTE

NORTHERN MANHATTAN PERINATAL PARTNERSHIP (NY)

NORTHWEST FLORIDA ASSOCIATION FOR THE EDUCATION OF YOUNG CHILDREN

OFFICE OF CHILD ADVOCACY–KOSAIR CHILDREN'S HOSPITAL (KY)

OHIO ASSOCIATION OF CHILD CARING AGENCIES

OHIO YOUTH ADVOCATE PROGRAM

OKLAHOMA INSTITUTE FOR CHILD ADVOCACY

OREGON FAMILIES AS LEADERS

PARENT ACTION (MD)

PARENT PARTNERSHIP PROGRAM (IA)

PARENT RESOURCES ON DISABILITIES (OR)

PARENTS FOR BEHAVIORALLY DIFFERENT CHILDREN (NM)

PARENTS REACHING OUT

PARENTS REACHING OUT - RHODE ISLAND

PENNSYLVANIA PARTNERSHIPS FOR CHILDREN

PHILADELPHIA CITIZENS FOR CHILDREN AND YOUTH

PLANNED PARENTHOOD FEDERATION OF AMERICA

PPEP (PORTABLE PRACTICAL EDUCATION PREPARATION) (AZ)

PUBLIC ASSISTANCE TASK FORCE, WESTMINSTER PRESBYTERIAN CHURCH (DE)

QUEENS COMPREHENSIVE PERINATAL COUNCIL (NY)

RESOURCE CENTER NETWORK OF LOS ANGELES

RESULTS

RHEEDLEN (NY)

ROCHESTER AREA CHILDREN'S COLLABORATIVE (NY)

RUTH DYKEMAN CHILDREN'S CENTER (WA)

RYTHER CHILD CENTER (WA)

SOCIETY FOR PEDIATRIC RESEARCH

SOCIETY OF ADOLESCENT MEDICINE

SOUTH SHORE DAY CARE SERVICES (MA)

SOUTHERN EARLY CHILDHOOD ASSOCIATION (AK)

SPINA BIFIDA ASSOCIATION OF AMERICA

ST. JOHN'S EPISCOPALIAN CHURCH

ST. LOUIS CHILDREN'S HOSPITAL

ST. MICHAEL'S DAY NURSERY (DE)

STATE COMMUNITIES AID ASSOCIATION (NY)

STATE MEDICAL CENTER CHILDREN'S HOSPITAL (MA)

STATEWIDE YOUTH ADVOCATES (NY)

THE BLACK CHILDREN INSTITUTE OF TENNESSEE

THE CHILDREN'S AID SOCIETY (NY)

THE CHILDREN'S GUILD (OR)

THE CHILDREN'S MEDICAL CENTER OF DAYTON (OH)

THE DIVISION FOR EARLY CHILDHOOD OF THE COUNCIL FOR EXCEPTIONAL CHILDREN (PA)

THE DIVISION FOR EARLY CHILDHOOD OF THE COUNCIL FOR EXCEPTIONAL CHILDREN (VA)

THE LEGAL AID SOCIETY (NY)

THE NATIONAL CAUCUS AND CENTER ON BLACK AGED

UNITARIAN UNIVERSALIST SERVICE COMMITTEE (MA)

UNITED STATES ASSOCIATION FOR CHILD CARE

UNIVERSITY OF COLORADO HEALTH SCIENCES CENTER, SCHOOL OF NURSING

UTAH CHILDREN

UTAH COMMITTEE TO PREVENT CHILD ABUSE

UTAH FAMILY VOICES

VALLEY CHILDREN'S HOSPITAL (CA)

VOICES FOR ILLINOIS CHILDREN

WASHINGTON FOOD POLICY ACTION CENTER (WA)

WEST VIRGINIA CHILD CARE ASSOCIATION

WEST VIRGINIA FAMILY VOICES

WILLIAM F. RYAN COMMUNITY HEALTH CENTER (NY)

WISCONSIN COUNCIL ON CHILDREN AND FAMILIES

WISCONSIN COUNCIL ON DEVELOPMENTAL DISABILITIES

WISCONSIN HEAD START DIRECTORS ASSOCIATION

WISCONSIN MATERNAL AND CHILD HEALTH COALITION

WOMEN'S LEGAL DEFENSE FUND

WYOMING PARENT INFORMATION CENTER

YWCA OF THE U.S.A

Children's Health Week

DRAFT

Several weeks ago the President and the First Lady led a week-long effort to increase support for health reform by emphasizing the needs of the elderly and how the Health Security Act responds to them.

We are recommending that the Administration at some point during April or May engage in a comparable one week or two week campaign dedicated to children and families and how health reform and the Health Security Act benefit them -- a Children's Week, or a Children and Families Week.

CDF and other children's groups would be anxious to help identify existing events that could be used as a springboard, develop new events and generate media during the week. Possible weeks to target are: the week of April 18, since the March of Dimes will be conducting its annual walk-a-thon in numerous cities around the country on April 23-24, and those events would fit naturally into children's week; the week of May 2, which culminates in Mother's Day (May 8); or the week starting May 9, with a Mother's Day kick-off.

During Children's Health Week, the President and First Lady and other Administration spokespersons would target their health-related public appearances on the needs of children and families and the ways the President's plan responds to those needs. Speeches to child-related audiences around the country would be preceded or followed by visits to health sites that serve children -- a children's hospital, a pediatrician's office, a rural health clinic, a school-based health clinic, an immunization program or fair. National and local children's organizations would help obtain the maximum impact from these events.

During the week, other events would occur:

- Reports from children's groups on problems in the current system for children and how the Health Security Act solves them could be timed to be released that week.

- We would attempt to arrange supportive hearings in key committees (e.g., Senate Labor and Human Resources; House Energy and Commerce) on the positive impact on children of health reform with universal, affordable coverage and comprehensive benefits.

- We could release again (with substantial additional numbers of signers) the list of children's groups supporting health reform in general and the President's plan in particular. (On March 10th, 250 groups held an initial release of this statement.)

- We could conduct some event with prominent physicians and medical researchers analogous to and building on the designation of "children's health heroes" that the White House engaged in during December in conjunction with UNICEF.

- The Administration could release new poll results targeted on children and families. Several months ago, Celinda Lake said that child and family issues had the most resonance in the polls on health reform that she and others had conducted. Children's Week presents an opportunity to reframe the health debate around the needs of America's middle class families with children.

These are only a few representative ideas. Obviously, there are many other events and media possibilities. We look forward to talking to you about this.

March 30, 1994

PROTECTING CHILDREN IN THE HEALTH SECURITY ACT

Universal coverage is essential for children.

The Health Security Act protects children by providing universal coverage, eliminating pre-existing condition exclusions, and assuring continuity of coverage for families. These are critical steps toward improving the health of our children. Without guaranteed, universal coverage, millions of children will continue to be uninsured each year, and hundreds of thousands more will spend a lifetime excluded from private insurance.

Children need comprehensive benefits.

Health care reform should include comprehensive benefits for the full range of services needed to address children's physical, developmental, and mental health conditions. Congress has defined comprehensive benefits for children through the Medicaid Early and Periodic Screening Diagnosis and Treatment (EPSDT) program. This is the model for benefits for all children.

The effectiveness and cost-effectiveness of child health services have been proven -- from immunizations and well child care through early intervention services to reduce disability. For children with special needs, medically necessary and appropriate services can enable them to live healthier, more productive lives with their families. Preventing disability and fostering development are important goals of health care for children.

Child health coverage under the Health Security Act needs improvement.

The Health Security Act aims to provide comprehensive coverage for all Americans, with an appropriate focus on prevention services. However, it leaves critical gaps for children.

- Some families, particularly those whose children have special needs, will lose benefits they now have under private coverage or Medicaid.
- The comprehensive, model EPSDT benefits package is provided only to the poorest children through a capped entitlement.
- For rehabilitation (e.g., physical, occupational, or speech therapies), home health and extended care services, Title I benefits are limited, following only illness or injury. Thus certain congenital and other conditions are excluded.
- Arbitrary limits and trade-offs on mental health coverage in Title I will severely restrict children's access to medically necessary and appropriate services.
- The long-term care program would serve only a small subset of severely impaired children.
- With the sharp separation between acute and long-term care services, many children will have health needs that are not addressed in either place.

What Must be Done?

Ideally, the Health Security Act, Title I benefits package should be amended to provide a

comprehensive range of services for all children. An alternative is to create a new supplemental benefit program for special needs children (see attached). At a minimum, the following changes must to made to the Health Security Act to ensure that children who are now insured for needed services to not lose that coverage:

- o Revise Title IV, §§ 4221 and 4222 to clarify that no child who meets the Medicaid eligibility standards under current law would be denied benefits.

- o Amend the core benefits package under Title I, §§ 1118, 1119, and 1123 to ensure that home health, extended care, and outpatient rehabilitation services will not be denied to children with congenital and other conditions.

- o Amend Title I, § 1115 to provide for appropriate mental health services for children.

- o Revise the Title II long-term care program by providing standards for children. Specifically: a) replace the institutionalization criteria with a standard of "comparable severity" and b) make mandatory services developmentally appropriate for children.

- o Continue the Medicaid waiver programs (e.g. the "Katie Beckett" waiver) for children now receiving, and those on waiting lists for, home and community based services.

- o Amend the "wrap-around" program in Title IV, § 4222 to cover all children with family incomes at or below 200% of poverty (with no cap and on a subsidized basis) and to permit those with incomes above 200% to buy wrap-around coverage. The wrap-around benefits should start where the Title I benefits leave off and should extend to the range of services currently covered under EPSDT.

Can we afford the additional cost of comprehensive benefits for all children?

Most of the services needed by children are already included in Title I. Basic coverage is there for hospital and physician services, as well as some prescribed drugs, mental health, and rehabilitation services. While children with disabilities' health expenditures are times higher than those of non-disabled children, 80% of this difference is accounted for by their higher use of hospital care, physician services, and prescribed medications.

Only a small proportion of children have special needs that require wrap-around benefits or long-term care services. An estimated 15% of children have some special health needs, but less than 1 percent need the most intensive services (Figure 1).

Moreover, funds budgeted for the Title IV "wrap-around" for Medicaid children would be sufficient for much of the cost. Additional costs for non-poor children will be low, because they are less likely to have a disability. For example, in 1992 the rate of disability among children in families with incomes above $35,000 was less than half that of those with incomes below $10,000.

NO CHILD -- REGARDLESS OF FAMILY INCOME -- SHOULD LOSE BENEFITS AS A RESULT OF HEALTH CARE REFORM. Congress must act now to ensure that comprehensive child health benefits are a part of any package. Families must be supported as they care for their children. Children deserve every opportunity to reach their full potential.

For more information, contact: Polly Arango, Family Voices (505-867-2368), Allan Bergman, United Cerebral Palsy Associations (202-842-1266), Gregg Hailley, Children's Defense Fund (202-662-3541), Kay Johnson, March of Dimes (202-659-1800) or Graham Newsom, American Academy of Pediatrics (202-347-8600).

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:

- o Extend to all children the services under the Medicaid wrap-around program for "children with special needs" (§ 4222);
- o Leave in place the federal/state Medicaid "long-term care" benefits (§ 4221), with required coordination through the supplemental program; and
- o 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 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 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 foregoing 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, regardless of location, so long as they meet provider qualification standards.

G. Provider reimbursement:

- o 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.
- o special all-inclusive capitation payments for overall care and management.
- o Secretary to develop standards for global and fee-based payments.

H. Administration:

- o By state agency with expertise in care and management of programs and services for children with special needs;
- o Federal-State match for both medical and administrative costs.
- o 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 for children to include family support services and such services as are developmentally appropriate.

(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).

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. Jennifer L. Howse
President
March of Dimes
Birth Defects Foundation
1275 Mamaronack Avenue
White Plains, New York 10805

Dear Dr. Howse:

Thank you for your letter concerning coverage for children with birth defects under the Health Security Act. Let me assure you that the President has proposed a strong comprehensive acute care benefit package that will be guaranteed for all Americans, regardless of their medical condition.

First, by outlawing pre-existing condition exclusions the President's proposal will guarantee that all children, including those with birth defects, have access to health insurance and to a full range of acute care medical services, regardless of their medical condition. This is a profound change for children who have disabilities and their families. Families with children with disabilities will no longer be denied health coverage, or charged exorbitant insurance premiums, or locked into jobs for fear of losing their health coverage, or denied renewal just when they need health care the most. The families of children with disabilities will no longer face the threat of losing everything they have in their attempts to purchase and retain access to affordable, quality health care.

Second, the President has proposed an excellent comprehensive benefit package that includes a wide range of services including, physician, hospital, laboratory, prescription drugs, and preventive services. In addition, the benefit package includes acute care related outpatient rehabilitation services, extended care services, and home health care services. In order to specify the acute orientation of these three benefits, insurance has traditionally placed limits on these benefits or related their applicability to acute illness or injury.

The Health Security Act never intended to exclude a particular diagnosis from coverage from any benefit. If our use of the term "illness and injury" appears to have this effect, we are eager to work with members of Congress and child health advocates to assure that this benefit serves the acute care needs of all children. In the meantime, it is critical to understand that any child born with a birth defect that requires surgery, professional services, etc. will have full coverage for those services. In addition, if rehabilitative services are necessary following such services, that will be covered within the parameters of the benefit.

Nonetheless, we know that the comprehensive benefit package will not meet all of the long-term support needs for some children. To help address this, two new programs have been proposed:

- A major new expansion in community-based long-term care that provide a range of community supports to people with severe disabilities, regardless of their age or income.

- A new federal program for poor children which will include Medicaid services that are not included in the comprehensive benefit package, such as hearing aids, transportation, and some therapies.

The long term care program will likely cover ongoing supports that are not there today for many children with severe disabilities. This benefit is not means tested. We recognize this is only a first step in establishing a comprehensive publicly funded long term care program, but it is a strong beginning. The over $38 billion per year in new federal funding for long term care at full phase-in is a significant improvement over the limited, means tested long term supports currently available to Americans with disabilities. In addition, the extensive new federal funding for long term care is expected to free up resources so that states and localities can expand and improve long term supports for people who do not qualify for the new program, but nonetheless experience significant disabilities.

Second, the new children's program will supplement Alliance coverage for low income children. This program covers therapies, hearing aids, dental services, transportation, and similar services not included in the comprehensive acute care benefit package.

Also, the Maternal and Child Health Block Grant and its component for children with special health care needs will continue in its mission of assuring family centered community-based coordinated systems of care. States will continue to be able to use these funds to compliment services available through the guaranteed benefit package.

Finally, of course, children with disabilities continue to have the guarantee of free appropriate public education, including related services, under the Individuals with Disabilities Education Act. As is currently the case, it is expected that various educationally related rehabilitation services will be covered under this program.

I hope this information is helpful. The Department will continue to work together with the March of Dimes to assure the best possible benefit for all children in the final legislation.

Sincerely,

Donna E. Shalala

February 2, 1994

MEMORANDUM FOR HILLARY RODHAM CLINTON

FROM: LYNN MARGHERIO

SUBJECT: CHILDREN'S HOSPITAL OF PHILADELPHIA

SEQUENCE

Introductory Remarks:

Edmond Notebaert, President, CEO, Children's Hospital of Philadelphia

Lawrence A. McAndrews, President, National Association of Children's Hospitals and Related Institutions

C. Everett Koop

You speak for 20–25 minutes

Q&A

Closing:

John M. O'Donnell, Ph.D., Executive Director, the College of Physicians of Philadelphia

BACKGROUND

2000+ physicians (pediatricians plus a mix of other physicians) will comprise the audience.

A physician audience, their overriding concerns are preservation of choice and physician autonomy.

As pediatricians, they have more specific concerns.

- Children will be disadvantaged under a system of managed competition.

- Special needs children - - including those with chronic illnesses - - will not get adequate services due to limitations in the guaranteed benefits package.

  We cover some of these children through the Medicaid wrap-around program and through the home and community-based long-term care program. There will be those that slip through the cracks, however, as our benefit is limited to post-acute care therapy and therapy that improves or restores function.

We would recommend addressing these concerns upfront in your opening remarks. Hopefully, that will limit questions about this issue in the Q&A session.

Note: Dr. Sue (Sue Aronson - wife of Gerald Aronson, President of the local AAP chapter) will be there. You and she were on a trip to France together in 1989.

OUTLINE OF REMARKS

I. Acknowledgements

The prime cosponsors are the Children's Hospital of Philadelphia and the Philadelphia College of Physicians.

The following organizations also cosponsored the event: **American Academy of Pediatrics**, the Coalition of Black Pediatricians of Greater Philadelphia, Medical Society of Eastern Pennsylvania, National Association of Children's Hospitals and Related Institutions, Inc, the Philadelphia County Osteopathic Medical Society, Philadelphia Pediatric Society.

II. Children under current health care system

Too often today, children are the victim of what's wrong with our health care system.

- Over 8 million children are currently uninsured. 17 million are uninsured for part or all of the year.
- Preexisting condition exclusions discriminate against children with disabilities.
- One in five American children had no contact with a doctor in 1992.
- Thirty percent of all children under the age of two, and 50 percent of inner-city children, have not been immunized against preventable childhood disease.
- Fewer than half of non-HMO members receive routine preventive services.
- Even in the best-selling HMO packages, over 50% require cost sharing for well baby/well child care.
- Many insurance companies today use preexisting clauses to avoid prenatal care coverage.
- 19 million children on Medicaid face the prospect of seeing benefits deeply eroded because of state fiscal problems.

III. Children under reform

A. Comprehensive Benefits for Children

First, by outlawing preexisting condition exclusions and by guaranteeing community rating, the President's proposal will guarantee that all children, including those with birth defects, have access to affordable, health insurance and to a full range of acute care medical services, regardless of their medical condition. The families of children with disabilities will no longer face the threat of losing everything they have in their attempts to purchase and retain access to affordable, quality health care.

Under the President's proposal, every child will have a "medical home". The benefits package provides coverage for ongoing, continuous care, from preventive care (including well-baby and prenatal care, routine doctors' visits, TB tests, immunizations) through acute care and rehabilitation services.

B. Children with special needs

I know that ensuring access to care for children with chronic illness and disabilities is an area that many of you are concerned about.

Under the Health Security Act, families of children with disabilities will no longer be denied health coverage, or charged exorbitant insurance premiums, or locked into jobs for fear of losing their health coverage, or denied renewal just when they need health care the most.

Second, the President has proposed an excellent comprehensive benefit package that includes a wide range of services including physician, hospital, laboratory, prescription drugs, and preventive services. In addition, the benefit package includes acute care related outpatient rehabilitation services, extended care services and home health care services. In devising this benefit, we have tried to be consistent with typical insurance policies in today's marketplace. These insurance policies have traditionawlly place limites on these benefits or related them to acute illness or injury.

Any child born with a birth defect that requires surgery or any other professional services will have full coverage for these services **and** will be covered for any necessary rehabilitation that may be necessary following these services.

Nonetheless, we know that the comprehensive benefit package will not meet all of the long-term support needs for some children. To help address this, two new programs have been proposed:

- A major new expansion in community–based long–term care that provides a range of community supports to people with disabilities.

- A new federal program for poor children which will include Medicaid services that are not included in the comprehensive benefit package.

The over $38 billion per year in new federal funding for long term care at full phase in is a significant improvement over the limited, means tested long term supports currently available to Americans with disabilities.

Also, the Maternal and Child Health Block Grant and its component for children with special health care needs will continue in its mission of assuring family centered community–based coordinated systems of care. States will continue to be able to use these funds to complement services available through the guaranteed benefit package.

QUESTIONS FROM DR. C. EVERETT KOOP

1. *Will the American Health Securities Act legislation require that services for children with disabilities and special health care needs use the comprehensive, community based, family centered approach? What if the child is covered by Medicaid?*

The Health Security Act promotes comprehensive and accessible health care for all Americans, including children with disabilities and special health care needs. The Act includes several provisions to ensure that a choice of care arrangements are available at the community level for all individuals. In addition, a well designed quality system based on health plan monitoring using standardized performance indicators will assure that all populations receive quality care. For children with special health care needs, the research clearly shows that quality care means family centered, coordinated and community based approaches. By providing families with report cards on plan performance at the time of annual enrollment, the Act also recognizes the important role that families play in decisions surrounding their children's health care.

Children who are currently eligible for Medicaid services will receive most of their services through an alliance health plan providing the comprehensive benefit package. Additional services will also be provided in a new Federal program of "wrap around" services to address any other needs that they may have. This new program will have national standards developed to assure uniform benefits for children and will be coordinated with other programs for children including parts B and H of the Individuals with Disabilities Education Act.

2. *State Maternal and Child Health programs also have responsibility for creating and managing such programs. Will these state maternal and child programs continue to perform this function under the American Health Security Act?*

The Title V mandates for family centered, community based, coordinated systems of care for children with special health care needs established in 1989 are ones that this administration fully supports. The Health Security Act does not change this legislative directive, however as universal coverage is phased in, the role of State Maternal and Child Health Programs will change. Resources currently expended on the actual provision or purchase of direct medical services will no longer be necessary to the extent that these services will be covered under the comprehensive benefit package. Therefore, State programs will be freed up to focus even more on the assessment, planning,

evaluation, and assurance functions for which they are responsible. This will allow them to be even more effective at assuring that systems of care are developed that do respond to the needs of children with special health care needs and their families.

3. *Sadly, about 15% of America's children have a chronic health problem, while as many as 2% have disabilities or special health care needs that severely restrict their ability to function in school and family settings. Can the families of these children be assured that in the future their children will receive at least the same level of services under the American Health Security Act? What process will families use to gain access to these services? Will there be one comprehensive plan for children with special health care needs, or will they be split into subgroups according to family income, diagnosis or severity of their problems? If there are such subgroups, what process will families use to move into the right group and perhaps move to another group according to need, and who controls that process?*

For the first time, the Health Security Act will assure that all children, including children with special health care needs regardless of their income, diagnosis, or severity, have access to affordable and guaranteed coverage for a comprehensive set of benefits. The current patchwork of coverage for families with disabled children will be streamlined into a uniform package for all children backed up by the continuation and coordination of other existing federal programs, including the Title V program and Parts H and B of IDEA. Currently, disabled children are twice as likely to be publicly insured as non-disabled children and nearly 500,000 disabled children are uninsured. When disabled children do have private health insurance they are more likely to see the cost of that coverage increase or have the scope of benefits reduced over time. The Health Security Act guarantees renewal of a consistent set of benefits regardless of health status, income, or attachment to the workforce.

To gain access to the provider of their choice, families will choose each year which health plan provides services in the way that best meets their needs. These options include a managed care type of plan, a PPO type of plan, and a fee for service plan. Whichever plan they choose, they will have access to all the benefits in the comprehensive package and will be protected from high medical expenses by annual limits on out of pocket costs.

Recognizing that children with special health care needs often require specialty services, the Act also requires that health plans contract with sufficient academic health centers to provide access to their specialty services. In addition, children's hospitals may apply for and be designated as essential

community providers for certain services which they provide. This designation would then require health plans providing services in that area to establish agreements for services with them.

In addition, the Health Security Act significantly expands the availability of long term care services for severely disabled children. Eligibility for this program will be uniform across states while services to be offered will be determined by states to assure appropriate tailoring of this program to community needs. Representatives of the disability community will be involved at each step of the of this state based, federally matched program.

5. *Title V of the Social Security Act provides the current safety net for maternal and child health. For optimum care of children in the future as well as for a system to provide accountability for maternal and child health, there has to be some comprehensive coordination of the provision of Title V and the Health Security Act. Those interested in comprehensive maternal and child health believe that such melding should include mandates and authorities to carry out four major roles -- each complimentary to the others.*

a) *the promotion of health of all women of reproductive age, children, and adolescents by carrying out population based public health functions.*

b) *supporting the comprehensive community based family centered systems I just mentioned, but including school based health programs.*

c) *providing coordination of care for special needs children and administer wrap around and long term care services which are financed separately from the basic benefits package.*

d) *enabling access for underserved maternal and child populations and to uncovered maternal and child health services.*

What plans does the Administration have to integrate the provisions of Title V and the Health Security Act?

The Health Security Act will provide the opportunity to "re-invent" public health and public health agencies at both the Federal and State levels. Universal coverage and a comprehensive benefit package will free up many public agencies to focus anew on the core functions of public health and the mandates for public health established through its Federal legislative base, including Title V. In addition, new funds and programs will further develop the ability of public and private non-profit organizations and schools to reach out to those most in

need who may require additional assistance in gaining access to the benefits they are entitled to. In this setting, Title V agencies at the State and Federal level will play an important role in the assurance and monitoring of the functioning and quality of this new system. States will be responsible for certifying plans on the basis of quality as well as monitoring and assuring access to services. Performance indicators for health plans to be developed by the National Health Board will serve to monitor quality to all populations, including children. Therefore Title V agencies can play an important role in assuring that these indicators will appropriately reflect the needs of children.

In addition, the Health Security Act establishes a provision to designate certain health providers as "essential community providers" to assure their eventual integration into a seamless health care system. This provision requires that health plans establish contracts with numerous recipients of Federal funds, including all recipients of Title V dollars (Title I, Subtitle F, page 294). By assuring the establishment of relationships between historical community providers with expertise in serving special populations and accountable health plans, this provision will promote the integration of Title V providers and populations into the health care system and promote coordination of care.

Finally, the Health Security Act establishes a new Federal program of support services for low income children with specific direction to coordinate services in this program with not only Title V, but services provided under parts B and H of the Individual with Disabilities Education Act, and other programs providing health and social services (Title IV, Subtitle C, page 822).

6. *Currently, Medicaid patients account for 44% of total patient days in children's hospitals nationwide. yet Medicaid pays children's hospitals on average less than 84 cents per child in spite of the improvements that have been made in Medicaid payments to disproportionate share providers. The President's plan calls for community based clinics serving low income people to be labeled essential providers. What can be done to assure that the concept of essential providers be extended to inpatient care as well as primary and ambulatory care? This is of special concern as we attempt to sustain a fragile health safety net for low income people during the transition to an increasingly competitive market.*

First, the Health Security Act will eliminate the burden of lower payments to providers, including hospitals, for publicly insured individuals. Once enrolled in an alliance health plan, low income individuals will be integrated into a single tier system of care for services covered in the comprehensive benefit package. Second, the Act's provision for essential community provider designation does

allow for hospital inpatient services to be covered in this designation. Institutional providers who are located in an underserved area or who provide services to a medically underserved populations are eligible for designation (Title I, Subtitle F, page 297). In addition, the Secretary of Health and Human Services will develop standards for additional designation if required to assure that health plans provide access to the full range of services in the benefits package.

7. *The President's proposed lowest cost sharing option has a mandatory $10 copayment per visit which includes physicians and therapists. Do you have any plans to subsidize low income families who would not be able to meet their copayment requirements and therefore, delay seeking prompt and necessary care?*

The Health Security Act includes specific provisions to assure the affordability of health services for low income individuals (Sec. 1371, page 183). First, all AFDC and SSI assisted families will have their copayments reduced to 20% of the normal cost sharing in lower cost sharing plans. In other words, a $2 copayment on office visits and a $1 copayment for prescriptions. In addition, for low income families (less than 150% of poverty) in areas where there are no lower cost sharing plans available, additional subsidies are available to bring cost sharing down to the levels of the lower cost sharing plan.

QUESTIONS AND ANSWERS
C. EVERETT KOOP (Cont.)

Q: Will children with congenital problems be eligible for the therapeutic, assistive technology, and habilitative services that they desperately need even if the services only maintain limited function and the child's status could not be said to be "improving"?

A: Under the Health Security Act, families of children with disabilities will no longer be denied health coverage, or charged exorbitant insurance premiums, or locked into jobs for fear of losing their health coverage, or denied renewal just when they need health care the most.

The President has proposed an excellent comprehensive benefit package that includes a wide range of services including physician, hospital, laboratory, prescription drugs, and preventive services. In addition, the benefit package includes acute care related outpatient rehabilitation services, extended care services and home health care services. In devising this benefit, we have tried to be consistent with typical insurance policies in today's marketplace. These insurance policies have traditionallly placed limits on these benefits or related them to acute illness or injury.

Any child born with a birth defect that requires surgery or any other professional services will have full coverage for these services **and** will be covered for any necessary rehabilitation that may be necessary following these services.

Nonetheless, we know that the comprehensive benefit package will not meet all of the long-term support needs for some children. To help address this, two new programs have been proposed:

- A major new expansion in community-based long-term care that provides a range of community supports to people with disabilities.

- A new federal program for poor children which will include Medicaid services that are not included in the comprehensive benefit package.

The over $38 billion per year in new federal funding for long term care at full phase in is a significant improvement over the limited, means tested long term supports currently available to Americans with disabilities.

QUESTIONS AND ANSWERS
CHILDREN'S HOSPITAL OF PHILADELPHIA

1. *Children's Hospital handles an enormous amount of Medicaid patients. Will the essential community provider designation affect this?*

First, the significant economic burden that providing services to Medicaid patients currently entails due to low reimbursement rates will be removed by the Health Security Act. Services provided to all individuals with a Health Security Card will be reimbursed independent of their income status.

Second, should Children's Hospital apply for and be designated as an essential community provider, they would have the opportunity to negotiate with health plans to either establish a provider participation agreement with terms and conditions "at least as favorable as those that are applicable to other providers participating in the health plan" or a written agreement for reimbursement of services based either on the fee schedule developed by the State or applicable regional alliance or using payment methodologies and rates similar to Medicare and specified by the Secretary of Health and Human Services (Title I, Subtitle E, page 250).

2. *What will be children's hospitals' role as essential providers?*

see above.

3. *What will be children's hospitals' role as essential providers?*

The Secretary of Health and Human Services will publish standards for the certification of additional categories of health care providers and organizations beyond those listed in the bill as essential community providers. A provider may be designated as essential under these standards if it is determined that health plans operating in the area served by the applicant would not otherwise be able to assure adequate access to the comprehensive benefit package without such certification. In addition, all public and private non-profit organizations who provide services to medically underserved populations or are located in underserved areas are eligible to apply for designation as "essential community providers". Therefore, childrens' hospitals that provide essential services have the opportunity to apply for and be designated as essential providers and have health plans required to contract with them.

4. *How will children with chronic illnesses be treated?*

The Health Security Act promotes comprehensive and accessible health care for all Americans, including children with chronic illnesses. The Act includes several provisions to ensure that a choice of care arrangements are available at the community level for all individuals. In addition, a well designed quality system based on health plan monitoring using standardized performance indicators will assure that all populations receive quality care. For children with chronic illnesses, the research clearly shows that quality care means family centered, coordinated and community based approaches. By providing families with report cards on plan performance at the time of annual enrollment, the Act also recognizes the important role that families play in decisions surrounding their children's health care.

Children with chronic illnesses who are currently eligible for Medicaid services will receive most of their services through an alliance health plan providing the comprehensive benefit package. Additional services will also be provided in a new Federal program of "wrap around" services to address any other needs that they may have. This new program will have national standards developed to assure uniform benefits for children and will be coordinated with other programs for children including parts B and H of the Individuals with Disabilities Education Act.

QUESTIONS AND ANSWERS
CHILDREN'S HOSPITAL OF PHILADELPHIA (cont.)

Q: What will be the role of poison control centers? (They feel strongly that poison control centers are a major preventive service. Theirs handled 35,000 calls last year. Georgetown Hospital's poison control center that serves all of DC is closing due to a lack of funding. And, in the past year, 28 centers across the country have closed. These centers are funded by state grants and private funding.)

A: Poison control activities are an excellent example of population-based public health. In addition to providing assistance and referral services, they also provide technical assistance to providers treating poisoned individuals. We will be increasing funding for core public health functions, which would include poison control activities.

In addition, as states benefit from the savings they will achieve under reform, they will have greater flexibility to target more of these funds into poison control centers.

QUESTIONS AND ANSWERS
AMERICAN ACADEMY OF PEDIATRICS - PENNSYLVANIA CHAPTER

1. Why should we believe that the needs of children and those who serve children will be adequately addressed when Congress marks up the Health Security Act?

In the current system, children are too often the victims of what doesn't work. Children with preexisting conditions get dropped from coverage. About 9 million children are currently uninsured. One in five American children had no contact with a doctor in 1992. I could go on with these kinds of appalling statistics. But, the important thing is not to simply identify what's wrong and shrug our shoulders, it's **fixing** what's wrong.

The President's approach goes further than any other bill to ensure that children have access to high-quality care at affordable prices. We'll work with the you and the Congress to make sure that health reform ensures that kids get a fair shake in health care. That the discrimination ends.

2. Pediatricians lack trust in the "sharks" who manage the insurance companies, and the politicians and bureaucrats in our state capital.

Pennsylvania Blue Shield recently announced a 25% decrease in the insurance reimbursement for immunization - - the most cost effective preventive care service. This action threatens attempts to increase immunization of children in their "medical home" and is inconsistent with national efforts to improve children's immunization status.

Pennsylvania pediatricians are suing the Pennsylvania Department of Public Welfare because of 1) their persistent failure to enroll eligible children into Medicaid; 2) their persistent failure to provide them the EPSDT services that Congress mandated; 3) their failure to comply with OBRA 89 comparability requirements for physician reimbursement.

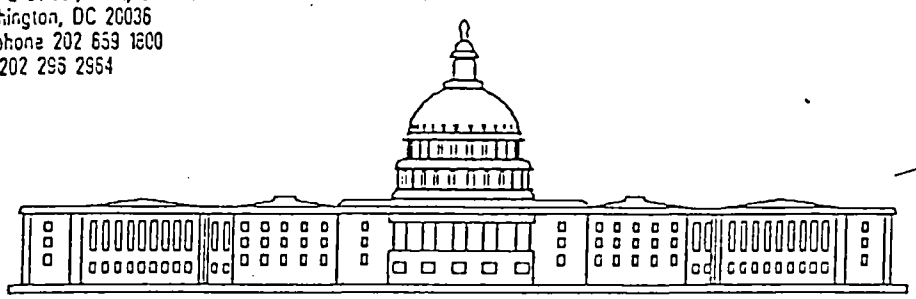
Finally, while 10% of Pennsylvania children are uninsured, neither the public Medicaid program nor the state subsidized, private Child Health Insurance Program for uninsured children have demonstrated success in locating and enrolling eligible children into their programs.

What will the Health Security Act do to address these things?

1) With respect to negotiations between providers and insurers under reform, the bill takes specific steps to increase the negotiating power for providers by through eliminating antitrust restrictions. We would encourage hospitals and other providers to join together to form their own community-based plans where you set the rules and you make the decisions.

2) Under reform, we are creating a single-tier system to replace the two-tier system we have in place - - where people with private insurance have better access to providers and where too often low-income individuals either do not get services or have a difficult time finding services due to low reimbursement rates. Children today who have to depend on Medicaid won't have to rely on the program except for residual services. The Medicaid program goes away for all practical purposes. Chidlren who are poor will have exactly the same insurance as middle-income and will have virtually all of their copayments paid. And providers will receive the same amount for a patient in a health plan, regardless of whether that patient is Medicaid or a private-paying patient.

March of Dimes
Birth Defects Foundation
National Government Affairs Office
1901 L Street, N.W., Suite 260
Washington, DC 20036
Telephone 202 659 1800
Fax 202 296 2964



March of Dimes

Office of Government Affairs

Date: 2/28/94

Pages (Including cover sheet): 10

Our Fax #: 202-296-2964

Our phone #: 202-659-1800

From: Kay Johnson & Vivian Gabor

To: The following people:

Fax #:

Polly Arango
Julie Beckett
Allan Bergman
Eve Brooks
Harriet Fox
Bob Griss
Gregg Haifley
Neal Halfon
Kathy Hess
Susan Campbell
Ann Langley
Kathy McGinley / Marty Ford
Peggy McManus
Christine Metzler
Katie Neas
Paul Newacheck
Jackie Noyes
Graham Newson
Steve White
Peters Wilson
Sara Rosenbaum/ Liz Wehr

Thanks for your comments.

SECOND DRAFT LETTER

PLEASE CALL TODAY IF POSSIBLE — DEADLINE NOON TUESDAY MARCH 1.

Kay

COVER LETTER DRAFT #2
February 28, 1994

Addressed to staff: Rep. Waxman (Andy Schneider), Stark (Trish Neuman), Sen. Kennedy (Deborah Von Zinkernagel), Harkin (Bobby Silverstein), Dodd (Susan Levinson), Moynihan (Karen Hein), Reigle (Debbie Chang).
Modified letter for Chafee (Christine Ferguson) attached

As groups concerned about the health of children, we are writing to share our views on how to construct a comprehensive benefit for children in the Health Security Act. As you know, we strongly believe that the benefit package for children should be as comprehensive as possible, and our groups are working toward that goal. We also believe that the EPSDT services package now provided to low-income children under Medicaid is a good model for benefits for all children. However, to the extent that our efforts fail to ensure comprehensive benefits for children in the basic package, a supplement package should be developed.

The attached legislative specifications represent our best thinking to date on this issue. Hopefully, these specifications can shape your thinking as you prepare to mark up a bill. We recognize that Congressional deliberations on health care reform are moving ahead quickly.

These specifications are a repackaging of the Health Security Act provisions for children with special needs not covered in the core benefit package. We have developed the specifications for a new program, with a focus on special needs, in addition to the acute care benefits now in Title I. Our proposal would join the additional coverage for children now included in Titles II and IV to create one supplemental benefits package for all children. This new configuration for a "wrap-around" package would fill in the gaps left by dividing children's acute from long-term care or by isolating poor children.

The program would provide those "medically necessary or appropriate" services needed by children that are not covered in the Title I benefit plan. It also would designate a state agency to coordinate child health services.

We believe that this is affordable -- using the federal funds for child health in Titles II and IV combined with state and family contributions. Studies show that while about 15 percent of all children have special health needs, only 1-3 percent need intensive services. Some children need only low cost benefits such as care coordination.

This proposal is being circulated to others, in hopes of building broad support. In the meantime, we would like to meet with you to discuss the substance and political prospects for enacting a supplemental benefit for all children. If you have questions, please do not hesitate to call Gregg Haifley at the Children's Defense Fund, Julie Beckett at Family Voices, or Cathy Hess at the Association of Maternal and Child Health Programs.

note>

modified for Christine Ferguson, Office of Senator Chafee

As groups concerned about the health of children, we are writing to share our views on how to construct a comprehensive benefit for children in the process of health care reform. As you know, we strongly believe that the benefit package for children should be as comprehensive as possible, and our groups are working toward that goal. We also believe that the EPSDT services package now provided to low-income children under Medicaid is a good model for benefits for all children. However, to the extent that our efforts fail to ensure comprehensive benefits for children in the basic package, a supplement package should be developed.

The attached legislative specifications represent our best thinking to date on this issue. Hopefully, these specifications can shape your thinking as you prepare to mark up a bill. We recognize that Congressional deliberations on health care reform are moving ahead quickly.

While we recognize that S.1770 outlines, rather than defines, a core benefits package, we thought you might like to see this a repackaging of the Health Security Act provisions for children with special needs. Given your long-standing interest in this population and your experience in constructing legislative solutions to meet special health needs, we are eager to hear how our vision (here applied to the Health Security Act) might fit with that of S. 1770.

These specifications for a new program focus on special needs, to wrap-around the acute care benefits now in Title I of the Clinton bill. Our proposal would join the additional coverage for children now included in Titles II and IV to create one supplemental benefits package for all children. This new configuration for a "wrap-around" package would fill in the gaps left by dividing children's acute from long-term care or by isolating poor children.

The program would provide those "medically necessary or appropriate" services needed by children that are not covered in the Title I benefit plan. It also would designate a state agency to coordinate child health services.

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This proposal is being circulated to others, in hopes of building broad support. In the meantime, we would like to meet with you to discuss the substance and political prospects for enacting a supplemental benefit for all children. If you have questions, please do not hesitate to call Gregg Haifley at the Children's Defense Fund, Julie Beckett at Family Voices, or Cathy Hess at the Association of Maternal and Child Health Programs.

DRAFT
Sincerely,

American Academy of Pediatrics
American Occupational Therapy Association
American Speech-Language-Hearing Association
Association of Maternal and Child Health Programs
Children's Defense Fund
Children Now
Family Voices
March of Dimes Birth Defects Foundation
National Association of Child Advocates
National Association of Children's Hospitals and Related Institutions
United Cerebral Palsy Associations

SPECIFICATIONS FOR A SUPPLEMENTAL CHILDREN'S PROGRAM AMENDMENT 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 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.

1. **Overall drafting structure**: A new Part under Title II, Subtitle B, of the Health Security Act. The program would consolidate into one supplemental (wrap-around) benefit for children the following provisions of the Health Security Act:

- the pediatric provisions of Medicaid (Title IV), including both the federal/state "long-term care" benefits under § 4221 and the new children's wrap around under § 4222; and

- the pediatric component of the Title II long-term care program.

2. **Purposes**

(1) to provide coverage for health and related services not covered under the guaranteed benefit package that are used by children with 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 multi-specialty institutions 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 remedial care and 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.

4. **Financing**: Federal-state financing plus family contributions through cost sharing based on family income (as defined below, item 5).

(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:

- o § 4221 (long term care and other benefits)
- o § 4222 (wrap-around benefits for poor children)

(2) Reallocated funds from the long-term care block grant; and

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

Assumptions for cost-estimates:

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

5. **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.

6. **Eligibility:** Children under age 21 with a need for medically necessary items and services not covered in the comprehensive benefit package.

The target population would include, but not be limited to, children who:

- o Receive or qualification for SSI on the basis of disability;
- o Receive services for children with special health care needs under the Title V Maternal and Child Health Services Block Grant;
- o Receive services through Parts B or H of the IDEA, with need for related services;
- o Receive services through state child welfare programs under Title IV B or E of the Social Security Act;
- o Meet current Medicaid eligibility standards.

7. **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.

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.

8. **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 agencies, state mental health agencies, state special education agencies, state 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.

9. Provider reimbursement:

- o fee schedule negotiated by state agency with providers, in accordance with statewide alliance fee schedule as developed for children with special needs.
- o special all-inclusive capitation payments for overall care and management.
- o Secretary to develop standards for global and fee-based payments.

11. Administration:

- o By state agency with expertise in care and management of children with special needs;
- o Federal-State match for both medical and administrative costs.
- o 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.

February 1994

BACKGROUND ON SUPPLEMENTAL SERVICES PROGRAM FOR CHILDREN WITH SPECIAL NEEDS

Children need comprehensive coverage. Health care reform should include a comprehensive benefit package for children that would guarantee coverage for the full range of services needed to address the physical, developmental, and mental health conditions. The effectiveness and cost-effectiveness of child health interventions has been well documented -- from immunizations through early intervention to reduce disability. For children with special needs, medically necessary and appropriate services can open the door to a fuller and more productive life. Preventing disability and fostering development are important goals of health care for children.

The Health Security Act leaves gaps in child health coverage. The Health Security Act includes provisions related to children's coverage in Title I (basic benefits), Title II (long-term care), and Title IV (wrap-around benefits for Medicaid eligible). These two component leave gaps for children, especially those with special needs. For example, the long-term care benefits are better suited to adults than children, and many non-Medicaid, near-poor children need supplemental coverage for services to limit developmental disabilities.

Children with special health needs are a relatively small proportion of the total population. An estimated 15% of children have some special health needs, but only 1-3 percent need intensive services. Estimates of the number of children with special needs show that:

- o 15% (nearly 10 million) of all children have some chronic health impairment.
- o About 6% (4 million) of all children have a limitation of usual childhood activities.
- o 3% (2 million) of children have a disability severe enough to meet federal disability guidelines;
- o About 1% (about 700,000) have both a disability and a low income that qualifies them for Supplemental Security Income (SSI). [1]

The additional cost of a supplemental program for children with special needs will not be large. Most of the services needs of children will be met through the benefits package in Title I. In fact, with some modification, a comprehensive child health benefits package could be structured in Title I. However, if a supplemental approach is used, Title I still would provide for hospital and physician services, as well as some coverage for prescribed drugs, mental health, and rehabilitation services. National data show that while disabled children's health expenditures are three times higher than those of non-

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[1] Newacheck, Hughes, McManus, Perrin, Valdez, and Fox. *Meeting Children's Long Term Care Needs Under the Health Security Act's Home and Community Based Services Program,* January 1994.

disabled children, 80% of this difference is accounted for by their higher use of hospital care, physician services, and prescribed medications. Another reason that costs for a supplemental program would be low is that the Health Security Act provides wrap-around coverage for low income children eligible for Medicaid. The added costs of extending coverage for children above poverty will be proportionately lower because the non-poor children are less likely to have a disability. For example, in 1992 the rate of disability among children in families with incomes above $35,000 was less than half that for children in families with incomes below $10,000. [2]

A supplemental benefit administered by a child health agency is needed. There is need for a supplemental benefit for children with special needs regardless of age or incomes. In addition, building on existing federal-state programs (e.g. Title V MCH Block Grant, IDEA-Part H Early Intervention, and Medicaid waivers), a program is needed to develop systems of care to ensure quality, continuity, and coordination between multiple payers and providers. Such a program would support the role of families of children with special needs.

Financing through Federal and State funds. Currently, Federal and State dollars are used to finance programs for children with special health needs through IDEA, MCH Block Grant, Medicaid, and SSI. Under the Health Security Act's home and community-based services program (Title II) will require Federal-State matching similar to Medicaid, only with a generally higher Federal contribution. The Medicaid wrap-around program (Title IV, § 4221) is 100% federally funded. The proposed supplemental program would require a match from states on both services and administration. Federal funds would come from general revenues, from a portion of the funds now in the Health Security Act's Title II long-term care program, current federal Medicaid spending, and from the surcharge on regional and corporate alliances (similar to the funds set aside for the academic health center account).

Administration by a lead state agency. There are several types of state agencies that currently administer programs for children with special needs. State maternal and child health agencies across the country have managed such programs for over 50 years, changing program style to fit the evolving health delivery system. Other state agencies administer programs for person with disabilities, Medicaid waiver programs, and IDEA-Part H programs. Under the Health Security Act, states will have responsibility for establishment and oversight of health alliances, as well as for home and community-based services, public health, and enabling services. New state agencies may emerge under a reformed health system. Under this supplemental program, states select an appropriate lead agency that would have responsibility to: provide coverage for supplemental services; monitor and assess quality of all services provided to children with special needs; and develop systems of care appropriate for children with special needs, including provider certification and care coordination.

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[2] Paul Newacheck. Institute for Health Policy Studies. Unpublished analysis. 1994.

EPSDT

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Bill is not a mistake

1/7 revised

Avoid Red. in Service

- Child < 18 1 of 4 exempted from 4221. Exemption represented ——
- Financed through §1934 4222.

Consortium for Citizens with Disabilities

The Consortium for Citizens with Disabilities Health Task Force is a coalition of over 65 national organizations working to enact comprehensive health care reform that will meet the needs of persons with disabilities and chronic illnesses, and their families.

TESTIMONY ON BEHALF OF

THE CONSORTIUM FOR CITIZENS WITH DISABILITIES

HEALTH TASK FORCE

Presented by

Janet O'Keeffe, Dr.P.H., R.N.
Co-Chair of the CCD Health Task Force
Assistant Director for Public Interest Policy
American Psychological Association

RESPECTFULLY SUBMITTED TO

THE SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES

FEBRUARY 11, 1994

ON BEHALF OF:

Aids Action Council
American Academy of Physical Medicine and Rehabilitation
American Association on Mental Retardation
American Association for Respiratory Care
American Association of University Affiliated Programs for Persons with Developmental Disabilities
American Congress of Rehabilitation Medicine
American Network of Community Options and Resources
American Occupational Therapy Association
American Psychological Association
American Speech-Language-Hearing Association
American State of the Art Prosthetic Association
Amputee Coalition of America
Association of Academic Physiatrists
Association of Maternal and Child Health Programs
Bazelon Center for Mental Health Law
Center on Disability and Health
Council for Exceptional Children
Epilepsy Foundation of America

Continued.....

Federation of Families for Children's Mental Health
International Association of Psychosocial Rehabilitation Centers
Joseph P. Kennedy, Jr. Foundation
Learning Disabilities Association of America
National Association of Developmental Disabilities Councils
National Association of Medical Equipment Services
National Association of Protection and Advocacy Systems
National Association of School Psychologists
National Association of the Deaf
National Center for Learning Disabilities
National Community Mental Healthcare Council
National Consortium for Physical Education and Recreation for Individuals with Disabilities
National Council on Independent Living
National Easter Seal Society
National Head Injury Foundation
National Mental Health Association
National Multiple Sclerosis Society
National Spinal Cord Injury
National Rehabilitation Association
National Transplant Support Network
NISH - Creating Employment Opportunities for People with Severe Disabilities
Research Institute for Independent Living
RESNA - An Interdisciplinary Association for the Advancement of Rehabilitation and Assistive Technologies
Spina Bifida Association of America
Task Force for Health Care Parity for the Environmentally Ill
The Arc
United Cerebral Palsy Associations, Inc.

For additional information, please contact
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The Consortium for Citizens with Disabilities (CCD) is a working coalition of over 100 national consumer, advocacy, provider and professional organizations, which advocates on behalf of people of all ages with physical and mental disabilities and their families. Since 1973, CCD has advocated for federal legislation, regulations, and funding to benefit people with disabilities. This testimony is presented on behalf of the undersigned members of CCD.

People with disabilities include individuals with physical and mental impairments, conditions or disorders, and people with acute or chronic illnesses, which impair their ability to function. The 49 million Americans with disabilities have an enormous stake in the current health care reform debate. Lack of adequate health care coverage is a crucial issue for many persons with disabilities and chronic illnesses, who have experienced first hand the myriad problems with the current system.

The U.S. health care system provides high quality care, but it is overly expensive, often wasteful, and does not assure adequate health care coverage for all Americans. Escalating and uncontrolled costs make insurance unaffordable for an increasing number of Americans, and discriminatory practices by insurance companies exclude millions more Americans who need health care. Current health insurance is also biased towards acute care and fails to cover necessary services for persons with chronic illnesses and conditions. For many persons with disabilities, lack of access to comprehensive health care undermines the promise of the Americans with Disabilities Act for inclusion, independence and empowerment.

Persons with disabilities and chronic illnesses are disproportionately represented among both the uninsured and the under-insured in the current system of private health insurance. As it operates today, the U.S. health insurance system fails persons with disabilities and chronic conditions in fundamental ways:

- It excludes many persons with disabilities and chronic conditions as "medically uninsurable" or offers them insurance only with pre-existing condition exclusions. In a recent Census Bureau survey, 43 percent of persons with severe disabilities reported that they did not have private health insurance.

- It often charges prohibitive rates to persons with ongoing health needs, making insurance unaffordable for many.

- It does not pay for many necessary health-related services, including adequate rehabilitation, assistive technology, and long-term services and supports.

- It places annual and life-time limits on health care services.

- If often fails to provide protection against catastrophic health care costs.

- It allows insurers to terminate insurance coverage when a person becomes ill.

For all these reasons, CCD strongly endorses the need for far-reaching and comprehensive reform of the American health care system.

When evaluating the adequacy of a health system reform proposal, whether the needs of persons with disabilities and chronic illnesses are met is an essential litmus test. It is our strong belief that a health care system that meets the needs of persons with disabilities and chronic illnesses will meet the needs of all Americans.

We are here today to share with you our evaluation of the Health Security Act (HSA). To begin, we strongly commend President Clinton for introducing this legislation and for committing his Administration to ensuring comprehensive, affordable health coverage for every American. We also strongly support the Administration's proposal to expand home and community-based long-term services and supports for individuals with severe disabilities and commend him for recognizing the importance of including long-term services and supports as part of his health care reform effort.

POSITIVE FEATURES OF THE HEALTH SECURITY ACT

There are many positive features in the Health Security Act that address issues of concern to persons with disabilities. These features must be retained in any health reform legislation enacted by Congress. Legislative proposals that do not include these features do not constitute reform and will be vigorously opposed by the disability community. These fundamental features and the positive ways HSA addresses them are:

Universal Coverage. All legal residents of the United States will be covered by 1998 and health care coverage will not be dependent upon employment status, age, health, disability, or ability to pay.

Non-Discrimination. Federal civil rights laws, including Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act, will govern all parts of the health care system, including health alliances, health plans, the National Health Board, and providers. These laws will provide important protections for persons with disabilities, including assurances that negative assumptions regarding the quality of life of individuals with disabilities will not be used to make determinations about the medical necessity and appropriateness of services. These protections are critical for persons with disabilities and must be retained in any health care reform legislation passed by the Congress.

Elimination of Pre-Existing Condition Exclusions. No one will be denied coverage for any health problem.

Equitable Financing and Mechanisms to Spread Risk as Broadly as Possible.

- **Mandatory community rating.** Community rating is the cornerstone of equitable financing. It eliminates the exorbitant premiums that people with disabilities and chronic illnesses have been forced to pay for inadequate coverage. Community rating will also help to increase employment opportunities and ensure retention of employees with disabilities. Currently, many employers are unable to afford or obtain health insurance for employees who have a disability, or who have a family member with a disability or chronic illness. This situation discourages the employment of persons with disabilities.

- **Mandatory Health Alliances.** Community rating in a multi-payer system requires that risk pools be structured to spread the costs of heath care as broadly as possible. Therefore, we strongly support the requirement that all employers with fewer than 5000 employees be required to participate in the alliance. Without this level of participation, the risk and costs of health care will not be spread widely enough. Regional health alliances will enable small and medium size employers, the self-employed, and for-profit and non-profit organizations that employ people with disabilities, to benefit from the negotiating power of a large pool to obtain affordable, comprehensive coverage for their employees.

  Exclusive, mandatory health alliances will require all residents in a geographic area to enroll in health plans offered through the alliance. This will assure portability of coverage. In our current system insurers pick and choose who they will cover, and employers often offer only one plan, which is not portable when people change their job. In marked contrast, requiring that everyone purchase insurance from a single alliance will assure that everyone can choose among a number of health plans, and keep their plan if they change or lose their job. Freedom of choice of health plans is particularly important for persons with disabilities and chronic illnesses who are Medicaid-eligible. Allowing persons who are Medicaid eligible to choose a health plan from those offered by the alliance will solve one of the major problems faced by Medicaid recipients in the current system: inadequate care due to a shortage of providers willing to accept Medicaid patients.

  There are proposed alternatives to exclusive alliances, including a proposal to allow multiple alliances in a geographic area and the option for consumers to purchase health insurance outside the alliance. **CCD strongly opposes this proposal because it would perpetuate the current segmented health insurance market that fails to spread risk adequately.** We are greatly concerned that allowing individuals and businesses to purchase insurance outside the alliance will allow insurers to continue skimming the low risks out

of the population; this will drive up costs for the plans that enroll a broader cross mix of the population, which would include a larger proportion of persons who are high users of health care. A voluntary and competing alliance approach will only continue the current system where too many insurance companies compete in a segmented market, making it impossible to adequately spread risk. Additionally, it will reduce the state's ability to provide stringent oversight of both marketing practices and quality of care.

- **Subsidies for Small Businesses With Low Profit Margins and Persons With Low Incomes.** All businesses will be able to deduct 100 percent of the cost of insurance as a business expense. Additionally, small employers with low wage workers, and individuals and families with low incomes will be eligible for subsidies for the community-rated premiums. In addition, persons with low incomes will receive cost-sharing discounts.

The Elimination of Financial Barriers to Services.

- **Elimination of lifetime caps on medically necessary or appropriate covered services.** Persons with high ongoing health costs will be assured of coverage.

- **Protection against catastrophic out-of-pocket costs.** Deductibles and co-payments will be limited to $1500 annually for an individual and $3000 annually for a family. No balance billing will be allowed, i.e. providers will not be allowed to charge patients more than the amount negotiated with the health plan.

Comprehensive Benefits Package. Every American will have coverage for a specified, broad range of preventive, diagnostic, and treatment services. Many of these services are particularly important for persons with disabilities:

- Inpatient and outpatient rehabilitation services.

- Outpatient prescription drugs.

- Experimental treatments through approved clinical trials.

- Preventive services.

- Mental health and substance abuse treatment services.

- Durable medical equipment, orthotics (orthopedic braces) and prosthetics (artificial limbs), and prosthetic devices that replace all or part of the function of an internal body organ.

- Home health and extended care services.

Funding for Long-Term Services. The proposal recognizes that long-term services are crucial components of health care for persons of all ages with disabilities and chronic illnesses, and must be included in any plan to reform the nation's health care system. While long-term services and supports are not included in the mandated benefits package, the Administration has proposed to expand the availability of these services through a new program of home and community-based services, and to provide tax credits for personal assistance services for working persons with disabilities. Without these services, many individuals may be inappropriately institutionalized at a higher cost, both in economic and in human terms.

Chronic conditions account for 90 percent of all health problems. Chronic disease and illness are major causes of disability. The prevalence of functional impairments due to chronic illness, congenital conditions and trauma, has increased rapidly in the past decades and is expected to increase further in the coming years. This is due to advances in medical technology that save lives, but which often leave the survivor with significant disabilities. Yet, while treatment for acute episodes of care is covered, many persons with chronic illnesses cannot obtain the services they need to maintain their fragile margin of health. For these persons, it is not so easy to draw a clear line of distinction between acute and long-term services and the coordination of acute and long-term services is crucial.

Other people with disabilities need long-term services and supports to function independently. For many children and adults with disabilities, these services and supports can mean the difference between independence and dependence. CCD has several recommendations for refinements to the Long-Term Services provision of the Health Security Act, which we presented to the Committee in December 1993, and so we will not discuss them in this testimony.

The Incorporation of the Acute Portion of Medicaid into the New System. This step will eliminate the current two-tiered system of health care by providing every American with the same choice of health plans.

Cost Containment. The proposal includes measures to ensure that health insurance remains affordable. Without effective cost containment, increased costs will be shifted to consumers in the form of higher premiums, increased cost-sharing, and reduced benefits. Effective cost-containment measures include:

- Caps on premium increases.

- Competition among health plans in the regional health alliance.

- Standardization of health insurance forms to reduce administrative costs.

- Medicare prescription drug rebates.

Consumer Participation and Consumer Protections. The proposal includes a system of government and private oversight with enforcement procedures, including the appointment of an ombudsman at the regional alliance level. Other important provisions that will assure consumer involvement and protections are:

- A guarantee of due process rights with regard to benefit determinations, grievance procedures, and access to judicial review; provisions to protect the confidentiality of medical records and to assure access to regulatory proceedings.

- The establishment of regional health care alliances, which will increase the negotiating power of consumers, particularly small businesses and self-employed individuals. The mandated participation of consumers in the governance and administration of the health alliances will help assure accountability and responsiveness to consumer concerns.

- Consumer choice will be assured. Consumers will not be restricted to the plan their employer selects, but will be allowed to choose among a range of plans that they can keep if they change jobs. All managed care plans will have an out-of-network option. Consumers will be able to enroll in and disenroll from plans during "open season" and for "cause."

- Administrative simplification will make it easier for consumers to understand their health care coverage and their rights.

Consumer Protections During the Transition to the New System. There are a number of provisions designed to ensure maintenance of current health care coverage and benefits during the transition period. These include: requirements to help preserve current coverage, restrictions on premium increases, limits on the duration of pre-existing condition exclusions, and a national transitional health insurance risk pool. These protections are essential for persons with disabilities and chronic illnesses who may lose their coverage during the transition period as the insurance industry consolidates.

Research Initiatives. The HSA includes new funding for health research focused on prevention and outcomes research, which we strongly support. Priority areas include child and adolescent health, birth defects, chronic disease and conditions, mental health, environmental health, substance abuse, and the development of functional measures.

RECOMMENDED REFINEMENTS TO THE HEALTH SECURITY ACT

Legislation to address the major problems of access, cost, and quality for a large, heterogenous population will, of necessity, be complex and highly detailed. Provisions to reform financial, organizational, and service arrangements must take account of major variations in population density, ethnic composition, health infrastructure, and economic circumstances. In an undertaking of such enormous complexity and scope, there is a danger that the specialized needs of subgroups of persons with the most serious and disabling illnesses and conditions will not be understood and addressed.

To assure that a reformed health system will meet the specialized needs of persons with disabilities and chronic illnesses and conditions, CCD recommends several refinements to the provisions of the Administration's Health Security Act. It is important to note that while these recommendations relate specifically to the Health Security Act, *the problems they address are not problems with the bill per se, but problems with the current health system. As such, they must be adequately addressed in any health reform legislation that the Congress enacts. At the same time, the positive aspects of the current system must be retained.*

I. Reducing Financial Incentives to Underserve

The continuation of a multi-payer system of health insurance as proposed in the Health Security Act will reduce the extent to which risk and associated health care costs are spread. Therefore, individual health insurance plans will continue to be at risk for insolvency if they incur catastrophic costs. This situation and the need to contain costs generally create a variety of financial incentives to underserve persons with extensive or special health care needs. These incentives exist throughout our current health care system but are particularly problematic in capitated managed care plans.

As an example, certain types of managed care plans place individual physicians at financial risk when they serve persons with a need for intensive, ongoing services. This is a problem particularly for non-salaried physicians who receive a capitated payment for each person enrolled. In one such plan, a family whose child was born with multiple disabilities had great difficulty finding a pediatrician in their health plan who was willing to accept the child as a patient, because the physicians stated they would lose money if they accepted responsibility for the child, because he would require too much care. Other managed care plans pose similar problems of access and under-service. Some managed care plans attempt to pass on risk to providers in the form of financial incentives that seem especially likely to lead to underservice. These include bonuses or penalties to providers related to meeting or exceeding utilization limits and policies requiring physicians to assume the cost of out-of-plan specialty care. A recent GAO report concluded that the more risk is

shifted to physicians, the greater the potential for inappropriate reductions in services. *Therefore, CCD RECOMMENDS:*

1. ***Contractual provisions in managed care plans that shift financial risk to physicians and other health care providers should be strictly prohibited.***

A. The Need for Risk Adjustment

The risk adjustment formula is critical in determining how much the alliance will pay to each plan. Plans that serve a higher number of high cost enrolees should receive more resources. While the Health Security Act includes provisions for risk-adjustment of premiums and capitated payments, it is the consensus of experts that current risk adjustment data and methodology do not permit accurate estimates of risk based on factors other than age. *Therefore, CCD recommends:*

1. ***There must be increased funding for research on the factors associated with high levels of health care utilization. The findings of this research will greatly assist in the development of a risk adjustment formula. This research could be conducted by the National Health Board, the Agency for Health Care Policy and Research and the National Institute on Disability and Rehabilitation Research.***

2. ***Different methods of risk adjustment should be considered. Given the nascent state of the risk adjustment field, it may be more appropriate to provide half of the risk adjustment payment at the time of enrollment, and the remainder only if the health plan documents higher utilization at the end of the year. This approach would guard against people being classified as "high users" solely because they have a disability. Health care utilization by persons with disabilities varies enormously yet insurance companies often assume that all persons with disabilities are "high cost." Once a pattern of higher utilization is established, the full risk adjustment amount could be paid prospectively.***

3. ***In conjunction with the previous recommendation, health plans receiving risk adjustments prospectively must be required to collect data on the factors associated with high utilization. These data must be made available to the National Health Board to assist in the development of accurate risk adjustment. Accurate risk adjustment is essential to assure that there are no economic incentives for providers to underserve people with disabilities, and to guarantee that the amount, duration, scope, and quality of services delivered to people with disabilities are determined by their actual needs. The data collected must include information on the type of disability or chronic illness, and information about the type and severity of a person's functional limitations.***

4. *While we oppose placing physicians at financial risk, should such practices be allowed in managed care plans, then risk adjustment payments should be made to the physician who is responsible for the care of persons with severe and ongoing health needs, not to the health plan.*

5. *While accurate risk adjustment methods are being developed, there must be mandatory reinsurance requirements so that plans do not have an incentive to restrict services for persons who incur extremely high costs.*

6. *Persons with disabilities, parents of children with disabilities, and professionals with expertise in serving persons with disabilities should be represented on the Advisory Committee for the Risk Adjustment System.*

7. *The provisions of the bill regulating the marketing of health plans must be retained. If health plans are allowed to market only to low risk individuals, some plans will wind up with a disproportionate share of high-risk individuals.*

B. The Need for Time-Intensive Services

Another incentive to underserve is related to the time-intensive treatment needs of some persons with disabilities. If providers are not adequately reimbursed for their time (e.g. volume and time-based services), particularly in non-salaried, capitated care, or fee-for service arrangements, or if salaried physicians are penalized for not seeing a set number of patients in a given time period, they may be reluctant to provide services to persons with particular disabilities who require more time-intensive service. For example, a gynecologist may be reluctant to treat women with severe cognitive impairments because they may require considerably more time than is usually allotted for a given procedure. While there has been no systematic research on this issue, there is a large amount of anecdotal evidence documenting the problem.

Managed care plans that specialize in the treatment of certain health conditions such as AIDS, report that they need to assign a far smaller caseload to individual physicians because persons with certain conditions need both more services, and more time-intensive services. This need has been recognized by the Physician Payment Review Commission (PPRC), which has proposed a plan to compensate doctors for the time they spend with persons who have disabilities. In its annual report to Congress in 1991, the PPRC endorsed the use of special modifier that would increase payment by a fixed percentage for visit with patients who have communication barriers, disabling cognitive or physical impairments, or an unusual need for counseling or coordination of care.

Risk adjustment formulas consider aggregate utilization and expense, but do not take account of the need for more time-intensive services by some persons with disabilities, who may or may not be high-users of care. ***Therefore, CCD recommends:***

1. ***The presence of physical, mental, and communicative functional impairments must be added to the list of factors used to calculate risk adjustment formulas.***

2. ***Reimbursement formulas for all health professionals must include adjustments that take into account the need for more time-intensive services by some persons with disabilities.***

3. ***Financial practices in managed care health plans that penalize physicians and other health providers for not seeing a pre-determined number of patients in a particular time period should be prohibited.***

II. The Elimination of Financial Barriers to Care

CCD is concerned about the effect of price competition among health plans on the ability of persons with disabilities to have a meaningful choice of both health plans and providers. If insurance plans are going to compete on the basis of cost, then choice of insurance plans will, in part, be based on ability to pay. If persons will have to pay more to join fee-for-service plans and to utilize specialists outside of a managed care plan, then access to some specialists will be dependent on ability to pay. These costs may be prohibitive for many persons with disabilities, particularly when added to the costs of supplemental insurance for access to benefits beyond the federally guaranteed minimum. To address this problem, ***CCD recommends that:***

1. ***Cost sharing provisions must include subsidies for all low income persons with disabilities and chronic illnesses to join the plan that is best able to meet their needs. This includes subsidies for premiums, deductibles, and co-payments. Additionally, there must be lower limits on allowable out-of-pocket costs for persons with low incomes.***

The plan provides for reductions in cost-sharing for low-income families, i.e. for families with adjusted gross incomes below 150 percent of the applicable poverty level. *CCD RECOMMENDS:*

1. ***When determining adjusted gross income, disability-related expenses should be an allowable deduction.***

III. Comprehensive Benefits

In the health care reform debate, the question of which services to include in the mandated benefits package is a critical one for persons with disabilities. The opponents of comprehensive reform insist that any mandated benefits package should be kept to a bare minimum and that people shouldn't be "forced to buy benefits they don't need or want." This attitude is short-sighted in the extreme. No one is able to predict what health services they will need in the future. No one can say with any certainty that they will never be in a major accident, will never develop a chronic illness, will never have a child, spouse, or sibling with a chronic health condition or disability. Often, those most at risk for these conditions believe they are at low risk and so would be unlikely to purchase a policy with adequate benefits if they were given a choice. For example, young men in their twenties are the population group at highest risk for traumatic brain injury, yet this group comprises a large percentage of the uninsured.

While a great deal of attention has been given to the 37 million Americans without insurance, there are also millions who are under-insured. The Office of Technology Assessment estimates there are between 38 million and 55 million persons under age 65 years of age who are under-insured. Under-insurance is the result of several factors, including: (1) lack of coverage for pre-existing conditions, (2) exclusion from coverage of certain categories of health care and related services, including preventive and diagnostic services, prescription drugs, extended rehabilitation, durable medical equipment, orthotics and prosthetics, assistive technology, and long-term care, (3) annual and lifetime caps and high copayments for certain conditions or treatments, most usually for mental health and substance abuse services, (4) no limits on out-of-pocket payments for covered services, (5) no limits on expenses that exceed "usual, customary and reasonable" charges for covered benefits, and (6) a host of other exclusions based on restricted definitions of "medical necessity," or arbitrary limitations on services, such as rehabilitation. As a result, many families ***with insurance*** are faced with financial ruin in the event of a catastrophic illness or accident. In one study of uncompensated hospital care, 47 percent of the 1689 patients who incurred uncompensated costs ***had*** health insurance.

These limitations in coverage are often not apparent until a person becomes seriously ill. Consequently, most Americans report high levels of satisfaction with their current health insurance coverage. It is only when persons experience a catastrophic illness or accidents that require a wide range of ongoing medical, rehabilitative and support services, that they discover just how few services their policies cover. They also find out that hospital and physician charges that the insurer determines are above "usual, customary, and reasonable" charges, are neither paid by the insurer nor applied to the out-of-pocket limits. Thus, out-of-pocket expenses are often far higher than stated limits. Additionally, many insurance plans nominally include a particular benefit, but the services covered are so limited that

they are often insufficient in relation to their needs.

As an example, an HMO typically covers 60 days of rehabilitation, but a person with a severe stroke, a spinal cord injury, or a traumatic brain injury may require intensive rehabilitation for six months or longer, and intermittent maintenance or preventive services for another six to twelve months or for an even longer period. Persons with serious mental illness generally exhaust their inpatient lifetime mental health benefit within a year. Health insurance also rarely, if ever, covers long-term care, services and supports.

The mandated benefit package in the Health Security Act includes many services that are essential for persons with disabilities and chronic, disabling illnesses. The limitations on the scope, duration, and indications for these benefits must clearly cover what people need and are currently receiving.

There are several issues related to the mandated benefit package in the Health Security Act that require clarifications and changes. These will be discussed below.

A. Outpatient Rehabilitation

Rehabilitation services are indispensable for persons who have experienced a loss or attenuation of physical, mental or communicative functioning as the result of a genetic condition, a congenital disorder or condition, a developmental condition, a disease, an illness or an accident. Rehabilitation is an essential component of the treatment of all these conditions. Additionally, just as primary preventive services like immunizations prevent the incidence of costly disease, secondary preventive services like rehabilitation prevent the incidence of numerous health problems and disabilities. If rehabilitation services to maintain function and to prevent deterioration are not adequately covered, children and adults with disabilities will be at risk for deterioration in their functional status and for the development of complications.

It is irrational to use heroic methods to prevent death and then ignore the need to prevent the complications of chronic illness and the development of secondary disabilities. These conditions lead to higher acute costs over time. Given these inevitable costs, the provision of comprehensive rehabilitation services to persons with disabilities is a rational approach to ensuring system-wide cost reductions by preventing expensive complications. Rehabilitation services also increase individual functioning and productivity.

Section 1123 covers outpatient rehabilitation services such as Physical Therapy, Occupational Therapy, and Speech Therapy, but only when they are provided "to restore functional capacity or to minimize limitations on physical and cognitive functions as a result of an illness or injury." This provision is unduly restrictive for

three reasons.

(1) **The requirement in Section 1123 that rehabilitation services be available only to persons whose need for services results from illness or injury, effectively excludes persons with congenital, developmental and other conditions from receiving services.**

The effect of this provision is to perpetuate a pre-existing condition exclusion for persons with congenital conditions, i.e. conditions that are present at birth. It makes an arbitrary distinction between those born with a disability and those who acquire a disability after birth, even if it is only weeks after birth. For example, under this provision, a child who develops meningitis (an infection of the brain) hours after birth and develops cerebral palsy would be able to receive these services, but a child born with cerebral palsy would not. This is discriminatory and unacceptable policy. To correct this problem *CCD RECOMMENDS:*

1. ***The phrase "illness or injury" must be replaced by the phrase "illness, injury, disorder, or other health condition." This language is consistent with language in the Health Security Act pertaining to the development of practice guidelines. It is also consistent in its effect with language in many current private insurance policies.***

(2) **The requirement that rehabilitation services be provided to restore functioning and to minimize limitations on physical and cognitive functions must be interpreted to encompass medically necessary and appropriate prevention and maintenance.**

While payment for services designed to *maintain* function or to *prevent or minimize deterioration* is provided under current public and private insurance, it is not clear that these services would be covered using the proposed language. Services required to maintain functioning or to prevent or minimize deterioration can be critical to preventing secondary disabilities or exacerbations of conditions. Without therapy, many individuals may lose the little functioning they have. For example, without maintenance physical therapy, a child with cerebral palsy could develop a dislocation of the hip, resulting in a need for expensive surgery and hospitalization.

The standard for re-evaluation in the bill uses improved function as the sole criteria. Maintenance and prevention are also appropriate standards for continuation. Therefore, *CCD RECOMMENDS:*

1. ***Indications for outpatient rehabilitation services should also include maintenance of functioning and the prevention of deterioration.***

(3) **The definition of outpatient rehabilitation services fails to recognize the full range of services covered under public and private insurance.**

Rehabilitation comprises a range of skilled services provided to individuals in order to minimize physical, cognitive and emotional impairments, and to restore or maximize functional capacity. The full recovery of persons with catastrophic illnesses, injuries and conditions is dependent on the provision of these services. Similarly, individuals with congenital conditions need these services both to attain their full functional capacity and to maintain that capacity. In addition to the three therapies listed in Section 1123, rehabilitation services also include a range of other services, including: respiratory therapy; audiology services (including hearing tests); speech-language pathology services for speech or language problems, augmentative communication and feeding and swallowing problems; cognitive therapies; and orientation and mobility training for persons with severe visual impairments. Additional services can be provided in a comprehensive outpatient rehabilitation facility (CORF) and are covered by Medicare include: psychological counseling, nursing services, and social services. Therefore, *CCD RECOMMENDS:*

1. ***The full range of outpatient rehabilitation services, as enumerated above, should be included in the mandated benefits package.***

B. Durable Medical Equipment (DME) and Orthotics and Prosthetics (O&P)

Durable medical equipment (DME) includes such items as wheelchairs, crutches, hospital beds for use in the home, oxygen equipment, and a wide variety of devices that assist people with disabilities and chronic illnesses. Orthotics are orthopedic braces for the arms, legs, back and neck. Prosthetics are artificial arms, legs, and eyes, while prosthetic devices include devices such as hip replacement components and colostomy devices.

CCD is concerned that the definition of DME in the Health Security Act references the overly restrictive, acute-care oriented definition currently used in Medicare. This definition was formulated in 1965 when Medicare was enacted and reflects an outdated orientation towards persons with disabilities as homebound and dependent. This perception of people with disabilities is very different from that embodied in the Americans with Disabilities Act. Therefore, the durable medical equipment benefit within the Health Security Act should be redrafted to appropriately reflect the needs of people of all ages with disabilities and chronic illnesses.

Currently, there are a number of DME items not covered or otherwise reimbursable under the Medicare program because the item does not meet all the requirements of the four-part test Medicare has established to determine coverage. Even though such

items may have significant therapeutic benefit for particular individuals under specific circumstances, they are considered to be "presumptively nonmedical" by Medicare. The rigidity of the four-part test has resulted in the denial of Medicare beneficiary access to a number of DME items that could maintain and/or improve the health status of millions of older Americans and Americans with disabilities, as well as prevent injury.

CCD RECOMMENDS:

1. ***Some items not currently covered and reimbursable by Medicare should be covered and reimbursable under the Health Security Act and any comprehensive health care reform proposal. These items include, but are not limited to: bath tub lifts and seats; bed baths; bed lifters; dehumidifiers and humidifiers; grab bars; hygiene items (i.e., incontinent pads, irrigating kits); portable whirlpool pumps; raised toilet seats; staircase rail(s); white canes; and air conditioners. These items are relatively inexpensive and may have significant therapeutic benefit for particular individuals under specific circumstances. Coverage and payment for these DME items, in the long run, may save substantial expenditures otherwise spent on more costly corrective therapies and items.***

CCD strongly supports the Health Security Act's definition of "prosthetic devices," which reflects technological advances that have been incorporated into contemporary practice by health care professionals. The bill incorporates a **functional** test, specifying that "prosthetic devices" are covered not just if they replace the body member itself, but if they "replace all or part of the *function* of an internal body organ."

This language recognizes that prosthetic devices include devices that are surgically inserted. An example of such a device would be a pacemaker. It also recognizes that prosthetic devices include devices that are physically attached to the body, such as colostomy bags and supplies directly related to colostomy care.

Technological advances are enabling health care professionals to prescribe devices that replace all or part of the function of an internal body organ without surgically inserting or physically attaching the device to the body. We are pleased that by including a "functional" definition, the bill recognizes that prosthetic devices include assistive technology devices and other external devices such as augmentative communication devices.

Augmentative communication devices replace all or part of the malfunctioning or non-functioning element of the body's oral motor mechanisms, consisting of the speech center of the brain as well as the nerves, muscles, and organs that together control the production of speech and improve the functions of speaking for

individuals whose oral motor mechanisms do not work. Obviously, "improving functional ability" includes improving the ability to speak; otherwise, Medicare and private insurance policies would not pay for an artificial larynx for this purpose.

The use of this contemporary "functional" definition of prosthetic devices will enable people who require augmentative communication devices for effective communication to receive them. Too often, under the current system, augmentative communication devices are covered only for persons who have had their larynx surgically removed.

CCD recognizes that coverage for such external devices is subject to the general policy that all devices provided under the comprehensive benefits package must be prescribed by a qualified health care professional within the scope of the professional's practice and must be medically necessary or appropriate.

CCD also supports the inclusion of assistive technology devices as authorized expenditures under the Health Security Act's new long-term services formula grant program for home and community-based services. The availability of these devices through the long-term services program will enable individuals for whom such devices are not otherwise covered under the comprehensive benefits package to obtain needed services. We believe that eventually the false dichotomy between acute and long-term care must be eliminated.

The Health Security Act's current language on durable medical equipment, orthotics and prosthetics, and prosthetic devices must be clarified so that it is consistent with private insurance coverage and Medicare policy. ***CCD's RECOMMENDATIONS to do this are as follows:***

1. ***Clarify that accessories and supplies used directly with these devices to achieve the therapeutic benefits and proper functioning of such equipment or devices are covered.***

2. ***Clarify that the replacement of such equipment and devices is covered, not only for a change in a person's condition but also in cases of loss, irreparable damage, and wear.***

3. ***Clarify that repairs and maintenance of durable medical equipment, orthotics and prosthetics, and prosthetic devices are covered, as are fitting and training for the use of these items. These clarifications merely codify current Medicare policy and the policy of most private insurers with respect to coverage of accessories and supplies, repair and replacement, maintenance, and fitting and training, and will not add additional costs to the benefit package.***

Finally, the bill specifies that an item or service is covered only if it "improves functional ability or prevents further deterioration in function." *CCD RECOMMENDS:*

1. ***Items or services should also be covered if they will "minimize" further deterioration in function. This language is consistent with the purpose of the covered devices and equipment and conforms the provision to the language in the section of the bill pertaining to outpatient rehabilitation therapies. We believe that providing services to minimize deterioration will be cost-effective.***

Hearing Aids

Hearing aids are prosthetic devices but they are explicitly excluded from the mandated benefits package. If surgery for a cochlear implant to improve hearing is a covered benefit, why aren't hearing aids to improve hearing also covered? The importance of hearing aids for children with severe hearing loss cannot be overestimated. The ability to hear and understand speech is crucial for language development in young children. If high cost and inappropriate utilization are a concern, at the very least, hearing aids should be provided to children who have a hearing impairment that interferes with their ability to understand speech. It is virtually certain that hearing aids will not be prescribed for children unless they need them. Therefore, *CCD RECOMMENDS:*

1. ***There should be no arbitrary distinctions in the DME and O & P benefit that prevent people with disabilities and chronic disabling illnesses from receiving the health care services they need to function independently.***

2. ***The definition of durable medical equipment in the final legislation should be broader than the current Medicare definition, which is overly restrictive and does not take account of many of the needs of younger persons with disabilities.***

3. ***Hearing aids for children, at a minimum, MUST be covered.***

Disposable Medical Supplies

There is no mention in the mandated benefits package of disposable medical supplies. This category includes such items as surgical dressings, and catheterization and tracheostomy supplies, which are currently covered under Medicare and many private health plans. Such supplies are very cost-effective because they prevent infections, which are potentially life threatening. It is also not clear whether syringes will be covered for persons who need them for injectable medications, e.g. insulin for persons with diabetes. *CCD RECOMMENDS:*

1. *Disposable medical supplies, including syringes, should be covered when medically necessary.*

D. Extended Care and Home Health Services

The indications for extended care and home health services are similar to those used for the outpatient rehabilitation benefit and are equally problematic. As written, these services will only be available for persons whose need for services results from illness or injury. As in the outpatient rehabilitation benefit, this provision effectively excludes persons with congenital, developmental, and other conditions from receiving services.

As noted earlier, the effect of this provision is to perpetuate a pre-existing condition exclusion for persons with congenital conditions, i.e. conditions that are present at birth. It makes an arbitrary distinction between those born with a disability and those who acquire a disability after birth. *Therefore, CCD RECOMMENDS:*

1. *The phrase "illness or injury" must be replaced by the phrase "illness, injury, disorder, or other health condition."*

2. *The full range of outpatient treatment and rehabilitation services, including respiratory therapy, should be available under the Extended Care and Home Care benefit.*

E. Prescription Drugs

(1) Formularies

Overly restrictive prescription drug formularies could have a detrimental effect on the quality of care for some persons with special medication needs. This is a particularly important issue for people with rare disorders, and people with low incidence and prevalence conditions. For persons with these conditions, there may be only one available drug treatment, and this drug may not be included in a formulary, or may be prescribed for an "off label" purpose. Access to the entire range of available pharmaceuticals is also critical for persons with conditions such as epilepsy, where treatment is highly individualized and persons may need to try a number of different drugs in varying combinations prescribed by their physician in order to achieve effective control of their seizures. *Therefore, CCD RECOMMENDS:*

1. *Minimum standards for the operation of prescription drug formularies must be established to ensure appropriate access to medically necessary*

medications. At a minimum, the standards should include those set out in Section 1927(d) of Title XIX. In addition, access to medications not on the formulary should be guaranteed through a prior authorization process when justified by medical necessity. A plan's prior authorization process should ensure a response within 24 hours, and the provision of a 72 hour emergency supply of a drug when medically necessary as required in current Medicaid law.

(2) Generic Drugs

While the use of generic drugs should be encouraged as a way to control the costs of prescription drugs, for certain conditions such as epilepsy, the mandatory substitution of generic drugs without the informed consent of the consumer and the treating physician could severely compromise the effectiveness of treatment. There may be significant differences between the characteristics of a brand name and a generic anti-seizure medication, as well as differences among different generic anti-seizure drugs. In some individuals, these differences could result in adverse effects, including a loss of seizure control and the development of toxic side-effects. ***Therefore, CCD RECOMMENDS:***

1. ***Health plans should not be allowed to substitute generic drugs for prescribed medications, without the informed consent of the consumer and the treating physician.***

F. Mental Health and Substance Abuse Services

The mental health and substance abuse services are extremely limited in scope and duration and will be inadequate to meet the needs of persons with serious and persistent mental illness, and persons with psychiatric disabilities. Benefit caps for both intensive nonresidential services, inpatient and residential services are so inadequate that they will lead to severe service fragmentation, unnecessarily restrictive care, poor outcomes and higher costs. We strongly support the planned expansion of benefits in the year 2001, which offers fully comprehensive and flexible benefits, but have major concerns about how persons with psychiatric disabilities and persons with drug dependencies will receive the services they need prior to that time.

Services that are particularly important for people with disabling mental illness include in-home services, case management, partial hospitalization, psychiatric rehabilitation and other intensive, non-residential services (INR). INR services are essential for children with serious emotional disturbances, who should be provided treatment in non-residential settings whenever possible, so that they are not separated

from their families. INR services have also been demonstrated to be both cost-effective and more acceptable to consumers of care than 24-hour residential placements.

These services are severely limited under the standard mental health benefit during the period 1998-2001. In addition to inadequate benefits, the higher cost-sharing requirements for mental health services are a major problem for persons with disabling mental illness, particularly since individuals with disabling mental illnesses often require a high volume of services. It is not uncommon for individuals with disabling mental illness to require daily rehabilitation and medication services. High cost-sharing is a major barrier to care because persons with disabling mental illnesses generally have low-incomes resulting from their inability to work. Many are unable to meet any cost-sharing requirements. To address the serious deficiencies in the mental health benefit, *CCD RECOMMENDS:*

1. ***The elimination of arbitrary restrictions on the amount, duration and scope of services.***

2. ***The discriminatory cost-sharing requirements for mental health services must be eliminated for those who cannot reasonably be expected to meet them.***

3. ***Cost-sharing for mental health services must be counted toward the out-of-pocket limit on an individual's annual health expenditures.***

4. ***Persons with disabling mental illness who are Medicaid eligible must continue to receive optional Medicaid benefits such as rehabilitation, clinic services and case management. Given the major deficiencies in the proposed mental health benefit, the continuation of these services is essential.***

IV. Extra-Contractual Services

Currently, some private insurance policies will pay for services not specifically included in the plan, i.e. extra-contractual services, in order to improve the quality of life of a beneficiary and to save money for the insurer over the long-term. For example, Aetna paid to retrofit an individual's house to make it accessible because it cost less to provide services in the home than in a hospital or rehabilitation facility. There is some concern that the language in the Health Security Act related to duplication of benefits in supplemental insurance may limit or prohibit the provision of extra-contractual services by insurance plans offering the mandated benefit package. Therefore,
CCD RECOMMENDS:

1. ***Health plans should be allowed to offer extra-contractual services at their discretion, whenever they will result in an improvement in the beneficiary's***

quality of life and a cost saving to the health plan.

V. Services for Children with Special Health Care Needs Under the Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT)

The Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandates under Medicaid require that children up to their twenty-first birthday are eligible to receive services for the detection and treatment of health conditions, developmental, mental and emotional problems and disabilities. In OBRA 1989, Congress strengthened the protections for children under this program to assure that they receive all the treatment services they need irrespective of any limits in a state's Medicaid plan. This gave children a right to necessary and appropriate services for which the federal and state governments would pay under the existing Medicaid matching formula. Eligibility for EPSDT is, of course, dependent on Medicaid eligibility which can vary by state.

Under current EPSDT law, states are mandated to pay for a wide range of community-based health and mental health services. As a result of the OBRA 1989 expansions, the benefits provided through the EPSDT program are more comprehensive in both scope, amount, and duration than those in the currently proposed basic benefits package. Some of these services may be available under the Administration's proposed long-term services benefit. Services currently provided under the EPSDT mandate include:

- Rehabilitation, including physical, cognitive, psychiatric, psychological, behavioral and other services, e.g. physical therapy, occupational therapy, speech-language pathology and audiology services, psychological and social work services;
- Clinic services for both physical and mental conditions;
- Assistive technology and equipment;
- Targeted case management, which includes the coordination of services, facilitation of access to various benefit programs, and intensive case management services for those with complex or extensive needs;
- Personal care services, including attendant care; and
- Hearing aids.

These services are critical to the full health and functioning of children eligible for Medicaid and for all children. It is by no means certain that the federal regulations governing the new program proposed in the Health Security Act will include this

wide range of services that children now have access to through many state Medicaid EPSDT programs, nor does the bill clarify whether any limits will be allowed on the scope, amount, and duration of services.

The proposals in the Health Security Act for children under Medicaid beginning with Sec. 4221, et seq., are very confusing. It appears that all children currently eligible for Medicaid, (with the exception of "Katie Beckett" children as authorized by TEFRA 134), continue their eligibility for benefits not included in the comprehensive benefit package. However, it appears that children will be eligible for different service packages, depending on how they become eligible for Medicaid. There may also be differences in the funding streams, payment mechanisms and points of access between children. Difference in these areas may result in significant negative consequences for children and their families. Moreover, children who live in low-income households will be eligible for a more comprehensive set of services than children who live in non-low-income households. In the latter situation, families could only obtain such services by paying the full cost. This new "two-tiered" system is totally inconsistent with some of the President's overarching principles for health care reform.

Under Sec. 4222 of the Health Security Act, low-income children who meet the eligibility criteria under current Medicaid law would be provided additional "supplemental" services under a new, fully-federally financed program modeled upon the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandate of Medicaid. The legislation does not provide details of this program but directs the Secretary of HHS to issue regulations on how the program is to be administered no later than July 1, 1995. The Administration has estimated that this program will be allocated $9.8 billion over five years, beginning with $264 million in FY 1996. Although annual appropriations are envisioned to increase to $3.2 billion in the year 2000, these figures suggest a very limited program.

This "supplemental" program in Sec. 4222 would provide one hundred percent federal funding for items and services in Section 1905 (a), including also Section 1905 (r), of Title XIX of the Social Security Act, which are not included in the HSA mandated benefits package. The items and services listed in Section 1905 are identical to the current array of EPSDT mandated services.

Sec. 4221 indicates that no change is made in eligibility for Medicaid services; we infer from this that for cash assistance recipient children (AFDC and SSI), the federal government will continue to match, on the basis of an open-ended entitlement, state funds for all reimbursable services for which the state generates its matching funds. To further confuse the issue, the eligibility for the new program under Sec. 4222 clearly includes children on cash assistance programs (SSI and AFDC).

If this new "supplemental" program in Section 4222 will provide funding for the

items and services in Section 1905 that are not included in the mandated benefits package, for both cash-assistance and non-cash assistance children, we are concerned that the program is underfunded. But if the language in Section 4221 means that states will continue to be responsible, under existing federal/state matching requirements for all services for children on AFDC and SSI as mandated in OBRA 1989, then it appears that they will not be funded through the new program in Section 4222. If this is correct, then the amount allocated for the new program would not fall quite so short of the need.

The Administration's proposal sets the new program's base at FY 1993 spending levels. Implementation of the EPSDT mandate, including expansions in OBRA 1989, is currently very uneven among the states. Few states have conducted appropriate outreach to low-income families, and as a result, many of the children who should have access to full and comprehensive benefits under EPSDT have not been identified. The Health Care Financing Administration reports that **in FY 1993, the year for which the Health Security Act caps the federal contribution, only 41 percent of all children eligible for EPSDT had been enrolled by the states.** A number of states, however, have recently put together comprehensive, prevention focused, statewide initiatives. Kansas (Kan-B-Healthy), North Carolina (Healthy Children and Teens), Oklahoma (Sooner Start), Wisconsin (Healthcheck) and other states are attempting to fully implement EPSDT. However, these initiatives are all relatively new and have reached only a limited number of the children they are targeting and so current spending is substantially below what is needed. Also many Medicaid families are unaware of their entitlement to services not included in the state's overall Medicaid plan and thus are not accessing the full range of services to which they are entitled. Providers, too, are ignorant of the extent to which they could lawfully provide medically necessary and appropriate reimbursable services to these children.

The Administration also has not taken account of the enormous variability in state spending on EPSDT services. This raises many questions that must be answered. How will the new program compensate for the lack of appropriate EPSDT programming in many states? How will federal resources be allocated with this existing disparity? The comprehensive of the benefits and the integrity of the service and support systems in place must be maintained, but mechanisms and supports for improvements must be made available where necessary.

It is also essential that provider reimbursement for all covered services be adequate. Otherwise, children may suffer as they do now in having access only to those providers who will accept low reimbursement rates. In addition, if states are not required to raise their Medicaid reimbursement rates for the services in Section 4221 and 4222 so that they are compatible with provider rates paid by health plans, we could well see the continuation of a "two-tiered" system. For many children, this would mean continued financial barriers to services because no providers will accept

these lower rates.

We are pleased to see that the Administration has recognized the importance of the wide array of services provided under the EPSDT mandate for children. However, it is disturbing that the proposal suggested to replace the EPSDT mandate is so unclear, undefined and, we believe, underfunded. It is unclear why this proposal, which could drastically change and perhaps endanger the EPSDT mandate, has been offered at the same time that the Administration promulgated a notice of proposed rulemaking to further the implementation of the EPSDT mandate on October 1, 1993. The confusion over financing is compounded by the description in Secs. 9001, 9002, 9011 and 9012, which describe state payments to the health alliances. These payments will affect the availability of services as well as the availability of other state resources for other Medicaid-reimbursable services that are not included in the basic benefit package, i.e., mandated and optional Medicaid services which are not provided by health plans, e.g. services provided under the Individuals with Disabilities Education Act (IDEA).

All of these funding issues are compounded by the unclear relationship to the state maintenance of effort payments and the cash assistance payments to the health alliances. The Medicare Catastrophic Amendments of 1988 authorized state Medicaid agencies to receive federal reimbursement for special education related services contained in a student's Individualized Education Plan under the Individuals with Education Act and early intervention services included in an Individual Family Services Plan under Part H of IDEA. As a result, most state Medicaid agencies are now allowing school districts and early intervention providers to obtain reimbursement for services provided. The state match for the federal Medicaid funds is often provided either by the local education agency or a state general fund match from the lead agency for early intervention. Many states' programs and services under IDEA have become dependent on this important source of funding during the last six years. **The President's proposal is unclear about the future of this important source of funding to support critical school and early intervention services.**

In any new proposal to fund these critical services, the relationship of any services funded under any "supplemental" program to services provide though health plans, services provided in schools (especially those provided under IDEA, and other health services must be considered. Such coordination will assure that children get all the services they need in an appropriate manner. Such integration will also streamline access for families.

To fulfill the promise of the EPSDT mandate, a comprehensive benefit package must be available to assure the health and optimal functioning of all children. Therefore, *CCD STRONGLY RECOMMENDS:*

1. *The Medicaid EPSDT mandate should be continued with the current eligibility criteria, including the criteria for children eligible under the "Katie Beckett" TEFRA 134 provisions. This will ensure that no children will lose any health care they now have, as they Administration has promised.*

2. *A comparable "supplemental" benefits package funded by the states in partnership with the federal government should be provided to all children. This program should be affordable and have a cap on out-of-pocket costs based on family income.*

Early identification of disabilities and health needs and the subsequent provision of necessary treatment for all conditions are critically important as Congress recognized in 1989 when it strengthened the EPSDT mandate. However, the Administration's proposal to develop a fully federally-funded "supplemental" program does not provide assurances that the full range of EPSDT services currently available under Medicaid will continue to be available. Therefore, *CCD RECOMMENDS:*

1. *The financing must be adequate to meet the treatment needs of children. State participation should be considered.*

2. *The provisions of any "supplemental" program, whether its Medicaid or non-Medicaid funded, must be clarified and better articulated in the legislative language, especially with regard to state maintenance of effort, integration with the Alliances and Health Plans, and relationship to other programs and funding streams.*

VI. Continued Availability of Services Currently Received Through Medicaid

While we applaud the integration of Medicaid beneficiaries into the alliances for acute care services -- a strategy which will help to eliminate the current two-tiered nature of our health system -- Medicaid-eligible individuals must be assured a real choice among the full range of health plans. Individuals with disabilities or chronic health conditions may need to choose a high-cost plan because of its range of specialists or relationship to a center of excellence. Low-income persons whose health needs require extensive specialty care will need a subsidy in order to afford a fee-for-service option or point-of-service options in managed care plans. A subsidy to purchase fee-for-service plans during the transition period was included in the Administration's September 7 draft, in recognition of the fact that many primary care providers -- and health plans -- will not be prepared to meet the specialized health care needs of some individuals with disabilities and chronic illnesses. We urge the Committee to consider this earlier proposal.

Another concern is that adult, non-cash assistance Medicaid beneficiaries who are

receiving services not covered in the HSA mandated benefits package will lose these benefits. These include important services such as dental care and medical transportation for persons with no other means to access health services. Individuals with low incomes who have disabilities may need these services to achieve full functioning. (See the section on EPSDT for additional concerns about children's services under Medicaid). We are also concerned about those individuals who are currently working and continue to be eligible for Medicaid under Section 1619(b) of the Social Security Act.

CCD has major concerns about the co-payment requirements for individuals who are low income and who use a high volume of service. The cap on out-of-pocket expenses should be lower for low income individuals to prevent individuals from putting off care, which could lead to the development of more expensive complications.

Finally, CCD is concerned that persons eligible for long-term services should continue to receive optional Medicaid benefits such as rehabilitation, clinic services, personal care, home and community waiver services and case management. Given the major deficiencies in the proposed mental health benefit, in particular, the continuation of these services is particularly essential to individuals with mental illness. Therefore, *CCD RECOMMENDS:*

1. ***Individuals currently eligible for Medicaid services should continue to receive the full range of Medicaid covered services.***

2. ***Medicaid eligible individuals with disabilities and individuals with low incomes should be subsidized to choose a high-cost plan, a fee-for-service plan or to use a point-of-service option if their health care needs require that they have ongoing access to specialists, centers of excellence and other specialty care.***

3. ***The cost-sharing requirements for Medicaid beneficiaries and individuals with low incomes should be lowered to eliminate financial barriers to care.***

VII. Assuring Choice of Providers in all Managed Care Plans

As health care costs have continued to rise at double digit rates, insurers and employers have searched for ways to control costs. One response has been a growth in managed care plans of many different types. These include staff-model Health Maintenance Organizations (HMOs), Individual Practice Associations (IPAs), and Preferred Provider Organizations (PPOs). The number of people enrolled in managed health care plans has increased dramatically. Today, there are very few fee-for-service plans that do not employ "managed care" techniques, such as utilization

review and pre-admission certification for non-emergency hospitalizations.

Apart from a few well-established HMOs, such as Kaiser in California, the development of many managed care entities is a relatively recent phenomenon and there are serious concerns about some of the financial practices they employ to control utilization. CCD is concerned that while there are incentives in these plans to keep people healthy and decrease inappropriate utilization of expensive services, many plans offer financial incentives to decrease ***appropriate*** utilization. For example, some plans will withhold a percentage of a provider's income (15 - 20 percent) if they have exceeded a targeted number of referrals to specialists and hospitalizations. To address these concerns, ***CCD RECOMMENDS:***

1. ***The Point of Service option for managed care plans must be maintained.***

2. ***There must be strong provisions to assure that physician referrals to physician and non-physician specialists are financially neutral and based solely on the health needs of the patient. Just as physicians should not receive payment for referrals, so they should not receive payment for denying referrals. The legislation must expressly prohibit financial penalties for making referrals and bonus payments for not making referrals.***

3. ***There must be a prohibition against balance billing for medically necessary services obtained outside a network.***

A. Single Source Contracting

The Health Security Act currently preempts state laws that prohibit health plans from contracting with a "single source" to provide all of the services for a particular aspect of health care. For instance, under the HSA, health plans would be able to contract with one orthotic and prosthetic practitioner to provide all of the orthopedic braces and artificial limbs prescribed by physicians in the health plan. Similarly, one home medical equipment supplier could be chosen to service all of the home equipment needs of the plan's beneficiaries.

This approach is undesirable in a number of respects. First, qualified providers will be prevented from gaining access to and competing in the health care market. Monopolies of providers of particular types of services will be encouraged by this policy, thereby decreasing competition and eventually driving up prices. Some qualified providers could be forced out of business. The combined effect of allowing single source providers and decreases in the number of qualified providers in a given area will reduce the service options available to consumers. Consumers will be prevented from choosing a health care provider with whom they may have developed a long-standing relationship or one who is conveniently located.

The quality of care may also be compromised when managed care plans contract with a single provider for a specialized service. As an example, in the area of orthotics and prosthetics (O & P), many certified O & P practitioners specialize in different aspects of orthotic and prosthetic care. One may specialize in advanced upper limb protheses and another in orthopedic braces for the management of spinal conditions such as scoliosis. Other providers may specialize in advanced fitting techniques and material applications. In an area like O & P, where "one size does *not* fit all", allowing a plan to contract with a single provider severely restricts access to providers with expertise in a given area, and has to potential to seriously undermine the quality of care that a persons receives. Consumers must be given a real choice of providers for all services covered under a health plan. Therefore, *CCD RECOMMENDS:*

1. ***The legislation must include incentives for health plans to contract with as many providers as necessary to meet the health care needs of their beneficiaries, particularly persons with disabilities and chronic, disabling illnesses.***

2. ***No health plan should be allowed to engage in practices that have the effect of discriminating against any type or category of provider, or within a category of providers, as long as the provider is authorized under state law or regulations to provide health and mental health services. This will allow the consumer to have a real choice when selecting a health professional for a particular condition. This freedom of choice is particularly important for persons seeking mental health services, where interpersonal variables are important factors in treatment success.***

B. Gatekeepers

While the Health Security Act enables choice of providers outside of a managed care network, it does so at a substantial cost to the enrollee of at least 20 percent of the cost of the service, and there are no provisions to address the problem of balance billing for "out-of-network" services. In addition, in managed care systems, neither the person with a chronic condition or disability, such as severe spinal or head injury, stroke or cancer, nor the generalist gatekeeper are necessarily aware of the services available and needed. To remedy these problems, it is necessary to give individuals who need ongoing specialized services for their particular condition, a right to choose his or her gatekeeper physician, including an appropriate specialists for the condition involved. Each health plan would be obligated to create panels including specialists dealing with the major disabilities.

The National Health Board would define the conditions requiring specialized, ongoing care and would issue guidelines to assist plans in determining appropriate

specialties to be represented on such panels. For example, specialists in physical medicine and rehabilitation would be relevant for managing spinal cord injury or head injury or stroke; specialists in neurology would be relevant for managing stroke, epilepsy, multiple sclerosis, and Alzheimer's disease; specialists in oncology would be relevant to managing cancer.

This right to choose one's main and primary physician is very important and particularly important to a person with a serious health problem. This right is all the more significant in managed care where the main or primary physician has gatekeeper functions. A specialist often is the main or primary physician in terms of personal contact and management for people with disabilities, and would generally be the best informed and competent manager of resources and services for persons with chronic disease or disability. However, managed care systems often prohibit the use of specialists in such roles. To address this problem, *CCD recommends the following change to Section 1402:*

Requirements Related to Enrollment and Coverage by Health Plans

"(h) Any health plan which utilizes a gatekeeper or similar process to approve health care services prior to their provision, shall provide each enrollee who has a chronic condition or disability likely to require substantial health care services over a prolonged period of time, a choice of his or her gatekeeper physician from a panel of physicians which shall include specialists in the medical management of the condition. The National Health Board shall develop and publish a list of the chronic conditions and disabilities that are likely to require substantial specialized health care services over a prolonged period of time. The National Health Board is authorized to develop guidelines to assist health plans in determining which physicians are specialists in the medical management of the conditions or disabilities defined by the Board under this section. A health plan shall annually establish panels of physicians who agree to serve as gatekeeper physicians, including specialists in the medical management of chronic conditions or disabilities such as specialists in physical medicine and rehabilitation, and neurology.

Suggested Report Language:

Individuals with chronic conditions or disabilities of a certain type including spinal cord injury, head injury, or stroke will often need ongoing medical management of a specialist in medicine. This person will often be the primary physician of the patient in terms of the amount of contacts with the patient and the decision making about his or her condition. Individuals with such conditions and disabilities generally desire to have a physician who specializes in the condition they have manage their care in managed care systems. This amendment provides that such individuals have a right to annually select a gatekeeper physician from a panel that shall include specialists in the conditions defined by the NHB as being of such a nature to require

specialists case management rather than generalist case management. Many organizations representing persons with disabilities have urged that persons with disabilities be empowered to select a specialist as their gatekeeper case manager. Conditions which lend themselves to better case management by specialists are usually severe disabilities, for example spinal cord injury, multiple sclerosis, head injury, or AIDS. These conditions often affect many body systems and require a comprehensive approach to medical management and rehabilitation services. Specialists in treating such conditions are trained to understand such complex conditions and to be knowledgeable about the resources available to manage such conditions effectively. Physical medicine and rehabilitation specialists are trained and experienced in handling the comprehensive rehabilitation needs and most general medical problems of persons with severe physical disability of the neuromuscular and musculoskeletal systems. Specialists in neurology are trained and experienced in the diagnosis and medical management of persons with neurological conditions such as epilepsy, stroke and Alzheimer's disease.

C. Access to Academic Health Centers and Centers of Excellence

Academic health centers are entities operated by or affiliated with a school of medicine or osteopathy or a teaching hospital. It is through such centers that many specialized treatments are available, including treatments for rare diseases and disorders, and for unusually severe conditions. A major issue of concern to persons with disabilities and special health care needs is whether persons in managed care settings will be able to receive services at specialized treatment centers. The Health Security Act says that a state "may" require alliances to assure that at least one accountable health plan has a contract with a "center of excellence." This provision does not adequately address the concerns of persons with special health needs. Additionally, we are concerned that persons with disabilities will be financially penalized for receiving medically necessary, specialist services outside the network if these services are not provided in the network. Given that a large percentage of the population is currently enrolled in managed care plans, and this percentage is expected to increase, it is essential that final legislation includes provisions to assure access for all Americans to academic health centers and centers of excellence. Therefore, *CCD RECOMMENDS:*

1. ***Regional and corporate alliances must ensure that all health plans have sufficient contracts with eligible academic health centers and centers of excellence so their enrollees can receive specialized treatment services.***

2. ***There should be effective quality assurance mechanisms in managed care plans to ensure that people with disabilities and chronic conditions who need ongoing specialized services have appropriate access to these services, and should not be financially penalized when their medical condition requires specialty services.***

VIII. Consumer Involvement and Protections

To ensure that the health care needs of persons with disabilities are met, *CCD RECOMMENDS:*

1. ***An advisory committee under the auspices of the National Health Board should be established to address the needs of persons with disabilities and chronic illnesses.***

2. ***There must be a formal process for the incorporation of consumer input in the development of "report cards" for health plans. Additionally, these report cards must assess not only the quality of care delivered to the "average" person, but must include assessments of the quality of care delivered to persons with disabilities and chronic health needs.***

IX. Education and Training of Health Providers

While the Health Security Act has provisions to increase the number of primary health care doctors and nurses, it has no comparable provisions to increase training for other key health and rehabilitation professionals including physical therapists, occupational therapists, speech-language pathologists, audiologists, respiratory therapists, rehabilitation psychologists, and nutritionists. These health professionals provide necessary services and supports to individuals with disabilities and their families. Many of these services enable individuals with disabilities to remain in their homes with their families, preventing the need for more costly institutionalization. Because there are documented shortages in many of these profession, *CCD RECOMMENDS:*

1. ***The Health Security Act must include provisions to ensure a sufficient number of health and rehabilitation service providers.***

Another major concern of CCD is the lack of education and training for both primary care providers *and* specialists in the delivery of health care to children and adults with disabilities. Like all Americans, individuals with disabilities need access to a range of primary health care services, which do not have to be provided by specialists in their particular disability. For example, children with mental retardation will experience the same broad array of health problems that are experienced by all children, e.g. ear aches, sore throats, chicken pox and other childhood diseases. Treatment for many of these problems is appropriately provided by a family doctor, a pediatrician, a pediatric nurse practitioner, or a physician assistant. All of these primary care providers, and specialists as well, need to be educated regarding the special needs of individuals with physical mental, and communicative disabilities. Therefore, *CCD RECOMMENDS:*

1. ***There must be provisions in the Health Security Act requiring that the training of primary care providers include appropriate content dealing with the delivery of primary health care for children and adults with physical, mental, and communicative disabilities. This content should be available in both basic education and continuing education programs. Programs providing this content should be carried out in collaboration with physical medicine and rehabilitation programs or other specialty programs serving the needs of persons with physical, mental and communicative disabilities.***

Finally, in determining the appropriate ratio of primary care providers to specialists, it is essential to consider secular trends in the incidence and prevalence of specific disabilities and illnesses. For example, in the past decade there has been a dramatic increase in the survival of persons with severe traumatic brain injuries and a concomitant increase in the need for neurologists, neuropsychologists, and rehabilitation psychologists to treat these individuals. Therefore, *CCD RECOMMENDS:*

1. ***The National Council on Graduate Medical Education should be required to take account of the incidence and prevalence of disabling conditions, as well as changes in the needs of persons with specific disabilities, in determining the appropriate specialty mix needed.***

Closing

In closing, we would like to state that CCD is committed to working with both the Administration and Congress to assure adoption of our recommendations to improve the Health Security Act and to enact comprehensive health care reform in 1994. With the exception of President Clinton's plan and the Single Payer Plan introduced by Senator Wellstone and Rep. McDermott, all of the other bills currently being considered in the 103rd Congress fail to address the needs of persons with disabilities in fundamental ways. We strongly urge the Committee to reject those proposals that do not guarantee universal coverage for comprehensive benefits, protection from catastrophic costs, and cost containment measures that will slow the growth in health care costs so that comprehensive benefits remain affordable.

As you proceed with your work on health reform legislation, we would like you to remember one point: "In the long-term, the success of the health care system must be judged less on its success in serving the majority of the population, most of whom have few or simple medical care needs, and more on how effectively it addresses the problems of those with serious and persistent disabling illness, who depend on the health system for their functioning, perhaps even for their lives. To the extent that the reforms address these important issues successfully, they are likely to serve us all well."[1]

1. Mechanic, David. Mental health services in the context of health insurance reform. *The Milbank Quarterly*, Vol. 71(3), 1993.